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Learning from the Experiences of Friends and Relatives Who Care for People with Life-Limiting Conditions to Improve Support Services in Glasgow.

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Abstract

Introduction

The number of people living longer with life-limiting conditions continues to increase. However, this increase has not been matched with adequate growth to health and social care services. Consequently, there is an increasing reliance on family members and friends who offer their time and resources to act as a caregiver. Caring for people who are living with life-limiting conditions is predominantly expected of female family members. The caring role has become increasingly enduring and complex and puts those undertaking it at an increased risk of experiencing negative consequences related to their physical and mental health. This thesis describes a three-year project that explored the population of people from Glasgow who care for individuals with at least one life-limiting condition and their experiences with support services.

Methods

The aim of the project was to begin the process of developing an intervention for caregivers, that could be implemented in NHS Greater Glasgow and Clyde. This project was underpinned by the transformative intervention paradigm and influenced by feminist theory. Three steps of data collection and analysis were undertaken to achieve the aim. The steps included a modified systematic review of outcome measures used in trials of interventions for caregivers. This was followed by a secondary analysis of needs assessments carried out by the Glasgow City Carers Team. Finally, focus groups and interviews were carried out with caregivers from Glasgow to describe their experiences in using interventions and working with professional groups to help identify what was missing from what was available.

Findings

This project identified that there is considerable heterogeneity in caregiver intervention description and evaluation, which makes drawing conclusions about efficacy difficult. This variation is mirrored in the demographics of people who require needs assessments for their caring responsibilities in Glasgow. Speaking directly to caregivers through focus groups and an interview identified that professionals who interact with caregivers often add to, rather than reduce caregiver burden and stress. Participants described that current support is not flexible enough for them and does not offer continuity and accessibility. What is missing from what is available is a single point of contact that supports caregivers to manage their own health and wellbeing alongside the health of the person for whom they care. Consequently, an array of interventions and approaches to care and support for caregivers may be useful to caregivers. However, as many people who support people with life-limiting conditions do not recognise themselves as caregivers, access and visibility must be considered for any future interventions.

Conclusion

Future research should consider place-based interventions that address the unmet needs of caregivers. However, changes to existing services and professional conduct that offers caregivers continuity, opportunities to work in collaboration and respectfully communicate might reduce or remove the need for some caregiver interventions altogether.

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Contents

List of Tables

List of Figures

List of Publications

Drummond M, Johnston B, Quinn TJ. Measuring the success of interventions for caregivers: a focussed systematic review. Current Opinion in Supportive and Palliative Care. 2019;13(4):351-9.

Drummond M, Johnston B, Quinn TJ. Cutting through the intersections to care for caregivers: Secondary data analysis of a carers support service in Glasgow, Scotland. Health & Social Care in the Community. 2021; 00: 1– 10. https://doi.org/10.1111/hsc.13463

List of Presentations

European Association of Palliative Care Conference 2020 Oral Presentation: Measuring the success of interventions for caregivers of people with life-limiting conditions: a focused, systematic review [A-1114-0036-00309]

European Association of Palliative Care Conference 2020 Oral Presentation: Cutting through the intersections to care for caregivers: secondary data analysis of a caregiver's support service [A-1114-0016-00312]

Scottish Partnership for Palliative Care Autumn Season Poster Presentation: Using social media to disseminate evidence related to palliative and end of life care during the Covid-19 pandemic.

Medical, Veterinary and Life Sciences Post Graduate Induction Day Poster Presentation: Developing an intervention for caregivers of people with life-limiting conditions.

U21 Health Sciences Group Doctoral Student Forum Poster Presentation: Developing an intervention for caregivers of people with life-limiting conditions.

List of Abbreviations

Abbreviation	Explanation
BPSD	Behavioural and Psychological Symptoms of Dementia
CAM	Case Management
CBT	Cognitive Behavioural Therapy
CONSORT	Consolidated Standards of Reporting Trials
COS	Core Outcome Set
GP	General Practitioner
HIC	High Income Countries
HSCP	Health and Social Care Partnership
IAOCO	International Alliance of Caregiver Organizations
LMIC	Lower Middle-Income Countries
MRC	Medical Research Council
MVLS	Medical, Veterinary and Life Sciences
NHS	National Health Service
NIHR	National Institute for Health Research
NMC	Nursing and Midwifery Council
PCPI	Patient, Caregiver and Public Involvement
PPI	Patient and Public Involvement
PROM	Patient Reported Outcome Measure
SBAR	Situation Background Assessment Recommendation
SPQDN	Specialist Practitioner Qualification in District Nursing
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

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Chapter One: Introduction

1.1 Introduction

In 2015, 101 million adults aged over 60 were care dependent (World Health Organization (WHO), 2018a). However, by 2050 the proportion of the population of adults over 60 is expected to double (WHO, 2018a). The World Health Organization (2017) define care dependent as "the need for frequent human help or care beyond that habitually required by a healthy adult" (p1). For adults over the age of 60, the need for help or care is usually related to the management of life-limiting conditions (WHO, 2017). A life-limiting condition is a condition that is degenerative and progressive with no reasonable hope of cure (Chambers, 2018). The term life-limiting was originally related to malignancy but has diversified alongside the expansion of palliative care and now includes up to 400 different diagnoses (Noyes et al., 2013). Conditions that are considered life-limiting include frailty, dementia, stroke, heart failure and cancer. Life-limiting conditions are attributed to 71% (41 million) of deaths around the world (WHO, 2018b). Cardiovascular disease accounts for 17.9 million deaths, followed by cancer (9 million), respiratory disease (3.9 million) and diabetes (1.6 million) (WHO, 2018b).

Palliative care was originally developed in relation to cancer and associated pain management. However, as the prevalence of life-limiting conditions has grown, more research was needed to understand the lived experiences of people affected by non-cancer life-limiting conditions (Oishi and Murtagh, 2014). Palliative care is a multi-disciplinary approach that considers the physical, emotional, and spiritual needs of individuals diagnosed with any life-limiting condition and their caregivers (Sepúlveda et al., 2002). The principles of palliative care are now applied as early as possible in the trajectory of an illness, as complications at the end of life can often be linked to care at earlier stages (Sepúlveda et al., 2002).

Most care delivered to people living with at least one life-limiting condition is carried out by family members and friends (International Alliance of Carer Organizations (IAOCO), 2018). There are an estimated 43.5million caregivers in the United States of American (IAOCO, 2019) and between 20% and 44% of the population of Europe consider themselves caregivers (Verbakel et al., 2017). In the UK there is approximately 11.5 million people with caring responsibilities (Carers UK, 2020). However, these are conservative estimates because many people who support friends and relatives do not recognise themselves as caregivers (Knowles et al., 2016). The number of people who undertake caring roles will continue to rise because significant advances in technology and medicine have been matched with growing economic inequality (Lawson et al., 2020). Therefore, although people are living longer with life-limiting conditions, they are not necessarily healthier. This has transformed the caring role into one that is increasingly complex and enduring.

Caring for someone with a life-limiting condition is an arduous role that can put the person delivering care at an increased risk of experiencing mental and physical ill-health (Gardiner et al., 2020; Hayes et al., 2009; Victor et al., 2021). The associated risks increase for caregivers who live in areas with higher socio-economic deprivation (Thomas et al., 2015). However, not everyone caring for someone with a life-limiting condition experiences negative consequences, nor do the negative consequences necessarily mean that those at risk do not want to be delivering care (Al-Janabi et al., 2008). Consequently, the caring role and relationship is a highly individualised experience.

On average, 75% of unpaid care work is done by women and girls, and the time and energy that they are expected to give to unpaid care work is the reason why they are disproportionately negatively affected by climate change and Covid-19 (Lawson et al., 2020). The need for better understanding, value and support for caregivers came to the attention of feminist academics and activists in the late 1970s and remains a priority within feminism (Dalley, 1988; Lawson et al., 2020). Initially, feminists recognised that women and girls were not receiving adequate recognition and remuneration for their caring labour compared to men in paid employment (Dalley, 1988; Ungerson and Kember, 1997). However, due to work migration patterns and ageing populations, more men are increasing the amount of care they undertake (Stanfors et al., 2019). This has created the need for a more nuanced understanding within feminism about how best to address the underappreciation for unpaid care work (Carers UK, 2019; Gott et al., 2020; Hoang et al., 2012; Morgan et al., 2020). It is now recommended that research and interventions that purport to understand and support caregivers are developed with an understanding of the gendered expectations of women (and girls) and men (and boys), as well as other social determinants of health (Gott et al., 2020). This will ensure we are working towards more equitable care for people living with life-limiting conditions and their caregivers (Gott et al., 2020).

The research around caregiving is substantial and diverse and could not be covered in a single Introduction. In this Introduction, I will focus on context, definitions associated with caring for someone with a life-limiting condition, existing evidence on the impact that the role has on caregivers, the frameworks that interventions have been informed by and how the application of feminist theory could strengthen existing evidence, support and inform future interventions.

1.2 Political Context for Project

Lawson et al. (2020) calculated that the unpaid labour of caregivers is valued at around $10.8 trillion annually, which is three times the valuation of the tech industry. Carers UK (2020) estimated that the value of care provided from March 2020 to November 2020 during the Covid-19 pandemic was £135 billion (£530 million contributed by caregivers every day). To put this in perspective, the annual spending on health and social care in the UK is currently valued at £140 billion (The Kings Fund, 2020). However, their societal contribution extends beyond finances. Nancy Fraser (Fraser, 2016; Fraser and Jaeggi, 2018) has written extensively on Capitalism and care, and described unpaid caring labour as the basis for culture and political organisation. The contribution made by caregivers is, therefore, essential to maintaining functional communities and our health and social care systems.

The UK is considered to have some of the most advanced legislation in relation to recognising the caring role (IAOCO, 2018). Governments in Scotland, England, Wales and Northern Ireland all now outline an entitlement for caregivers to access individualised assessment of needs. However, the Carers (Scotland) Act 2016 (Scottish Government, 2016) is the first to centre the needs of the caregiver, rather than including caregivers' rights within the health and social care provision of people requiring care and support.

Scotland implemented the Carers (Scotland) Act in 2018, which recognised the need for caregivers to access timely support from health and social care services (Scottish Government, 2016). This created the foundations from which an idea for funded doctoral research related to caregivers of people with life-limiting conditions was envisioned by Professor Bridget Johnston, of the University of Glasgow. Dr Terry Quinn joined her to complete the supervisory team. If caregivers were legally entitled to an assessment of needs and adequate support, then Professor Johnston believed that that support should be evidence-based and co-produced by caregivers and the professionals expected to deliver it.

Professor Johnston and Dr Quinn are both clinical academics working in NHS Greater Glasgow and Clyde. NHS Greater Glasgow and Clyde is the largest Health Board in Scotland, with a population of approximately 1.2 million people (Glasgow Indicators Project, 2021). NHS Greater Glasgow and Clyde primarily covers Glasgow City and the surrounding areas (Glasgow Indicators Project, 2021). The life expectancy in and around Glasgow is notoriously poor compared to other major UK cities (Cowley et al., 2016). When socio-economic deprivation is adjusted for, all-cause mortality is 12% higher in Glasgow compared to Liverpool and Manchester (Schofield et al., 2021). Making sense of the complicated reasons that lead to higher rates of excess deaths in Glasgow was once described as the “Glasgow Effect” (Cowley et al., 2016). However, further population analyses have instead demonstrated a “Political Effect” whereby the most vulnerable populations in Glasgow are paying the biggest price for the UK Governments ongoing austerity measures (Schofield et al., 2021). Consequently, understanding those most vulnerable to health inequality within Glasgow, and then taking steps to improve outcomes is a public health priority (Walsh et al., 2021). Therefore, exploring the population of Glaswegian caregivers and how they can be supported, as new legislation is operationalised, will work towards better health outcomes for Glasgow.

Careful consideration was expected to be given to the place in which study participants were living and caring. This is because where we live can influence our health and wellbeing, which can be health promoting (salutogenic) or health damaging (pathogenic) (Bambra, 2016). This was one of the few prerequisites of the project and was a key factor because senior managers within NHS Greater Glasgow and Clyde recognised the poorer socio-economic outcomes for people living in Glasgow compared to other cities in the UK (Schofield et al., 2021). They wanted to ensure that the voices and experiences of caregivers living in Glasgow were threaded through the project. They were particularly interested in the inclusion of people living in deprived areas. Generally, there has been a growing understanding of the impact of situation has resulted in an increase in place-based research. Place-based health research attempts to describe, theorise or conceptualise the causal pathways within an area, neighbourhood or location that can influence the collective community health (Cummins et al., 2007). From this, place-based interventions can then be designed and delivered to improve standards of living or change behaviour within a defined socio-geographic area

(Glover et al., 2021). However, this has been noted as an oversight within palliative and end of life care literature (Chambers et al., 2019).

1.3 Describing Caregivers

For this project I spent a considerable amount of time at the start thinking about what term I would use to refer to people who care for those living with a life-limiting condition. When deciding, I reflected on my role at 17 years old as Carer in a Care Home. Prior to this job, I had no previous exposure to carers or caregivers outside of care homes. I quickly became confused when the term carer was discussed but not about people who worked in the care home. I remember this confusion clearly, so I wanted to ensure there was no ambiguity around who I was referring to in this research. I then took time explore the terms used in legislation, research and grey literature to inform a decision, and found interesting differences.

1.4 Terminology in Legislation

Within UK Legislation, the preferred term is carer and describe a carer as someone who voluntarily delivers care to a person with health and/or social care needs. This care would otherwise need to be provided by the local authority and is beyond what is typically expected of their age and relationship.

1.5 Terminology in Research

Decisions around cost and clinical effectiveness of interventions that are delivered by health and social care services often (and should) come from the findings of meta-analyses (Clegg et al., 2022). Meta-analyses are considered the highest quality evidence available and should include clear descriptions or definitions of target populations used for recruitment (Polit and Beck, 2004). Therefore, meta-analyses on caregivers of people with life-limiting conditions offer a comprehensive overview of how the caring role is defined by researchers.

A ten-year (January 2011- January 2021) time-limited search of nursing and medical literature databases (EMBASE, Medline, CINAHL and PsychInfo) was carried out on publications related to caregivers of people with life-limiting conditions. Terms used in the search to capture appropriate literature were carer, caregiver, care giver, relative, friend, informal caregiver, informal carer, spouse and family member. This produced six meta-analyses (Chien et al., 2011; Lau and Au, 2011; Ploeg et al., 2018; Schulman-Green et al., 2020; Sherifali et al., 2018; Walter and Pinquart, 2019). From the retrieved meta-analyses, the most used term was caregiver, sometimes with a descriptor word alongside caregiver, such as family or dementia (Lau and Au, 2011; Schulman-Green et al., 2020; Walter and Pinquart, 2019). Although the most used term was caregiver, authors did not justify their choice even when they included studies that used alternative terms, such as carer. The timeline of publication dates suggests that there has been an increasing need to synthesise findings from the vast body of caregiver-related research, with four of the six reviews published since 2018.

1.6 Terminology in Grey Literature

It was also important for me to consider the literature that would be commonly accessed by people with caring roles and responsibilities, which will not typically be a statute or peer-reviewed papers in academic journals. People looking for information will instead, likely begin with an online search.

Wikipedia, the popular reference website has an entry under caregiver, which describes people in both paid and unpaid caring roles as a “member of a person's social network who helps them with activities of daily living. Since they have no specific professional training, they are often described as informal caregivers. Caregivers most commonly assist with impairments related to old age, disability, a disease, or a mental disorder.” A focused search for “Caregiver support UK” directs internet uses to the Carers UK webpage “Get Support”. Carers UK is the biggest charity in the UK supporting caregivers. Carers UK provide the following definition “Carers provide unpaid care by looking after an ill, older or disabled family member, friend or partner. It could be a few hours a week or round the clock, in their own home or down the motorway”. The next result is the website for Age UK, which is a charity supporting older adults in the UK. Their definition is “If you look after a partner, relative or friend who is disabled or ill due to physical or mental health, you are a carer, even if you don’t think of yourself as one.”.

1.6.1 Deciding on a term for this project

The final issue when I was selecting a term relates to “hidden carers”, the people who deliver care to family members and friends but do not identify with or want to be described as any care-related terms (Knowles et al., 2016). Larkin and Milne (2014) critically reflected on caregiver discourse and what the confusion around appropriate terminology means for caregiver empowerment. The author outlined the complexity of the issue and describe selecting a term (their choice is carer) as problematic. This is because caring, in some capacity, is necessary in all human relationships. Therefore, making the distinction between when caring changes from a normative activity into something that goes beyond that can be difficult. These lines are further complicated by cultural differences and gendered expectations of women and men. Many caregivers of people with life limiting conditions are required to undertake complex medical and nursing interventions, as well as an increasing volume of administrative and referral tasks on behalf of the person for whom they care. This means the caring role overlaps not only with daughter/wife/husband roles but also with professional roles, such as nurse, social worker, or administrator. Some people are concerned that by rejecting a care-related term they are protecting the cared-for person, for others, they are concerned over juggling multiple roles within one relationship, and the level of complexity and responsibility they considered themselves having and whether they had earned the title (Knowles et al., 2016). A literature review was carried out that explored the development of caregiver identity (Eifert et al, 2015). The authors suggested that because so much of the concept of identity is socially constructed, caregivers are more likely to accept the caregiver identity (and therefore accept help) through interactions with others because this facilitates exposure and normalisation. However, there is often an interdependency within the caring relationship as well as a regular (re)negotiation of responsibility and power (Larkin and Milne, 2014). These issues make selecting and embedding a fixed term that accurately represents the large and variable population of people who care very difficult.

Larkin and Milne (2014) concluded that this incongruence between language and theoretical foundation limits caregiver empowerment, activism and ultimately, their political influence. It also adds an unnecessary challenge to support services and interventions, as there needs to be an appropriate term to describe the target population. Without this, users of the interventions and services will not know that it is suitable for them. Morgan et al. (2021) use the term *carering* to describe the conceptual challenges around caregiver identity and identification, and the influence that policymakers, researchers and society have on the role and its social position. They suggest that health and social care should not rely on self-identification from caregivers because of the ambiguity around the label and its acceptance by people who care.

The concept of hidden carers only confused the decision I had to make. Molyneaux et al. (2011) highlighted that overall, carer does tend to be the most popular term used. The authors emphasise the good intentions behind the selection of carer to describe people who care for family members and friends with life-limiting conditions, disabilities, and mental illness. It was meant to help the primarily female population who were extending their familial role in the absence of adequate health and social care support. However, as it is also used in paid employment roles, the use of carer only adds to obfuscation of the caring role. For this project, I ultimately decided to use caregiver to limit any possibility of confusing my population of interest with people in professional roles who are paid to deliver care to people with life-limiting conditions.

1.7 Life-limiting conditions and care

The list of conditions that are described as life-limiting is diverse (Noyes et al., 2013). So too are the associated caring roles and responsibilities. This results in an often intense and unpredictable experience, whereby the health and wellbeing of the caregiver becomes intrinsically linked to the person for whom they care (Gardiner et al., 2020). Although caring for someone with a life-limiting condition is a unique experience, it typically involves a mix of supporting someone with symptom management, cognition, and managing physical disability (Teixeira et al., 2020; Walshe, 2020; Wimo et al., 2002). Caregivers often must learn, undertake and oversee complex care such as skin integrity, wound care, medication administration (including invasive routes), hydration, bladder and bowel management, suctioning and socialisation (Teixeira et al., 2020). In the UK, when the person is receiving end of life care and their preferred place of death is their home, caregivers often work in collaboration with district nurses and community staff nurses to do this (Walshe, 2020).

Caring for someone with at least one life-limiting condition can extend throughout most of the day. For example, Zhao et al. (2021) found that most (58.2%) caregivers of people with severe stroke care for over eight hours a day. However, for many conditions such as dementia, the time spent caring can be unpredictable and variable. It can often depend on issues beyond the caregiver's control, such as severity of dementia and behavioural disturbances (Wimo et al., 2002). Furthermore, somewhat counter-intuitively, the use of support services was found to be a predictor for more hours spent caring by caregivers (Wimo et al., 2002). The array of tasks and responsibilities involved in caring for someone with at least one life-limiting condition is why there is such a wide range of associated negative consequences, and these are further compounded when dealing with multimorbidity and the end of life.

1.8 Multimorbidity

The rapid increase in ageing populations all over the world, coupled with the increased prevalence of life-limiting conditions, created the challenge of multi-morbidity. Multi-morbidity is defined as the co-occurrence of at least two chronic conditions and is directly associated with advancing age (Garin et al., 2015). Multimorbidity is also associated with increased use of unplanned care and mortality. Barnett et al. (2012) examined the link between multimorbidity and socioeconomic status by undertaking a cross-sectional analysis of data from over 1.7 million people registered at a General Practice in Scotland in 2007. They found that the onset of multimorbidity occurred 10-15 years earlier among people living in areas of higher multiple deprivation compared to people living in more affluent areas. They also found that the presence of mental ill health increased as the number of physical life-limiting conditions increased. McLean et al. (2014) used the same Scottish dataset as Barnett et al. (2012) to examine the link between socioeconomic status and multimorbidity in more detail across age groups. The researchers found that mixed physical and mental multimorbidity was two to three times more common in the most deprived compared with the least deprived in all age groups under 75 years. Deprivation was also associated with a higher prevalence in seven out of the 10 most common conditions (depression, drugs misuse, anxiety, dyspepsia, pain, chronic heart disease, and diabetes). Lower socioeconomic status and increased occurrence of multimorbidity has also been identified in cross-sectional studies in Denmark (Schiøtz et al., 2017), Canada (Agborsangaya et al., 2012), Spain (Violán et al., 2014), Norway (Vinjerui et al., 2020) and New Zealand (Stanley et al., 2018). Multi-morbidity is an important consideration when attempting to understand the caring role within the Glasgow population. This is because it is likely that caregivers in Glasgow will be caring for people with or at risk of developing multi-morbidity. Support services and interventions will need to be aware of the impact that this will have on the complexity of the caring role and the caregiver’s ability to commit and engage.

1.9 The consequences of caring

Caring for family members and friends is a natural part of most relationships and can produce positive outcomes. However, the risks associated with caring for someone with a life-limiting condition are well documented. This is because it can be physically and mentally exhausting for all involved. Hilton et al. (2016) estimated that the average person over the age of 20 will spend nearly 9% of their remaining lifetime caring for an older adult. This varies between the sexes, with 7% for men and 10% for women, which equates to a difference of two years. The peak of time spent caring also differs between women and men. Men over the age of 70 will spend an average of 15% of their remaining life caring and for women, the peak is between 50 and 69 years, with 14% of their remaining life spent caring. These age groups bring about different demands, with most of the female age range occurring during working years, compared to older men who will have an increased likelihood of health problems. This split between age and sex may be why there is such a wide range of risks associated with caring for someone with a life-limiting condition.

1.9.1 Psychological Impact

When consulting the caregiver literature to understand the risks associated with the role, the psychological impact is often the focus. This is because of the increased risk that caregivers face compared to non-caregivers in relation to poor mental health. For example, spouses of people living with dementia are four times more likely to be diagnosed with depression compared to non-caregiver spouses (Joling et al., 2010). Furthermore, in research carried out by Carers UK (2019), when asked to rate anxiety out of ten, the caregiver average was 5.4 compared to a national average of 2.9. Caregivers also reported a level of happiness that was more than a third lower than non-caregivers and 35% of caregivers were lonely, compared to the national average of 5%. The risk factors associated with experiencing such negative consequences are wide-ranging. Female and offspring caregivers of people living with dementia are associated with higher rates of depressive symptoms, as are the occurrence of behavioural and psychological symptoms of dementia (BPSD) (Watson et al., 2018). Advancing age is associated with increased risk of depressive symptoms and anxiety for caregivers of people with moderate-severe stroke (Zhao, 2021). Furthermore, more hours' spent caring is associated with increased risk of anxiety and depressive symptoms for caregivers of people with moderate-severe stroke and heart failure (Chung et al., 2010; Zhao et al., 2021).

Psychological disturbances such as anxiety and depressive symptoms are distinct issues with their own management and treatment options. However, the concept of caregiver burden was developed to attempt to understand these issues when they occur because of, or are exacerbated by, the caring role (Watson et al., 2018). Zarit et al. (1986) developed an understanding of caregiver burden that reflects the variability in how the common negative consequences can present. Prior to the seminal research by Zarit et al. (1980; 1986) into caregiver burden, they argued that the focus of this complex concept had been on the type and intensity of care required of the caregiver as the main predictors of associated burden. Instead, their research suggested that caregivers can experience significant burden when they do not have adequate social or familial support (Zarit et al., 1980). This demonstrates that caregiver burden is a complex phenomenon and a caregiver's risk of experiencing it is not necessarily straightforward.

Three literature reviews were retrieved that relate to caregiver burden when caring for someone with a life-limiting condition. A systematic review by Chiao et al. (2015) of 21 studies related to caregivers of people with dementia suggested that research on caregiver burden tends to focus on characteristics of the cared-for person, such as diagnosis, or type(s) of care required, or characteristics of the caregiver, such as socio-demographic or psychological factors. They concluded that although the concept of caregiver burden is a popular focus within caregiver research, it lacks a cohesive definition and understanding. However, a meta-analysis by Acton and Kang (2001) of caregiver interventions on burden demonstrated the difficulty in defining the concept. The authors described how caregivers can find their role burdensome due to the financial, physical, and psychological pressures that the role can create. It is suggested that burden can also be caused by challenges related to the diagnosis of the cared-for person, such as the behavioural and psychological symptoms of dementia. Del-Pino-Casado et al. (2019) did offer a clear definition. They examined the relationship between caregiver burden and sense of coherence and define it as a state characterised by fatigue, stress, and difficulties adjusting to the caregiving role. When burden is experienced, the caregiver is at an increased risk of a diagnosis of anxiety and/or depression. Their analysis included 35 studies and identified that a caregiver's sense of coherence was moderately associated with the levels of burden they experienced. The authors describe a sense of coherence, as a person's ability to understand a situation and effectively access appropriate support when necessary (material, psychological and social). This understanding, awareness and subsequent support then adjusts their cognition to a state whereby they feel supported and can cope adequately (del-Pino-Casado et al., 2019). Although there is no one universal definition of caregiver burden, the descriptions and definitions place it firmly within the psychological realms of the caregiver experience. However, other factors can predispose a caregiver to burden.

1.9.2 Physical Impact

Caring for someone with a life-limiting condition can be physically demanding. The majority of palliative and end of life care is carried out by caregivers, and this will often be without adequate equipment and support (Salifu et al., 2021). Teixeira et al. (2020) carried out an ethnographic study of 10 caregivers and 10 relatives in Portugal who provided palliative care to people with advanced, progressive disease at home. Their study detailed the breadth of physical demands put upon caregivers, and how common physical health concerns (such as back pain and reduced time for rehabilitation) is among caregivers, as well as the impact this has on the person for whom they care. Although caregivers can be supported by formal services, such as home carers and district nurses, there are often long gaps through the day and night where laborious tasks (such as bathing and assistance with continence management) fall onto the caregiver. Furthermore, caregivers are often forced to neglect their own health when they do not have access to support to cover their absence (Carers UK, 2020). This only exacerbates their injuries and ailments.

1.9.3 Financial Impact

Gardiner et al. (2016; 2020) identified that many caregivers face a multidimensional financial burden when caring for someone requiring palliative and end of life care and/or with a life-limiting illness. Their critical debate (Gardiner et al., 2020) and systematic review (Gardiner et al., 2016) on the financial costs associated with the role identified that caregivers face a wide range of costs. These can include adaptions to housing, buying equipment necessary to keep both the caregiver and the person for whom they care safe, and reduced income from early retirement or reduced working hours. Furthermore, they identified a diagnosis inequity, whereby caregivers of people with non-cancer diagnoses are often ineligible for financial support or state benefits that caregivers of people with cancer can access. The result of financial strain caused by caring for someone requiring palliative and end of life care is a complex caregiver burden that can negatively affect a caregiver’s employment, relationships, and ability to cope (Gardiner et al., 2016). These reviews highlight the importance of measuring financial strain in caregivers when assessing risk and burden.

These findings echo recent research that highlights the extent to which the Covid-19 pandemic has exacerbated the financial strain on caregivers. Bennett et al. (2020) found that caregivers were twice as likely as non-caregivers to use foodbanks during the pandemic, with female caregivers more likely than male caregivers. They also identified that caregivers under the age of 30 were more likely to live in a house where someone had gone hungry in the last week. Furthermore, unemployed caregivers were more likely to go hungry and use foodbanks than caregivers in employment. A survey by Carers UK (2020) identified that caregivers who care for at least 35 hours per week were at an increased risk of financial hardship. Twenty-six percent of caregivers said the Covid-19 pandemic had increased the costs of necessities such as food, deliveries, and household bills. Carers UK (2020) highlight that during the pandemic the Carers Allowance (which is the lowest State benefit available at £67.25 a week) was not increased in line with other benefits and that 15% of caregivers who receive Carers Allowance are, or have been, in debt due to their caring role. However, there is some variation, as caregivers in Scotland did receive a small increase in Carers Allowance. These findings are particularly troubling considering caregivers from lower socioeconomic backgrounds who are more likely to be caring for people with multimorbidity and are at an increased risk of experiencing poorer physical and mental ill-health themselves.

1.9.4 Spiritual Impact

The processes of ageing and dying are inevitabilities. These processes whether experienced first-hand or witnessed, can prompt people to consider what meaning their life has. This exploration of self and life is what Mowat (2013) suggested is spirituality. Mowat (2013) argued that when health and social care professionals offer spiritual support to older adults and caregivers it enables the individuals to create and find meaning in their life. The WHO considers spirituality and spiritual care to be fundamental aspects of palliative and end of life care. Spirituality has been defined by the European Association for Palliative Care as “The dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred” (Best et al., 2020, p.2). However, spirituality is notoriously difficult to define and conceptualise (Sinclair et al., 2006). It can be aligned with a religious belief, or a secular concept (Mowat and O'Neill, 2013). Considering who requires spiritual support should, therefore, not be based on assumptions or stereotypes.

The caring role is undoubtedly a spiritual experience for many people. However, how the caring role impacts a person's spirituality and the ways in which health and social care services can offer caregivers spiritual support is neglected in the literature compared to other aspects of health and wellbeing. This is surprising because it is cited as an effective coping mechanism for caregivers to process their experiences (Anderson and White, 2018), including during the Covid-19 pandemic (Carers UK, 2020). Furthermore, Kim et al. (2014) measured spirituality and its impact on depressive symptoms among caregivers and older adults in Korea. They found that spirituality between caregivers and the person for whom they care are inter-dependent, like their physical and mental wellbeing. They identified that spirituality gave people a higher sense of purpose in life, which in turn reduced the reporting of depressive symptoms. This also demonstrates that with appropriately assessed and targeted support, caregivers, and the person for whom they care, can benefit from their caring relationship.

1.9.5 Personal Gains

The caring experience is fundamental to life and although it is undoubtedly a complex and demanding role, not every caregiver's experience is negative nor do all caregivers require support. A qualitative exploration by Anderson and White (2018) of caring for someone with a serious illness found that some caregivers described the opportunity to care for a loved one as a gift. For caregivers of parents, some were thankful for the opportunity to reciprocate the love and care they received as children. Understanding the positive aspects of the role and the possible personal gains enables researchers and clinicians to appreciate what is at risk when caregivers are not adequately supported.

Mackenzie and Greenwood (2012) carried out a systematic review of research related to caregivers of people with stroke. From nine studies, the researchers identified that caregivers found satisfaction and pride when the cared-for person's physical condition improved. Caregivers also found meaning and purpose to life when caring for a loved-one, and that positive outcomes from caring grew over time. The influence that the health of the cared-for person can have on the caregiver’s perceived stress and satisfaction was also identified by de Labra et al. (2015) in relation to caregivers of people with dementia. They found that the severity of the dementia positively correlated to caregiver satisfaction. This was echoed in a study by Netto et al. (2009). The authors found that caregivers reported feeling more patient with the person for whom they care over time because their caring role allowed them to better understand dementia and how to manage challenges that arose. This in turn, enhanced the caregiver’s perception of their personal growth and improved relationships with the person for whom they care and the wider family.

Caregivers who become stronger and wiser because of their caring role go through a transitional period of intense learning and adaption that can be physically and mentally challenging. Many caregivers need to experience negative consequences to then experience positives. One aspect of a caregiver’s experience or role could be improving while another is suffering. Positives and negative aspects of caring can exist concurrently. For example, a caregiver who scores highly on an outcome measure related to a risk such as anxiety may also be feeling satisfied or proud at mastering a new skill related to caring. Carbonneau et al. (2010) developed a framework to enable researchers to consider the positive aspects of caring for someone with a life-limiting condition. They argued that their framework was necessary because the consequences of caring are not a spectrum with positives at one end and the negatives at another. This approach can lead researchers to overlook positive aspects and experiences as the risks are more likely to be the focus. Measuring positive aspects of caring can also be part of measuring psychological impact because caregivers who struggle to identify positives are at an increased risk of anxiety and depression. However, Gérain and Zech (2021) argued that the positive experiences and aspects as outlined by Carbonneau et al. (2010) do not balance the “deleterious” consequences. This suggests a disparity between researchers and caregivers related to the risks that caregivers are willing to take (including to what extent) and what is important to them.

1.10 Existing Interventions

In response to the variation in negative consequences and risks associated with caring for someone with a life-limiting condition, there is a body of literature on interventions that seek to alleviate at least one risk for caregivers. From these studies, there are now systematic reviews and meta-analyses evaluating their efficacy, with thirteen published since 2011 (Chien et al., 2011; Elvish et al., 2013;

Farquhar et al., 2016; Griffin et al., 2015; Irons et al., 2020; Jensen et al., 2015; Leng et al., 2020; Ploeg et al., 2018; Qiu et al., 2019; Rausch et al., 2017; Teahan et al., 2020; Walter and Pinquart, 2019; Wiegelmann et al., 2021).

Caregivers of people with dementia feature most prominently in these reviews, with eleven reviews focusing on this caregiver group (Chien et al., 2011; Elvish et al., 2013; Griffin et al., 2015; Irons et al., 2020; Jensen et al., 2015; Leng et al., 2020; Qiu et al., 2019; Rausch et al., 2017; Teahan et al., 2020; Walter and Pinquart, 2019; Wiegelmann et al., 2021). This attention to caregivers of people living with dementia was also identified in Young et al. (2020), who undertook a systematic review of systematic reviews and meta-analyses of interventions for caregivers of people with age-related life-limiting conditions. They included 33 reviews from 1990-2018 and concluded that researchers generally overlook the social determinants of health among caregivers. Their review included data from over 20,000 caregivers, but they argued that the lack of disaggregated and analysed characteristic data portrayed caregivers as a homogenous group. They also identified that caregiver characteristics such as age, sex, location, and ethnicity were not generally discussed in relation to how they influence outcomes. They also suggested that other age-related chronic conditions such as stroke should be of consideration to researchers. They recommend that theory-driven research should include a diverse caregiver population and that interventions should be tailored to populations of caregivers most at risk. This will ensure interventions are appropriately targeted and cost effective.

Addressing the mental health risks associated with the caring role through courses of psychological or psychosocial interventions appears to be a priority across the literature. These types of interventions showed promising effects on caregiver burden, depression, wellbeing and general health (Elvish et al., 2013; Irons et al., 2020; Leng et al., 2020; Teahan et al., 2020). Although burden was a key outcome, for many of the included studies, there was inconsistency in how it was measured. Two reviews also highlighted that dropout rates were a concern, but that this issue was not adequately reported in trials (Qiu et al., 2019; Wiegelmann et al., 2021). Cognitive behavioural therapy was among the most popular type of intervention. However, variations in how interventions were described, delivered and categorised were identified by reviewers (Elvish et al., 2013; Walter and Pinquart, 2019; Wiegelmann et al., 2021).

However, not all interventions that were reviewed are psychosocial or psychological interventions. Educational, findings from support group and creative arts interventions have also been synthesised (Chien et al., 2011; Griffin et al., 2015; Irons et al., 2020; Jensen et al., 2015). Support group interventions had a small-moderate effect on psychological wellbeing (Chien et al., 2011). Educational interventions showed some improvement to outcomes for both caregivers and the person for whom they care (Griffin et al., 2015; Jensen et al., 2015). Music and singing interventions were the most promising types for creative arts interventions, with researchers identifying a large positive effect on wellbeing and caregiver-care recipient relationship (Irons et al., 2020).

Corry et al. (2015) carried out a systematic review of eight systematic reviews related to caregivers of people with life-limiting conditions. They also identified variability in relation to addressing and measuring the psychological burden of caring for someone with a life-limiting condition through caregiver interventions. They suggested that to improve the quality and rigour of interventions, future researchers draw on a multi-disciplinary team when designing them and consider both generic caregiver interventions and condition-specific interventions to establish the best way to support caregivers and reduce hospital admissions. Therefore, although an array of interventions has been studied, there is no consensus on the type of intervention most likely to improve caregiver wellbeing, or what aspect(s) of wellbeing interventions should be aiming to improve or support.

1.11 Unmet Needs

We now find ourselves in a position where we have legislation that outlines a duty for health and social care professionals to offer caregivers evidence-based support, and high-quality literature reviews that demonstrate that there are interventions available that likely improve aspects of caregiver's lives that are often detrimentally affected by their caring role. However, caregivers continue to experience higher rates of physical and mental ill-health compared to the public (Carers Trust Scotland, 202; Carers UK, 2019). Aoun et al. (2015) suggest that this is because inadequate attention has been given to understanding the unmet needs of caregivers.

Unmet needs can be defined as the difference between the support a caregiver thinks are necessary to manage their own health and wellbeing and the health and wellbeing of the person for whom they care, and the support they actually receive (Denham et al., 2020). The prevalence of caregivers who have unmet needs has been estimated at between 44.3-97%, with younger caregivers, poor social support, caregiver sons, non-white ethnicity and depression all risk factors for experiencing greater unmet needs (Beach and Schulz, 2017; Jennings et al., 2015; Lambert et al., 2012). Existing evidence on unmet needs suggests they can be assessed and addressed in a variety of ways (Denham et al., 2020; Jennings et al., 2015). Although approaches to understanding unmet needs vary between research teams, researchers often select or develop a model that blends theory and evidence to consider the multidimensional aspects of the caring role and what support is missing. However, intervention trials that use quantitative outcome measures across a range of domains, such as quality of life and psychological symptoms, may have some relevance to unmet needs (Mansfield et al., 2017). By understanding the most popular outcome measures used in existing trials, which typically attempt to quantify the difference that interventions make to common risks associated with the caring role, caregivers could then be asked to prioritise them.

1.12 Intervention Development Frameworks

Developing, implementing and evaluating new interventions and their impact in clinical practice can be a complicated, convoluted process (Cruz Rivera et al., 2017). However, this is necessary if the interventions are to effectively advance care (Moullin et al., 2015). Consequently, intervention frameworks have been developed to help with this process. Frameworks help researchers deal with the complexity of interventions for clinical practice and make informed decisions (Brown et al., 2008). However, with an array of frameworks available, selecting which framework is suitable for a project, including whether it is better to blend more than one framework or not, is not an easy decision (Moullin et al., 2015).

For caregiver interventions, Irons et al. (2020) recommended the Medical Research Councils (MRC) guidelines for complex interventions (Craig et al., 2008). The original MRC guidance from 2000 focused primarily on developing randomised controlled trials and did not adequately encourage researchers to be mindful of contextual factors or alternative methods (Moore et al., 2015). Subsequently, it has been updated three times (Craig et al., 2008; Moore et al., 2015; Skivington et al., 2021). The most recent MRC guidance reflects the need for a strong theoretical underpinning to intervention design, implementation and evaluation, and the use of alternative methods to move researchers away from focusing on “the binary question of effectiveness” (Skivington et al., 2021, p.2). The updated guidance reflects a need for evaluation to include how the intervention interacts with the context in which it is applied and whether it contributes to system change (Skivington et al., 2021).

When this project first began, the current MRC framework (Skivington et al., 2021) had not been published. At that time, through reflective discussions with the supervisory team, it was decided that the MRC guidance did not support the level of community involvement I hoped to have. From this, I was encouraged to explore alternatives. The transformative approaches outlined by Mertens (2007; 2008; 2010), seemed appropriate and a co-produced, theory-driven intervention was then considered.

Transformative intervention design dissuades researchers from having rigid plans that prioritises their needs over the community’s (Mertens, 2008). Dwanka-Mullan et al. (2010) also suggest that researchers interested in addressing health disparities through transformative research for racial, ethnic and low socio-economic groups take time to examine community characteristics and culture, as well as identify the structural processes in place that purport to support them. Transformative approaches outlined by Mertens (2007; 2008; 2010) to intervention design have been successfully implemented in interventions for very young adolescents and their caregivers (Cherewick et al., 2021), disabled adults (Purcal et al., 2019) and improving research engagement in underrepresented groups (Manalili et al., 2021). It is also recommended for research that aims to improve outcomes for lesbian, gay, bisexual and transgender groups (Huffman et al., 2020), caregivers (specifically in research undertaken by social workers) (Cash et al., 2019) and rural communities in Scotland (Russell et al., 2021).

The transformative intervention design framework is used by researchers who believe that community members are best placed to identify necessary improvements to care (Mertens, 2008). Following a review of existing evidence, researchers should seek needs assessment data and select methods that bring community members together to facilitate collaboration, such as focus groups to support intervention selection decisions (Mertens, 2008). It is a flexible framework that allows researchers to draw on other models of intervention development when necessary, but those frameworks are adapted to ensure that the voices of community members are prioritised throughout the process.

The variety of marginalised groups that may benefit from transformative research suggests that, although transformative approaches are novel in nurse-led research, they are worth considering. Transformative research is characterised by its challenge to current understandings or willingness to forge new pathways. Therefore, even when it does not achieve its desired outcomes, the knowledge that is created will inform future cyclical transformative research that will build on those lessons learned (Dankwa-Mullan et al., 2010). Indeed, Mertens (2008) is clear that transformative researchers should be aiming to reduce the oppression experienced by marginalised groups, but that it is sufficient to achieve a small step towards a bigger goal.

1.13 Feminist Theory

Feminist theory is described by Mertens (2008) as a commensurate theory to the transformative research. However, it has no one universal definition. Campbell and Bunting (1991) described it as a family of theories because, like families, there can be can divergent ideas and disagreements. It changes and adapts between individuals, communities, cultures, and continents. There is Andrea Dworkin's radical feminism, which seeks to dismantle the root cause of female oppression (Dworkin, 1976), to Kimberle Crenshaws theory of intersectionality (Crenshaw, 1991), which addresses the multidimensional oppression experienced by women of colour. However, there are also Marxist, liberal, socialist, and environmental feminist theories, all with potentially important considerations for caregivers of people with life-limiting conditions.

The various branches within feminism can be confusing and there are important criticisms to consider. For example, Gorelick (1991) argued that, by selecting feminist research methods to primarily amplify the voices of oppressed women and girls, participants will have limited benefits as they are only reflecting on those experiences and world view. Gorelick (1991) also suggested that feminist research risks grouping women together as one homogenous group all experiencing equal oppression and, therefore, ignores opportunities to consider alternative determinants beyond sex.

Previously, feminist academics and writers suggested that women should be aiming to emancipate ourselves from our homes and families in the pursuit of equality and safety. However, this reinforces the patriarchal, Capitalist argument that work done in the home (such as caring) is not skilled and valued labour. Bell hooks' feminist theory (hooks, 1984) offered concise direction in the application of feminist principles to everyday lives, research and activism. Hooks writes her name with no capitalisation, so the focus of the reader is not on her and her name, but her theory and writing. She defined feminism as the struggle to end sexist oppression and exploitation (1984; 2000). However, she emphasised the importance of accessible feminist scholarship that discusses race and class, as well as sex, as determinants of exploitation and oppression for both women and men (hooks, 1984). Furthermore, she acknowledged the safety and comfort that many people get from their homes and families, especially working-class women and men, and those who experience racism (hooks, 1981; 1984). Bell hooks (1984) described her work in the 1980's as radical feminism, but it is widely accepted that her theory was the foundation from which intersectionality was borne, which was first described in 1989 (Crenshaw, 1989).

Feminist theory is commensurate to transformative intervention design because it advocates for a redesign of social power and order, which is often needed when working towards improving the lives of people at risk of marginalisation and poverty (Mertens, 2008), such as caregivers from Glasgow. Feminist theory can also be a tool to consider the limitations of existing knowledge that might have been previously overlooked, especially for topics or areas of our lives that impact or apply more to women and girls. This process of unravelling and reconfiguring knowledge to identify gaps that require further attention is often referred to by feminists as *her*story (converse to *his*tory) (Morgan, 1970; Reid, 2021). Finally, feminist theory and transformative intervention design when used together encourage researchers to make space for the voices of people with lived experience to come through in their work. It encourages researchers to make genuine, rather than superficial relationships within their communities. As caregivers from Glasgow are rarely the focus of research, integrating their experiences throughout this project was an important aspect of it.

1.13 Chapter Conclusions

There is a range of interventions for caregivers that have potential benefits for mental health outcomes and legislation that recognises that health and social care professionals must provide care to caregivers. Yet, caregivers continue to experience an array of negative consequences associated with their caring role and sufficient consideration has not been given to understanding what matters most to them. Existing evidence suggests that more attention is required to caregivers of people with non-cancer diagnoses, as well as whether generic interventions or diagnosis-specific interventions are more suitable. This regard for caregiver groups also extends to caregiver demographics, with further attention required to understand how the caring role and its risks differ. Finally, there is a need for researchers to interrogate the extent to which existing outcome measures, which are vital for justifying resource allocation, measure the aspects of the caring role that matter most to caregivers.

1.13.1 Personal Motivation for Project

My interest in nursing was first sparked when I took a job as a cleaner in a dementia unit of a Care Home at 16 years old that was managed by an inspiring nurse called Linda. Linda created a community spirit among the residents, their families, and staff. When I was old enough, I transitioned into the role of Care Assistant and on completion of my undergraduate degree, worked as a Registered Nurse. Those formative years shaped my appreciation for people who care for friends and family members with life-limiting conditions in both paid and unpaid roles. The experiences also helped me realise that the fundamental components of my nursing, and latterly research practice, would always be respect and humility.

I moved into district nursing in 2011 to widen my clinical experience, with an interest in palliative and end of life care. Since joining the NHS, I have completed a master’s degree in Advanced Practice, a post graduate diploma and specialist practitioner qualification in District Nursing and independent prescribing. The development of my clinical and academic skills concurrently was a happenstance borne out of curiosity and fear. The more I learn, the more I realise how little I know. Academia has allowed me to accept and admit my limitations without fear, and in turn, build more collaborative relationships with people I care for and their support networks. The primary motivation for pursuing this PhD was because of the gratitude I felt for the support given to me by caregivers over the years, and I wanted to know how best to support them in turn.

1.13.2 Thesis Aim

The primary aim of this project was to begin the process of developing an intervention to support caregivers of people with life-limiting conditions.

This project is part-funded by NHS Greater Glasgow and Clyde, which released me from 80% of my clinical role to complete it. Therefore, there is an expectation that the needs of the Glasgow population are carefully considered at every stage.

1.13.3 Thesis Objectives

1. Evaluate how caregiver interventions measure their success.
2. Understand the population of people from Glasgow who access the primary support assessment service, the Glasgow Carers Support Team.
3. Examine the experiences of caregivers of people living with life-limiting conditions from Glasgow accessing and using supportive services and interventions to identify what support is missing from what is available.
4. Create a synthesis of work to inform the development of an intervention.

1.13.4 Covid-19 Mitigation

The Covid-19 pandemic impacted on this project in various ways. It ended recruitment to the qualitative study early, and latterly changed my working hours and role in clinical practice. During the pandemic, my clinical role progressed to charge nurse due to increased clinical demand in the out-of-hours district nursing service. This also increased the number of hours I worked and changed my working pattern.

Supervision meetings were online via Zoom and worked around my son’s routine, who was at home with me. When my supervisors’ clinical roles also increased, we kept in contact via phone calls and text messages.

From May 2021, I moved into a full-time role as Senior Clinical Studies Officer for ENRICH Scotland, which is a research network within NHS Research Scotland. A full-time role was always anticipated at the end of third year, as this was a three-year studentship that was due to be completed by end of June 2021 (delayed by nine months maternity leave). However, this was brought forward when the opportunity to join ENRICH became available. Funding for ENRICH Scotland, which comes from the Chief Scientist Office was only made possible because of Covid-19.

1.13.5 Thesis Structure

The organisation of this thesis reflects the outlined objectives:

Chapter One outlined the background to the topic, as well as the political and personal motivations for this doctoral project.

Chapter Two describes and evaluates the methodology implemented in this project, with discussion around the chosen paradigm, philosophical position, ethical considerations and model of intervention design. There is no specific methods chapter in this thesis. Rather the methods employed within the methodology that are mentioned in Chapter Two are explained in more detail within the corresponding study Chapters Three, Four and Five.

Chapter Three is an evaluation of how caregiver interventions measure success through a modified systematic review of interventions for caregivers of people with heart failure, dementia, or stroke survivors.

Chapter Four is a secondary data analysis of the Glasgow Carers Support Service. This is an analysis of all caregiver assessments carried out over a 12-month period to understand the demographics of caregivers who use this service and common negative consequences reported by this population.

Chapter Five is an examination of the experiences of caregivers of people with life-limiting conditions from Glasgow using support services and interventions. This was carried out through focus groups and interviews.

Chapter Six discusses interventions that should be considered based on the findings from Chapters Three to Five.

Chapter Seven is the final discussion. It outlines the key, overarching findings from this project, final conclusions and the implications for practice and future research, with some discussion around how Covid-19 might impact any future intervention developed from this project.

Chapter Two: Literature Pertaining to the Methodology

2.1 Introduction

Nursing research is a broad term that relates to research focused on nursing practice, the development of new types of care, the expansion of nursing theory and concepts as well as the evaluation of the impact of policy and roles on practice (Moule et al., 2017). Nurse-led research relates to research that is led by a nurse or nurses, but the research team could be interdisciplinary (Castro-Sánchez et al.). However, both terms are often used interchangeably. This chapter will explain the chosen methodology for this nurse-led, nursing research. It will initially outline why a methodology is important in nursing research and justify why the selected methodology and related methods were employed.

2.2 The Pursuit of Knowledge

The advancement of nursing knowledge generates valuable and robust insights that progress nursing practice and wider society (McCurry et al., 2010). Nursing knowledge does not only relate to clinical knowledge and practice, but to our theoretical and philosophical positions, exploration of our self, our worth and our socio-political influence to achieve common good (McCurry et al., 2010). However, because of the increasing prioritisation of cost analysis within nursing practice and education at the post graduate level, it could be easy to overlook the role of nursing theory within nursing research (Georges, 2005). This is understandable. It can be challenging to explore and understand that we are often expected to hold two potentially opposing roles simultaneously, as patient and caregiver advocate, and budget manager. Difficult financial decisions could negatively impact the physical and psychological wellbeing of those for whom we advocate for and work with. Nursing theory and knowledge informs how the profession deals with these types of competing demands (Kinsella, 2010). An examination of the philosophical and political position of nurse researchers is vital because the knowledge that is generated is intrinsically linked to the way in which the research is conducted (Kushner and Morrow, 2003). Rehg and SmithBattle (2015) suggest that this is vital for nursing doctoral students because it encourages critical reflection of knowledge claims, can challenge the hegemony of science, and recognise aspects of knowledge and theory that are often overlooked. Therefore, it is important to carefully consider and reflect on the chosen paradigm and associated methodology of nursing research.

2.3 Methodology

There can be some confusion about the differences between methodology and methods, especially for novice researchers in nursing (Grant and Giddings, 2002). Grant and Giddings (2002) define a methodology as the expression of the ontological and epistemological modes of enquiry employed by the researcher(s). In other words, a methodology is a framework that guides how all aspects of the research process should or could be done. Therefore, a methodology should align with the researchers philosophical and theoretical worldview as well as what the research hopes to achieve (Grant and Giddings, 2002). Whereas the methods are tools that are used to within that framework to gather and analyse data.

2.4 Paradigms in Nursing Research

Thomas Kuhn’s seminal work, *The Structure of Scientific Revolutions* (1970) is a blueprint for how paradigms are understood in modern research. Kuhn described five phases of paradigm development, from the pre-paradigm period (phase 1), where there is little consensus on a topic or area of interest, to post-revolution (phase 5), where new paradigms are well established, and science returns to “normal”. Kuhn defined a paradigm as the beliefs, assumptions, values, and practices shared by a research community. Furthermore, a paradigm should provide an overarching framework for research to be undertaken. Therefore, selecting a paradigm is a fundamental part of any research project because it requires the researcher to demonstrate their truth (ontology) and knowledge (epistemology) in relation to their area of interest to enable the development of knowledge (methodology), as well as consider their personal values (axiology) (Giddings and Grant, 2006).

Nairn (2019) highlighted that in relation to clinical nursing practice, knowledge must extend beyond academic discourse. It is expected that research will produce robust understandings of treatments, conditions, and support mechanisms. These findings then go on to produce guidelines and protocols, which facilitate optimal care for patients and caregivers. Patients and caregivers also expect nurses to apply objective knowledge in a person-centred manner that is culturally sensitive and compassionate (Bramley and Matiti, 2014). In relation to community nursing, the application of knowledge often takes place in challenging and unpredictable environments, from prisons to care homes to homes with hazards. Therefore, it is imperative that nurse researchers select a paradigm that aligns with their values and understanding of the research objective and prioritises the needs of the key stakeholders. In doing so, we will be provided with the means to create adequate solution(s), as well as new knowledge and understanding (Rehg and SmithBattle, 2015).

According to Weaver and Olson (2006), the main paradigms in nursing are:

- Positivism
- Post Positivism
- Interpretive
- Critical Social Theory

The Positivist philosophical position is that the world can be understood objectively, typically through sustained and systematic observations, and the researcher can maintain an objective position within the research process (Corry et al., 2019). Post Positivism acknowledges biases but still seeks objectivity through similar methods to Positivism (Corry et al., 2019). Interpretivism prioritises the voices of participants and embraces subjectivity, viewing truth as existing within multiple realities (Weaver and Olson, 2006). Finally, Critical Social Theory focuses on oppression through shared meanings of the political, social, cultural, and historical climate (Weaver and Olson, 2006). As it focuses on group experience, there is less scope for individual and personal experiences. However, an integrative review by Weaver and Olson (2006) found that none of these paradigms are more suited over another to nursing research, as each has their own set of limitations. Instead, they argued that nurse researchers should be willing to embrace different paradigms in the pursuit of new knowledge. By having an open mind and applying the principles of a chosen paradigm faithfully, the knowledge generated will be trustworthy and valuable. Furthermore, due to the debate about the suitability of certain paradigms in nursing research, nurse researchers should share their experiences to help the field come to a consensus about the suitability of certain paradigms (Grant and Giddings, 2002).

Nairn (2019) argued that new knowledge is part of the historical context it was created in and cannot be fully understood outside of these processes. This is an important consideration for this research as it takes place during significant political unrest and upheaval. In the five years prior to this project, the UK was attempting to recover from the Global Financial Crisis of 2008, and Scotland had an independence election in 2014. These historical events significantly influenced the health and social care systems that depend on, and support caregivers of people with life-limiting conditions. Furthermore, during this project there has been further political turbulence in the form of Brexit, President Trumps leadership of the United States of America and the ongoing Covid-19 pandemic. Undertaking a PhD during these socio-economic disruptions has undoubtedly shaped my political and philosophical position, and therefore the direction of this PhD and the knowledge that has been created from it. During political disturbances, marginalised groups, such as caregivers, are at risk of slipping further into the side-lines. Therefore, it was imperative that the selected paradigm underpinning this project was one that was sensitive to the needs of communities that can become political afterthoughts. This was why the more conventional paradigms did not feel like they were suited to the overall objective, and an alternative was sought.

2.5 Transformative Research

The transformative paradigm is an effective mixed-methods framework for social inquiry that aims to address injustice and inequality through advocacy for marginalised groups (Jackson et al., 2018). The transformative paradigm was developed by Donna Mertens (2007; 2008), whose research has focused on the inclusion of students with disabilities in educational institutions. She identified that researchers often overlooked the influence that research methodologies can have on upholding power. Instead, she developed the transformative paradigm to encourage researchers to draw on feminism, critical race theory, the experiences of people with disabilities and indigenous people, to address oppression (Mertens, 2008; 2010). Mertens (2008) warns transformative researchers that because the transformative paradigm is a challenge to the status quo, they may experience push-back. Therefore, co-production, community engagement and reflexivity in transformative research is so important (Mertens, 2007; 2010). These tools ensure that researchers build strong relationships with the populations they serve and keep community interests at the centre of research. Subsequently, any progress that is made will contribute to social change (Mertens, 2007; 2008; 2010).

The transformative ontological position is that reality has multiple perspectives, all of value and importance. These perspectives are constructed and influenced by race/ethnicity, socio-economic status, disability, sex, age, sexual orientation, and other characteristics that are often barriers to social justice (Mertens, 2010). It is a flexible paradigm that prioritises pragmatism. However, it is still quite a novel paradigm within nurse research. Nevertheless, many areas of nurse research do not lend themselves to the rigid procedures of traditional research methodology (Poradzisz and Florczak, 2018). This is because nurse research typically examines humans, who are varied, unique and, by the very nature of requiring nursing contact, marginalised. The transformative paradigm can support nurse researchers to address questions related to groups that do not typically hold power within society in creative and radical ways with useful outcomes (Poradzisz and Florczak, 2018).

This project was created by senior managers within NHS Greater Glasgow and Clyde in partnership with the University of Glasgow as a funded PhD. These three elements: high level management, a university and PhD study, have the potential to hold on to new knowledge that is not disseminated to the people who it directly affects because they exist within historically hierarchical systems. The transformative paradigm is heavily influenced by feminist and Marxist theory. There is, therefore, an expectation with transformative research that new knowledge will be redistributed away from the established structures of power. As this project was created because of the Carers (Scotland) Act (2016), it is important that any knowledge and findings that are produced by it should be shared with the central stakeholders, the caregivers themselves.

Typically, caring for someone with a life-limiting condition requires the caregiver to undertake physically and mentally exertive tasks (such as assistance with personal care), co-ordinate care (such as scheduling and assisting with hospital appointments) and manage social activities for the person for whom they care. These tasks are carried out around their own lives, which often include paid employment, other caring responsibilities and managing their own health needs. Caregivers are required to navigate through unpredictable and changeable financial and political systems, juggling their own needs with the needs of wider society. Caregivers are, therefore, in an ideal position to understand that policy makers, health and social care providers and service users all hold varying perspectives that could potentially clash with their own requirements and expectations from services and society.

2.6 Feminist Theory

When exploring the concept of paradigms and the importance of considering my political and philosophical positions as a researcher and district nurse, I found that much of my reading circulated back to feminism. Although this topic had been of passive interest to me and I would have always described myself as a feminist, it was not something I had considered in relation to my nursing practice. However, between my first and second year I had my first child and went on maternity leave, and these experiences cemented my commitment to feminism and feminist research.

2.7 Feminist Nursing Research

Since the 1980's, feminist theory has established itself in nursing research. Feminist nursing research is valued because the knowledge it produces relates to vulnerable populations, includes social analysis and has transformative potential (Kushner and Morrow, 2003). However, there can be confusion around what is considered feminist research in nursing. To support novice nurse researchers with an interest in feminist research, Im (2013) devised practical guidelines based on the definition of feminist research by Reinharz (1992), which are:

1. Any methods used by self-identified feminists or used as part of the women's movement.
2. Any methods used in research published in self-identified feminist journals or in feminist books, and
3. Any methods used in award-winning research from organisations that give awards to feminist researchers.

Webb (1993) worked with a more concise definition, "research on women, by women, for women" that engages with issues of particular concern for women. Furthermore, feminist research should aim to disclose women's hidden and oppressed experience within socio-political contexts of women's daily lives, and to help empower the oppressed groups (Im, 2013). It is the hidden nature of caring roles and responsibilities that has resulted in the associated risks because it is easy to ignore what we do not see. And finally, feminist research should also acknowledge researchers' personal bias, attitudes, values, and opinions (Im, 2013; Webb, 1993; Wilkinson, 1986). Traditionally, it was thought that feminist research should be carried out by females. However, Im (2013) supported mixed-sex research groups, so long as male researchers accept that their roles, especially during data collection, may be limited to ensure female participants can build trust and feel comfortable. This was an important consideration because a male supervisor was agreed and in place for this project.

Conducting research from a feminist perspective does not mean that males should or could not participate. In the context of this project, it is about being sensitive to the heavily gendered element of care and ensuring that the planning, analysis, and interpretation considers the cultural, social, and political influences attached to it. It also acknowledges that nursing science and theory are gendered. There is an increasing number of men and boys who undertake caring roles and responsibilities. However, the overall burden and expectations associated with care still fall onto women. By considering the project objective from a feminist perspective it was expected that the chosen intervention would have the highest chance of supporting the largely female population of caregivers. A feminist analysis would ensure that the experiences of male caregivers are acknowledged and treated with sensitivity.

2.8 Mixed-Methods Nursing Research

Quantitative research was historically considered the ultimate empirical exploration of the world, with randomised controlled trials as the litmus test for objectivity. However, these approaches are not necessarily suited to the interactive and unpredictable nature of clinical practice. The notion that subjectivity and our interpretation of our reality is somehow inferior dehumanises both the nurse and patient experience (Munhall, 2012). In contrast to quantitative research, qualitative research aims to understand human experiences and realities by interacting with people and producing rich, descriptive data (Munhall, 2012). The data that qualitative research deals with are words, which are collected and analysed in various ways (Braun and Clarke, 2013). Because of the competing demands on nursing knowledge and research to establish objective, safe parameters within a subjective world, both qualitative and quantitative data are valuable. It is because of this, that mixing complementary methods is popular within single or clusters of nursing research projects (Polit and Beck, 2004).

Giddings and Grant (2006) outlined the debate around whether mixed-methods research is a paradigm or a methodology. They concluded that it is a methodology that can effectively work within any paradigm. A review of mixed-methods research in nursing by Irvine et al. (2020) identified that this approach can be described as a pragmatic way to obtain a more thorough understanding of reality. However, mixing methods (also referred to a methodological triangulation) should be undertaken carefully and cautiously. This is because some methods have been developed from opposing philosophical positions (Polit and Beck, 2004). Subsequently, this confusion could deter nurse researchers from attempting triangulation. Morse (1991) argued that researchers should not focus on one type.

Instead, researchers should view methods as simply tools to facilitate new understanding, and embrace the versatility of mixing methods (Morse, 1991). Methodological triangulation can ensure the most appropriate methods are selected for each question. Furthermore, triangulation can form part of research validity testing because findings that are supported by multiple types of data increases confidence in the results (Webb, 1993; Polit and Beck, 2004). Finally, mixed-methods research is prioritised within the transformative paradigm.

Mertens (2008) suggests that instead of thinking about mixed methods within transformative research as a triangle, a crystal might be more appropriate. This is because a crystal is a prism that grows, changes and adapts, whereas a triangle is rigid and limited (Mertens, 2008). The mixed-methods researcher should be adaptable, integrating the quantitative and qualitative data to build a more nuanced understanding of their subject (Hesse-Biber, 2012). Although mixed-methods research should not be seen as “anything goes” (Giddings and Grant, 2006), the focus should always be on selecting methods that have the highest chance of increasing social justice and improving human rights (Mertens, 2008).

2.8.1 Justification for Mixed-Methods in this Project

As a team of healthcare and medical clinicians with professional and personal experience related to the caring role, we came to this project with diverging ideas of what type of intervention would be beneficial to caregivers. The transformative paradigm forced us to acknowledge these biases and strive to prevent them from disproportionately influencing the chosen intervention. It was hoped that by mixing complementary qualitative and quantitative methods, the chosen intervention would be developed from a variety of reliable findings and would have the highest chance at succeeding in supporting caregivers from Glasgow.

2.9 Transformative Intervention Design

The need for interventions that come from funders or emerge from community needs are suitable for the application of transformative intervention approaches (Mertens, 2008). Approaching intervention design from a transformative perspective allows researchers to draw on aspects of existing frameworks but through a transformative lens. Mertens (2007; 2008; 2010) outlines that a transformative researcher who is developing an intervention must:

- Use methods that are compatible with the values and traditions of a community.

- Select methods that bring community members together, such as focus groups.
- Seek needs assessment data.
- Take a cyclical approach, so that one inquiry informs subsequent decisions.
- Be ready to make adaptations to their plans when presented with new community findings or opportunities.
- Use community involvement and collaboration continuously.
- Integrate qualitative methods, including during evaluation.

These requirements are because transformative researchers believe that community members are best placed to articulate their needs and decide what is required to improve their lives (Mertens, 2008).

2.10 Step 1: Literature Reviews

Grant and Booth (2009) wrote that "gathering research, getting rid of rubbish and summarising the best of what remains captures the essence of the science of systematic review" (p26). In other words, a high-quality systematic review should produce a comprehensive overview of all primary research available within focused parameters to enable researchers to answer a specific question (Clarke, 2011). Literature reviews are useful tools to understand what is known about a topic, to identify gaps or inconsistencies, and to support the funding of research/projects (Polit and Beck, 2004). In nursing they are also used to inform evidence-based practice. It is for these reasons that a systematic review is a useful start to any doctoral research project. Depending on the research question, systematic reviews can take different forms (Grant and Booth, 2009). There are basic principles that should be followed, which include comprehensive search strategy, transparent inclusion/exclusion criteria and a synthesis of evidence (Clarke, 2011; Bettany-Saltikov, 2016).

The field of caregiver research is vast, with many overlapping disciplines having vested interests in understanding and supporting the caregiver role. There are already systematic reviews related to caregiver interventions. And yet, caregivers continue to experience mental and physical ill-health due to their caring role. This suggested that there may be a gap between academic, healthcare and caregiver priorities from interventions. Our reflective discussions identified that there may also be a lack of clarity and direction in what is deemed to be a successful intervention, which is judged by results from measured outcomes.

2.10.1 Justification for a Modified Systematic Review Approach

Outcome selection is a fundamental step in the research process and there are many outcome options available to researchers. In research related to life-limiting conditions and palliative and end of life care, Professor Johnston and Dr Quinn's previous work suggested that Patient Reported Outcome Measures (PROMs) are often utilised (Harrison et al., 2016; Johnston et al., 2017; Quinn et al., 2009). Patient Reported Outcome Measures set out to measure the impact of disease and interventions on aspects of daily living such as physical function, mental health, socialisation and wellbeing (Nelson et al., 2015). They are usually short, self-assessed questionnaires that are completed (at least) before and after an intervention to measure an aspect of the individual's life at that point in time (Ousey and Cook, 2011). There are methodological, ethical, and financial considerations when selecting outcome measures for caregivers. Researchers must select outcome measures that pose the least risk to the participants, as any adverse reactions experienced by participants may put the cared-for person at risk. Because we were striving to make meaningful change to the lives of caregivers through a supportive intervention, we decided that understanding how success is measured in interventions would be an insightful place to begin. We could then take our findings to caregivers and ask them how they compared to their priorities and understanding of what a successful intervention is.

A modified systematic review follows many of the steps associated with a systematic review. However, it falls short of the full process. Instead, a modified systematic review offers a narrative around catalogued trials (Grant and Booth, 2009). Although modified systematic reviews often do not include quality assessment, the method has been shown to produce insightful understandings of many related studies (Cornet and de Keizer, 2008). They are also recommended when forming one step of a bigger post-graduate project and when one person carries out most of the steps in the process (Barr-Walker, 2017; Grant and Booth, 2009). Because the primary extraction of studies was expected to be from Cochrane Reviews, quality assessment would have been undertaken elsewhere. Therefore, it would not be necessary to repeat this process.

2.11 Step 2: Secondary Data Analysis

There is no doubt about the power that data yields. Therefore, it would be reasonable to assume that those who collect and have access to data will also hold power and influence. This is not necessarily the case. The collection of health and social care data that is then used to inform clinical practice, service evaluation and resource allocation that affects entire populations is routine, daily practice for registered nurses and yet, registered nurses are not typically taught data science in undergraduate degrees. Data science “deals with various aspects including data management and analysis, to extract deeper insights for improving the functionality or services of a system (for example, healthcare and transport system)” (Dash et al., 2019). However, D’Ignazio and Klein (2020) argued that corporations and governments use aspects of data science such as analytics and management to maintain their power and reinforce an unequal status quo. To tackle this inequity in data power there is a need for more involvement in data science from women and people from other marginalised groups (D'Ignazio and Klein, 2020).

The concept of feminist data science was introduced by D’Ignazio and Klein (2020) in their book, Data Feminism. In it, the authors argued that there is a need for data science to be undertaken from a feminist perspective. This is because historically data science has been a male dominated pursuit that is used to reinforce patriarchal power structures. Data feminism is data science that seeks to create knowledge that tackles inequality and amplifies the voices of marginalised groups. They outline seven core principles of feminist data science that are incorporated throughout this thesis:

1. Examine power
2. Challenge power
3. Elevate emotion and embodiment
4. Rethink hierarchies
5. Embrace pluralism
6. Consider context
7. Make labour visible

Secondary data analysis is the analysis of previously collected data collected to test new hypotheses or explore new relationships (Polit and Beck, 2004). Analysing existing datasets is commonplace within nursing and healthcare research. This is because health and social care services have moved away from disease-focused care to more streamlined, person-centred and data driven care (Sousa et al., 2019). Although it might not be recognised as such, data analysis is routine practice in clinical nursing. This means that the volume of health and social care data is growing exponentially. Using readily available data for service evaluation can mitigate some of the most pressing financial challenges to modern health and social care services (Islam et al., 2018). Furthermore, analytics-based decision making is a fundamental component of value-based healthcare. Value-based healthcare is an emerging approach that aims to increase the value of existing resources available to a population (Gray, 2017).

Maximising the value of services that aim to support caregivers of people with life-limiting conditions is vital due to the growth in this population and increasing complexity of the role. It is unrealistic in the current economic climate to expect services to expand at the same rate as the number of caregivers. However, as the volume of data grows, so too do the variations within that data and the number of different platforms that store health and social care data. Furthermore, Dhindsa, et al. (2018) warned that although there is considerable hype around data analytics from existing healthcare data, the data itself can be of very poor quality. The real-world variances in routinely collected healthcare data often renders analytics impossible (Dhindsa et al., 2018). This is because healthcare data often includes free-text and images that reduce the possibility of achieving robust analysis (Baro et al., 2015). There may be meaning and insight to a human clinician reading an assessment. However, once the databases grow to a significant size, computer programs fail to create knowledge and insight of any worth. Because health and social care data have the potential to improve efficiency and cost effectiveness as well as save lives, these challenges must be overcome (Raghupathi and Raghupathi, 2014). Opportunities for clinicians to become involved in the analysis of routinely collected data should be welcomed and their experiences shared to ensure learning and development is distributed equally.

2.11.1 Justification for Secondary Data Analysis

Within the Glasgow City Health and Social Care Partnership there was an existing and well-established caregiver service that is overseen by the Social Work department. This service was set up in 2012 and had been reviewed annually, with its budget and reach growing year on year. It was important that we understood what type of help was already available to caregivers from Glasgow to prevent duplication of work, and to identify any opportunities for integrated working. As part of routine practice, the service records all caregiver assessments they undertake. Their database is reviewed and updated annually to assist with making important decisions around funding, staffing and efficiency. Furthermore, the assessments are periodically audited to gauge quality of care and identify training needs in the team.

It was decided that analysing routinely collected data accessed from this service would be a useful opportunity to develop secondary analysis skills, understand the challenges and opportunities that exist in routinely collected health and social care data and access needs assessment data that Mertens (2008) encourages transformative researchers to use whenever possible. As recommended by Dwanka-Mullan et al. (2010), this step gave me the opportunity to understand the primary support service available to caregivers in Glasgow. By considering the demographics of people who access the service, I was able to compare findings with existing evidence to understand how effective the service is at reaching caregivers. It serves as an opportunity to understand the population of caregivers in Glasgow who identify, or are identified, as requiring support to undertake their caring role that would otherwise not be possible. It was hoped that this would facilitate deeper understanding of this hard-to-reach population with minimal disruption to their lives and highlight the important work being carried out by the Carers Support Service.

Undertaking secondary analysis of routinely collected health and social care data from a feminist perspective with D'Ignazio and Klein's (2020) seven core principles, will also help to inform the development of data feminism and address issues relating to routinely collected data from a feminist perspective.

2.12 Step 3: Focus Groups

When deciding what method(s) of qualitative enquiry to use, Braun and Clarke (2013) suggest that researchers are guided by their chosen framework and research question, as they should work in symbiosis. My qualitative study was concerned with understanding how caregivers contextualise their experiences with interventions and services. Contextualist analysis accepts that people's interpretations of their lived experience offer valuable insight into our understanding of the world. The understanding of these experiences is also influenced by the setting in which they are shared (Madill et al., 2000). It is also important for researchers to be transparent about themselves because characteristics such as sex, age and ethnicity will influence the produced data and knowledge that is created from it (Madill et al., 2000). This is also a prerequisite for transformative and feminist research.

Focus groups are group discussions where participants discuss a topic chosen by the researcher. Participants can be prompted to discuss the topic(s) using films, photographs, stories, or a set of questions (Wilkinson, 1998). Focus groups create data from interactions between participants that would be unlikely to be created through other forms of qualitative data collection, such as interviews (Wilkinson, 1986; 1996; Polit and Beck, 2004). However, within feminist research, focus groups should not be selected only because they can be beneficial to the researcher, but for possible benefits to the participants. It is thought that by sharing experiences within a group setting with people who share characteristics, negative, troubling or unexpected emotions, understandings and thoughts will be normalised (Wilkinson, 1998). Personality type can affect participation in focus groups, as some people may not be comfortable sharing opinions or ideas that divert from group think (Polit and Beck, 2004). This is one of the reasons why group moderation is important in focus groups. The moderator should direct the group to ensure that all participants feel safe to contribute and prevent dominating people from taking over the discussion (Polit and Beck, 2004).

Focus groups with caregivers of people with life-limiting conditions have been successfully used to create insightful knowledge. However, there are limitations to experiential, contextual data. Polkinghorne (2005) argued that the quality of the data produced is dependent on the participants reflective and communication skills. This is because the researchers are not directly observing the experiences they wish to understand (Polkinghorne, 2005). Instead, it is the participants recollection and understanding of those experiences that are being replayed and shared. This was why I intended on undertaking focus groups with established support groups. It was hoped that participants would be known to each other and would support each other to reflect on their experiences in the setting of one of the types of interventions I wanted to understand. I was awarded £900 from the Elizabeth Stanfield Bell Wilson Scholarship to help with costs related to the focus groups, which included venue hire, providing light snacks and refreshments and a £20 voucher following participation.

2.12.1 Justification for Focus Groups

The purpose of exploring caregiver interventions and services from a contextualist perspective using focus groups was to understand how caregivers decide themselves what is useful and effective from interventions. I predicted that, as a district nurse, some (or most) of the participants would have had experiences with district nurses and might focus on their healthcare experiences if they were to speak to me in an interview. I wanted to limit this because I was interested in learning about all types of interventions and experiences. It was hoped that by offering a group of caregivers, who all know each other, open-ended questions they would support one another to reflect on a broad range of interventions and services.

2.13 Patient, Caregiver and Public Involvement

There is an expectation within transformative research that researchers will prioritise continued community participation and be sensitive to power dynamics between researchers and participants (Mertens, 2008). In a similar ethos to the transformative paradigm, the National Institute for Health Research (NIHR) champions the use of Patient and Public Involvement (PPI) (NIHR, 2021). The NIHR (2021) define PPI as “research being carried out with or by members of the public rather than to, about or for them”. They emphasise the importance of an active partnership between patients, caregivers, members of the public and researchers to influence the research process. Because of this, they have a wide range of resources to support PPI and it is increasingly expected that research will be difficult to fund without PPI involvement. At its best, PPI is a dynamic process that involves volunteers having an advisory role on all aspects of the research process, and offering expert feedback (Jackson et al., 2020). However, Jackson et al. (2020) suggested that because of PPI expectation from funders, it is increasingly seen as a tick box exercise. Furthermore, it can be tempting for researchers to employ it superficially instead of deal with the associated practical and conceptual challenges. Challenges associated with PPI include a lack of finances, logistical and time pressures, especially when recruiting volunteers from vulnerable populations, and recruitment difficulties. Nonetheless, these challenges are not unsurmountable. With the length of time allocated for this project, as well as a small amount of funding, there was no reason to expect the common challenges could not be overcome.

2.13.1 The role of Patient, Caregiver and Public Involvement in this Project

Although the NIHR (2021) use the term PPI, there are various terms, including Public Involvement and Patient, Caregiver, and Public Involvement, which are also used. For this project, I have selected Patient, Caregiver, and Public Involvement (PCPI). I have done so because it is important to acknowledge that caregivers involved in this project are voluntarily sharing their expert opinion related to the caring role, which is distinct from that of a patient and the public. Patient, Caregiver and Public Involvement was a mandatory aspect of this project and recruitment was carried out early in second year prior to any data collection activities. The primary method of recruitment was from a public event organised by a group of PhD students that was held in an accessible location in the city centre of Glasgow. At this event, each student gave a brief overview of their subject and volunteers could opt into any project that took their interest. I recruited Charles, who cared for his wife following a stroke. After an extended hospital stay, she was discharged to a care home, where she lived for a short period of time before her death. Charles input was of value because he is a male caregiver who has lived experience of caring for someone with a life-limiting condition at home and in a care home. These experiences became invaluable as the project progressed.

Initially, Charles and I met in a public venue of his choice. We met every 3-6 months depending on my workload and his availability. Our first two meetings lasted over two hours and were primarily spent getting to know each other, sharing our experiences in caring roles and background information about our families and work. This was while I was undertaking the secondary analysis study, so Charles gave his opinions on the early findings, primarily sharing his experience as a male caregiver in a predominantly female population. His opinion gave me the confidence to pursue this line on enquiry that became a recurring topic throughout the project. These initial meetings created a strong foundation from which a solid, collaborative relationship grew. He subsequently became involved in the focus group study, offering advice on focus group arrangements, topics of discussion and identified themes. During the Covid-19 lockdown we corresponded by email, as written correspondence was preferred by Charles over telephone communication.

I aimed to have two or three PCPI volunteers and recruited from the social media platform, Twitter. From this, I had two further PCPI volunteers who had advisory roles. One volunteer, Sophie, was caring for her mother with dementia, but who subsequently died. She is also a community nurse. The second PCPI volunteer recruited from Twitter was Janice. She was a caregiver to her husband with dementia and continues to be heavily involved in supporting caregivers through a caregiver charity. Meetings with Sophie and Janice were on the telephone, as both live in England. Because of the distances between me and the volunteers, these discussions were more general and related to the project in its entirety. We compared the overarching findings with their experiences. Both volunteers were able to share their experiences in multiple roles, such as caregivers, professionals, and advocates, and how they managed challenges that arose when the roles collided. These discussions led me on to think about the caring role as a distinct identity and the implications this could have on an intervention. Communication ended with Sophie following her mother's death, and Janice during the pandemic.

2.14 Ethics Overview

Research ethics relates to the expectation that researchers will consider relationships with participants, academic communities and wider society (Braun and Clarke, 2013). Nursing research is also governed by the ethical principles set out in the Declaration of Helsinki 1964, which was first developed for medical research but now extends to all research that involves human subjects, data, and tissue. The declaration emphasises the importance of upholding participants' safety, respect, rights, and health above all else. This is also referred to as beneficence; to do no harm (Polit and Beck, 2004). Research related to vulnerable groups requires specific safeguards and considerations, and any benefits generated from this research must be shared with the populations involved. Vulnerable populations are defined by Wilson and Neville (2009) as groups who are exposed to increased risk and health burden compared to the general population. They are often marginalised because they experience social, economic, and political discrimination, and usually depend on others (Wilson and Neville, 2009). These issues act as barriers to accessing health and social care support and can also increase risk when participating in research (Wilson and Neville, 2009). Anderson and Hatton (2000) made the following ethical recommendations for conducting research with vulnerable people:

1. Care should be taken when considering location of research activities. Locations should be accessible and have space for researchers to be around after meetings if participants want to discuss anything or debrief further.

2. Researchers should take time to discuss their research activities with colleagues. This is because exploring the adversity experienced by vulnerable populations can trigger feelings of helplessness and researchers can become overwhelmed.
3. Be respectful and considerate of external professionals who help with recruitment and conducting research activities. When working with vulnerable people, professionals can experience any number of psychological and professional challenges, and researchers have a duty to support them.

2.14.1 Ethics in Feminist Research

There is an argument within feminist theory that conducting research on oppressed groups for self-gain creates a conflict of interest. This was an issue that I grew increasingly aware of as my project progressed and is not something I have managed to resolve. To counter this issue, I increasingly used my social media accounts to follow caregivers and share their posts so that they reached wider audiences. I also consciously increased my advocacy for caregivers in my professional role; I attended meetings and volunteered for professional steering groups whenever the opportunity arose to create opportunities to encourage caregiver consideration and support. Studying vulnerable populations also risks objectifying participants rather than viewing them as equal partners in the research process. Transformative research requires researchers to prioritise building trust and relationships with their population(s) of interest. In doing so, this should ensure that researchers maintain their advocacy and develop cultural competency. A key part of this should be to only make promises that will be kept (Mertens, 2008). Successful transformative research will likely have an impact on wider society due to shifts in resource allocation. Researchers must have realistic aims and objectives. They should also be mindful of likely increased scrutiny, as researchers who question existing power structures will encounter people who benefit from the status quo and will try to prevent change (Mertens, 2008).

2.14.2 Ethics in Caregiver Research

Transformative and feminist research requires researchers to share information about themselves with participants. Participants in this project understand that they are speaking to a registered nurse. It would be dishonest not to consider that this may influence their feelings towards the researcher(s) and is a worthy reflective consideration. A benefit of experienced, registered nurses undertaking research is that we have the necessary skills to identify people who require emotional support and tailor our communication and body language appropriately. Furthermore, there is a legal obligation for registered nurses in the UK to work within the standards set out in the NMC Code of Professional Conduct. It is likely that caregivers of people with life-limiting conditions will have had many interactions with nurses and this could influence their feelings towards the profession, nursing research and their participation, especially if they have had negative experiences. Nevertheless, it is vital that nurse researchers and participants are mindful that any meetings are strictly for research purposes (Polit and Beck, 2004). Caution should be taken not to develop a pseudo-therapeutic relationship, particularly with qualitative research. When this occurs, it increases the nurse researchers' responsibilities and increases the participants risk of exploitation (Polit and Beck, 2004). Clinical advice should not be offered, unless the safety of a participant or someone for whom they care could be compromised.

When conducting research with caregivers, there must be extra consideration for the person for whom they care. This is because any negative consequences or side-effects experienced by caregivers due to research participation has the potential to put other vulnerable people at risk. For people with advanced illness, who could be approaching the end of their lives, the risk/benefit ratio for their caregiver participation needs careful consideration (Polit and Beck, 2004). Houde (2002) also suggested that as male caregivers are under-researched, researchers should consider using recruitment techniques that actively target men. He also recommended disaggregating data by sex and being mindful of the relationship that male caregivers have with the person for whom they care. He advocated that researcher's consider highlighting data from husbands or sons to enable a deeper understanding of the experiences of men who have caring responsibilities.

2.14.3 Ethical Approval

Obtaining ethical approval from an institutional or external review board is a valuable way to ensure that research with vulnerable people meets local, national and international ethical standards (Anderson and Hatton, 2000; Polit and Beck, 2004). Ethics applications for all research studies within this project were written by me and approval was obtained by the University of Glasgow Medical, Veterinary and Life Sciences (MVLS) ethics committee.

2.15 Chapter Summary

This project is underpinned by the transformative paradigm to ensure that the chosen recommendations would prioritise the needs of the caregiver above other competing demands. It was hoped that by combining transformative approaches to intervention design with feminist theory, learning from existing evidence will develop alongside a respectful challenge to the conventional approaches used within this rich field of research. This was necessary because whilst there is extensive existing evidence, there is also pervading marginalisation of caregivers. In doing this, I hoped to identify or develop an intervention or interventions that could make more meaningful improvements to the lives of caregivers in Glasgow. Finally, mixing complimentary qualitative and quantitative methods was selected to ensure that any decisions related to the chosen intervention were made with an open mind, led by the data I was presented with to effectively support caregivers from Glasgow.

Chapter Three: A Modified Systematic Review

3.1 Introduction

Chapter One evidenced the complexity in caring for someone with a life-limiting condition and the wide range of associated consequences many caregivers experience. To address the variable experiences and negative consequences associated with the role, there is an array of interventions that have been designed, tested and evaluated through systematic review and meta-analyses. Ultimately, it is the efficacy of these interventions that will inform how likely they are to reach caregivers outside of trial research and make meaningful improvements. To measure the efficacy, researchers are required to select appropriate outcome measures. Patient reported outcome measures (PROMs) measure various aspects of healthcare, including drug treatments, interventions and even hospital performance from the patient (or caregiver) perspective (Kingsley and Patel, 2017; Devlin et al., 2010). Although the development of these types of outcomes are expected to involve input from patients and caregivers, much of the process is directed by researchers (Makrinioti et al., 2020). Therefore, they will be influenced by funders, and researcher(s) priorities. Consequently, examining and describing what outcome measures are selected in intervention trials offers an insight into researcher priorities.

For interventions that aim to improve care, the design process often starts by defining and understanding the issue that requires an intervention, this then leads onto the selection of the intervention and ends with how it will be evaluated (Mertens, 2008; O'Cathain et al., 2019; Skivington et al., 2021; Wight et al., 2016; Zipfel et al., 2020). Depending on the model used and the team's expertise, these stages may be given different levels of time and attention (Wight et al., 2016). However, the intervention design process should be a creative and dynamic process where stages may need to be revisited (Mertens, 2008; O'Cathain et al, 2019). Consequently, researchers should expect to be reviewing evidence, considering theory and working with stakeholders in overlapping cycles (O'Cathain et al., 2019). It has also been suggested that researchers consider looking ahead to evaluation at an early stage because this will help to identify barriers and facilitators to implementation (O'Cathain et al., 2019). There is no consensus on what the success of caregiver interventions looks like. By taking time to consider what outcome measures are used in caregiver intervention research at this early stage in the project, I could start to plan the evaluation of my chosen intervention(s) and revisit this plan regularly. It would also help me to become more familiar with caregiver intervention research. This would ensure that when I began working with caregiver community members, I understood what researcher priorities were to then begin to compare them to caregivers' priorities. Identifying where these priorities align and differ would help me to select appropriate interventions and anticipate barriers I might face to the implementation of the findings of this project.

Although researchers must ensure only necessary and appropriate outcomes are selected regardless of the population of interest, extra care is required when research is related to caregivers. This is because any adverse reactions experienced by participants could potentially put the cared-for person at risk. The availability of time that the participant must be released from their caring role should be spent wisely. Selecting the appropriate PROMs in this environment can be challenging as there is an inevitability that symptoms associated with life-limiting conditions will worsen and their condition will deteriorate (Antunes et al., 2014). Therefore, the role of the caregiver will likely change and become increasingly complex, which is not something that an intervention can control for. However, it is not inevitable that all trials related to interventions for caregivers of people with life-limiting illnesses will only measure their success with PROMs. Other outcome measures, such as physical examinations and laboratory testing may also be carried out. The practical challenges combined with the ethical considerations are why the selection of outcome measures in trials associated with life-limiting conditions and caregivers is so important.

Using a well-validated tool is the best way to ensure research findings are coherent and accurate regardless of the perceived complexity of the intervention and/or outcome measures (Antunes et al., 2014; Johnston et al., 2017). Heterogeneity in the assessments used as study outcomes has been demonstrated in many areas of clinical research, including stroke (Quinn et al., 2009) dementia (Harrison et al., 2016) and cardiology (Rahimi et al., 2010). This inconsistency in outcome assessment complicates comparative or pooled analysis and can be a barrier to research progress.

Therefore, this modified systematic review sought to describe the outcomes used in caregiver researcher, with an emphasis on three exemplar non-cancer chronic conditions: stroke, dementia, and heart failure. These conditions also represent the archetypes of caring roles, including symptoms management (heart failure), physical disability (stroke) and cognition (dementia). Their inclusion maximises the potential to capture a range of outcome measures that reflects the diversity of caring.

This step in the intervention selection process precedes a qualitative step. Findings based on quantitative data should be complimented by findings based on qualitative data for research that is guided by the transformative paradigm (Mertens, 2008). The findings from this step informs questions put to caregivers during focus groups. Caregivers were asked about how the focus of the quantifiable outcome measures and intervention types implemented by researchers compare to what matters to them. Finally, the pooling of data from quantifiable measures is routine practice when deciding resource allocation for research and clinical practice (Mansfield et al., 2017). It may be that there is an overreliance in these types of outcome measures within caregiver research, contributing to a large body of research without reducing the marginalisation for caregivers. However, combining the results of these types of outcome measures continues to be relied upon. This is because they are widely accepted to facilitate understandings on the effects of interventions on unambiguous, commonly understood health and wellbeing outcomes (Wiercioch et al., 2021). It is because of the dependency on PROMs that Boyce et al. (2014) called for future research to “disentangle” (p.17) the motivations behind their selection and use to better understand their impact on quality of care.

The use of PROMS and the ability for participants to accurately complete them is impacted on a person’s health literacy, which is influenced by a person’s age, sex, ethnicity and socio-economic status (Eriksen et al., 2022). Researchers who recruit people from marginalised groups must ensure the outcome measures they select do not create a burden for participants (Eriksen et al., 2022). “Disentangling” the use of PROMS within caregiver intervention trials will ensure the outcome measures recommended for the suggested interventions are only the most appropriate with the strongest evidence base.

3.2 Methods

3.2.1 Aim and Objective

Aim

- Evaluate how caregiver interventions measure their success.

Objective

- To describe the outcomes used in trials of supportive interventions for adult caregivers of people living with heart failure, dementia, or stroke.

A modified systematic review approach was used, whereby a systematic search of key databases was followed by a synthesis and narrative of findings, with some tabular presentations and no quality assessment completed (Grant and Booth, 2009). The PRISMA guidelines were adhered to for reporting where relevant. The protocol was registered on Research Registry (reviewregistry:437).

3.2.2 Search Strategy

This review is not intended to provide a comprehensive review of all caregiver intervention studies. Rather, the devised search strategy should present an overview of the field. This approach is in keeping with previous reviews of population specific outcome assessments (17-19). The Cochrane database was the primary source of trial extraction. Cochrane systematic reviews were obtained by manually searching review group databases. The titles and abstracts were screened for studies that included caregivers as participants and/or caregiver outcomes.

Recognising that Cochrane reviews may not include contemporary studies, the Cochrane database search was followed by a time limited search (01/01/15-31/12/17) of CINAHL (EBSCO), Medline (OVID) and PsycInfo (EBSCO) databases. (Appendix 1 for search syntax.)

3.2.3 Selection Criteria

Trials were included if they used quantitively measured caregiver outcomes from interventions that aimed to improve adult caregivers' physical and psychological well-being and/or their ability to function in their caring role. Trials were excluded that did not report caregiver-specific outcomes, even if caregivers participated in the trials. Qualitative studies were excluded and trials where the intervention was respite care for the cared for person. Data obtained from conferences, unpublished studies and personal correspondence were excluded.

I screened titles and abstracts were screened, followed by full-text assessment of relevant results using Covidence (Veritas Health Innovation, Australia). Results were discussed with both supervisors, with disagreements resolved through discussion until consensus was reached.

3.2.4 Data Extraction and synthesis

Data were extracted that related to intervention, primary caregiver outcomes and secondary or un-categorised caregiver outcomes. I carried out the data extraction process and discussed with the supervisory team when guidance was required.

Because of the scale of heterogeneity that quickly became apparent, outcome assessment tools were classified in relation to the construct it was attempting to measure. The construct classifications were created by scoping the categorised outcome measures:

- ‘Psychological experience’ was used when the tool was attempting to measure an experience or symptom of the caregiver’s mental health, such as depression or anxiety.
- ‘General health’ was used when the tool was attempting to measure aspects of overall wellbeing or included aspects of physical health.
- ‘Coping’ was used when the tool measured physical and/or psychological aspects specific to caring in one tool, for example the caregivers perceived control over their caring role, or the quality of relationship between the caregiver and cared-for person.
- ‘Social support; was used when the use of community support and/or social services, or the caregivers support network (engagement with friends, family, etc.) were measured.
- ‘Disease knowledge’ was used when the tool attempted to measure the caregivers understanding of an aspect of the condition.

I also categorised each outcome measurement tool into validated or bespoke categories:

- A validated tool was one that had described previous validity and reliability testing.
- A bespoke outcome measure was one that was described by the study authors as being designed for that study, or where the researchers used an adapted version of a previously validated tool to fit their study.

The interventions were grouped into six categories for ease of interpretation due to the heterogeneity in intervention terminology. Again, this was done by scoping the results. Categories included:

1. ‘Psychotherapy’ typically included a cognitive behavioural intervention or counselling
2. ‘Education/training’ interventions usually involved training the caregiver (and sometimes the cared-for person) in an aspect of carrying out the caring role (such as coping with problematic behaviours) or disease management (such as oral care)
3. ‘Case management’ was used when the intervention was explicitly stated or implicitly described as case/care management
4. ‘Support (or enhanced support)’ typically blended more than one style of intervention with the aim of supporting the caregiver to continue in their caring role
5. ‘Alternative’ interventions included spiritual, mindfulness and reminiscence interventions
6. ‘Exercise’ interventions involved teaching the caregiver exercises that they could mediate with the cared-for person.

3.3 Results

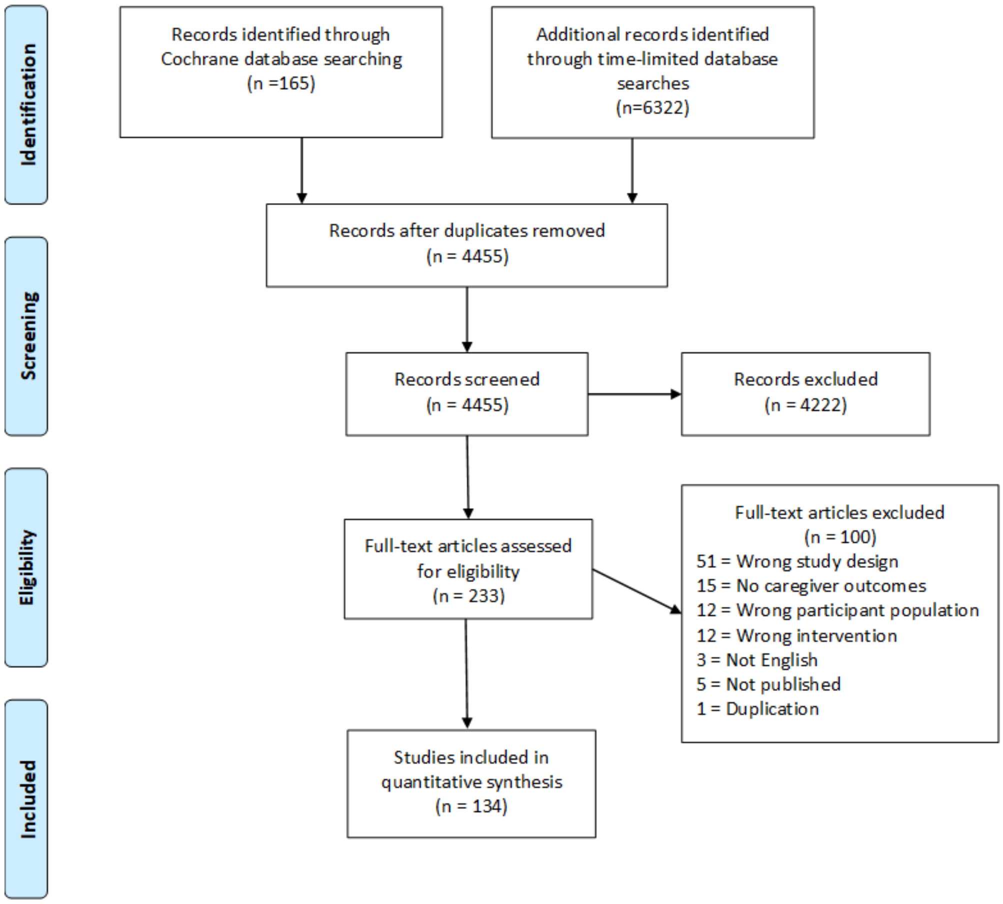


Figure 1: PRISMA chart of database search results.

Table 1: Intervention types grouped by diagnosis of the person requiring care.

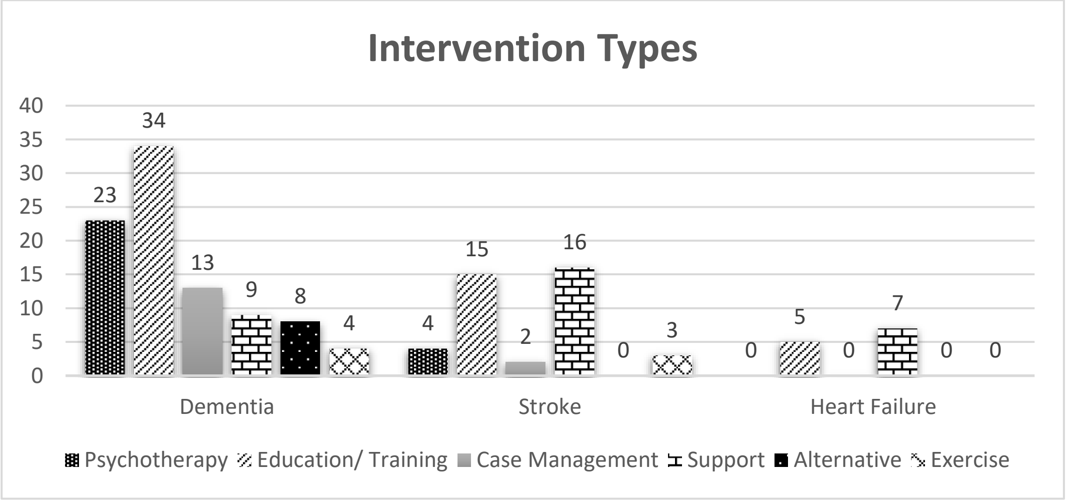
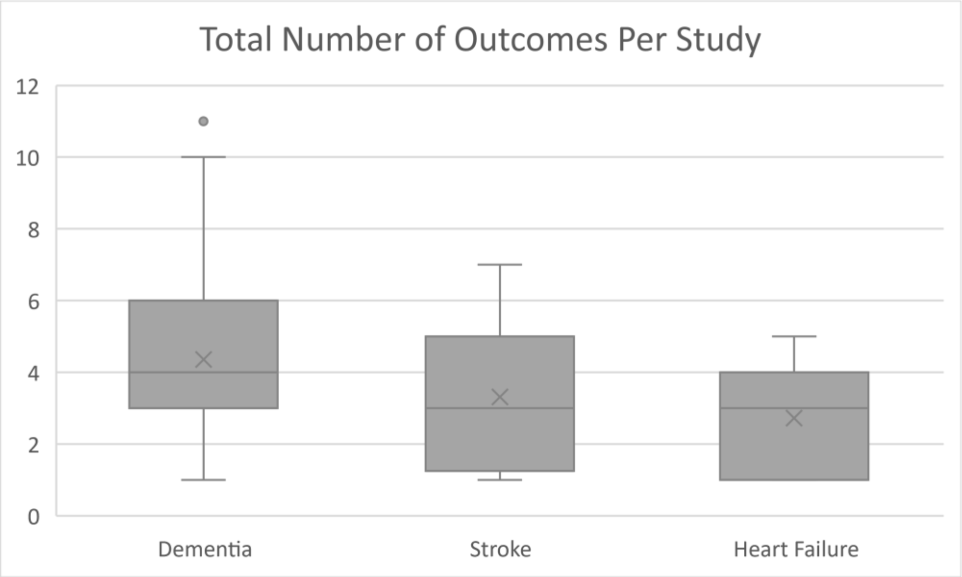


Table 2: Overview of outcomes of included studies by diagnosis of the person requiring care

	Dementia	Stroke	Heart Failure
Total No. of Studies	91	32	11
Total No. of Outcomes	176	76	22
Median number of outcomes per trial* IQR Range	4.4 3	3.3 3.25	2.7 2
Most Used Outcome Measure Tool(s)	CES-D N=30	SF-36 N=9	BDI N=2 SF 36 N=2 CES-D N=2 FAD N=2
No. of Bespoke Measure Tools (% of total number of outcomes)	55 (31%)	20 (26%)	4 (18%)

*Significant difference, p=0.01

Table 3: Box and Whisker Plot of the total number of outcomes per study grouped by diagnosis of the person requiring care.



A total of 134 trials were included in the analysis (Figure 1). Overall, 29% of outcome measures were bespoke (n=79/266) (Table 2). The overall mean number of outcomes per trial was four (RANGE:1-11) (Table 3). There was variation between diagnosis groups in the average number of outcome measures and the tools used. Table 4 shows that the psychological experience-based outcomes appeared among the most popular tools in all three groups. (Appendices 2-5 are detailed results of included trials, interventions and outcomes.)

Table 4: Construct measures of all outcomes (grouped by diagnosis of the person requiring care) including primary outcome measures

	Dementia	**Stroke**	**Heart Failure**
Coping	67 n=25	19 n=3	9 n=2
Psychological Experience	45 n=21	17 n=1	9 n=1
General Health	29 n=4	13 n=1	3 n=1
Disease Knowledge	5 n=2	10 n=1	1 n=0
Social Support	21 n=0	17 n=1	0 n=1
Miscellaneous	2 n=3	0 n=0	0 n=0
Studies with no primary caregiver outcome(s) or unspecified outcomes	36	25	6
***n= number of outcomes that were list as primary outcomes**			

Trials relating to the caregivers of people with dementia represented the largest group, with 91 trials (68% of total trials included) (Table 2). This group had the largest variation in number of outcome measures, with 176 outcome measures used and 139 of those only used in one study (Table 3). The most used tool was the Centre for Epidemiology Studies Depression Scale (CES-D) (n=30 trials) (Table 2). However, there were seven other tools that measured depression or depressive symptoms, most of which were used in only one trial. The second most-used tool was the Zarit Burden Inventory (ZBI) (n=23 trials). The Revised Memory and Behaviour Problem Checklist (RMBPC) was used in 13 trials, of which three were variations, including a modified version and two subscales used. The caregivers of people with dementia were the only group that also included outcome measures obtained from laboratory testing or physical examinations and miscellaneous measures that related to finance and safety (Table 5).

Table 5: Outcome measures obtained from a physical examination or laboratory test.

Test	**Outcome measure**	**No. of Trials**
Salivary cortisol	Stress	3
Catecholamines	Influence hypertension and ischemic heart disease	1
Plasma cortisol	Stress	1
Plasma renin	Stress	1
Plasma aldosterone	Stress	1
Actigraph monitor	Sleep quality	1
Plasma biomarkers	Stress	1
Heart rate	Stress	1
Blood pressure	Stress	1

Of the 32 studies that related to caregivers of stroke survivors, there were 76 different tools used to measure caregiver outcomes. Fifty-seven (75%) had been previously validated, with the remaining measures developed for their specific trial or adaptions/subscales of previously validated tools. The most popular tool used was the Short Form-36 (SF-36) (n=9 trials) used three times as a primary outcome. The CES-D was used in seven trials but only once as a primary outcome. The Caregiver Strain Index (CSI) and the Hospital Anxiety and Depression Scale (HADS) were used six times. The CSI was not listed as a primary outcome in any of the studies and the HADS was listed as a primary outcome twice. Disease knowledge was measured by ten tools, six of which were from bespoke questionnaires, making disease knowledge the most measured construct by a bespoke measure.

Of the 11 studies that related to caregivers of people with heart failure, four tools (Short Form Health Survey (SF-36), Beck Depression Inventory (BDI), CES-D and Family Assessment Device Questionnaire) were used twice, with all other tools used once. Most (n=18) of the tools that were used were validated, with one study using three bespoke measures. Depression was the most measured outcome, with four tools used to measure this (BDI; Beck Depression Inventory II (BDI-II); HADS; CES-D, all of which are validated. Quality of life was measured twice, using the SF-12 and SF-36. Five trials had an explicit primary outcome that was related to measuring an aspect of the caregiver.

3.4 Discussion

3.4.1 Overview

Inconsistency was identified in many aspects of measuring outcomes in caregiver intervention research. These inconsistencies included:

- Outcome selection
- Outcome implementation (including what they purported to measure)
- The use of bespoke and adapted/modified tools
- Outcome prioritisation between primary and secondary outcomes.

The prevalence of outcome measures with a psychological focus suggests some agreement in direction of supportive interventions for caregivers. However, there was a difference of opinion in the aspect of psychological impact (burden, strain, and depression all among the most popular outcomes) should be measured. The prioritisation of psychological impact from caring is understandable because of the variety of risks reported by caregivers, which includes depression, anxiety, stress and physical injury when caring for someone with a life-limiting condition (Carers UK, 2012). However, heterogeneity remained among the tools used to measure psychological consequences. For example, caregiver burden, a widely accepted complex experience that often occurs as part of caregiving was measured using ten different tools. Physical examinations and specimen tests were uncommon and only used in trials related to caregivers of people with dementia. Indeed, there does not seem to be any guidance available for researchers on the use of physical examinations and specimen testing in relation to caregiver intervention outcomes.

3.4.2 Outcome Selection

The heterogeneity in outcomes is also seen in outcomes used in the trials looking at specific diseases (Johnston et al., 2017, Quinn et al., 2009, Harrison et al., 2016). Such heterogeneity suggests that researchers have not established clear priorities and objectives for intervention trials related to life-limiting conditions. This may suggest that the people involved (the cared-for person and their caregivers) are not adequately consulted during the research process.

Moniz-Cook, et al. (2008b) recommended that outcome measures for caregivers involved with dementia research include psychological experience, burden, coping with behaviour and quality of life (QOL). The specific tools that are recommended include the CES-D and HADS for anxiety and depression, the GHQ for general distress and ZBI for burden, with more research required for QOL measures (Moniz-Cook et al., 2008b). In this review, there was some consensus around QOL tools as the SF-12/36 was the most popular tool in all three caregiver groups.

A structured review of PROMs for the Department of Health (Jenkinson et al., 2009) recommended the EQ-5D, which measures QOL, as an appropriate measure for stroke research. However, this recommendation is in relation to the stroke survivor and not necessarily their caregiver. The EQ-5D was cited in four studies within the stroke survivors' caregiver group. Qualitative interviews by Patchick et al (2014) with stroke survivors suggests that caregiver burden should also be a priority.

There is a dearth of literature concerning PROMs in the field of heart failure research. Two existing reviews did not find caregiver outcomes as a focus nor did they recommend their increased consideration or inclusion (Boren et al., 2009; Holland et al., 2009). However, Evangelista et al. (2016) reviewed interventions that aim to improve psychological outcomes for caregivers of people with heart failure. The authors identified that the most popular outcomes were caregiver burden (n=6), quality of life/health related quality of life (n=3), anxiety (n=3) and depression/depressive symptoms (n=4). These were followed by perceived control (n=1), stress mastery (n=1), caregiver confidence and preparedness (n=1), and caregiver mastery (n=1) (Evangelista et al., 2016).

Chang, et al. (2014) reviewed outcomes that are important to people with heart failure and found that caregiver burden, functional status, symptom management and survival were all priorities. Yet not all outcomes are of equal value to the caregiver and person for whom they care. Priorities may also change as the disease progresses. This caregiver group also yielded the smallest number of results from the Cochrane and database searches, which suggests an urgent need for more heart failure caregiver intervention research and reviews of existing studies.

Some of the variances identified could be addressed using pre-determined outcome measures. The COMET (Core Outcome Measures in Effectiveness Trials) Initiative is a database of literature related to core outcome sets (COS) that aim to specify an agreed minimum set of outcome measures, with consideration given to “what” and “how” this is carried out (http://www.comet-initiative.org/). Although COMET do not have a caregiver-specific COS, caregivers are mentioned as stakeholders in many of the COS development descriptions. Furthermore, there is a caregiver-specific recommendation within a COS related to dementia (caregiver burden) (McGrattan et al., 2018). However, there are missed opportunities for caregiver outcomes. For example, a COS for breathlessness at the end of life does not have a caregiver outcome recommendation, and yet the authors acknowledge that this symptom of advanced disease can be damaging for caregivers who witness it (Dorman et al., 2009).

The use of a COS would not prevent the use of additional necessary outcomes but would set a minimum standard from which the findings could inform robust systematic reviews and meta-analyses (Williamson et al., 2020). There is scope for multiple COS to be developed in relation to topic areas depending on diagnosis, intervention, or population. In relation to caregivers, there could be COS specific to life-limiting conditions, multimorbidity and interventions. Researchers could also consider whether there is a need for COS that are sensitive to sex, age, cultures, ethnicities, and locations within overarching topic areas.

Developing a COS specific to caregivers presents challenges. Researchers should consider whether COS are required by diagnosis or for a generic caregiver group. Furthermore, measures must be psychometrically robust while still capturing the nuances involved with caring for someone with a life-limiting condition (Ashford et al., 2015). It is important when working with potentially vulnerable groups, such as caregivers of people with life-limiting illnesses, that the measures are appropriate and safeguard participants. Due to these ethical and practical considerations, outcome measures that are selected should prioritise quality of life and family support (Hearn and Higginson, 1997). These challenges should not be insurmountable; instead, they highlight the importance of developing COS. Researchers and reviewers should work collaboratively to develop COS because of their potential to inform evidence-based practice by improving the reliability of findings from systematic reviews and meta-analyses (Williamson et al., 2020).

3.4.3 Outcome Implementation

There was ambiguity around the application and interpretation of certain outcome measure tools. The selection of tools and the concepts they are suitable for measuring is of fundamental importance in intervention trials. Inconsistent or inappropriate outcome measures could invalidate results and, consequently, impact the development of further interventions and trials (Quinn et al., 2009). Indeed, this finding is not uncommon. Evangelista et al. (2016) identified in their review that six studies used various tools to measure caregiver burden, one of which was the Caregiver Strain Index. This tool is designed to measure strain, not burden. The study that used the Caregiver Strain Index (Piette et al., 2015a) seemed to confuse caregiver strain and burden in their justification for using this tool, "…Caregiver Strain Index, a 10-item scale measuring strain from various potential sources of caregiving burden…" (p5). This explanation suggests that caregiver strain supersedes caregiver burden, rather than both being separate issues experienced by caregivers and requiring specific outcome measures.

An example identified in this review is the RMBPC, which is a valid and reliable tool that measures problematic behaviours typically associated with caring for someone with dementia, and their reactions/feelings to them. However, as an outcome it was used to measure other constructs such as caregiver burden, distress, and appraisal. Caregiver reactions to problematic behaviour is one aspect of caregiving that may contribute to the challenges of the caring role. Concepts like caregiver appraisal *(*which includes satisfaction and mastery (Lawton et al., 1989), are far greater than this one potentially challenging aspect of caring. The variation in what an outcome is considered able to measure suggests that researchers might be applying their own assumptions on what they consider to be the cause of burden/strain/appraisal etc.

Coping was a popular construct measure in all caregiver groups. However, it was broadly defined compared to other constructs. Outcome measures that related to coping ranged from how prepared the caregiver felt about undertaking their caring role (Preparedness for Caregiving Scale) to their desire to institutionalise the cared-for person (Desire to Institutionalise bespoke measure), to self-assessment of their competence in the role (Perceived Competence Scale). It is understandable that coping might be a necessary measure for caregiver intervention trials; if an intervention can enhance a caregiver's ability to cope with their role, then it is much more likely that the cared-for person will be safe and remain in their preferred place for as long as possible. However, there are validated tools to measure the explicit concept of coping, such as the Revised Ways of Coping Checklist (Vitaliano et al., 1985). Yet this tool was only used in one trial in its entirety, and a subscale used in one other.

A degree of inconsistency across disease groups is understandable because of the variations in role responsibility, unpredictability, and longevity. For example, the most used tools in the studies related to caregivers of stroke survivors were the Caregiver Burden Scale. However, the Zarit Burden Interview (ZBI) was the most used measure of burden among trials for caregivers of people with dementia. The ZBI was developed specifically for caregivers of people with dementia (Zarit et al., 1980) and the Caregiver Burden Scale has shown good validity and reliability when used to measure burden among caregivers of stroke survivors (Elmstahl et al., 1996).

3.4.4 Bespoke and Adapted/Modified outcomes

The use of bespoke/adapted outcomes was noted across all caregiver groups. In most studies the authors gave a description of their bespoke tool. However, there was often very little explanation why they opted to develop their own rather than using an established tool. Using tools that have previously undergone reliability and validity testing is important because these processes offer researchers reassurance that they are expected to measure the desired outcome consistently (Fitzner, 2007). This issue was also identified by Soobiah et al. (2019) who analysed the validity and reliability testing of 129 trials for people with dementia. The authors found that there was an overreliance on cognitive measures that did not have published validity and reliability testing. This is an important issue because using bespoke outcome measures impinge on an intervention's likelihood that it could be included in a systematic review or meta-analysis.

This also applies to the use of adapted and subscale tools that were used in many of the trials included in this review. There may be some concerns in outcome measure selection for potentially vulnerable groups and, therefore, there may be temptation to develop one that appears to fit better. However, outcome measures should not replace the therapeutic relationship; Instead, they should be used alongside it to instil a person-centred approach (Antunes et al., 2014). There may also be concerns regarding the suitability of older tools when there is new understanding and knowledge in a field of study, such as the management of life-limiting conditions. Concerns regarding the relevance of existing outcome measures should be based on a thorough assessment of their use to inform decisions around potential misuse and reliability (Rahimi et al., 2010). Adhering to this process will identify when there is a need for the development of new or updated outcome measures in a transparent and justifiable way.

3.4.5 Outcome Prioritisation

Many of the studies did not clearly specify which outcomes were of primary interest to the researchers and often reported many disparate measures. While richness of data is laudable, the interpretation of study results becomes difficult when many, potentially conflicting, results are presented with no clear indication on the primary outcome of interest. It is recognised that researchers can change the emphasis of a study report, focussing on positive secondary outcomes rather than the neutral primary outcome. It is for this reason publication of a trial protocol that clearly defines primary and secondary outcomes is now considered best practice. Ultimately, the absence of clear primary outcomes dilutes the findings and reduces the likelihood that they will inform clinical practice (Rahimi et al., 2010).

Poor prioritisation of outcome measures also raises questions about whether the participant’s time has been effectively used. In many instances more than one outcome measure seemed to be assessing the same construct within a trial. This is of importance when working with caregivers who are taking time away from caring for people with life-limiting illnesses, and potentially palliative and end-of-life care needs (Johnston et al., 2017).

Unfortunately, issues around transparency and the prioritisation of reported outcomes do not only exist in trials. Smith et al. (2015) carried out a review of Cochrane reviews published between 2007 and 2011. They identified that 37% of outcomes included in the methods section of a review were not reported in the findings section. Although some reviews did give reasonable explanations for missing outcomes, 14% did not offer any. This undoubtedly leads to questions of bias. Furthermore, the authors noted that several reviews included over 10 outcomes and suggest that there is a need for outcome prioritisation within reviews.

3.4.6 Addressing Diversity in Outcome Measures

This review has highlighted important considerations in the selection, implementation, and prioritisation of outcome measures when research is associated with a vulnerable population such as caregivers. Many of the challenges faced by researchers when selecting outcome measures can be overcome if COS are implemented or, when this is not possible, using outcomes that have had adequate validity and reliability testing. However, there are subsequent considerations when researchers are presenting data from outcomes where the participants are from diverse backgrounds. Researchers can consider how they report disaggregated data from outcome measures. Disaggregated data could be done by characteristics such as sex, ethnicity, age and by location, among others, depending on the research aim(s) and population. Furthermore, when selecting outcomes that have validity and reliability testing, researchers could report where testing processes accounted for applicable diversity and utilised PCPI during their design. Reporting disaggregated data from outcomes will add to the existing external validity data available (Fitzner, 2007) and help to identify specific groups or populations that require additional or adapted outcomes in a robust and transparent way.

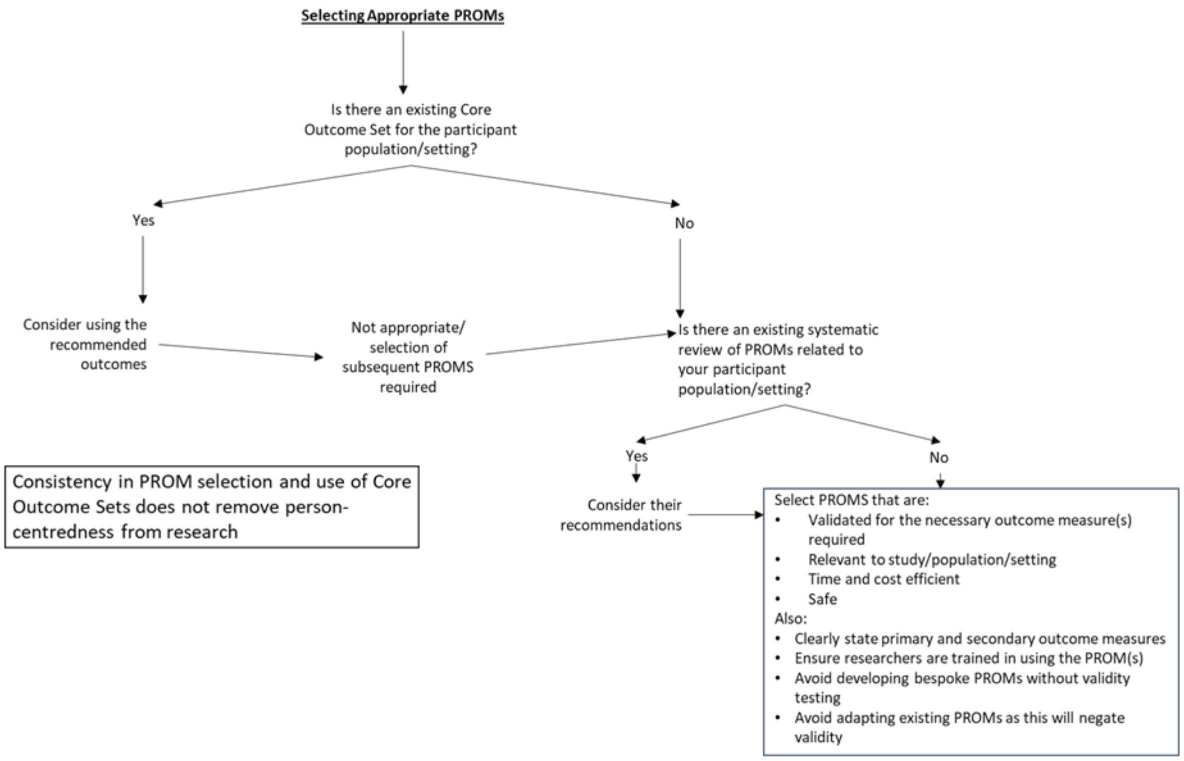


Figure 2: Flowchart of outcome selection in interventions for caregivers of people with life-limiting conditions.

3.4.7 Outcome Measures in Clinical Practice

Patient reported outcome measures for caregiver interventions are not just necessary within research trials. They are also useful tools that can be used when undertaking caregiver assessments of needs in clinical practice, including palliative and end of life care (Antunes et al., 2014). Therefore, the findings from this review have implications for health and social care professionals who are required to assess caregivers and deliver suitable interventions.

Ewing and Grand (2018) argued that caregiver assessments and review of their self-reported needs should become part of standard practice when clinicians are assessing the cared-for person. However, guidance on caregiver assessments, including recommendations in national policies (particularly in palliative and end of life care), are lacking, with far more emphasis given to the cared-for person's needs (Ewing and Grande, 2018). This is surprising because outcome measures in this context ensure that interventions are effective at addressing the caregiver's needs and help professionals to consider if/when it might be necessary to refer elsewhere (Riffin et al., 2020). Furthermore, assessment tools such as the Carer Support Needs Assessment Tool can be considered interventions. This is because, following the initial assessment of self-reported outcome and needs, clinicians are then triggered to deliver a five-stage, person-centred support process to the caregiver (Diffin et al., 2018).

Because of the array of negative consequences associated with the caring role, it is not surprising that assessing a caregiver's needs and the suitability of specific interventions can be challenging. Patient Reported Outcome Measures can guide clinicians in a systematic, reliable way through a potentially confusing and challenging process. However, interviews by Riffin et al. (2020) with primary care professionals suggested that it is still a long way from becoming part of routine practice. They identified that professionals undertaking caregiver assessments often do not use reliable and valid tools to assist with their assessments. Their interviews with professionals working in primary care evidenced that many use indirect and direct questioning, as well as assessments of the caregiver's appearance (losing weight, cleanliness etc) and non-verbal language to establish a caregiver's health and wellbeing. However, some caregivers who participated in the study suspected that professionals went out of their way not to assess the caregiver or ask how they are doing. Although the authors advocate for the use of formal caregiver assessment tools, they acknowledge that there are perceived barriers to their use in primary care. Time, concern about the privacy of the cared-for person and a lack of control over some of the challenges expressed by caregivers are all barriers to implementing caregiver assessments. However, using assessment tools will enable health and social care professionals to become more efficient with them and will undoubtedly prompt them to understand what services are available in their area to address the identified issues. Using tools that have been through reliability and validity testing means that professionals can presume that they will not impede on the privacy and dignity of the cared-for person. Therefore, the best way to overcome these barriers is to use the tools.

3.5 Limitations

This review was carried out before the decision was made to undertake this project from a feminist perspective. However, when writing up the findings from this stage, I was beginning to read and consider feminist theory. It was this reading, although prior to any formal decision being made, that prompted me to consider the extent to which diversity within participant groups is considered or addressed within the literature pertaining to PROMS. Nevertheless, if the decision to be informed by feminist theory had been made prior to this step in the intervention selection process, it might have impacted on its focus and findings more.

The decision to exclude respite interventions was one of the first decisions made in this project. This decision was made based on a combination of the heterogeneity in what respite is described as in described trials and my clinical experience whereby respite would be recommended primarily for the benefit of the care recipient (usually for symptom management). On reflection, this decision might not have been made again knowing how important respite time is to caregivers. However, the aim of this review is not to offer commentary on the efficacy of interventions, as there are already many of these reviews available, including two specifically on respite for people with dementia (Maayan et al., 2014; Vandepitte et al., 2016). Indeed, the diversity in respite conceptualisation, description, outcomes used, and target population have made drawing conclusions on its efficacy difficult (Maayan et al., 2014; Nehen and Hermann, 2015; Neville et al., 2015).

The selection of three life-limiting conditions does not cover the breadth of caregiver or life-limiting conditions research. Selecting these conditions allowed me to develop a pragmatic, focused overview. I also acknowledge the limitations associated with having one person carry out the literature searches, data collection and data synthesis. However, data analysis and reporting of the collected results were undertaken between all reviewers. It was anticipated that the review of trials included in Cochrane systematic reviews would be the primary source of study retrieval. However, more papers were retrieved from the time-limited, database searches. Because the findings were categorised by the diagnosis of the cared-for person, most of the retrieved studies are related to dementia trials. Therefore, any findings from this review may be more applicable to dementia trials than stroke, heart failure and other life-limiting conditions.

3.6 Chapter Summary

Describing the most common types of outcome measures used in caregiver intervention trials has identified researcher priorities. Researchers in this field have clearly recognised that the alleviation of psychological distress or challenges associated with caring for someone with a life-limiting condition should be their main concern. How this is done has no agreed format or process. The development of caregiver-specific COS would ensure that outcome selection in caregiver intervention research is robust, reliable, and valid. This would also ensure that outcomes for caregiver research can be consistent and transparent. Consistency in outcome selection and measurement will not remove person-centredness. This is because, by their nature, PROMs (especially those designed with PCPI involvement) allow caregivers to express their perceptions of their experiences and what is most important to them in a way that can be understood and translated by clinicians and researchers.

The inconsistencies in the selection and prioritisation of outcome measures could be viewed as a weakness in the field because it makes comparative analysis more difficult, which makes the identification of effective interventions more difficult. However, it supports the need for caregiver community involvement in selecting evaluation priorities. If researchers are unsure about the aspects of the caring role that interventions should be targeting, rather than being tempted to develop their own outcome measures, adapt existing ones or use a multitude of tools, caregivers could be consulted to help make decisions about what is important. This review process supported the need for collaboration with community members in this project, which is expected of transformative intervention research. It also supported the need for caregivers to be involved in deciding, not just the intervention but its evaluation. In doing so, this would share accountability and recognise their ability to articulate their needs best.

Transformative research encourages researchers to consider the role that research methodologies and methods have had in upholding existing power. Therefore, examining what outcome measures and types of interventions are prioritised by researchers and then asking caregivers how these compare to their priorities is in keeping with this paradigm. Chapter One outlined the range of systematic reviews and meta-analyses already published across an array of different interventions for caregivers. This review served as an opportunity to do something different and move away from the type of review that is plentiful in this area of research.

Chapter Four: A Secondary Analysis of Caregiver Needs Assessments

4.1 Introduction

Through a chance encounter in my clinical role, I met the Glasgow City Health and Social Care Partnership (HSCP) Carers Information Strategy Worker. About a year later, while working on my modified systematic review, I began to consider how the project would progress. I contacted the Carers Information Strategy Worker via email to discuss her role and to understand the services available to caregivers from Glasgow. She informed me that she was now in a new role but suggested I contact the Glasgow Carers Team lead, Fred Beckett. Fred was keen to meet and discuss my project in more detail and tell me about what services they offer. At our first meeting, it was explained that the primary role of the service was to offer caregivers a comprehensive assessment of needs. These assessments form the basis from which a specific support package is then designed. During this meeting I was offered an anonymised version of the service's most recent 12-months of caregiver assessments. It was suggested that these assessments would give me a more up-to-date understanding of the Glasgow caregiver population compared to data that was publicly available at that time. It might also help me understand what types of help and support caregivers were requesting. This was a step in the project that had not been anticipated prior to this meeting. However, transformative researchers should be adaptable and creative (Mertens, 2010). It was decided that although this was unexpected and unplanned, we should make use of it.

What became apparent from reviewing the literature related to caring for someone with a life-limiting condition, and how the efficacy of interventions that purport to alleviate an aspect of associated burden are assessed, is that reducing the psychological weight of the role is a priority among researchers and clinicians. What was not apparent is why there is such variability in the experiences of caregivers and whether there are characteristics that put caregivers at an increased risk of requiring additional support to continue caring.

Of the existing research, it is suggested that negative consequences can be somewhat predicted by considering caregiver characteristics such as age (Chow and Ho, 2014), income (Hu et al., 2016a) and duration of the caring role (Litzelman et al., 2015). However, the influence of caregiver sex on negative consequences, outcomes and how it affects a caregiver's decision to access support is an area that is overlooked within caregiver research (Baker et al., 2010; Greenwood and Smith, 2015). And this oversight is not unique to caregiver research. Criado Perez

(2019) identified the extent of the data bias in her book, Invisible Women: Exposing Data Bias in a World Designed for Men. Criado Perez (2019) made the case that a lack of sex disaggregated data has resulted in dangerous oversights that disproportionately affects the lives of women and girls. This became a possible route of investigation considering how female-dominated the caregiver population is and how issues around access to transportation, employment and healthcare can further complicate the caring role. However, as caregivers are predominantly a female population and existing findings are, therefore, primarily related to women, this oversight could potentially negatively impact male caregivers. Greenwood and Smith (2015) carried out a systematic review of the barriers and facilitators to male caregivers accessing help. They recommended that future research should compare female and male participants to identify where there are differences in experiences and outcomes (Greenwood and Smith, 2015).

For intervention research, Mertens (2008) encourages researchers to access needs assessment data and to consider disaggregating data to allow for nuanced findings of community needs. Population data for caregivers is available at a Scottish level and broken down by sex only. Therefore, little is known about the demographics of caregivers in Glasgow. There had been some reflective discussions with the supervisory team about whether (or not) to focus the intervention on a specific sub-group of caregivers, for example caregivers of people with dementia. However, I lacked enough evidence to support any decision on that at this stage. It was thought that a secondary analysis of needs assessments of caregivers in Glasgow would elicit a deeper understanding of who I might be designing or selecting an intervention for. Because of a need for more sex-disaggregated data in caregiver research and research more generally, it was decided that the secondary analysis of caregiver assessments would consider the potential effect of sex on caregiver outcomes.

4.2 Methods

4.2.1 Aim and Objectives

Aim

- Understand the population of people from Glasgow who access the primary support assessment service, the Glasgow Carers Support Team.

Objectives

- To describe the demographics of caregivers who use the Carers Support Service.
- To undertake comparative analysis of female and male adult caregivers in relation to the prevalence of negative consequences of caring.

For this study, a negative consequence was an aspect of the person's life that was self-reported as adversely affected because of their caring role. There is no set of criteria related to diagnoses, time spent caring or living arrangements that caregivers must meet to be entitled to assessment and support. Caregivers only need to be identified, or self-identify, as caregivers. Data related to the person for whom they care is limited because all reported data is self-reported by the caregiver and dependent on their priorities.

The principles of feminist data science are still novel. Therefore, it is important that the experience of undertaking a study like this from a feminist perspective is reported and reflected on. Sharing the challenges and successes will inform future research in this emerging and important area that bridges data science and feminist theory.

4.2.2 Sample

This analysis used a dataset held by the Glasgow Carers Team, which is curated by the Glasgow City HSCP. The Carers Team undertake individualised assessments of caregivers' needs. Caregivers are not considered to be in paid employment for their role, although some might receive state benefits related to it and this does not impact on their suitability to the service. Referrals to the service can be from hospital and community services, concerned friends and family, as well as the caregivers themselves. Assessments are carried out by social workers, usually in the caregiver's own home. Consultation style for data collection varied between practitioner and there was no set list of questions used for assessments. The dataset is collected for service evaluation and routine documentation of practice; I had no control over what was included.

The dataset forms part of a larger database that records all caregiver assessments carried out by the service. However, the datasets are reviewed and revised annually. This is done to improve the quality of the data collected. The service lead advised that the most recent years dataset was collected following a considerable review of what and how data are collected. I was advised that the most recent dataset was of the highest quality available, and that previous year's datasets were not available. The dataset includes socio-demographic and healthcare-related information of the caregiver and cared-for person. There were also several free-text fields that included other relevant information from discussions during the assessments.

The anonymised caregiver assessments were carried out in Glasgow City and Greater Glasgow over a twelve-month period (01/04/17 – 29/03/18). All assessments were submitted for analysis, not just those where a life-limiting condition of the cared-for person was listed. This was because any diagnoses of the cared-for person were a second-hand report by the caregiver and dependent on their understanding of the health of the person requiring care. I could not guarantee that the diagnoses listed in assessments were an exhaustive list or were the diagnoses caregivers was aware of or was what was having the biggest impact on their caring role. Nine-hundred and ninety-eight caregiver assessments were submitted for analysis. Although the service also assesses young caregivers, we only included caregivers who were 16 years and over in our analysis.

4.2.3 Ethics

Ethical approval to undertake secondary analysis of anonymised data was obtained from the University of Glasgow MVLS ethics committee (reference number 200170185).

4.2.4 Data Cleaning and Categorising

The original data fields were labelled as follows:

- Gender (categorical)
- Assessment subject age (at assessment start date) (categorical)
- Nature and history of caring relationship (free text)
- Provide details of caring role (free text)
- Carer diagnoses (free text)
- Support request (free text)
- Carer- Cared for person relationship (free text)
- Cared-for person diagnoses (free text)
- What is carer employment situation (categorical)

“Nature and history of caring relationship” and “Provide details of caring role” fields were where the assessor described the discussions they had with caregivers. For some assessments, both were completed, for others one or none were completed. It was decided that due to the variation in what was included in these fields, not just in the details, but in writing style of the assessor, that existing qualitative analysis frameworks were not suitable in this situation and, therefore, qualitative analysis would not be pursued. Instead, these fields would be categorised to allow for comparative analysis. Gender was presumed to be a synonym for sex as female and male were the options recorded.

The process of data cleaning was based on the framework outlined by Van den Broeck et al. (2005) whereby repeated cycles of screening, diagnosing, and editing of suspected data abnormalities were carried out until analysis was possible. When abnormalities were identified, a diagnostic and treatment process was triggered. I would rectify straightforward abnormalities (such as misspellings or inconsistent clinical categorisations). More complex abnormalities were discussed with the supervisory team until we reached a consensus. Most of the abnormalities were straightforward. However, the volume of such misspellings and inconsistent clinical categorisations meant that the process was arduous. Duplicate assessments were initially removed and then the demographic fields were cleaned.

Categorising the free-text fields of “Nature and history of caring relationship” and “Provide details of caring role” posed the only complex barrier to data cleaning. These fields contained insightful data, describing common areas of the caregivers’ lives that were detrimentally affected by their caring role(s). However, they were not collected or recorded consistently. Because of the disparities in the way the free-text fields were recorded, I scoped the first 25% of assessments to establish if there were recurring concerns identified by caregivers. I did not limit this process to any specific categories. The team then reviewed the categories and identified the following aspects of their lives that caregivers stated had been negatively impacted due to their caring role:

1. Social life/recreation: assessments that included descriptions of caregiver’s who were no longer able to afford adequate time to their social life or recreational time because of their caring role.
2. Independent identity: assessments that included descriptions of a person who felt their caring role superseded their previous roles and identities with the person for whom they care and/or other relationships; For example, a woman who no longer felt like a grandmother because she perceived that caring for her husband impacted on her ability to care for younger children in the family.
3. Personal/family finances: assessments that documented a reported loss or reduction in personal or family finances due to their caring role.

4. Self-care: assessments that included details where the caregiver was not able to attend personal appointments (typically healthcare related) due to their caring role.
5. Relationships: assessments that described a breakdown in at least one relationship (including the relationship between the caregiver and the person for whom they care) because of the caring role.
6. Psychological Impact: Assessments that described caregivers who reported their mental health had reduced or previous mental ill-health had been exacerbated because of the caring role.

Some data related to the diagnosis of the person or people requiring care were included in the findings. However, it is important to note that these diagnoses were reported by the caregiver and are not expected to be an exhaustive list of all health conditions those concerned may have; Rather they are likely to be the condition(s) of most concern to the caregiver or the condition(s) the caregiver is aware of. No significant analysis was undertaken related to these data because they are second-hand reports as written by social care staff.

As this study was undertaken from a feminist perspective, two examples of free-text entries were included to highlight the challenges in managing these data fields as well as why it was important to include them. Furthermore, the process of undertaking this type of study from a feminist perspective is reflected on within the discussion section.

4.2.5 Statistical Analysis

I used IBM SPSS Statistics for Windows, Version 27 to undertake descriptive statistical analysis. I used the Chi squared test to compare univariable categorical variables (using a confidence interval of $P<0.05$ to identify significant differences) comparing female and male caregivers in age, demographics, health diagnosis and the coded free-text fields. A Mann-Whitney U test was carried out to identify significance between age in female and male caregivers. When there was found to be a statistically significant difference between female and male caregiver variables, I carried out binary logistic regression analysis. Comparison data from the 2011 Scottish National Census was used in relation to caregiver sex. I also performed binary logistic regression of issues identified from the coded text and caregiver sex that might contribute to poorer psychological impact from the caring role because mental health was the most reported health issue by female and male caregivers, with a confidence interval (CI) and odds ration calculated.

Caregiver age was controlled for due to the significant difference between female and male caregivers’ age.

4.3 Results

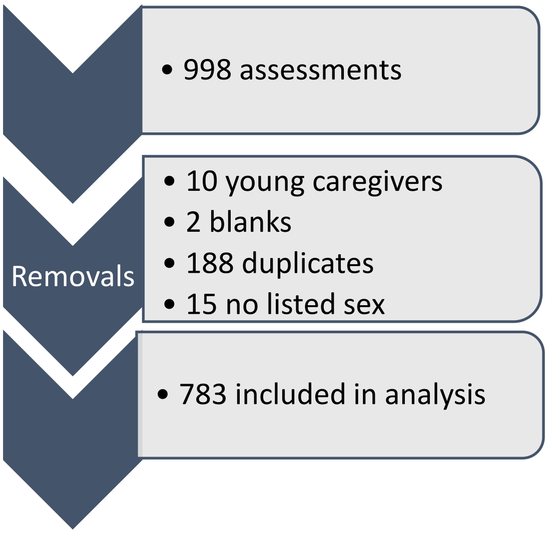


Figure 3: Summary of results from the data cleaning process

4.3.1 Caregiver Sociodemographic and Health Overview

Table 6: Data of caregiver age and categorised by sex. Comparison data from the 2011 Scottish National Census is also included.

Sex	Total		Census	Youngest	Oldest	Mean	Std. Dev
	N	%	%				
Female	552	69	59	17	92	52.1	22
Male	231	29	41	21	96	60.5	25
No sex listed	15	2					

In this dataset, of the 798 caregivers included, 552 (69%) were female and 231 (29%) were male (Table 6). Fifteen caregivers (2%) had no sex listed. A Mann-Whitney U test indicated that male caregivers (min=21, max=96, mean= 60.5) were significantly older than female caregivers (min=17, max=92, mean = 52.1, P=0.0001). Seventy one percent of female caregivers (n=394) were aged under 65 years of age, compared to 51% (n=120) of males.

Table 7 outlines the sociodemographic findings from our dataset. The only caregiver/cared-for relationships that differed significantly between sexes was when a parent was caring for a child (more common in female caregivers, P<0.001) and when the caregiver was caring for a parent (more common in male caregivers, P=0.017). Unemployed caregivers were significantly more likely to be female

(P=0.03), and retired caregivers were significantly more likely to be male (P<0.001). There was no significant difference among caregivers who were willing or able to continue in their caring role. When considering the types of support requested by the caregivers, male caregivers were significantly more likely to ask for respite than female caregivers (P=0.046).

Two hundred and fifty-nine female caregivers (46%) and 100 male caregivers (43%) had a health issue listed. Mental health was the most recorded health complaint for female and male caregivers (

Table 8). Specific mental health conditions were not listed; Instead, mental health was used as an umbrella term. I know this from reading the free text, where specific conditions such as anxiety, depression and schizophrenia were sometimes mentioned. In this dataset, male caregivers were significantly more likely to have heart disease, addiction issues, diabetes or health issues related to advancing age than female caregivers (

Table 8)

Table 7: Sociodemographic data recorded in the assessments included in the analysis. Comparative testing was calculated from Chi-Squared testing.

	Female		**Male**		**P**
	N	**%**	**N**	**%**	
Caregiver/Cared-For Person Relationship					
Spouse/ Partners	151	27	66	29	0.728
Parent - Child	199	36	16	7	<0.001
Child - Parent	77	14	48	21	0.017
Caregiver - Extended Family	21	4	3	1	0.064
Caregiver - Friend/Neighbour	2	0	3	1	0.134
Siblings	14	3	7	3	0.696
Relationship not listed	78	14	82	36	
Employment Status					
Employed	68	12	26	11	0.676
Unemployed	125	23	31	13	0.03
Retired	86	16	69	30	<0.001
Long-term sick	37	7	8	3	0.076
No employment status listed	155	28	66	29	
Future Caring Potential					
Could continue with help	263	48	97	42	0.148
Feels unable or unwilling to continue	28	5	18	8	0.140
Not specified	228	41	103	24	
Support Request					
Respite	16	3	17	7	0.046
Long-term residential care	21	4	9	4	0.951
In-home support	34	6	17	7	0.535
Emotional support	4	1	5	2	0.085
Recreational support	6	1	0	0	0.370
More than one	70	13	24	10	0.368
Help requested but not specified	173	31	56	24	0.046
Not specified	229	41	103	45	

Table 8: Caregivers self-reported health diagnoses data recorded in their assessments.

	Female		Male		P
	N	%	N	%	
Dementia	3	0.5	0	0	0.837
Stroke	4	0.7	4	1.7	0.201
Heart Failure	1	0.2	0	0	0.529
Mental Health	97	17.5	24	10.4	0.011
COPD	17	3.1	4	1.7	0.287
Cancer	9	1.6	3	1.3	0.730
Older age (frailty)	7	1.3	8	3.5	0.041
Heart Disease	7	1.2	13	5.6	0.0004
Arthritis	24	4.3	4	1.7	0.072
Addiction	0	0	4	1.7	0.013
Diabetes	10	1.2	10	4.3	0.042
Other	56	10.1	18	7.8	0.305
None listed	272	49	127	55	

P is 0.05 and was calculated from Chi-Squared testing.

Table 9: Binary regression model from data in Tables 7 and 8 where P<0.05.

	Odds Ratio	95% CI	P
Caregiver/Cared-for Person Relationship			
Parent-Child	13.7	13.0-14.3	>0.00
Child-Parent	1.1	-0.2-2.5	0.42
Employment Status			
Unemployed	1.0	0.5-1.5	0.55
Retired	1.3	0.8-1.8	0.57
Support Request			
Respite	0.3	-0.7-1.2	0.02
Help requested but not specified	1.0	0.6-1.5	>0.00
Caregiver Diagnosis			
Mental health	1.3	0.9-1.7	0.14
Older Age (frailty)	0.7	-0.5-1.9	0.49
Heart Disease	0.3	-0.9-1.5	0.01
Addiction	>0.0	-39165.8-39166.8	1.00
Diabetes	0.3	-0.4-1.0	0.001

When P suggested a significant difference between female and male caregivers in Table 7 and 8, a binary regression was performed to establish how the caregiver/cared-for relationships, employment status, support requests and caregiver diagnoses were influenced by sex. Overall, this model did not find a significance. However, female caregivers were 13.7 times more likely to be caring for a child (P=0.001).

Table 10: Categorised data from free-text fields that reported by caregivers as negatively impacted on due to caring responsibilities.

	Female		Male		P
	N	%	N	%	
Social Life/reaction	151	27	55	24	0.67
Independent Identity	85	15	31	13	0.84
Personal/family finances	56	10	24	10	0.04
Self-care	81	15	30	13	0.49
Relationships	145	26	49	21	0.58
Psychological Impact	240	43	82	35	0.04

Table 10 outlines the findings from the categorisation of free-text fields that relate to various aspects of daily living and personhood that caregivers expressed were negatively affected by their caring role. The reporting of the psychological impact of caring (P=0.04) and personal/family finances (P=0.04) differed significantly between female and male caregivers. Table 10 suggests that for caregivers using this support service, male and female caregivers experienced, recognised or reported most of the common negative consequences of caring equally.

Table 11: Categorisation data from the free-text fields to identify an association between psychological wellbeing (independent variable) and aspects of caregivers' lives impacted by the caring role (dependent variable).

	Odds Ratio	95% CI	P
Sex (female or male)	1.7	1.3-2.2	0.02
Social life	3.8	3.2-4.4	>0.00
Independent identity	1.4	0.4-2.3	0.51
Personal/family finances	3.3	2.6-4.1	0.01
Self-care	9.8	8.7-10.8	>0.00
Relationships	13.8	13.2-14.4	>0.00

Because mental ill-health was the most common health complaint listed by female and male caregivers, a binary regression was performed to establish the effects of caregiver sex, social life, independent identity, personal/family finances, self-care, and relationships on the likelihood of the caregiver experiencing a negative psychological impact from their caring role (Table 11). The binary regression model was statistically significant, with all but Independent Identity influencing psychological impact. The most significant influence on psychological impact were relationships.

4.3.2 Cared-for person diagnosis data

Table 12: Diagnosis of the person or people requiring care as listed in the caregiver assessments.

Diagnosis of the cared-for person	Female Caregivers		Male Caregivers	
	N	%	N	%
Dementia	86	15.55	59	25.54
Stroke	23	4.16	14	6.06
Heart failure	1	0.18	1	0.43
Mental health	31	5.61	18	7.79
COPD	19	3.44	9	3.90
Cancer	31	5.61	13	5.63
Other	91	16.46	21	9.09
Older Age (frailty)	18	3.25	28	12.12
Physical disability	14	2.53	10	4.33
Learning Disabilities	101	18.26	14	6.06
Heart disease	25	4.52	11	4.76
Autism Spectrum Disorder	78	14.1	9	3.90
Renal disease	9	1.63	4	1.73
Cerebral Palsy	10	1.81	2	0.87
Acquired Brain Injury	11	1.99	2	0.87
Global Development Delay	11	1.99	3	1.30
Arthritis	16	2.89	12	5.19
Addiction	9	1.63	5	2.16
Diabetes	20	3.62	12	5.19
Parkinson’s Disease	6	1.08	2	0.87

Error! Reference source not found. outlines the diagnoses of the cared-for person as reported by the caregiver during assessments. Conditions that were included in the “Other” category were rare genetic disorders and those assessments were of parental caregivers of children. Of the exemplar conditions selected for Chapter One (stroke, heart failure and dementia), dementia was the most common diagnosis described by caregivers in this dataset and was the most common diagnosis overall mentioned by male caregivers. This was followed by stroke and then heart failure.

4.3.3 Opportunities and Challenges to Social Care Data

The biggest challenge with managing this dataset was formatting the free-text fields into a coherent and consistent style that would permit analysis. Some of the free-text entries where conversations between the assessor and the caregiver were documented were written in a style that appeared to be a verbatim report of the caregivers needs during the assessment. Others seemed to be the assessor's opinion of the relationship between caregiver and the person for whom they care. Some assessments used recognised communication tools (for example, the Situation Background Assessment Recommendation (SBAR) technique). However, most did not. The variety in documentation styles offered a somewhat confusing picture as to what some of the assessments hoped to achieve. Regardless of these issues, some of the assessments offered insightful descriptions of the complicated lives many caregivers in Glasgow lead, and this was too emotive to write-off or ignore. An excerpt from one assessment is included below:

> Cared-for suffers from a number of health problems including Parkinson's, increased confusion, schizophrenia and arthritis. The caring role has lasted for all of their married life due to diagnoses. The burden of care is currently very onerous and is seriously impacting on the carer's health. Cared-for is now bed bound and catheterised, but deliberately tears the catheter bags and allows the contents to flow over the bed linen. Caregiver feels that she is a servant but has always felt this and was sorry for cared-for at one time but wishes that she had left him many years ago. Caregiver divulged that cared-for has 'headbutted' her twice in recent weeks, and she lost front teeth. When questioned Cared-for maintained that this was an accident, but caregiver stated that there was real force used. Cared-for has called her an "ugly bastard".

In the following example, the assessor gives a possibly incorrect assessment of the level of care offered by the caregiver to the person requiring care followed by comment on their relationship:

> Writer of the opinion, carer does not fulfil a full time substantial caring role, but he does have an indirect caring role for his mother whereby he does oversee her general wellbeing/ visits her on a daily basis/ cooks/ attends to light housework and attends to her daily shopping. Carer and his mother appear to also provide companionship to each other on a daily basis. Carer and his mother appear to have a volatile relationship, but both are dependent upon each other.

Many of the assessments were long descriptions of the needs of the person requiring support from the caregiver without much attention given to the caregiver. As these notes documented the conversations between the assessor and the caregiver, this suggests that when someone undertakes the caring role, they become so used to considering the person for whom they care that even when they are given an opportunity to be the focus of care and support, they miss it. Forty-three percent of assessments that recorded sociodemographic information had no free-text entries recorded and no explanation was given as to why these assessments were not completed.

4.4 Discussion

4.4.1 Overview of Findings

Previous research related to caregivers of people at end of life and living with life-limiting conditions and mental illness identified that the influence of caregiver sex on the risk of negative outcomes and consequences is often overlooked and misunderstood (Gardiner et al., 2020; Ghosh et al., 2020; Pinquart and Sörensen, 2006; Sharma et al., 2016). This study demonstrates that there is meaning and knowledge to be found by disaggregating caregiver data by sex. In our dataset, the most prominent difference between female and male caregivers related to age. Male caregivers were significantly more likely to be retired, caring for a parent, and living with heart disease, diabetes or addictions. Female caregivers were more likely to be of working age but economically inactive due to sickness and living with mental ill-health. Female caregivers were also more likely to report that their caring role was detrimental to their mental health. A review by Greenwood and Smith (2016) suggested that the importance of age is often overlooked in caregiver research. This led me to consider how the age and sex of caregivers might interact and influence the use of support services. However, it would be disingenuous to ignore the current debate around sex and gender identity. Therefore, it is important to also consider how gendered social identities might influence the caring role and how they might impact the help that caregivers are likely to seek and accept.

4.4.2 Intersections of caring

Akkan (2019) described the intersections of caring and its multiple social relations as a complex “inequality-creating phenomenon”. The intersection of age and sex was first identified by Krekula (2007). Krekula (2007) suggested that societies othering of older women was so endemic that the lives of older women were even overlooked in feminist research and theory. Instead, our understanding of female experiences primarily focuses on young, fertile women (Krekula, 2007). This ageism also extends to caring roles and responsibilities because of prejudices that exist in society related to who should do unpaid, caring labour (Akkan, 2019). This is because within the family, the age and stage of women and girls predicts the likelihood that caring responsibilities will be expected of her (Akkan, 2019, Young and Grundy, 2008).

Most female caregivers in this dataset were under 65 and therefore, within the working age population. However, a significant number of the female caregivers in this dataset were unemployed or economically inactive (46% of females). This compares to 31% of the general population and 44.5% of caregivers in Scotland from the 2011 census (Scottish Government, 2015). The Scottish census also found that 32% of female caregivers felt their caring responsibilities had impacted their employment, with 8.1% working fewer hours and 5.5% had left their work altogether. The challenges experienced by Scottish women with caring responsibilities entering or maintaining employment are echoed by women globally.

Caring is the main barrier to women entering, progressing and remaining in paid employment and why women tend to work in part-time, lower paid and less secure jobs (WHO, 2018b). Women spend more hours than men undertaking unpaid work and care (Organisation for Economic Co-operation and Development, 2018a) and more minutes per day in their caring role than they do in paid work (WHO, 2018b). Smith et al (2019) carried out secondary analysis of data from Statistics Canada's Labour Force Survey, collected over nineteen years, on the impact of caring responsibilities on labour market involvement. They found that women were 73% more likely to leave the labour market, over five times more likely to work part-time, and twice as likely to take urgent time off due to caring responsibilities (Smith et al., 2019). The risk of financial hardship or poverty because of caring responsibilities, therefore, disproportionately affects women and girls.

Caregivers in this dataset were 3.3 times more likely to report a negative psychological impact if they were experiencing financial hardship from their caring role. Poverty levels are highest among caregivers who care more than 20 hours a week and those caring for someone living in the same household (Aldridge and Hughes, 2016). In the UK, caregivers report delays in needs assessments, regularly using their own money to buy necessary equipment and most (69%) do not receive financial support from their local authority or health body (Carers UK, 2019c). Furthermore, Gardiner et al. (2016; 2020) identified that these common financial strains increase significantly when caring for someone receiving palliative and end of life care. End of life caregiving often causes further stressful life events, such as moving to a new house or early retirement to cope with the increased care requirements (Gardiner et al., 2020). The financial risks associated with the role for working-aged women extend beyond the caregiver, because women with children are more likely to take on caring responsibilities (Young and Grundy, 2008), and women are far more likely to be single parents (Organisation for Economic Co-operation and Development, 2018b). Any financial hardship experienced by working age female caregivers has the potential to impact children.

Female caregivers in our dataset were also significantly more likely to have mental ill-health listed and to report that caring was psychologically detrimental to them. This supports previous research that found female caregivers articulate more strain (Fromme et al., 2005) and experience higher levels of burden (Chiao et al., 2015) than male caregivers. Why women and men report different levels of common caregiver stressors has been debated in the literature (Pinquart and Sörensen, 2006). Fromme et al. (2005) suggested that women report more strain because sharing emotions is more normalised among women compared to men. Females do tend to have better social support (Wong and Hsieh, 2019), and poor social networks is linked to an increased risk of caregiver burden (Ghosh et al., 2020). Nevertheless, research suggests that not only are women more likely to care for more hours than men (Pinquart and Sörensen, 2006), but women tend to care for people with more complex needs. The magnitude of these differences has been found to be influenced by how gendered national labour and workforce policy is (Stanfors et al., 2019). Therefore, if we consider the increased risk of financial burden and likelihood that female caregivers will have multiple caring responsibilities, women may indeed be more likely to express their struggles, but they will likely have more stressful demands. Fortunately, Chapters Two and Four demonstrate that addressing the psychological impact of caring is a priority in caregiver literature.

4.4.3 Physical health, sex, and care

The othering of older women, as outlined by Krekula (2007), has some considerations for the male caregivers in this dataset. Older caregivers were more likely to be male and this seems to be an increasing trend across the UK, as caregivers over the age of 85 are more likely to be men (Carers UK, 2019c).

Othering is a concern because it frames people who do not fit the preconceived expectations of a group as inferior and contributes to deeper marginalisation. Therefore, as caregivers are a predominantly female population, there is a risk of othering male caregivers. Male caregivers are exposed to harmful social expectations based on sexist stereotypes. For example, Williams et al (2017) examined how caregivers construct their views of the appropriate roles for women and men in providing palliative and end of life care for family members. They found that female participants described men as strong, independent and self-sufficient (Williams et al., 2017). These masculine stereotypes are at odds with the reality that many men will have less experience of caring and household labour throughout their life course (Ferrant, 2014). Therefore, the help and support they need is likely very different to women. However, a literature review by Houde (2002) detected methodological issues in caregiver research in relation to men. The authors recommended that researchers proactively seek to recruit men into caregiver research, especially intervention trials (Houde, 2002).

As well as being older, male caregivers in our dataset were found to have significantly higher rates of heart disease and diabetes mellitus than female caregivers. There is a dearth of research available related to the prevalence of heart disease and diabetes among male caregivers. However, it is established that long-term exposure to stressful situations can be detrimental to cardiovascular health (Dimsdale, 2008). Lebrec, et al. (2016) found that caregivers with diabetes were more likely to be males and that caregivers with diabetes had a significantly higher rate of outpatient visits. Men in our dataset were also more likely than women to be caring for their parents. This mirrors the findings by Morgan et al. (2020), whose literature review demonstrated the complexity of caring as an older adult. Older caregivers will likely have their own set of health and social care needs, may have their own caregiver(s) or be in a mutually caring relationship with the person for whom they care. The authors suggest that health and social care service providers anticipate how these factors can impact on a caregiver’s ability to use and access their services (Morgan et al., 2020).

Regarding caregiver’s social life, independent identity, self-care and relationships, there was no significant difference experienced between female and male caregivers in this dataset. This echoes a meta-analysis on differences in caregiver stressors and social resources, which found only small to very small differences between female and male caregivers (Pinquart and Sörensen, 2006). However, this is inconsistent with findings from Wong and Hsieh (2019). They identified gendered differences between female and male caregivers' ability to maintain and manage their relationships and social networks when caring for a spouse or partner. This study analysed data from heterosexual caring relationships aged between 57 and 85. These varying results demonstrates the need for further analysis of how age and sex influence one another and the caring experience.

4.4.4 Gender and the caring role

Gender has historically been the term used to discuss the differences in socialisation and behaviour between men and women, and the spectrum between masculinity and femininity. Typically, masculine traits and behaviours present as hiding emotions, an expectation of financial success (or at least primary earner), to be admired and respected, as well as a tendency towards reckless and dangerous behaviours, including violence (Chapple and Ziebland, 2002). The female equivalent of such expectations is femininity, where emotions, socialisation and family care are expected.

Caring for someone with a life-limiting condition is a heavily gendered role that comes with socially constructed expectations of both women and men. The gendered aspect of the role was suggested from the included needs assessments. Many of the assessments were women caring for people from a wider variety of relationships than male caregivers, who were predominantly caring for a partner or spouse, and many were struggling with mental ill-health. Therefore, the socialisation and expectation of women and girls to undertake most of the caring responsibilities within families may be a contributing factor, whereby women are unable to control how much care they give and to whom. However, as the role is so heavily associated with women and girls, this might have repercussions for men who are caring for someone with a life-limiting condition.

4.4.5 Masculinities

It has been suggested that the challenges experienced by men who care, and the likelihood that they will access support, depends on how influenced they are by the social and cultural expectations of men (Baker et al., 2010). Connell and Messerschmidt's (2005) work on masculinity defined it not as a biological trait but as a configuration of behaviours that differ depending on the gender relations and social setting.

Some valuable research on men’s experiences living with life-limiting conditions offers insights into how ageing is anticipated by men, and whether illness and the ageing process challenges their masculinity. Research into Parkinson’s disease (Gibson and Kierans, 2017), prostate cancer (Chapple and Ziebland, 2002) and diabetes (Quaglia, 2020) suggested that some of the most common and serious challenges to masculinity from illness and ageing are sexual dysfunction, incontinence, and asking for help. There is a sense in the study by Gibson and Kierans (2017) that some men have a perception of how older men should feel and behave. Many will slip into that role when asked about certain aspects of their lives and masculinity even if that role might not actually be representative of how they feel and behave. For example, participants described being too old for sex and sexual intimacy with a partner, that companionship was more important to them. Yet, when asked directly about pornography, they confirmed that it was watched because they still had sexual desires and libidos.

The contradiction between perceived and actual behaviour is one of the reasons why it has been argued that masculinity is inherently bad for men’s health (Quaglia, 2020). Interviews with men who have a diagnosis of diabetes identified that being actively involved in the management of one’s health and conditions such as diabetes (for example, through maintaining a balanced diet, exercising and monitoring capillary blood glucose monitoring) was often viewed as feminising (Quaglia, 2020). The researchers termed the participants who chose not to follow recommendations for diabetic management “free spirited”. Men who fell into this category were less likely to deny or limit pleasures such as carbohydrates, alcohol, and cigarettes. The level of self-surveillance that resulted in rigid adherence to guidelines was described as obsessive and unnecessary for many in this group. Of the nine men (out of 40 participants) who fell into this category, seven were working class.

Robertson (2006) conducted focus groups and interviews with men to explore how the male body in everyday life intersects with their health and wellbeing. He identified that it is important for men to feel that their body can undertake necessary instrumental functions. Indeed, pressure to maintain established standards of masculinity that have developed in younger years into older age was identified in research by Ozturk et al. (2020). Ozturk et al. (2020) conducted in-depth interviews with 12 gay men who were at least 50 years old. Participants shared their experiences with dealing with masculinities, ageing and the added pressure of being required to conform to heteronormativity.

These findings could also have serious considerations for male caregivers more generally. A role as heavily gendered towards the feminine may pose a significant threat to a mans perceived masculinities. For example, so much of the caring role requires physical demands that many men will be expected and expect of themselves to provide. Masculinities could prevent male caregivers from being perceived to need and ask for help when required. These issues are further complicated by the reality that men (including Glaswegian men) generally have poorer health, take more risks, and have a lower life expectancy compared to women (National Office of Statistics, 2020; White et al., 2011; Cowley et al., 2016). Therefore, male caregivers may be grappling with changes to their identity, relationships and health that might require support to enable them to continue caring. As male caregivers tend to care for partners and spouses, their position within the family could be transitioning away from financial breadwinner to primary caregiver.

4.4.6 Gender Identities

The analysis of the included dataset focused primarily on the binary categorisation of biological sex. However, the concept of gender identity, and its importance alongside or instead of sex, has garnered increasing attention in recent years. Transgender identities are not new; what has changed is the growing number of young people registered female at birth but who describe themselves as transmen or non-binary and seek medical treatment to address the disparity (National Office of Statistics, 2019; National Gender Identity Development Service, 2020; Butler and Hutchinson, 2020). Subsequently, there has also been an increase in the number of (predominantly young) people who describe themselves as previously having a transgender identity but no longer do (referred to as detransitioners) (Butler and Hutchinson, 2020). There is a dearth of research related to gender identities (including transgender, non-binary and detransitioners) within caregiver research, with a few notable contributions.

Baker et al. (2010) set out to explore how masculinity can influence a male caregiver's experience of caring for someone with dementia. They wanted to understand if gender role conflict and gender identity (described in this study as how masculine or feminine a person feels) would influence caregiver strain and gain among men who care for female partners with dementia. Seventy men completed questionnaires related to caregiver strain, gender identity, caregiver gains and gender role conflict. They identified that gender identity and restrictive emotionality did not impact caregiver strain or gain. However, they identified that caregiver education and self-reported health impacted on caregiver gains.

The researchers posited that the lack of influence from a masculine gender identity on caregiver strain and gain could be due to a response bias, whereby male caregivers defended themselves against perceived threats to their masculinity. They, therefore, consciously, or subconsciously, rated their femininity lower so as not to feel their masculinity was under threat. However, this is a rather simplistic view that suggests masculinity is a fixed position and that femininity is universally considered to be the lesser of two, rather than acknowledging that people are complex, and individuals are a mixture of characteristics. Furthermore, it contradicts Connell's (Connell and Messerschmidt, 2005; Connell, 2005) seminal work on masculinities within gender theory, which positions it as a spectrum of behaviours that are socially constructed. The suggestion by Baker et al. (2010) is a potentially sexist and misogynistic analysis. It does nothing to challenge gendered stereotypes by suggesting that men and their masculinities are not as useful as femininities in caring relationships and roles.

Gott et al. (2020) also considered gender identity in their palliative care "Call to Arms" essay. The paper offers a valuable overview of the myriad of challenges faced by the (primarily female) caregiver workforce who undertake palliative care. However, there are some issues with the paper. The authors conflate sex with gender (even when trying to differentiate between them) and use intersex conditions and chromosome variations to argue that sex is not binary. They also use the term "cis", without evidencing those participants in the described studies were asked whether they would describe themselves as such. Cis is a term that relates to people who would describe themselves as having a gender identity that matches their biological sex. However, having a gender identity is not a universal trait (Sullivan, 2020) and cis is a controversial label for many people. Furthermore, using intersex and chromosome variations to suggest sex is not binary is contentious. Without acknowledging these issues, the insights are diluted.

The general concept of gender identity is contentious (Sullivan, 2020), including within feminism and feminist theory (Fraser, 2020). In recent years there has been increasing attention in the media on the subject. However, nursing literature has generally stayed quiet. This was recognised by Ion et al. (Ion et al., 2021), who argued that nurses should become more vocal. Their editorial offers a comprehensive overview of the debate and the repercussions that some academics have faced when they have raised concerns about specific aspects of the subject. For example, there is debate around how much of sex and gender identity are socially constructed. Some areas of academia and activism argue that both are, or that it does no harm to behave as if they are. However, for some, gender identity represents a manifestation of female oppression; and those who hold this position have faced considerable opposition. In these arguments, the caring role might demonstrate that, regardless of chosen or described gender identity, females do the bulk of the unpaid, undervalued labour. Therefore, opting for gender descriptors over sex could potentially impact on important population statistics. Ion et al. (2021) argued that nurses are in an ideal position to understand the impact that changes, such as the replacement of sex for gender identity, will have in the real world and what this would mean for patients and caregivers. Although it may seem unlikely that a compromise will be achieved in this debate, Fraser (2020) was optimistic. She argued that careful, pragmatic discourse could address essentialism in gender identity to ensure women's social identities are not limited to the stereotypes of femininity without, in turn, arguing that femininity does not exist at all.

4.4.7 Mind the (data) gap

Ultimately, there is a lack of empirical data to draw conclusions about gender identity and its role within caring for people with life-limiting conditions. No caregivers in the Carers UK (2019) survey are reported as transgender. A question in the UK (and Scottish) Census was added to the most recent Census that relates to gender identity this was not without controversy (Sullivan, 2020). The confusions identified in the essay by Gott et al. (2020) characterise this issue. However, if the lack of gender identity data is not rectified, it will create a data gap. More research is required to build on the findings identified by Baker et al. (2010) to understand if gender identities, including masculinities affect and shape the caregiver experience. This is will also prevent further conflation of sex with gender. This will be increasingly important if the tendency for young people who describe themselves as having a gender identity continues, as these are the current young caregivers and future adult caregivers that professional services will be supporting.

4.4.8 Analysing Analytics

Using the seven core principles of data feminism (D'Ignazio and Klein, 2020), I will outline how the process of undertaking descriptive, statistical secondary analysis of routinely collected health and social care data was influenced by the feminist perspective.

4.4.8.1 Examine Power

This principle relates to analysing how power operates in the world. Power is defined as “the current configuration of structural privilege and oppression, in which some groups experience unearned advantages because supporting and previous systems were designed by people like them or with them in mind” (D'Ignazio and Klein, 2020, p24). When examining the power related to a support service ran by a public sector organisation that aims to improve the lives of a marginalised group through person-centred support, it is difficult to associate this with unearned privilege. Rather, this service is evidence of the power that can be created through determination and activism. Caregiver activism in the UK has been driven by charities such as Carers UK, the biggest caregiver charity in the UK and has been established for over 50 years, as well as individual and grass roots activism led by caregivers.

4.4.8.2 Challenge Power

This principle relates to a commitment to challenging unequal power structures to work towards justice. The Carers Support Team was established in 2012, with every completed assessment included in a dataset that is collated over a 12-month period. It is then sent to the Scottish Government for review; The outcome of this review then informs future investment in the service. Fred Beckett reported to me in our meetings that this service was the first of its kind in Scotland and has since been replicated in other areas, with their team acting as a blueprint. In a time when health and social care funding was squeezed, to have a service that not only maintains itself but grows demonstrates the value in its mission. This service is the embodiment of challenging power structures to achieve justice. They primarily deliver support to a vulnerable and marginalised population, many of whom live in areas of deprivation. Reading and categorising the free text was an emotional experience for me but a constant reminder of why caregiver support is so necessary. It also highlighted that being able to use data from a service that is publicly funded that helps some of the most marginalised people in Glasgow was a privilege and an opportunity to highlight the indispensable support that the service offers.

This service was started during the recovery period of the financial crash of 2008, prior to the Carers Act being introduced formally in 2016. Now, what the service offers (assessment of needs for caregivers) has legal protection but since 2016 there has been no bigger challenge to health and social care services than the Covid-19 pandemic. Since March 2020, the number of caregivers and complexity of the caring role and, therefore, the demand for this service have all increased significantly. It is hoped that publishing the findings of this study in an open-access journal and thesis will highlight that the team deliver an essential service to a wider audience and will provide some evidence for the need for continued investment and growth.

4.4.8.3 Elevate Emotion and Embodiment

This principal highlights how data feminism can be used to value multiple forms of knowledge, including the knowledge that comes from people as living, feeling subjective bodies in the world. Baro et al. (2015) carried out a systematic review to develop a definition of big data that relates to healthcare data. They identified that healthcare professionals are well versed in connecting data from complex, variable sources to create insightful knowledge. Consequently, they recommended the need for more “human experts” in clinical practice and analytics to improve healthcare data processes. As a Registered Nurse who has experience of using data obtained during consultations, observations and from samples to create care plans with small numbers of people and their families, this was not a new process for me, nor is it uncommon.

However, what was new to me was using statistical modelling and calculations to create knowledge that could be used to understand a larger group. When I was going through the free text fields, I anticipated that there were predominantly three groups of caregivers requiring support from the service. These groups were parents of young children with complex needs, working and older women caring for at least one adult with life-limiting conditions, and older men adjusting to caring for someone with a life-limiting condition. When this was confirmed by analysing the demographic data and undertaking statistical modelling it was reassuring that the study was producing reliable and insightful results.

4.4.8.4 Rethink Hierarchies

For this principle, data feminism should challenge historical systems of counting and classification that could perpetuate oppression. It is widely accepted that research and healthcare have let down women and other marginalised groups. Rather than consider that our lives are complex and the decisions we make, and subsequent outcomes, are a result of many competing demands (many of which are out of our control), it was presumed that quantitative research based on clinical trials with mainly white male participants was an acceptable way to understand the world. Therefore, undertaking research that is related to caregivers from Glasgow is a challenge to research hierarchies. This is because this is a population, predominantly of women, many of whom are living in areas of multiple deprivation and juggling caring responsibilities with work, their own health concerns and families. Todd et al (2020) highlighted that research on routinely collected data not only produces valuable knowledge related to under-represented populations, but it is also a way of overcoming the methodological and practical barriers related to research that requires active participation.

4.4.8.5 Embrace Pluralism

This principle relates to the synthesis of multiple perspectives, with priority given to local and experiential ways of knowing. Although this study has primarily depended on quantitative data and analytics, it is one part of a wider mixed-methods project that draws on a variety of data sources and perspectives to inform the development of an intervention. Furthermore, the data is drawn from a local pool of caregivers and reviews data gathered through experiential social care practice. This demonstrates the merit of embracing local and experiential ways of knowing and doing. By evaluating the process of data collection and reflecting on the challenges created by the variations in documentation styles, we have identified how important it is that health and social care services streamline their caregiver data collection processes. Unfortunately, this issue is not unique to caregivers, as Hanratty et al (Hanratty et al., 2020) identified similar issues in care home data. They argued for an urgent review of care home documentation and the development of a minimum national dataset. With the Glasgow Carers Support Team now acting as a blueprint for other services across Scotland, this recommendation could also apply to caregiver assessments.

4.4.8.6 Consider Context

This principle relates to the context from which data is gathered as data feminism posits that data cannot be totally neutral or objective. Understanding the context of data is an essential component of the ethical evaluation of a study. Managing the variations in the free text was the biggest challenge in this study. Because most of the dataset was compiled of free text even the seemingly categorised fields required considerable time for cleaning. Prior to this process it is unlikely that knowledge could have been created. There is little doubt that storing sensitive and identifiable data in a format that is difficult to analyse is not an appropriate use of time and resources, nor is it ethical or responsible.

But what if the people who are involved with these practices are not aware of these issues? This is one of the many challenges faced by health and social care services that increasingly collect and rely on data, and why the professional and legal regulation related to it is evolving so fast. Dhindsa, et al. (2018) recommended a holistic approach in dealing with poor data quality and quantity. This approach involves organisations developing policies related to data management in partnership with patients, clinicians, data scientists and the public. This would help clinicians and social care professionals understand more about their role in data analytics. Moreover, Sousa, et al. (2019) advised that streamlining data strategies will enhance decision making. This should involve a clear focus for the service, distinct criteria for data selection and the development of measures to make the data meaningful. They argued that this model encourages straightforward and, eventually, predictive healthcare analytics to take place. Furthermore, it could reduce the potential for harm from confident decisions based on data that is thought to be of higher quality than it is (Pence, 2014).

4.4.8.7 Make Labour Visible

This principle relates to clearly demonstrating who is involved in data science and ensuring the laborious elements of the process are recognised and reported. For this study, the most intensive labour related to the cleaning and categorisation processes. Data cleaning is a vital step because it allows researchers to identify and fix errors that could impact study results and, therefore, its validity (Van den Broeck et al., 2005). However, this is not something that is easy to evidence or demonstrate and was not necessarily anticipated during the planning stages of this study. Cleaning data is not an uncommon challenge in analysing routinely collected health and social care data. Dash et al. (2019) described the associated problems as “data overload”. However, because there is a need to be respectful to the dataset source, it is difficult to discuss this challenge without potentially discrediting the process or deterring others from undertaking similar tasks.

As this was an unexpected step in the project, the timeframes were initially tight. Therefore, when it became apparent how arduous the cleaning of the demographic information was going to be there was a temptation to discontinue. However, it was reading the free text fields and the emotional response this triggered that was the driving force behind persevering. Whenever there was doubt, those entries would refocus my attention and appreciation that it was an important step in achieving the overall thesis aim.

4.5 Limitations

There will be caregivers who have been referred to this service at other times who are not included in this dataset. Although the service has a broad inclusion criterion, there will also be caregivers who do not want to or have not accessed this service. There was also a significant number of assessments that only included demographic information and there are limited data related to specific roles and tasks expected of the caregiver due to the health and wellbeing of the care recipient. Furthermore, the dataset lacked important socio-demographic data, such as ethnicity and postcode that would have enhanced analysis and understanding of the caregiver population in Glasgow. These issues limit the generalisability of our findings. However, I have attempted to counter this by comparing the findings with published findings from other sources where possible.

Opting to include all assessments in the analysis, rather than exclude those without a listed life-limiting condition could potentially dilute these findings in relation to caregivers of people with life-limiting conditions, who are the focus of this project. However, the assessments are not carried out by healthcare professionals and health categorisations, although important, are not the focus of the service. Therefore, excluding assessments where a life-limiting condition is not listed is risking excluding the very caregivers I sought to support. It is not anticipated that the diagnoses listed is an exhaustive list of all health complaints experienced by the cared-for person.

4.6 Chapter Summary

Undertaking this study was not without its challenges. However, none of them were new in relation to secondary analysis of routinely collected health and social care data. Unfortunately, it is unlikely that without the time and resources afforded to a full-time doctoral student compared to a researcher or clinician that this study would have been possible. This highlights the pressing need for improvements to the way health and social care data are collected, stored, and shared to enable insights and knowledge.

The included dataset highlights how health and social care services are becoming data dependent in their design, implementation, and evaluation. Historically, social workers, registered nurse, medical doctors, and members of the allied health professions have not been expected to acquire skills that are typically related to data science. However, increasingly more decisions around our roles and responsibilities are based on datasets that we are involved in collating. There are also significant ethical considerations for clinicians who are collecting, recording, and interpreting this data. Patient, caregivers, and service users have a right to trust that data that is being collected about them (or us as we will all be a patient and/or caregiver at some point in our lives) is stored safely and used for a specific purpose that is clearly understood, and the data collectors must also understand those objectives.

There is also an expectation for health and social care professions to offer person-centred care for people with life-limiting conditions. This expectation now extends to their caregivers. It is not enough to have a standardised list of presumptions about the support that caregivers require based on the diagnosis of their loved-one. We must consider aspects and characteristics of their personhood and how these affect their ability to care. We have a duty to consider the influence of those intersections and make decisions accordingly. We should also consider our own intersections and how these could affect how we are viewed by the people we are caring for and the care that we give. This might involve education for health and social care professionals in relation to data science. A more streamlined approach would be beneficial to services as it would identify failings and facilitate improvements appropriately. Furthermore, it would improve the lives of hard-to-reach and vulnerable populations, such as caregivers from Glasgow, to ensure their lives are better understood.

Although this stage was not initially planned for, it was anticipated that I would explore what help was already available in Glasgow and for whom it is available to. That process developed into an important step in the process of designing or selecting an intervention. It helped me to identify demographics and characteristics common among caregivers from Glasgow who require professional support, which then informed the planning of the qualitative study that follows in the next chapter. From this study, I identified that caregivers from Glasgow who access needs assessments are predominantly female adults of working age, of which many are economically inactive. Male caregivers who access needs assessments are more likely to be of retirement age and caring for parents. Mental ill-health is the most common health complaint listed for both female and male caregivers, with dementia being the most listed life-limiting condition for the people requiring care. Spousal caregivers were a common caring relationship requiring support for both female and male caregivers. Of the caregivers who described their ability to continue in their caring role, most were willing or able if given adequate support. Finally, the variation in demographics between female and male caregivers, as well as support requests and health diagnoses of caregivers and the person for whom they care, suggests the need for a truly person-centred intervention.

From analysing this dataset, I was able to identify the demographics of caregivers in Glasgow who access the Glasgow Carers Team to understand the population(s) most likely to benefit from the chosen intervention or interventions. The findings from this analysis could also be used to inform the selection of necessary sociodemographic data to be collected in any future pilot or feasibility trial to monitor who the intervention was reaching and how this compares to those accessing needs assessments.

Chapter 5: The Battlefield

5.1 Introduction

The previous chapters have identified what researchers and clinicians consider to be the priorities of interventions for caregivers of people with life-limiting conditions and the characteristics of caregivers who identify, or are identified, as requiring additional support to carry on in their caring role. There was a concern that expectations related to what is deliverable and what is important from interventions can differ between caregivers and services. Caregiver sex, ethnicity and cultural variations can influence negative consequences, role perceptions, and therefore, the help that is required (Anngela-Cole and Hilton, 2009). Consequently, as the caregiver population continues to increase, it is imperative that available support services are reviewed regularly. Speaking directly to caregivers to understand how they experience support services and interventions is a vital component in this process.

Focus groups and interviews have been successfully used in previous studies to understand how support services and interventions are experienced by caregivers of people with life-limiting conditions (Sutcliffe et al., 2015; Jamieson et al.; 2016, Morrisby et al.; 2021, Peel and Harding, 2014). In two studies, the word *maze* is used to describe the process of navigating the way through the health and social care systems to achieve a caregivers' desired level of support (Jamieson et al., 2016; Peel and Harding, 2014). Caregivers also described examples of delays to service input and a lack of clarity around what to do when their circumstances changed (primarily in relation to disease progression in the person for whom they care) (Sutcliffe et al., 2015). Caregivers reported that their understanding of the person for whom they cared was either overlooked by professional services or conversely, used to plug gaps when services could not provide appropriate care (Jamieson et al., 2016). Peel and Harding (2014) identified that professional services were generally not sensitive to caregivers needs, and lacked flexibility when caring for someone with dementia, often claiming that requests were "beyond our remit" (p652). Such challenges resulted in anger or mistrust amongst caregivers towards entire groups of professionals or more generally towards the Health Service following mis-or poor communication from only a few professional encounters (Peel and Harding, 2014).

From these findings, the researchers in all studies suggested the need for better communication between formal support services and caregivers to enable respectful collaboration and the delivery of person-centred care for both the caregiver and the person for whom they care. These studies were carried out in England (Peel and Harding, 2014; Sutcliffe et al., 2015) and Australia (Jamieson et al., 2016; McDonald et al., 2017). As legislation in Scotland is the most progressive in relation to caregiver recognition and their right to access support. It is, therefore, important to understand how the Carers Act is operationalised and whether it alleviates some of the challenges identified by caregivers in other countries.

5.2 Methods

5.2.1 Aim

- To examine the experiences of caregivers of people living with life-limiting conditions from Glasgow accessing and using supportive services and interventions to identify what support is missing from what is available.

In keeping with the modified systematic review, the exemplar conditions of stroke, heart failure and dementia were selected so that I could speak to caregivers who assisted with symptom management, cognition and physical disability.

5.2.2 Design

This qualitative, descriptive study is underpinned by the transformative paradigm using semi-structured focus groups and interviews to gather data. Qualitative descriptive studies provide a comprehensive overview of a phenomenon or event using accessible language (Polit and Beck, 2004). They are typically of relevance to nurse-researchers who are primarily concerned with understanding clinical issues and experiences, rather than developing theory (Kim et al., 2017). Sandelewski (2000) argued that, because of concern that descriptive studies are of lesser quality than other methods, qualitative researchers may be tempted to mis-label or represent their research as other methods such as grounded theory or phenomenology. This is unnecessary and misleading. A systematic review of qualitative descriptive studies by Kim et al. (2017) identified that the flexibility of qualitative descriptive enquiry allows researchers to address their study aims in creative ways. Because the aim of this study was to pragmatically explore caregivers' experiences with health and social care services, it was decided that qualitative descriptive was the most appropriate design.

In reporting our study and findings, we have used the consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007) (See Appendix 6).

5.2.3 Patient, Caregiver and Public Involvement

I worked closely with the Patient, Caregiver and Public Involvement volunteer (Charles) in this study. In reporting the involvement of Charles, I have followed the updated version of the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) short form reporting checklist for health and social care research (Staniszewska et al., 2017) (See appendix 7).

5.2.4 Participants

Purposive, snowball sampling techniques (Palinkas et al., 2015) were used to recruit participants by contacting local caregiver support groups running in Glasgow City and the Greater Glasgow and Clyde area. Purposive sampling is a common recruitment technique in qualitative descriptive studies because it offers flexibility to ensure participants are recruited who will likely be able to assist with addressing the pragmatic study aim (Kim et al., 2017). It also allows the researchers to adapt their recruitment strategies if more diversity is required in the sample population (Kim et al., 2017)

I contacted charities such as Alliance Scotland, Chest Heart Stroke Scotland, Alzheimer's Scotland and Quarriers. I also advertised on social media platforms (Facebook and Twitter), in libraries/community centres and in a local newspaper. To attempt to diversify the sample of participants, I displayed the advert in community centres within more ethnically diverse population centres around Glasgow, such as Pollokshields and Pollokshaws.

Following an expression of interest, possible participants were given a copy of the participant information sheet and were invited to share it with anyone with caring responsibilities that they thought might be interested in participating. All contact with potential participants was made via email and telephone. I confirmed that they met the following inclusion criteria:

1. Over 16 years old.
2. Living in an area with a Glasgow postcode.
3. Caring for someone living with dementia, heart failure or stroke.
4. Experience of support services/interventions and willing to talk about this.

Participants and potential participants had no prior relationship with any of the study team.

5.2.5 Data Collection

Focus groups were selected as the primary method of data collection. Focus groups are group discussions that create interaction data through discussions among participants (Kitzinger, 1995). This enhances the level of inquiry and can produce data that might not be possible from other methods of enquiry (Kitzinger, 1995). However, when a potential participant who met the inclusion criteria was told that, at that time, there were no other focus groups set up, she expressed a preference to be interviewed instead. This was an unexpected development, but it was decided that an amendment to the ethical approval would be added for interviews to take place if preferred.

The original plan was to recruit from established caregiver support groups and focus groups would take place between people with an established relationship. However, only two focus groups were carried out with caregivers from support groups (Table 15).

The meetings took place between September 2019 and March 2020. All meetings were recorded and transcribed verbatim. I facilitated all meetings. I was supported at the focus groups by a second researcher who was familiar with the study brief. Their role was to assist participants and take field notes during the discussions. Each of the researchers who assisted at the focus groups are current or post-doctoral students (two females and one male) with a background in clinical nursing, so were available to offer emotional support if/when necessary. Only researchers and participants were present during meetings.

The proposed topics of discussion (Table 13) were developed to enable me to address the study aim. The topics were initially discussed with Charles and I, then a pilot test was conducted to finalise the discussion points and check the recording equipment. The questions were reviewed following each focus group; because the focus groups were so active and discursive, no changes were necessary. Prior to starting the meeting, participants were given a copy of the topics to be covered, the ground rules, space to write notes and a pen. Each meeting started with the researchers briefly discussing their clinical and research interests, and any experiences they have in a caring role. This was to prevent a knowledge and power hierarchy that can be created when researchers do not share personal information about themselves with participants. This arrangement was not altered for the interview in any way.

Table 13: Topics of discussion.

Focus of the discussions
• **Your experience as a caregiver: who do you care for, what types of care do you provide, and for how long?** • **What is your current level of support: NHS/social work/third sector services, family/extended support network?** • **Are there any services you rely on to fulfil your caring role?** • **What type(s) of support is missing that you would like to have?** • **How do you decide if a service or support is useful/helpful?**

5.2.6 Ethical Consideration

Ethical approval was obtained from the University of Glasgow College of Medical, Veterinary and Life Sciences ethics committee (application number 200190048). An amendment to the ethical approval was added to include interviews. All names have been anonymised.

5.2.7 Data Analysis

I was guided by Braun and Clarke's thematic analysis method (Braun and Clarke, 2006; 2013) and applied an intersectional lens to enhance the critical reflection (Hill Collins and Bilge, 2018). Braun and Clarke's (2006; 2013) method follows six stages of data organisation, reduction, and refinement. I undertook complete coding, analysing the data line by line, comparing the coded data with field notes. I preferred using printed copies of transcripts, note taking and colour coding, as this facilitated deeper immersion in the data. A code book was completed using Microsoft Word and shared with my supervisors. A mix of data-derived and researcher-derived codes were created from this process. The team then discussed initial codes and patterns. Through discussion, we defined and redefined the themes and subthemes.

Braun and Clarke (2013) recommend analysing focus group and interview data separately because they are described as distinct data collection methods. During the early coding stages, we treated the interview data independently. However, when we identified patterns in the interview data that aligned with the focus groups, we had to decide whether to include the interview data. Guest et al.

(2012) suggested that findings from multiple methods can enhance findings by producing opportunities to compare data and evidence convergence (or divergence). Michel (1999) argued that some personality types and people who are vulnerable can be silenced in a group scenario and, therefore, dissuades researchers from relying solely on focus groups. We ultimately decided to include interview data that matched with the identified themes.

Once I was familiar with the data, and the first round of coding was complete, I applied the principles of intersectionality to the identified codes. This study utilises intersectionality as an analytic tool to consider the major axes of social division involved with caregivers to enhance findings.

We did not discuss our identified themes with study participants, but we did consult with Charles.

5.2.8 Validity and Reliability

The suitability of the term's "validity" and "reliability" within qualitative research is a contested subject (Noble and Smith, 2015). This is because they are traditionally related to tests and measures within quantitative research that could be repeatedly used with a dataset to produce predictable results. Instead, alternative terms such as "dependability" and "trustworthiness" have been suggested as more suitable in qualitative research (Guest et al., 2012). However, Long and Johnson (2000) argued that when alternative terms are used in qualitative studies, they often lack suitable explanations and definitions. Instead, it is suggested that as "validity" and "reliability" are commonly understood to relate to the general perception of the study's credibility and rigour, which are necessary components of all research, they are not unsuitable for qualitative research.

My supervisors and I all currently have clinical roles working with people with life-limiting conditions, and in palliative and end of life care. The team have all had personal and professional experiences working with caregivers and as caregivers. Therefore, we acknowledge that there will be a level of bias in our interpretation. Transformative research does not attempt to remove all bias. This is because it is anticipated that the research process will have an impact on the researchers and visa-versa, which will produce interesting insights (Mertens, 2008). Instead, Mertens (2008). Braun and Clarke (2019) highlight the importance of reflexivity and self-transformation in qualitative research, which are necessary to achieve positive, creative change. Following initial coding, the team met regularly for reflexive discussions. During these meetings we discussed the identified themes and subthemes, as well as any biases that might have influenced our interpretation. These meetings also helped us to reach consensus with any disagreements or differences.

As well as the need for reflexivity, the following methods were employed in this study. They are recommended by Guest et al. (2012) to enhance validity and reliability in qualitative research that uses thematic analysis:

1. Brainstorming (with Charles) to identify topics to be covered and suitable questions to ask.
2. A pre-test of the study brief and proposed questions was carried out.
3. Training was given to researchers accompanying me to the focus groups on the background of the study and the reasons for the proposed questions. We also had an in-depth debrief following the focus groups to improve data quality and consistency.
4. All meetings were transcribed using the highest quality verbatim service available.
5. The use of verbatim quotes to evidence the identified themes.

5.3 Findings

Recruitment took longer than anticipated and was halted due to the Covid-19 pandemic. When the national Covid-19 lockdown was imposed, three people had expressed an interest but did not meet the inclusion criteria; three people dropped out who met the inclusion criteria while we were attempting to arrange a meeting (no reasons given); and three people who met the inclusion criteria were unable to participate (due to Covid-19 restrictions on research participation).

Of the participants (n=15), fourteen were white, British women, and only one was under retirement age (Table). No participants were in employment at the time of the study. One participant was a white, British male of retirement age. Most (n=10) of the participants were caring for someone living with dementia, and most (n=10) were in a spousal relationship with the person for whom they care. Two participants were caring for their husbands who were living with heart failure, and three participants were caring for a stroke survivor. The average length of meeting was 72 minutes, and most participants knew the other attendees prior to the focus group, with the shortest focus group being between strangers (Table)

Table 14: Characteristics of participants in the study.

Participant	Age group	Sex	Race	Relationship to CF Person	Diagnosis of CF Person	Employment status
1	65+	F	White-British	Spouse	Dementia	Retired
2	65+	F	White-British	Spouse	Dementia	Retired
3	65+	F	White-British	Adult Child	Dementia	Retired
4	65+	F	White-British	Spouse	Dementia	Retired
5	40 - 50	F	White-British	Adult Child	Stroke	Unemployed
6	65+	F	White-British	Spouse	Dementia	Retired
7	65+	F	White-British	Spouse	Dementia	Retired
8	65+	F	White-British	Spouse	Dementia	Retired
9	65+	F	White-British	Adult Child	Dementia	Retired
10	65+	F	White-British	Daughter-In-law	Dementia	Retired
11	65+	F	White-British	Spouse	Stroke	Retired
12	65+	M	White-British	Spouse	Stroke	Retired
13	65+	F	White-British	Spouse	Heart Failure	Retired
14	65+	F	White-British	Spouse	Heart Failure	Retired
15	51 - 65	F	White-British	Adult Child	Dementia	Retired

Table 15: Details of each meeting.

MEETING	NUMBER OF PARTICIPANTS	LOCATION	PARTICIPANT RELATIONSHIP	LENGTH (MINUTES)
1	5	Established support group	Friends	70
2	5	Established support group	Friends	60
3	2	Local library	Strangers	50
4	2	Participant’s home	Friends	90
5	1	Participant’s home	n/a	90

We identified one central feature that was common to most participants and their experiences with accessing and using services and interventions that purport to support them in their caring role. There were then three identified themes; each theme has corresponding sub-categories.

5.3.1 Central Feature: The Battlefield

The battlefield was the central feature of the focus groups and interview. Every identified theme had an element of conflict within it. The caregivers’ verbal language, body language and descriptions of the challenges they face in obtaining support and utilising services was that of a person who has been unwillingly recruited into a battle that they cannot avoid:

> P2: Years ago, you used to get eight weeks’ respite a year, and it's now down to two. Now, there's not one person, you included, who only get two weeks’ holiday, a year. I think it's illegal. I get paid by the government, carer’s money, to look after John, so they're paying, the government, they're paying me. Why do I only get two weeks? I should get at least four weeks, same as what the workers get. And it's 24/7 care, it's not nine to five, Monday to Friday.
>
> So, they cut it down to two, never saw the telly, never saw the newspapers, I was never told, they never told me, I'm a carer, they never lettered me and said, look, this is what’s happened. It was all kept under the table. Because if it had been in the newspaper, there would have been a public outcry about that, because that was ridiculous. And I said to them, its false economy, what

> you’ve done, because within a year or two, you'll see them all, people giving up sooner. And I'll probably be one of them, giving up sooner, because you just can't do it anymore.

The caregiver battles did not just come from formal services, but also from support from family and friends:

> P5: I think the family is waiting for me to fail, you know what I mean. I feel like they're waiting for me to turn round and say, well I just can't do this anymore, and she's got to go in a home. But that’ll never happen, because I know that’s my mum’s wish, she's never to go in a home.

They were not alone in their fight. During our meetings, and as evidenced in many of the provided quotes, caregivers were supported and reassured by one another when they spoke of their challenges in accessing help, and when recounting arguments with family and friends. The group facilitator in meetings one, two and four said very little during the meetings because caregivers were so comfortable talking among themselves and the discussions flowed naturally. It was obvious that the friendships formed between caregivers were very important in normalising and understanding common negative caring experiences.

This was most apparent when speaking to caregivers of people with dementia. The health and social care systems did not appear to be equipped to cope with the enduring and complex needs of the caregiver and cared-for person:

> P2: I just think, anything you try to get, whether it's befrienders, or carers, or anything, everything is so f****** hard. It's hard, hard work. And you're that knackered that your brain, with chasing people and running after people.

In the following quote, two caregivers are offering advice to their friend who is in the process of choosing a care home for her husband:

> P1: You have to fight for what you want. You have to fight for it. Don't be frightened, just get on your strong body armour, and you know, it's your hubby, you know what he wants. And what maybe he’ll come, he’ll become, but…
>
> P4: I think he's terrified.
>
> P1: But you need to, you know, you need to ask all the questions.
>
> P2: And then, as you say, you can cry later.

The constant battle to obtain help had resulted in many caregivers appearing to be exhausted and disillusioned. When one caregiver expressed hopelessness, the group did not challenge or offer alternative positions. Instead, there was a feeling of solidarity and understanding in the room:

> P5: There's just nothing, I have no…I don't see a way out, you know what I mean, I just don't.

In the following quote, a participant summarises her experiences trying to access help to care for her mother who had a stroke and has limited rehabilitation potential:

> P5: I mean, I've had about three mental breakdowns, because it's like, every time I turn, there's a door, there's a door, there's a door, you know what I mean. And it's like, there's nothing, you know what I mean, there's nobody opening that door and saying, come on, this is it, we've got this sorted, that sorted. It's just false promises, everything is false promises.

5.3.2 Theme 1: Bureaucratic Barriers

Understanding the caregiver's experiences with support services and professionals was a central research question and their experiences relates to our first identified theme. There are high stakes involved with these relationships. When they work well, professionals, particularly professional carers, become intrinsic parts of the family's support network:

> P6: She's great… I absolutely love them all.

However, the period between asking for help and obtaining help would often be lengthy, complicated and filled with endless bureaucracy. Dealing with the bureaucracy was one of the biggest battles faced by caregivers and was out of their control. When things went wrong, we heard of traumatic episodes and irreparable relationships, all to the detriment of the cared-for person and caregivers physical and mental health:

> P5: She had a really bad experience with carers, so she doesn't allow them in anymore, so it's my responsibility for everything.

Some of the bureaucracy experienced by caregivers was created because professionals did not appreciate or understand that caregivers are experts in the person for whom they care:

> P11: And when I went up to see him in intensive care the nurse said, oh, he's come through the operation fine, we're just taking the tube out; took the tube out and right away I said, he's had a stroke. And the nurse was like that, oh, I think you're jumping the gun a wee bit, he'll be fine.

5.3.2.1 Sub-category: Communication

Communication was a recurring issue with caregivers when discussing their experiences with support services. Caregivers often found themselves in avoidable battles because clinicians struggled to communicate the complications related to the bureaucracy. This would result in needless delays in obtaining help and created lasting memories for many caregivers.

During meeting four, we witnessed an example of poor communication when one participant received a phone call from the hospital ward her husband was currently staying on. She was notified on that Friday afternoon that her husband was to be discharged from hospital, although she had previously been told no hospital discharges happen on a Friday afternoon. As she does not drive, she had to then phone various family members to see who was available to collect him, however, the ward was also unable to give her a discharge time. She also had to phone the home care service and check that this could be reinstated following his discharge, which the ward staff had failed to do themselves.

Here, one participant (P7) describes her contrasting experiences with doctors involved in the process of diagnosing her husband's dementia:

1. He went, could you tell me what you're doing – no, I'm seeing this patient, I'm not seeing visitors. I said, I'm his wife, I'm his power of attorney, I should be here with him – no, no, no, outside. And I had to go back out, that waiting room was chock-a-block, and I had to walk, back along that corridor, everybody staring at me. And there was a woman sitting, and she went, don't upset yourself, dear, she said, he's a very rude, ignorant man. And I went, well he'll not be rude to me again. And the next thing, Peter came flying out, he went, not going back here.
2. The consultant tapped me on the shoulder, and he went, are you with Mr Jones, and I went, yes, and he went, what relation, and I went, I'm his wife. He went, do you want to come in, and I went, oh right. So, I went in, and I sat over against the wall, and he was asking me questions as well as asking Peter. He was so, so nice. He explained everything.

Caregivers seemed to be empathetic towards the stresses and limitations of nurses. Even when caregivers were unnecessarily doing the nurses' jobs for them, they seemed keen to forge alliances:

> P11: It's not the nursing staff's fault, but they're pushed. I mean I used to go up and sit, and I'd end up helping, you know, I was going to other wee men that didn't have visitors…"

However, there was less understanding when social workers were working with provisions out with their control. Caregivers anticipated confrontations with social workers:

> P2:So, I phoned up social work and I said, my daughters booked a holiday for ten days, we're going away, I've checked that the home had space, and everything. And she went, no, I don't think so, I said, why? She went, you only get two weeks a year, you've already had a week. And I went, no, that wasn't a break, that was a family emergency, my brother, he was dying. And she went, no, no, that's a week, that's one of your weeks. So, what you'll have to do is come back early from your holiday and pick him up or pay the money to keep him in for the extra few days.
>
> P3: That's terrible, isn't it?
>
> P2: And I said, look, I've been with him for eight years, and I've never, ever asked to use respite. The first time is this year, because things have progressed so much, I need the help now. I didn't need help before, I said, other people need it, and now I need it, I need it now, and you're telling me, no, and it's all to do with budget, it's all to do with funding.

Some participants also described feeling frustrated at being described as a carer or caregiver by professionals. Instead, when asked for alternatives, they preferred to continue seeing themselves as "wife" or "daughter" or similar:

> P15: Yeah. You don't. You don't really because you think, well it's something I've got to do, I'm looking after them. It's like your kids. Your kids are ill, what do you do? You're there all the time looking after them. It's just something you do. And you don't… Some say are you a carer? And you think, you go, I am really a carer but I'm not. I don't count myself as a carer. It's like a job. It's like a job you're not getting paid for.

5.3.2.2 Sub-Category: Autonomy Over Time

Rather than trying to limit the bureaucracy to reduce stress experienced by caregivers, professionals would offer participants relaxation and complimentary interventions through third sector services to manage the increasing stress that their services and treatment was causing. However, some of these interventions overlooked the importance of considering the age and disability of caregivers. Although these experiences were often told through laughter, there could have been serious implications, including injury, with this oversight. In the following example, two friends humorously recount one experience:

> P13: And not the tai chi either and that. I never liked that.
>
> P14: We got tai chi one time and they…I mean, they tried to get us to…
>
> P13: Because I was in pain with my hip.
>
> P14: stand…trying to stand on one leg and I’ve got rheumatoid arthritis and she’s saying, stand on one leg, and you’re holding on to the chair and you’re, kind of, falling over. I went, I am sorry, this is not for me.

Caregivers of people with dementia and heart failure described experiences with massage, music therapy and yoga, which seemed helpful. However, the consensus was that courses of therapies were difficult to commit to due to the unpredictability of the caring role:

> P15: But the likes of the yoga helped me, but I can't commit to a six-week block. ‘Cause you don’t know. And you don’t want to keep saying to people all the time, you know, no I can't do it because of this, this and this.

Mindfulness was also discussed, but they were not impressed:

> P3: Mindfulness, no thank you. One session was enough for me. No, one session was enough. It was a woman that came to the group, right, mindfulness, you’ll love it. Right, okay, I’ll give it a try. And I'm sitting there, and the wee bell ringing and you were…You just stopped doing whatever… No talking. And then it was round the table to see, what do you think of yourself? What do other people think of you? How do you know what somebody thinks of you? And I'm sitting there and I'm going, this is not for me.

Instead of wanting structured activities, many caregivers expressed a need for short periods away from the cared-for person to spend as they wished. This was usually described as spending time with a friend doing an unstructured activity of their choosing. Activities such as knitting, colouring in and drinking gin were popular choices:

> P13: We've both got our bus passes so we can go on for nothing. So, we just say, right, where are we going? Let's get into town, see for the first bus, let's get on it, let's go. And we go for lunch. And then you've charged your batteries, you can come back, and you can…
>
> P14: You can get ready to start it all again.
>
> P13: …Be ready to start again.

5.3.2.3 Sub-Category: Once a Caregiver, always a Caregiver

Some of the new skills that caregivers developed because of the bureaucracy they experienced became useful outside of their caring relationship. For many caregivers, they gained new skills in communication and advocacy:

> P15: On a positive side, I think I'm strong. I think I'm really… I think I am really strong. I don't like confrontation. Don't like adversity. But I think you learn to manage it. You learn to manage it.".

For others, they developed a deeper understanding of their loved-one's condition(s) and how to access help:

> P14: We wouldn't know what you were talking about. We'd maybe go along shaking our heads, but we wouldn't have a clue. And…but at the meetings, you get somebody to tell you what the words meant. Makes you a wee bit wiser.

However, this was not always easy and there appeared to be an age inequity, whereby older caregivers struggled most with learning and applying new knowledge and skills:

> P6: Sixty odds, it's really hard to start learning how to pay bills.

One of the other challenges faced by caregivers occurred when their new skills overlapped with the roles of support services. In the next example, one woman, who has cared for both her parents, discusses the conflict that arises when she visits a care home:

> P3: The carers up there, even, will say, excuse me, I'll manage, and I went, I'm not touching them, I'm just saying, that wee man is going to fall. Because I can see the signs, or whatever. And maybe I shouldn't be, but once a

> carer, always a carer, you can't just switch off because you're in somebody else's place. But …

> P4: I think it's because you're working with somebody in the house, and you're constantly watching them, so if you go anywhere, you just automatically tune in.

> P2: You never switch off, yeah, that's the problem, you just, even when you do get a break, you don't switch off.

Some of the challenges faced by older women were overcome when they learned with an ally. In the following quote, two friends who care for their husbands with heart failure discuss how they work together to access help and support. Both women are in their eighties and met through a caregiver's support group. One friend is proactive and outspoken, whereas the other one is shy but very organised (Figure 4 photographed with permission and included below, one for each year since she started caring for her husband). She has kept every hospital appointment letter. It would appear the year after his diagnosis was their busiest yet. This friendship between two caregivers has moulded them into a formidable unit:

> P14: We've got to go away to all these meetings to find out what there is out there for carers. We travel everywhere, wherever there's a carers meeting and there's going to be counsellors and everything there, we go to find out 'cause it's the only way you're…nobody tells you. It's like a secret society. Nobody tells you what you're entitled to.

Figure 4: Photo taken during meeting three of the diaries and every hospital letter kept by one participant from the year her husband was diagnosed with heart failure.

5.3.3 Theme 2: Navigating the System

This theme relates to participants opinions of support systems and services. Alongside the bureaucracy imposed and upheld by professionals, caregivers battled through a complicated health and social care system.

5.3.3.1 Sub-Category: Inconsistency

Caring for someone with dementia was not a steady process because of an unpredictable illness trajectory. The support that was offered was inconsistent and unreliable, which made the unpredictability of the caring role worse:

> P3: Consistency is a great thing for dementia. There was no consistency, whatsoever.

Instead, there would be periods of stability, which would get them discharged from services because they did not require active input. This was followed by changeable, rocky periods when they would waste time tracking down professionals who they had previously contacted.

Because of this, when asked to describe what was missing from what was available, participants described wanting a more streamlined system of support. Their ability to care for their relatives would be improved if they had someone they could contact for the duration of their caring role, or if professionals involved in their relative's care made themselves worked more closely with them and viewed them as collaborators of care rather than challenges to care.

Example 1

> P8: If I had somebody that I could say, right… Phone up and say, can I speak to so-and-so and… If something's worrying me, be able to talk to them. But you don't have that… I'd be glad, so long as somebody came here and gave me some information or here to help me then, no they're more than welcome to come. Don't really care.

Example 2

> P10: I've been asking for a named person, somebody that I can phone up and talk to for 14 years, and I've not got anybody. What I'm told… Oh you've been coming here that long, just phone up anybody. That's not the point. I'd like to… Well, if I'm phoning you, I'd like to phone you up and say, right… Or some… Somebody phoning and when you answer the phone, can I speak to Jessica, and I've got somebody I can talk to. I don't need to keep going through the same thing over and over again with different people.

Example 3

> P15: You need that one point of contact, and it needs to be for… Not only for the cared for, it needs to be for you.

5.3.3.2 Sub-Category: Secrecy

To develop a sense of control and perception of winning the battles created by the system, many caregivers quickly learned to withhold information from professionals. Often this was because they had lost their trust:

> P7: My daughter went, stop telling her things. And she went, did you tell her about that, and I went, no, she said, well don't bother, because that's nobody's business except yours.

However, sometimes it was to protect the cared-for person from judgement:

> P6: And I thought, you can't really tell somebody that your man thinks your daughter's you, and he wants to marry her, he wants to go to bed with her, you know.

5.3.4 Theme 3: Battle Wounds

The final theme relates to the impact that the battles from accessing support services had on various aspects of the caregivers' lives.

5.3.4.1 Sub-Category: Physical and Psychological Impact

I heard many harrowing stories of personal sacrifice by caregivers risking their own health and well-being to continue in their caring role that was forced upon them due to inadequate support. During my meetings it was clear that caregivers who were newer to their role struggled to deal with the pressure. This caused some to feel guilty about their decisions, especially when they felt mistakes had been made. Some caregivers also discussed their resentment at the enduring nature of the role. When this issue was raised, other, more experienced, caregivers would offer reassurance about those feelings. These discussions did not come across as harsh or abrupt, instead they evidenced the importance of peer-support in normalising and accepting common experiences and emotions associated with caring for someone with a life-limiting condition:

> P1: I understand everything you're saying, where you feel resentment. I'm by that stage of resentment now because I've looked after Simon since 2012, so I'm by all those stages of resentment.

> P2: But you get by the stage of feeling resentment because it has to be done, and if no one else is going to do it, then you've got to do it.

One participant reflected on her perception of what unifies caregivers, which were all elements of personal sacrifice:

> P15: Unique to every… There'll be similarities, lots of similarities, exhaustion, you know, all that kind of thing. Sore back, depression, anxiety. You know, physical impacts, losing friends, retirement. I would say the commonality there and obviously money is then difficult.

The way the caring role changes and evolves alongside the cared-for person was referred to by one caregiver as her "parallel journey" because:

> P15: There was…I mean, it was just…I don't even think I've done it any, you know, favour, the way I've explained it all. I can't explain the…your whole life changes completely. Changes completely. Whether you choose or don't chose to be that.

5.3.4.2 Sub-Category: Changing Relationships

It was clear among caregivers of people with dementia, that the caring role had drastically changed their relationship with the person for whom they care. Some of the caregivers I spoke to were now caring for their loved-one from a distance as they had moved into care homes. This change in living arrangements was the point where they felt they had to accept that the war was lost. For one caregiver, she felt that her husband's imminent admission was the end of their marriage. She was being forced to separate from him, which seems to have been overlooked by professionals involved in their care:

> P2: I'm having to split with John after 43 years, the first thing they've got to say to me is, do you own your house. I've been roaring and greeting, sobbing, I greet every day at some point in time. Because it's, you know, we're not together anymore, that's it.

However, another caregiver was pleasantly surprised to find that she had maintained her caregiver role and identity when her mother moved into a care home, as she had expected this to change or even end. It was clear that this was testament to the care homes appreciation for family members and friends as part of their care home community:

> P15: So… But I still… In spite of her being in a care home, I still feel… I don't… It doesn't diminish my responsibility for caring about my mum.

Relationship changes went beyond the caring relationships, and into extended families and friends. One participant described how she struggled to accept that her and her husband were increasingly reliant on her children for support. However, there were some positive changes to relationships and support networks. Participants formed a strong united front with other caregivers, and attending support groups became a priority within their often unpredictable and stressful weeks:

> P15: I go to a support group… Because I do need something. Your sanity would go. It would definitely go… The Internet, I found it's too wide and I'm not… Sometimes it's the silliest wee things that I just want to ask somebody. And I didn't feel… I just don't feel the Internet…I needed to be able to express it as opposed to put in writing, you know, I felt as if I just needed somebody to say, aye, that's okay or… You know, or, don't be worrying, you know, just take… Be patient, and things like that.

5.3.5 Patient, Caregiver and Public Involvement Findings

The process of reviewing the identified themes and corresponding data triggered an emotional reaction in Charles. Descriptions related to the general lack of support and, more specifically, respite offered to caregivers resonated with him. This process enabled Charles to reflect on his own caring relationship and, for the first time, fully recognise the extent of the sacrifices he made to his health and well-being when caring for his wife.

5.4 Discussion

5.4.1 Waging War

This study examined the experiences of caregivers from Glasgow who had accessed supportive interventions and services. Obtaining help that met the needs of the caregiver and the person for whom they care was an ongoing battle. Consistent with previous research (Barken, 2014; Teixeira et al., 2020; Peel and Harding, 2014; Sutcliffe et al., 2015), we identified that some services and interventions that support caregivers are not dependable when caregivers need them, nor can they adapt to the needs of the caregiver and fluctuations in support requirements. When their circumstances changed, the caregivers would find themselves battling with service providers once more. Caregivers often found themselves also battling with their families and, indeed, themselves during the process of understanding and accepting their caring role and the complex emotions entangled within their caring relationship. This mirrors findings from Peel and Harding (2014) who identified that caregivers often used battle and fighting discourse to describe obtaining help and support. One participant in that study compared the process to being a soldier in World War Two, as they went from one battle to another. Rather than finding allies amongst professionals and services that are meant to be supporting caregivers, they forged alliances with other caregivers who supported them in their fight. The benefits of peer support are cited as important for caregivers of people with life-limiting conditions (Sutcliffe et al., 2015), and interactions between participants during some of the meetings in this study demonstrated this. As previously identified by Barken (Barken, 2014), participants in this study found the courage to share emotional stories and challenging situations with their friends and fellow participants.

5.4.2 Forming Alliances

The interventions that caregivers in this study described using, or being offered, were often prescribed, short-term interventions. These interventions typically offer caregivers the opportunity to learn skills like mindfulness or training that can help them longer term beyond the intervention. However, this type of support was often described as unsuitable. This was due to the unpredictability of the caring role. As those types of interventions require caregivers to attend at a set day and time every week (or so), caregivers anticipated that they would be unable to complete the programme. Consequently, they would probably not sign up at all. And yet, most (n=13) of the caregivers I spoke to attended support groups that had set times every week. This suggests that although short-term courses might offer caregivers the opportunity to learn useful and transferable skills, they are not the type of intervention deemed necessary for many caregivers in Glasgow. Instead, participants appreciated the opportunity to build relationships with peers and interventions that carry less pressure to attend. However, as most participants in this study already attended peer support groups, this type of support is currently available. Therefore, researchers who develop an intervention that includes peer support should consider what their intervention adds to what is already available.

Of the thirteen participants who attended support groups, twelve shared similar demographics. They were white, British women of retirement age from Glasgow who were caring for parents or partners living with dementia or heart failure. It seemed that sharing these demographics formed the foundation of friendships. For women, the ageing process is one of intense and immense change in their physical and mental health, relationships and contribution to society. This was described by participants in a study by Hofmeier et al. (2017) as perceived invisibility and irrelevance, where they were expected to be unseen and unheard, and prevented from having meaningful roles. These changes were characterised by a loss of control and self-determination. Tuohy and Coony (2019) suggested that this is because of how older women understand their autonomy. Ageing creates a trade-off whereby they must choose between accepting help or autonomy (Tuohy and Cooney, 2019). This transpired in our discussions when one caregiver discussed her reluctance to accept help from her sons, who then became irritated and frustrated with her. It is understandable that the subversion of relationships as defining as the mother-child relationship will require significant personal re-adjustment and re-alignment. Misunderstandings and ignorance described by women in relation to the ageing process are supported by an increasing body of historical medical evidence, which suggests the systemic marginalisation of older women in society. Time and again major complications related to health complaints and treatment were dismissed and ignored (Criado Perez, 2019).

A caregiver I interviewed emphasised how unique each caregiver experience is, but then offered some similarities. All were objectively negative: “Exhaustion... Sore back. Depression. Anxiety. You know, physical impacts, losing friends…”. I also heard stories of caregivers of people living with dementia regularly managing culturally and socially unacceptable behaviours, such as public defecation and sexual disinhibition. These types of behaviours are categorised within behavioural and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms. Other BPSD include wandering, sleep disorders, personality changes, aggression and apathy (Baharudin et al., 2019). The BPSD occur in up to 97% of people who live with dementia over the course of their illness (Steinberg et al., 2008). However, Baharuden et al. (2019) suggested that how caregivers feel about BPSD varies, not by frequency or how common they are, but by type. Aggression and disinhibition were among the BPSD that increased caregiver burden the most (Baharudin et al., 2019).

Although violent, abusive or harmful behaviours from the cared-for person are not an uncommon experience among caregivers, how they are experienced and interpreted by caregivers remains a neglected area of research (Isham et al., 2020). This weakness is surprising because the impact that witnessing disinhibition or experiencing aggression from a loved one would normally be recognised as potentially troubling or traumatising. If we consider that caregiver research prioritises alleviating the psychological risks associated with the role, understanding BPSD should receive adequate attention. Fortunately, there has been some valuable recent studies aiming to address this (Herron et al., 2019; Isham et al., 2020; Spencer et al., 2019).

Spencer et al (2019) analysed interview and diary data from caregivers experiencing violence and intimidation due to cognitive impairment. The study is a harrowing read, detailing the fear, isolation and turmoil experienced by many caregivers. One 74-year-old participant was forced to move into temporary homeless accommodation in a woman's shelter for her own safety. It was common for caregivers in the study to develop management tactics that centred on containing violence and aggression rather than preventing it, as outbursts were inevitable. A caregiver's social support networks were linked to how likely they were to feel personally responsible for the behaviours, with those who were more open about their experiences shouldering less responsibility. Some of the coping mechanisms employed by caregivers meant they were perceived to be callous and detached. This echoes my experiences speaking to caregivers in our focus groups. One participant talked of overcoming her feelings of resentment and continued to care for her husband who was aggressive and disinhibited. She said she continued because "it has to be done, and if no one else is going to do it, then you've got to do it", implying that if someone else was available she would not be his caregiver.

Herron et al. (2019) analysed seven interviews with people who had previously cared for someone living with dementia who experienced BPSD such as hitting, spitting and kicking to understand how these are experienced by caregivers. They highlighted that there is concern within dementia research that labels such as aggression and violence place blame on the person with dementia. It is suggested that, instead, researchers should strive to understand what the person is trying to communicate through their behaviour. Herron et al. (2019) argued that discourse related to violent behaviours by people with dementia towards caregivers should move away from a victim and perpetrator position. Instead, they contend that violence should be placed within a broader continuum of care to build a more nuanced framework for understanding this complex phenomenon. I disagree with this position and suggest that violence, aggression, and victim are objective, categorical words. Violence and aggression are used to describe a spectrum of behaviours that might not be intentionally harmful, but nonetheless are. I adopt the position of Ekman (2013), whose book explored prostitution and surrogacy in Sweden from a Marxist-Feminist position. Ekman (2013) expressed concern around the increasingly popular move to frame women who experience prostitution or surrogacy not as victims but as survivors or even active subjects. Ekman (2013) argued that the word victim is increasingly used as a character trait to imply a woman is weak, passive and powerless. This removes the legal status of the word victim, which simply means to be hurt, damaged or killed because of the behaviour of another person(s). I suggest this argument applies to caregivers who experience violent and aggressive behaviours from the person for whom they care. Care and consideration are required when selecting appropriate language to describe behaviours associated with illness and disability. However, being overly cautious about what language to use to describe dangerous behaviours could dilute the seriousness of the caregiver's experiences and could also potentially confuse social networks and professionals.

Drastic changes in behaviour and personality are not just associated with living with dementia but are common with many life-limiting conditions. For example, following a stroke, some people experience mood and emotional disturbances, including uncontrollable anger. Unpredictable outbursts of laughing or crying is referred to as post stroke emotional incontinence and occurs in up to 34% of stroke survivors (Kim and Choi-Kwon, 2000). Furthermore, side effects from Parkinson's medication can cause impulsive and compulsive behaviours including gambling and drug addictions, overeating and hypersexuality. Up to 30% of people with Parkinson's experiencing at least one impulsive or compulsive behaviour (Erga et al., 2017). How these develop and the likelihood that they will be swiftly identified and appropriately managed depend heavily on the ability of the caregiver to advocate for the person for whom they care. Such advocation requires the caregiver to override any embarrassment or shame that they might be experiencing (Lu et al., 2020). Although these issues are common, other than gambling addiction, the assessment and impact of impulsive and compulsive behaviours have not been given sufficient attention from researchers (Weintraub et al., 2009). A meta-synthesis of systematic reviews of studies related to living with heart failure, chronic kidney disease and COPD found that mood and behavioural changes are common in all disease groups and are often cited by caregivers as a significant challenge in the caring role and relationship (May et al., 2016).

It is likely that these issues have generally been ignored by researchers because the need to balance understanding without stigmatising the cared-for person can prove too difficult (Isham et al., 2020). However, by ignoring or overlooking these common issues in caring relationships, researchers could be adding to the stigma that they are trying to prevent. Avoiding them could miss an opportunity to share how common these experiences are, and normalise how caregivers feel about them, as well as support caregivers who want to end their caring role because of them. Researchers and clinicians can acknowledge that behaviours associated with certain conditions, however unavoidable or typical, can coexist with feelings of fear, frustration and embarrassment by those who witness them. Admitting that there may be no easy solution or management could help caregivers and professionals to understand the gravity of their situation and have realistic expectations of management potential. This is a useful consideration for this project. It suggests that a useful intervention might be one that allows practitioners delivering the intervention to access training and education on supporting people with and those caring for BPSD. Opportunities to develop an intervention that allows caregivers and professionals to develop a trusting relationship so that problematic BPSD can be shared without fear of judgement or misunderstanding would also be worth considering.

5.4.3 Battle Fatigue

Caregivers in this study discussed experiences with third sector support services that did not consider the caregivers' age, (dis)ability and what we know about the changeable trajectory of the caring journey. This is an important issue for caregiver support services and research. Three meta-analyses of trials for caregivers of people with life-limiting conditions suggest that interventions such as mindfulness, meditation and massage tend to run from between four and fifteen weeks (Dharmawardene et al., 2016; Jensen et al., 2015; Lee et al., 2020). As is often the case in caregiver research, heterogeneity in intervention style and outcomes were issues identified in these reviews; these are undoubtedly important issues in this field of research. However, they also reported a need for greater analysis or discussion of dropout rates and causes. One review highlighted the importance of completing interventions for caregivers to obtain the maximum benefit, suggesting that further research was needed to “increase compliance” (Lee et al., 2020). However, analysing data from participants who drop out could help researchers and clinicians understand if there is an acceptable minimum for intervention participation, which would support caregivers who are unable to commit to the full duration (Dharmawardene et al., 2016). Indeed, Mertens (2008) advised transformative researchers to test interventions for the shortest duration necessary to limit participants exposure to any risks associated with intervention trial research.

Unfortunately, the likelihood is that caregivers who are unable to complete the duration of an intervention are the people who have the most to benefit from support and have the most at risk. This paradox was identified in a qualitative enquiry by Stjernswärd and Hansson (2020) of caregivers’ experiences of a web-based mindfulness intervention, which included participants’ challenges of use. The researchers found that participants were worried about whether they would be able to complete the duration of the intervention, which was described as a personal failure. Although caregivers in this study did not appear to consider potential failure as a reason for not engaging with supportive interventions, they did cite it as a reason for not accepting invitations from friends. This cycle of self-sabotage, where caregivers decline beneficial activities because of previous failings, is echoed by Vicstrom et al. (2008) who interviewed caregivers of people living with dementia.

5.4.4 The Final Frontier

Health and social care services appeared to under-estimate the expertise of caregivers. Beyond knowing the cared-for person intimately, many caregivers of people with life-limiting conditions learn and undertake technical skills, such as bladder and bowel management, enteral feeding, and wound care (Teixeira et al., 2020). In interviews conducted by Barken, et al. (2017) with caregivers of people with dementia, one daughter described her role as interpreter, teacher, team-builder and liaison between her mother who lived with dementia and staff who worked in a long-term residential living facility. However, the experiences discussed in this study are at odds with findings from Useros, et al. (2012), who suggest that nurses appreciate the complexity of the caring role and understand the importance of supporting caregivers. So, the reason for this mistreatment could be found elsewhere. Unfortunately, undervaluing and under-estimating the knowledge and skills that caring responsibilities and relationships bestow onto caregivers is a chronic oversight globally. Oxfam’s recent Time to Care (Lawson et al., 2020) report into wealth inequality highlighted the misconception of caring roles and responsibilities as “low value, women’s work”. They argued that this perpetuates harmful norms, and because of this, sexist beliefs go unchallenged.

5.4.5 Caregiver Identity, Classification and Language

Many participants in this study said they did not see themselves as carers or caregivers and did not wish to be referred to as such by professionals, who nevertheless continued to do so. However, by virtue of attending a carers support group, they were able to recognise or accept in some way that they were a caregiver. Social psychologists developed theories to understand how our perception of the self can shape our thoughts and behaviours at a micro and macro level. These theories include identity theory and social identity theory. Both theories overlap somewhat and are reflexive in nature. Social identity theory relates to self-categorising or identification, and the level of awareness an individual has about what social groups or categories they fall into (Stets and Burke, 2000). As people age and change, the social groups they align themselves with, will change too. Therefore, each person belongs to a unique set of social groups and identities. Identity theory is also related to how society is structured by groups and categorisations. However, it primarily relates to understanding behaviours and the roles we enact and expect from others depending on our own identity categorisation, and our presumed categorisation of others (Stets and Burke, 2000). People will generally feel most comfort and confidence when they are able to perform their suited role(s) within social groups that align with their self-categorisation. When there is a mismatch between what type of role is available to them, for example a leadership role has already been taken or is challenged, they are less likely to stay within that social group. Social psychologists have dedicated a significant amount of time developing their ideas, and much of that work is beyond the remit of this project. Understanding a caregiver’s sense of self and identity was not something that was considered necessary for this project. However, it became a recurring issue when speaking to caregivers. Once it was noticed it was hard to ignore and made more obvious when reading discussions between caregivers on social media.

Identity theory and social identity theory created the foundations from which the Caregiver Identity Theory was derived. The Caregiver Identity Theory was initially considered a theoretical explanation for why the caring role and its associated strains and gains are so difficult to predict (Miller et al., 2008). Because caregivers of people with life-limiting conditions have many competing demands, Caregiver Identity Theory (Montgomery and Kosloski, 2009; Montgomery and Kosloski, 2013) suggests that people who care undergo a series of transformations, whereby their original role (for example, of daughter) is never lost. Instead, it develops into the caregiver. There is so much variability within the role because the form that it takes is influenced by family ethos, culture and societal pressures, particularly gendered expectations of females. The role changes over time, depending on the needs of the cared-for person, and in turn, how the caregiver views and understands themselves within this relationship. Although changes can be small and slow, there can also be significant transitional markers, such as support from professional services, admission to care home, and death. The theory suggests that caregiver distress occurs when there is a mismatch between role demands and the caregiver's understanding of their role at that time. Since its identification, this theory has been successfully applied within caregiver research (Savundranayagam and Montgomery, 2010; Miller et al., 2008; Beatie, et al., 2021; Miller et al., 2020).

Beatie, et al. (2021) interviewed caregivers of people with mild cognitive impairment to understand the development of caregiver identity at an earlier stage in the role development. Their findings suggest that the development of the caregiver identity is a fluid process, rather than the more rigid, staged process outlined by Montgomery and Kosloski (2009; 2013). This fluid, sometimes transient process of their shifting identity was mirrored in the participants descriptions of mild cognitive impairment. This fluidity in caregiver identity was also identified by Morgan, et al. (2021) in their narrative study of older partners who provide end of life care. Like participants in this study, the shifts and changes were because they were fighting against acceptance of the role and label in case it superseded their original relationship of spouse or partner.

Miller et al. (2020) used the Caregiver Identity Theory as a framework to explore whether caregiver burden and depression are associated with the health and wellbeing of the person for whom they care. They identified that caregivers reported higher burden and depression when the person for whom they care required more support with activities (including instrumental activities) of daily living. They suggest that the theory can be used to guide professionals to ask caregivers how they support the person for whom they care, and what they expect to be doing. This will establish if there is a gap between perceived and actual role, which could predict a caregiver's likelihood of experiencing caregiver burden and depression. These findings mirror those of Savundranayagam and Montogmery (2010), who measured 358 spousal caregivers for stress, burden and depression associated with their caring role. They identified that spousal caregivers have an acute awareness of role obligation and tend to set limits for what should be expected of a spousal caregiver. They found that assisting with activities of daily living can be stressful. However, it is not the specific activities that are stressful. They become psychologically challenging when the caregiver perceives them to be beyond what was expected of their relationship. Although both studies had similar findings, their conclusions differ. Miller et al (2020), suggested that interventions should alleviate some of the responsibility associated by helping with activities of daily living. Whereas Savundranayagam and Montomery (2010) suggested that professionals could help caregivers to reframe their spousal relationships to accept that it can include assistance with the activities of daily living that cause them stress and distress.

Miller et al. (2008) carried out 11 in-depth interviews with caregivers of elderly parents to understand what influences the development of the caregiver identity. They found that there are two key components: structures of parenting and structures of competence. Overall, caregivers developed a parental relationship with their parents, which was often adopted from their parents' style and approach to parenting them. Nine of the participants were female and two were male. Therefore, anticipated caregiving and anticipation of perceived competence often starts through female socialisation. Women tend to be aware of expectations that they will become caregivers of families if/when needed and will be expected to do so competently. However, the authors did not consider female socialisation in their analysis.

Paoletti (2002) undertook several qualitative studies with caregivers, and provided a commentary of them, analysed through a feminist lens. She suggested that the caregiver identity goes hand in hand with the female identity; that they cannot really be separated. It is because of how central care is to women that we generally take on and undertake the role effectively. This is not entirely positive, as Paoletti (2002) goes on to highlight that this dependent relationship between care and womanhood may be due to a “compulsory altruism” (p808) imposed on women. Women effectively care for family members who need it but sacrifice parts of themselves in the process. This seems to be evidenced in the high rates and variety of negative consequences that many women experience from the caring role. This contrasts with male caregivers, who Paoletti (2002) suggested often only really adopt the caring role and identity when no women are available to do so. Indeed, most (66%) of the male caregivers in our secondary analysis study were caring for their partners.

Knowles et al. (2016) referred to adults who care for someone with life-limiting conditions but do not identify with terms related to carer (their selected terminology) as “hidden carers”. The reasons for not identifying with caregiver-related terms were complex. They varied from protecting the cared-for person, concern over which of their roles would take priority, and the level of complexity and responsibility they considered themselves having (Knowles et al., 2016). These findings were echoed in a literature review of the development of caregiver identity by Eifert et al. (2015). The review suggested that because so much of the concept of identity is socially constructed, caregivers are more likely to accept the caregiver identity (and therefore accept help) through interactions with others because this facilitates exposure and normalisation. However, findings from this project paint a mixed picture in relation to identity and support. The focus group participants who attended support groups with other caregivers and, therefore, had regular exposure and normalisation of the role continued to reject caregiver labels. This suggests that exposure and normalisation might be required outside of the caregiver community and come from wider society. This could include a more streamlined approach to nomenclature in caregiver law, policy, and literature, which are currently inconsistent. Clear, universal definitions and categorisations, agreed in partnership with the people who undertake this role, could prompt more people to accept the caregiver identity. This would increase uptake in support, particularly during the periods of highest vulnerability, which are the major transitional periods.

Women and men who care for people with life-limiting conditions undoubtedly have different risks associated with their differing demographics. However, they also share some risks, which are further complicated by gendered roles and expectations associated with femininity and masculinity. There is a need for researchers and health and social care professionals to appreciate the different pressures associated with the caring role due to gender, and actively seek to overcome them. With the demand for caregivers increasing, the caregiver identity and role should transgress the limitations previously imposed by gender. In doing so, this would enable women and men who care to access appropriate help and support that sensitively accounts for the social and physical differences between female and male caregivers to unify caregivers and create a kinship.

5.4.6 Addressing Language Discrepancies

In recent years there has been considerable work done to encourage professionals and the public to be more considerate of language, both oral and written, that relates to illness and disability. There are now clear and appropriate terms that should be used that relate to people living with conditions such as dementia and following stroke, as well as how to describe their behaviour and clinical presentations. Yet, the same attention has not been given to the language that relates to the people who care for these groups.

In selecting caregiver as the preferred term for this project, I was initially confident in my decision instead of carer (or some variation of it). However, Chapter Two evidenced the patchy and variable use of caregiver and related terms in research, policy, and law. I became increasingly uncomfortable with my chosen term, when among the PCPI volunteers I spoke with, their preferred term (including what they had recorded on their social media accounts that I interacted with) seemed to be carer or unpaid carer. This was replaced with confusion when participants I spoke to in focus groups told me they did not like any of the terms. However, terms/categorisations/labels such as carer or caregiver used on social media appear to act as a signal to others that this person shares something in common with them and could be an ally or source of support. Vital services such as the Carers Support Team would be impossible to notice without including a word such as carer.

5.4.7 Epistemic Injustice

The reason for the lack of clarity around terminology for caregivers has been identified in another area associated with the caring role. In research by Isham et al. (2020), it is suggested that a lack of accepted terminology related to violent verbal and physical abuse experienced by caregivers may be a result of epistemic injustice. Epistemic injustice, as outlined by Miranda Fricker, is a theoretical argument related to understanding why certain groups and populations in society lack collective knowledge and power related to their experiences and lives. Fricker (2010) posits that marginalised groups are less understood because of the lack of power they yield. This lack of power and knowledge is based on their characteristics that the dominating group do not possess. Characteristics are typically related to sex, ethnicity, and disability, among others. Isham et al. (2020) carried out in-depth interviews with older female caregivers who experienced violence from the person for whom they care. Overall, there was a perception that they do not see themselves as domestic abuse victims. For some, this was because they thought the term is commonly associated with younger women experiencing violence and abuse from husbands. For others, they thought it did not accurately represent people who abuse their caregivers due to health issues beyond their control (typically due to cognitive impairments). Isham et al. (2020) were careful not to differentiate between caregiver groups, including abuse experienced by caregivers from people with dementia.

This argument has some considerations for the lack of agreed nomenclature for caregivers of people with life-limiting conditions. There are two types of epistemic injustice, the first being testimonial (Fricker, 2010). Testimonial injustice relates to the credibility of the person. It is suggested that a person who experiences epistemic injustice does so because certain characteristics mean they are not considered to be credible. Therefore, their experiences and opinions are not taken as seriously as others. Caregivers I spoke to were clear that the label they were most comfortable with related to their original role, for example mother, daughter, husband and wife rather than caregiver or some variation of carer. Molyneax et al. (2011) suggested that for some people who care, they consider the adoption of the word carer (or similar) as relinquishing their previous role and all the benefits that it brought. Certainly, this was observed when a woman who attended a focus group considered her husband’s admission to a care home to be the unwilling end of their marriage. She considered herself to no longer be his wife because they could not to live with each other, and she was surrendering the responsibility of his care to others. Yet, we continue to use terms like carer and caregiver when we are repeatedly told by people who care that they would rather be referred to as their original role.

Health and social care professionals who are well positioned to advocate on behalf of people who care, may be guilty of being paternalistic and applying labels to a group that are not comfortable with what we use. Nevertheless, there is a need for a descriptor or label to describe people who care for people with life-limiting conditions and the second type of epistemic injustice might have some explanatory power for this situation.

The second type of epistemic injustice relates to hermeneutical injustice (Fricker, 2010). This occurs when a person or a groups experiences are not well understood, including by themselves, as well as others because they have historically been overlooked or side-lined. This exclusion means that there is a collective gap in discourse and knowledge in places (such as the media) that they access related to their experiences. Consequently, they are also unable to describe themselves. Because the caring role is not accurately understood and appreciated by society and the media, many caregivers are unable to understand their experiences, the value in their role and the need for a label or descriptor to what they do. However, Beeby (2011) suggested that Fricker's explanation of hermeneutical injustice can simplify hermeneutical and epistemic problems in society. She argued that Fricker focuses on the implications for the individual or group directly affected by the lack of related knowledge. Instead, our understanding of epistemic injustices should acknowledge the collective loss experienced by knowledge and power gaps. Although this is a valid critique, in the case of caregiver nomenclature, it is difficult to separate the individual from the collective. This is because care, caring and the caring role are so universally experienced.

The issues in discourse and language development related to caring for someone with a life-limiting condition could impact the reach of the chosen intervention(s) for this project. Ideally, recommended interventions would be accessed by people who are comfortable identifying with or recognising their caring role *and* would also be accessible to people who do not want to be referred to as caregivers or carers. This highlights the importance of the referral process for the chosen intervention and if accepting a caregiver/carer identity will gatekeep it from those who do not acknowledge or identify with their caring role. It might also be important to consider the name of the intervention or role involved in delivering it, so that those who are concerned that adopting or accepting a caring role will supersede their original role will still approach or be open to accepting help from those involved.

5.4.8 Making Sense of Theory

Identity Theory and Social Identity Theory suggest that labels and categorisations are an important part of the self and society, and that people will be part of a variety of roles and categorisations, which grows over time. Furthermore, the Caregiver Identity Theory suggests that how much a person adopts or accepts the reality of their caring role could determine how likely they are to experience some of the most debilitating negative consequences associated with it. The example of hermeneutical injustice described by Fricker (2010) is a woman who was sexually harassed at work in the 1970s but unable to have her complaint taken seriously or be compensated from her medical insurance provider because there was no legal terminology to describe her experience. It is possible, and vital that a person who cares for someone with a life-limiting condition should have an appropriate term to describe their caring role and be able to continue in their original role. The problem seems to be that there is an expectation that the caregiver categorisation, if accepted by the person who cares, will supersede the original role.

This was identified by Harding and Higginson (2001) who interviewed 18 caregivers of people requiring palliative and end of life care at home. Generally, participants were hesitant to self-identify as caregiver. They considered their responsibilities to be acceptable expectations of their family role and were willing to put their lives on hold for the sake of the person for whom they care. They described living in limbo because of the unpredictability associated with caring for someone requiring palliative care, but with a strong sense that this is the correct way to behave. Some participants rejected the terms caregiver or carer because they did not think they spent enough time caring or the tasks they assisted with were not complex enough to any label. Of the 18 participants, 12 were women, but there was no differentiation between the sexes in how the findings were reported. In understanding how influential socialisation into the caring role is for women, it would be useful to know whether there were differences between women and men, or between caring relationships (spousal, adult-children etc).

The focus of discussion by Harding and Higginson (2001) is on ambivalence. Ambivalence is defined as having two opposing feelings at the same time or being uncertain about how you feel. This word is appropriate for the complexity of nomenclature related to caring for someone with a life-limiting condition. It succinctly summarises the challenges faced by caregivers of people with life-limiting conditions and the need for appropriate language to describe their role. Many want to remain primarily in their original role and be seen by the person for whom they care, support services and their wider support network, as wife/daughter/husband etc. However, they also need to identify and access services that can help them balance their new responsibilities to the person for whom they care. Ultimately, the issues related to caregiver discourse and nomenclature create additional barrier for caregivers. Without recognising the caring role, they, and those around them, are less likely to recognise the impact it has on their lives and identify when help is needed. If "hidden caregivers" do not use caregiver services or get involved in caregiver activism, the population of people who care risk continued and deepening marginalisation. With the number of caregivers growing substantially due to the Covid-19 pandemic, so too has the population of "hidden caregivers". Therefore, addressing these issues is vital.

5.4.9 Normalisation and Acceptance of being a Caregiver

Most (n=13/15) participants in this study attended a peer support group, and all of those who did were women. The success of peer support seemed to be because the groups were a non-judgmental place for people to discuss anything related to their caring role. In other relationships and social interactions, caregivers minimised their struggles and emotions, but in a peer-support group, sharing challenges and emotional responses was actively encouraged. It is not a panacea for all the issues they face but it was an important part of their ability to recognise their caring role, understand how common their challenges were and find appropriate help when needed. The benefits of peer support were not necessarily surprising. Peer support has been shown to create an opportunity for many caregivers to foster friendships at a time when previously established social connections are lost (May et al., 2016). It can also reduce caregiver burden and depression (Chien et al., 2011a; Hughes et al., 2020). However, Carter et al. (2020) identified heterogeneity in intervention styles and outcomes for peer support interventions for caregivers of people living with dementia. They recommended peer-support interventions follow the MRC Framework for complex interventions to fulfil identified gaps in process, outcome and rigour.

What peer support appeared to offer participants in this study was an environment where their socially and culturally taboo experiences and feelings, no matter how common they were, can be accepted without judgement. Furthermore, peers offered practical advice that was not restricted by professional boundaries. It may be this type of environment, where pragmatic advice is in abundance and acceptance is expected, that initiates the process of accepting a label or role such as caregiver or carer. However, more research is required to better understand the social and cultural influences of peer support on caregivers.

5.5 Reflexivity

Because much of our discussions with caregivers related to professional groups, within our reflective discussions we considered any professional biases we possessed. To offer balance, we actively sought to analyse examples of interactions with caregivers and nursing and medical professionals that seemed to fall short of expected standards of practice.

The emotional reaction that reading this study had with Charles had not been anticipated. Because Charles and I were communicating via email, it was more difficult to offer support when this transpired. However, face-to-face meetings were not possible due to lockdown restrictions. How researchers and PCPI volunteers communicate is an important consideration for future PCPI activity during the pandemic.

There were two components to this study that were not considered when the study was designed. The first is the use of interviews for data collection; the second is the blending of interview and focus group data. Although there was some trepidation, as a novice researcher, about going against the recommendations by Braun and Clarke (2013) not to mix two sources of data, the Covid-19 pandemic made this seem difficult to avoid. I analysed the focus groups first and then, when I analysed the interview, I was confronted with more evidence to support my identified themes that I did not want to ignore. The insights she shared were invaluable to the study. I also received positive feedback from her following our meeting, and she put me in contact with three caregiver friends who wanted to participate in a focus group. However, this was cancelled due to Covid-19 restrictions.

Undoubtedly the Covid-19 pandemic has made elements of research far more difficult. It also coerced me into making decisions that would otherwise not have happened. However, it demonstrated that careful and mindful adaptability and creativity can produce positive and useful insights.

Using battle, military and fighting-related metaphors and language in relation to describing or discussing aspects of the caring role is in direct opposition to discussions around language and, more specifically, metaphors that relate to living with a life-limiting condition. Lane et al. (2013) suggested that the use of military-related language in the realms of health and illness are not appropriate because they create the expectation that the affected individuals will have a "fighting attitude" (p. 282). Such language risks positioning the individual in opposition to a disease and simplifies the complex mix of health and social care needs that every individual with a diagnosis will have (Lane et al., 2013). However, Nie et al. (2016) suggested that military metaphors can be useful. They can encourage individuals to tap into a reserve of energy when their situation is particularly critical and they can be used within wider society to increase fundraising and awareness of causes (Nie et al., 2016).

The use of metaphors to describe new experiences or knowledge is nothing new in healthcare literature. Wurzbach (1999) wrote a review of their use in nursing literature and suggested that the use of military comparisons is one of the earliest metaphors, dating back to the 1800s. The author argued that their popularity in nursing stems from the struggles nurses often experience in dealing with bureaucracy, hierarchies, power imbalances and personal responsibility, like military personnel (Wurzbach, 1999). This explanation also draws parallels between the caring roles described by participants in this study. Participants outlined examples where they struggled with service providers, endless administration, the hierarchies that emerged when the person for whom they cared became unwell and how they coped with the responsibility the role put upon them. Wurzbach (1999) did not dissuade nurses from using metaphors entirely. Instead, she highlighted the importance of understanding them within their historical context and then considering how this applies to the times and situations in which they are to be used.

The choice to use such language in this study was reviewed regularly. Other than the concerns about this type of discourse within the realms of research related to living with life-limiting conditions, there was a concern that it would be pitting caregivers against healthcare professionals. If they felt inadequately supported, they had lost a fight or war against our professional peers. Throughout the pandemic this type of language has been often used in the mainstream media whereby caregivers were described as a “hidden army”, heroes and (along with other vital roles) “frontline” workers. And again, the use of military metaphors drew criticisms, including from caregivers (Akhtar, 2020). Cox (2020) suggested that these comparisons pressure individuals who are working under extra pressure and with less support to behave heroically. This simplifies discussions around such roles, which make pleas for adequate personal safety, pay and recognition easier to ignore (Cox, 2020). Although Cox (2020) was arguing about the use of military language in relation to healthcare workers, these issues apply to the caring role. Indeed, this is not the first study to identify military language being used by caregivers when discussing their experiences accessing help through formal services. Peel and Harding (2014) also described military metaphors and comparisons when speaking to caregivers of people with dementia. They made a clear distinction that caregivers were describing battles with professionals and services, not the illness of the person for whom they care.

Ultimately, battlefield and military language was used within this study because it was led by the participants. Such terms were not mentioned in any questions or discussion topics put to participants. Instead, the “fighting attitude” described in this study was strongest when caregivers were speaking to one another. Ignoring their chosen descriptions of dealing with the challenges related to obtaining help could be potentially paternalistic. To interpret such language negatively because it is deemed to be so in other related areas did not seem like a decision I should make. I believe the decisions around how appropriate (or not) such language is in this situation should be a matter for caregivers.

5.6 Limitations

Although we did not set out to only recruit female participants of retirement age, most of the participants in this study shared these demographics. Therefore, we acknowledge there are limitations to our findings outside of this population group. Most of the participants were caring for someone living with dementia, therefore, we acknowledge that the findings will resonate primarily with caregivers of people living with dementia.

5.7 Chapter Summary

The caring role is a complex and intense human experience that forces many caregivers into a fight (rather than flight) mode to have any chance of achieving person and family-centred support. This can negatively impact their physical and mental wellbeing; the constant anticipation of fights and arguments seemed exhausting. Frustrating or argumentative interactions with people (both professionals and family members/friends) create long-lasting wounds that can be prevented if professionals anticipate their battle fatigue and strive to offer adaptable and consistent services. However, the likelihood of this is reduced by societies that dismiss those who undertake the role as unskilled and unknowledgeable. Yet, their contribution to communities and wider society is indispensable.

Many participants in this study described the need for a similar intervention. The most popular description of what is missing from what is available from existing support is a single point of contact who respects their expertise in the person for whom they care, who looks for opportunities to collaborate with caregivers, and can work around their caring responsibilities. These aspects of practice would help them to manage their own health and wellbeing alongside the health and wellbeing of the person for whom they care. Participants also said they do not want to be discharged during stable periods in their caring relationship and want access that is not tied up with bureaucratic tape. Finally, participants seemed sympathetic towards registered nurses compared to other professional groups, such as social workers. However, this might have been because they knew I was a nurse when speaking to me. Some of what is described could contribute towards a specific intervention delivered by a specific professional group. However, other aspects of what is missing from what is available could be weaved into existing services and relates to a cultural shift towards more respectful, flexible, person-centred care.

Chapter 6: Intervention Suggestions

6.1 Introduction

The original plan for this project was to develop one intervention that could be tested through a pilot or feasibility study. However, the possibility of this happening in the time available for a doctoral project became impossible due to the complexity of the topic, the implications of the findings and the Covid-19 pandemic, which stopped all non-pandemic-related research in March 2020. As I had been working towards selecting one intervention from the beginning until the pandemic, I thought it would be a useful exercise to describe all possible interventions and then select the most favourable intervention to be described in more detail. It was hoped that by doing this, it could form the basis of future research applications.

When analysing the assessments carried out by the Carers Support Team, I identified that many caregivers in Glasgow who require support with their caring role have mental and physical ill-health. Mental ill-health can be because of long-term ill-health prior to, or separate from, their caring role, as well as because of it. Many caregivers are caring for someone with at least one life-limiting condition and living with long-term or life limiting conditions themselves. The focus groups and interviews with caregivers highlighted that many caregivers are forced to neglect their own health and wellbeing because of a lack of existing services that offer flexible, long-lasting support that works around their caring role. Although there is some mistrust or scepticism around formal health and social care professionals and groups, caregivers do want the opportunity to build a positive relationship with a single professional; someone who can get to know the caregiver and the person for whom they care, signpost them to appropriate services and understands the complexity in the caring relationship and associated care arrangements. This chapter will describe five possible interventions that could be considered appropriate for caregivers of people with life-limiting conditions. The recommended interventions are based on the findings from the preceding chapters. The final intervention described is the intervention closest to what participants in Chapter Six described needing, and is therefore, a possible trial for future researchers to consider is described in detail. These recommendations could form the basis of future research to test either the interventions described, or components of each could be blended into a new intervention.

6.2 Intervention Suggestions

6.2.1 Intervention 1: Cognitive reframing

Cognitive behavioural therapy (CBT) is a “family” of therapies that can be delivered in various forms and includes psychoeducation, cognitive restructuring, behavioural activation and problem solving (Davies et al., 2018). Each of these components can be delivered individually or in different combinations tweaked to the target populations needs. Cognitive behavioural therapy is traditionally delivered face-to-face in groups or individually, but can also be delivered electronically (via email, videos, telephone). Self-help methods of CBT require very little professional input and are paced by the person depending on their needs and availability. There are also now blended options available. The Cochrane Database includes 49 systematic reviews of CBT on various populations. Reviews of interest include CBT with adults with COPD (Pollok et al., 2019), older adults with depression (Wilson et al., 2008), parents of children with life-limiting conditions (Law et al., 2019) and people with dementia (Orgeta et al., 2014). These reviews found that CBT might be effective at reducing depression and depressive symptoms, but generally evidence was low quality.

The most appropriate review for consideration for this project is the Cochrane review of cognitive reframing for caregivers of people with dementia (Vernooij-Dassen et al., 2011). The authors of this review argued that there is a consensus that CBT is a positive way to improve caregiver’s psychological wellbeing and delays admission to care facilities. Because many of these interventions involve multiple mechanisms of action, this review was carried out to help pinpoint what part of CBT is the most beneficial. Cognitive reframing focuses on changing self-defeating or distressing thoughts into thoughts to support adaptive behaviour and improve caregivers coping, self-efficacy, burden, quality of life and psychological morbidity. This review found that cognitive reframing could significantly reduce depression, anxiety, and stress in caregivers of people with dementia.

Following from this, the authors suggest a hypothesis for further research: cognitive reframing operates primarily through caregivers’ attributions about personal strength and resilience. This hypothesis could be considered as there is limited evidence available on non-cancer caregiver results for cognitive reframing interventions. Therefore, this type of intervention could be considered for caregivers of people with life-limiting conditions in Glasgow. Chapter One described how cognitive behavioural therapies have demonstrated some favourable findings, but that heterogeneity is an issue in existing studies. Participants in Chapter Five described feeling defeated by challenges in their caring relationship, such as when their loved one moved into a care home or when they were unable to manage their own health and had to rely on others for support. Therefore, there is an existing evidence base to build on and the possibility that cognitive reframing for caregivers in Glasgow may be beneficial.

6.2.2 Intervention 2: Intimate partner violence advocacy

Caring for someone with a life-limiting condition is not often framed outside of caregiver literature as a typically traumatic experience or relationship. However, elder abuse was described by some participants of the focus groups. Therefore, it may be appropriate to consider a trauma-informed intervention that has previously been trialled with people who experience intimate partner violence. Advocacy-based interventions for women who experience intimate partner violence concluded that intensive advocacy may improve quality of life, self-esteem and reduce physical abuse up to two years after the intervention (Rivas et al., 2015; Trabold et al., 2020). Brief advocacy may provide small short-term mental health benefits and reduce abuse (Rivas et al., 2015). Advocacy interventions involve the advocate working in partnership with the participant to help set and achieve personalised goals, to understand and make sense of the situation as an expert in their own life. The most common need identified by participants in Chapter Five was that they wanted one person to speak to, who was there to help them and was on their side. Therefore, an intervention with an advocacy component could address this need. Trauma-informed care is supported by NHS Education for Scotland. NHS Education for Scotland developed the National Trauma Training Framework, suggesting that there would be organisational support for such an intervention to be tested. However, this is generally a neglected area of caregiver research. Therefore, the scale of the issue is not necessarily fully understood and the need for this type of intervention might not be easy to evidence to funders and professionals who might be involved in delivering it.

6.2.3 Intervention 3: Internet-based psychoeducation

In the post-Covid-19 era it is important to consider how interventions can be delivered. An internet-based psychoeducational intervention may be appropriate. A review of the literature related to psychological interventions found that psychoeducational programs with small groups of caregivers of people with dementia that provide information, support, basic coping strategies, and help-seeking can reduce depression and anxiety in participants (Cheng et al., 2019). The reviewers suggest that packaging cognitive behavioural therapy techniques into an educational format makes them easier to be delivered to groups. Problem-solving psychoeducational programs showed promise in their review. A meta-analysis of problem-solving interventions aimed at reducing stress on the general population found that short duration interventions with female participants showed the most positive effect (Van Daele et al., 2012).

A systematic review of psychoeducational programs for caregivers of people with dementia included three internet-based interventions (Frias et al., 2020). These interventions were accessed through an online portal that the caregiver could access when they had time. Researchers identified a significant impact on caregivers' stress, depression, anxiety, and distress in the intervention groups. They were delivered by a mix of social workers, nurses, and gerontologists. A database search of CINAHL, embase and psychinfo retrieved problem-based psychoeducational interventions since 2010 involving caregivers of people with dementia. However, only one result was produced for internet-based interventions suggesting this is a possible area that requires more attention from researchers. As participants in the focus groups expressed concern about interventions that require them to attend at a set date and time, they might find an online intervention more feasible and acceptable. Attendance and completion dates could be flexible and work around their caring responsibilities, which were all described as important aspects of interventions and professional practice.

6.2.4 Intervention Four: Peer- support

The support that caregivers obtained from their peers was very evident when speaking to participants in Chapter Five. Caregivers shared realistic, up-to-date advice with one another and showed genuine understanding and empathy for the challenges they faced. This suggests that a peer-support intervention or a peer-support component within another intervention could be worth considering.

Existing evidence on peer support interventions for caregivers gives a mixed picture. A scoping review by Carter et al. (2020) of 36 peer-support interventions for caregivers of people living with dementia found that most peer-support interventions usually have multiple components to them. Although most (n=24) reported positive results in either some or all outcomes, it was difficult to establish which component of the interventions or peer-support had the biggest positive influence. The authors conclude that peer-support likely has potential benefits, but that more research is required. Self-management, peer-support interventions for the stroke survivor can facilitate shared experiences, social comparisons, vicarious learning, and mutual gain (Clark et al., 2020). However, more research is required to understand how this could involve caregivers. A systematic review of caregiver interventions that included one peer-support intervention found no difference in burden or emotional state in comparison to the control group (Wilson et al., 2008). It has been suggested that peer-support is a flexible intervention that can be facilitated by a wide variety of professionals. However, it is best when delivered by the same person for the course of the intervention and researchers should consider the length of time the intervention is delivered to identify if there is an optimum time expectation for intervention users (Hughes et al., 2020). Participants in Chapter Five who attended focus groups described the aspects of peer support that they found useful, usually it was that they built trusting friendships and obtained practical advice about accessing help. It was clear that peer support groups that bring caregivers of similar demographics together will likely be more successful at encouraging meaningful relationships among attendees. Therefore, although peer support groups already exist in Glasgow, researchers considering a peer support intervention might find it useful to map the attendees of existing peer support. Their findings could then be compared to the demographics of caregivers identified in the needs assessments described in Chapter Four to ensure that similar groups exist for caregivers who are not only accessible to and accessed by white, British people of retirement age.

6.2.5 Care home consideration

Participants in Chapter Five described how moving a person requiring care into a care home for people living with dementia, stroke and heart failure is usually only considered following a major crisis or once all other options have been exhausted. The possibility of this can cause relationships to break down within families and worries of financial crisis. The caregivers I spoke to who were at that stage in their caring journey had been living with BPSD, recurring admissions to hospital and trying to navigate a system that has failed them. They were vulnerable, stressed and defeated. All the interventions listed until this point could be designed or adjusted to be tested at the point of admission to care home to help the caregiver adjust to this new role and their new life. Indeed, the Covid-19 pandemic has highlighted the need for more intervention trials to be developed and tested within care homes that are co-designed by, and recruit caregivers as participants (Shenkin et al., 2022).

6.2.6 Intervention Five: Case Management

The final intervention suggested is for case management and its selection came about from reflective discussions with my supervisory team. I was unable to ignore the feeling that as a district nurse and independent prescriber, I had the necessary skills and experience to deliver an intervention to caregivers that would help caregivers to manage their own health and wellbeing alongside the health and wellbeing of the person for whom they care. I was confident that district nurses in Glasgow could deliver an intervention that included the components that participants in Chapter Five described to me as currently missing. Furthermore, a case management delivered by district nurses would address some of the issues related to poor discharge planning, inappropriate medication changes and lack of continuity many participants described experiencing. Findings from the modified systematic review have informed the outcome measures that are recommended for use with a case management intervention for caregivers of people with life-limiting conditions.

Recommending a case management intervention for caregivers of people with life-limiting conditions for these reasons is in keeping with the transformative intervention framework. Transformative interventions should be responsive and flexible interventions that are congruent with the culture of the community it is for (Mertens, 2008).

6.2.6.1 Background to Intervention Selection

Caring for someone with a life-limiting condition can span many years. In the UK, most (46.2%) caregivers are in their 50s and 60s (Storey et al., 2019). However, 20.1% of caregivers are in their 70s and 13.3% are over 80 (Storey et al., 2019). Many caregivers are required to balance the health and social care needs of the person for whom they care with their own health and wellbeing. This creates a risk when one becomes unwell, as the health of the other can become destabilised. For example, when a caregiver experiences symptom of depression, the risk of admission to the emergency department for the person for whom they care increases (Guterman et al., 2019). Therefore, caregivers should be supported to manage their own health and social care needs alongside those of the person for whom they care.

The district nursing service is the primary community nursing service in the UK that delivers care to people in the homely environment. It runs seven days a week with no waiting list. Referral criteria to the service vary between areas. However, generally district nurses attend to the nursing needs of people who are housebound. The housebound status of a person can be temporary, for example following an operation that has affected mobility, or long-term due to frailty or physical or mental illness. An exception to the housebound rule, is for people receiving palliative and end-of-life care. Because of these requirements, most people on a district nursing caseload are over the age of 65. However, in areas of higher deprivation, people tend to be younger with more complex health and social care needs. District nurses are senior nurses who hold a specialist nursing qualification (SPQDN) that is recorded on the UK Nursing and Midwifery Councils (NMC) national nursing register. They are usually nurse prescribers with similar prescribing powers to that of a General Practitioner (GP) and manage caseloads with the assistance of registered community staff nurses and support staff. People who are not housebound but have a nursing need usually attend treatment rooms, which are based in health centres or General Practitioner surgeries. A treatment room nurse is not required to hold the SPQDN qualification.

In the decade that I worked within the Glasgow City District Nursing team; the district nursing role has been transformed. Due to ageing populations, there has been an increased demand for care led by district nurses. However, this has been matched with a reduction in workforce due to mass retirement and low job satisfaction (Maybin et al., 2016). The increased demand with a dwindling workforce was why the Scottish Government formally reviewed community nursing services in 2008. The review identified a critical need for alternative models or adaptions to the current models of community health and social care services (Leask et al., 2020). To cope with the increased demand and complexity in care, coupled with a reduced workforce, district nursing services have introduced new ways of working that vary between areas. In NHS Greater Glasgow and Clyde, some of the changes include agile working and electronic record keeping. District nurses now undertake non-medical prescribing and study at master’s level to obtain the SPQDN qualification. However, Dickson and Coulter Smith (2013) suggested that some service changes because of the review were imposed on teams to meet national policy demands, rather than created by or alongside the district nurses themselves. This apparent oversight increased resistance to change and job discontent, further exacerbating the workforce and workload crises (Dickson and Coulter Smith, 2013). Focus groups and interviews with community nurses in Scotland led Gray et al (2011) identified that clinicians need to be involved in change discourse to ensure they feel validated and empowered to then adopt service remodelling. Changes to district nursing practice will have a higher success rate if they come from district nurses.

A model of nursing care that has shown promise within community nursing is case management. Case management interventions are complex interventions that have been successfully implemented into community care for people living with a wide variety of health and social care needs, including older people with age-related health issues and multimorbidity (You et al., 2013). Broadly speaking, it is an approach to the coordination, integration and management of health and social care that is suitable for many health conditions (Lukersmith et al., 2016).

Case management is recommended by the National Institute for Health Research (NIHR) to reduce the burden on caregivers and can delay care home admission for the cared for person (Huntley et al., 2016). A Cochrane review of case management in people with dementia found that caregiver wellbeing was improved with case management involvement (Reilly et al., 2015). However, heterogeneity around the intervention styles and inconsistencies in reporting caregiver outcomes affected this understanding. They recommended a need for further robust, high-quality research where case management is led by a case manager who has clear roles and responsibilities, not just care co-ordination (Reilly et al., 2015). The issue of heterogeneity in intervention style and delivery is a prevailing feature in case management (Lukersmith et al., 2016). It was identified in a systematic review of systematic reviews by Duan-Porter et al. (2020) related to interventions to delay long-term care home admission, which included four reviews of case management interventions. They suggested future case management interventions may need to have relatively high-frequency contacts that are initiated early in the course of life-limiting and chronic conditions and extend for several years.

Although case management usually involves working with, or supporting, caregivers, the case managers are primarily linked to the person with the life-limiting condition. The caregiver, benefits because the health and wellbeing of the person for whom they care improves. However, a study by Hsu et al. (2019) suggested that older adults with high needs can benefit from case management. They defined high-needs older adults as those living with cognitive impairment, elder abuse, disability, poverty, solitude and depression (Hsu et al., 2019). Therefore, many caregivers of people with life-limiting conditions will be older adults with high-needs and could benefit from a case management intervention.

When we spoke to caregivers in focus groups, most participants requested one point of contact who could support them throughout their caring experience. When crises hit, either due to their own health or the health of the person for whom they care, caregivers spoke of their frustration when trying to access services and professionals who had previously been helpful. Caregivers were often discharged when deadlines were reached or during periods of relative stability. Furthermore, many had had contact with the district nursing service and reflected more positively on their contact with nursing professionals compared to social workers. However, this could be influenced by their willingness to participate in a study led by a registered nurse.

6.2.6.2 Existing Evidence

Jansen et al. (2011b) undertook a case management randomised controlled trial led by district nurses with 99 people with dementia and their caregivers. The intervention ran for one year and compared case management with usual care. The district nurses acting as case managers met with people with dementia and their caregivers twice, the first visit to assess the people with dementia and the second to assess the caregiver’s capacity and burden. Following these meetings, if no further visits were scheduled, a three-monthly telephone call was planned. Between times, the district nurses adapted their support as necessary to include co-ordination with, and referrals to, other services. The intervention showed no benefit of case management compared to usual care. The researchers suggested that this might have been because the needs of the people with dementia and caregivers were not sufficiently complex to require case management. Furthermore, although caregivers generally reported overall satisfaction with the intervention, some suggested improvements to care co-ordination and time spent on consultations.

Ciccone et al. (2010) carried out a feasibility study of a care management intervention based on self-management and empowerment for people with heart failure and diabetes. This intervention placed trained care managers into GP practices and lasted 18 months. Care managers undertook comprehensive assessments, referred to specialist services, held case conferences when required, and liaised closely with the participants GPs. Care managers had to be registered nurses with either hospital or district nursing experience. Participants in this study increased their self-efficacy, coping and ability to access social support. Self-monitoring behaviour also increased dramatically during the study period with an additional 20%–27% of patients in each condition taking a more active role in the management of their condition. Furthermore, the care managers developed standardised guidelines to ensure care for people with cardiovascular disease, diabetes and heart failure was provided on schedule. The authors used the term care management to describe their intervention, but the provided description meets the definition of case management used in this protocol.

Community-based case management has also been trialled in various forms across England. Sheiff et al. (2009) undertook a qualitative examination of case management in primary care in England, primarily related to the multi-site Evercare trial. From analysing 231 interviews, they found that case management is highly valued by patients and caregivers. This is because it offered speedy access to a professional who could offer support on a range of issues such as medication, assessment, and management of acute infection (which prevented some hospital admissions) and many were anxious about being discharged from the intervention. Most of the case managers in this study had a background in community nursing, including district nursing. This issue of access to a single point of contact was described as missing from what is currently available in Glasgow by many of the participants in Chapter Five. The range of problems caregivers required support with included re-assessment, management of infections and medication, as well as discharge planning and advocacy during hospital admissions. This suggests that a case management intervention delivered by a professional who can support the caregiver with aspects of caring for someone with a life-limiting condition, such as medication, acute infection and hospital admissions/discharges, as well as help them to manage their own health and wellbeing would be acceptable to caregivers in Glasgow. However, Chapter Four highlights that the demographics of people who require a caregiver needs assessment is quite varied. As well as many caregivers being older women, many are older men caring for the oldest old in society, and women of working age caring for people with a variety of conditions. Therefore, the case manager would need to deliver or signpost to financial support, support for working families and families with young children, as well as support for older people. It is not clear how achievable it would be to keep this level of knowledge up to date when it is coupled with the advanced clinical skills required. This would likely have implications for the case managers caseload size. This is because adequate time for training and referrals would need to be embedded in non-patient facing time planning, and this might generally impact the feasibility of the intervention.

6.2.6.3 Recommended methodology for future Case Management research

A feasibility trial of a case management intervention that is led by district nurses for caregivers of people with life-limiting conditions who require community nursing care compared to usual care is recommended. A feasibility test has been selected as this will inform an appropriate study design and related parameters that can be employed in a future cluster randomised trial. The Covid-19 pandemic has had a detrimental effect on the mental health and wellbeing of some members of the community nursing population (Mitchell et al., 2021), so changes to practice should be implemented carefully and sensitively.

6.2.6.4 Intervention objectives

1. Develop a case management intervention that is acceptable to caregivers of people with life-limiting conditions and district nurses.
2. Understand the operational implications of running, monitoring, and maintaining a trial of a case management intervention within an existing district nursing service.
3. Understand district nurses' and caregivers' experiences and opinions of the intervention, as a basis for refinement for a definitive trial.
4. Calculate the number of caregivers and district nurses required to power a full trial of the intervention.
5. Anticipate challenges to recruitment and retention for a full trial.
6. Understand potential contamination between trial arms.
7. Confirm primary and secondary outcome measures and their time schedule.

6.2.6.5 Study design

Participants would receive either case management delivered by a registered nurse, who has the recorded specialised practitioner in district nursing qualification and non-medical prescribing on the NMC register, or usual care at a ratio of 1:1. Participants would be assigned a cluster based on the sector within Glasgow City HSCP that the district nurse works in. The feasibility trial will last 90 days. For district nurses, this trial would identify if the case management model enhanced district nurses' sense of autonomy and job satisfaction by collecting qualitative data through interviews at 90 days.

A protocol should follow the Medical Research Council's Complex Intervention framework (Craig et al., 2019).

6.2.6.6 Patient, Caregiver and Public Involvement

A feasibility trial of this nature should utilise Patient Caregiver and Public Involvement (PCPI) by setting up an advisory panel of PCPI volunteers. The advisory panel would ideally be a district nurse, a caregiver of someone with a life-limiting condition and a member of the public who has used district nursing services but does not identify as a caregiver. This selection is to ensure the range of experiences related to district nursing are represented, and logistical challenges are foreseen and accounted for. A PCPI impact assessment could be created to measure their involvement and impact.

6.2.6.7 Study population

Caregivers of people with life-limiting conditions who require community nursing care from either the district nursing or treatment room services would be recruited. A life-limiting condition is defined as a degenerative and progressive illness that has no reasonable hope of cure (2018).

6.2.6.8 Sample size

District nursing caseloads vary significantly. It is estimated that district nurses working full time in Glasgow currently hold caseloads of up to 70 patients. However, caseloads can vary from week to week. The Covid-19 pandemic has caused greater than normal fluctuations due to increased demand for end-of-life care at home. It is not anticipated that many of the caregivers participating in the intervention would require palliative and end of life care. Formal guidance on sample sizes for feasibility tests does not exist and sample sizes vary (Billingham et al., 2013). Case finding by the district nurses delivering the intervention is an important part of the feasibility test. Therefore, the initial sample size for recruited caregivers is conservative at 10 per one district nurse in each arm. For the district nurse delivering the intervention, s/he can increase her caseload to a maximum of 40 caregivers. Initially, two district nurses (1:1) could be recruited who will hold a caseload. A district nurse from the Northeast Sector and a district nurse from the South Sector could be recruited, and these would form the two clusters. Using these geographic boundaries should reduce the risk of contamination and bias and ensure a diverse group of caregivers are recruited in relation to age, sex, location and ethnicity.

6.2.6.9 Recruitment

Recruitment could be through advertisements in General Practice surgeries and health centres in the Northeast and South sectors of Glasgow City Health and Social Care Partnership. District nurses and treatment room nurses could also be approached and given posters and leaflets to give to people they have identified on their caseload as caregivers.

Inclusion criteria for caregivers are:

1. At least 16 years old.
2. Provides ongoing, informal care to an adult with a life-limiting condition.
3. Requires active input from the district nursing or treatment room service to manage an aspect of their health that aligns with that service’s referral criteria.
4. The current episode of care is expected to be required for at least one month or the caregiver has required at least two episodes of care (excluding the current) in the previous 12-month period.
5. Can provide written, informed consent to participate in research.

The exclusion criteria for caregivers are:

1. Current episode of care is the first episode of care from the district nursing service or treatment room service and is expected to be completed within one month.
2. Already has an assigned case manager through a similar intervention.
3. Receives input from mental health services to manage a severe or enduring mental health condition.

Inclusion criteria for district nurses are:

1. A registered nurse with a specialist practitioner qualification in district nursing (SPQDN), recorded on the NMC register.
2. An independent nurse prescriber qualification documented on the NMC register.

Exclusion criteria for district nurses are:

1. No specialist practitioner qualification recorded on the NMC register (typically this would be a caseload holder who is an SPQDN student)

Participants must meet the inclusion criteria and none of the exclusion criteria. Participation is voluntary. A written and signed informed consent form will be obtained from all participants before the start of the pre-trial measurements.

6.2.6.10 The CAse Management (CAM) intervention

The CAse Management (CAM) intervention is based on the definition of case management by Reilly et al (Reilly et al., 2015) who defined it as a community-based intervention that predominantly focuses on the planning and co-ordination of care required to meet the identified needs of the person requiring community nursing input. In-line with the priorities outlined by participants in Chapter Five and the variation in demographics identified in Chapter Four, the CAM intervention is multi-dimensional and involves case-finding, comprehensive assessment, care provision, planning and care giving, care co-ordination, monitoring and evaluation (Sadler et al., 2018). Recognising that the dataset analysed in Chapter Four was missing ethnicity and specific location data, and that participants in Chapter Five shared many of the same demographics, case finding would be an important aspect of the CAM intervention. The district nurse delivering the intervention would ensure s/he works with community teams who support diverse populations across Glasgow to make the intervention known to as many caregivers and professionals as possible.

6.2.6.11 Goals

The aim of the intervention would be for the district nurse to manage the caregiver’s identified nursing needs as well as act as their overall health and social care co-ordinator. This will reduce their often-fragmented support, which should improve patient and service outcomes (Sadler et al., 2018). District nurses tend to care for people over extended periods of time (although not necessarily continuously), and this naturally fosters trusting relationships. However, as the CAM district nurse would also act as case manager, it is expected that this role and title could facilitate a more empowered relationship and encourage associated professionals to recognise the status of the district nurse.

The feasibility and acceptability of the intervention should be tested to establish the interest and participation of district nurses. Following the Covid-19 pandemic, district nurses have often felt isolated (Mitchell et al., 2021). The legacy of the pandemic might create barriers to recruitment and retention, as district nurses could feel overloaded and overwhelmed in relation to new ways of working. It is not expected that there would be significant barriers to recruiting and retaining caregivers as the care they will receive through the CAM intervention would be an enhanced version of the care they receive outside of the trial. The logistics of the trial would also need to be explored, including how the CAM district nurse felt working alongside district nurses and General Practitioners outside of the trial and how feasible this was.

6.2.6.12 Training

A training manual would be developed for district nurses to ensure they are delivering a standardised intervention to caregivers. The case manager would also undergo a period shadowing the older adult's community mental health team and the Glasgow City HSCP Carers Team. This would enable the CAM district nurse to learn about the current services available to caregivers who are struggling with their role or experiencing mental illness, and how to effectively sign-post and refer to relevant services. This could also facilitate good working relationships with services that are closely associated with this intervention.

6.2.6.13 Mode of delivery

The first meeting is a fundamental step in case management and district nursing care, and key to the CAM intervention. Kennedy (2002) identified five features of the assessment visit carried out by district nurses that demonstrate its importance for the person's future relationship with the district nurse. Although this study was carried out in 2002, and the nursing skills associated with district nursing and level of education required have significantly increased, these key elements persist:

1. Look beyond the task they have been referred to undertake and build the bigger picture.
2. Act courteously, respectfully and professionally in the person's home to build lasting trust.

3. Make sense of the evidence through observing the person and their environment carefully.
4. Determine present and future care needs.
5. Work within the constraints of professional and personal resources.

It is expected that care will be carried out at the person's home; however, support will be available for telephone consultations and in the health centre or GP clinic if the caregiver prefers.

6.2.6.14 Frequency of contact and duration

The first visit would be scheduled for two hours. Subsequent visits would not be expected to last longer than one hour. Following the first visit, the visit schedule would depend on the identified nursing needs. It may be that care is required daily, or several times a day, so support will be required from other members of the district nursing team. For people who require visits more than once a week, the case manager would attend at least weekly unless requested by the caregiver or wider district nursing team. For less regular care, the case manager would attend at least monthly.

6.2.6.15 Co-ordination of services

The CAM district nurse would notify all relevant professionals involved in the person's care that they are acting as case manager. It is anticipated that this would typically include a GP, social worker, community social care workers and specialist nursing and medical professionals related to their diagnoses.

6.2.6.16 Case Management tasks

The case manager would undertake a full, person-centred assessment of nursing and social care needs. The case manager would also carry out direct patient care, such as (but not limited to) complex wound care, medication administration and support with chemotherapy. The case manager would work around the caring responsibilities of the caregiver and ensure that visits or meetings are scheduled in a place of the caregiver's choice, which might be the home of the person for whom they care if they do not live together. This could also include the treatment room clinic if the caregiver expresses a desire to leave the home. The case manager would call a case conference if this is necessary, and where other professionals trigger such a meeting, the case manager will attend to ensure they support the caregiver and act as advocate. If a caregiver is admitted to hospital, the case manager would work closely with the hospital teams to facilitate a speedy discharge. As the case manager is a district nurse, they will have access to the equipment ordering service available. If the caregiver and the person for whom they care both require district nursing input, the case manager will work closely with the district nursing team and carry out nursing care to that person when visiting the caregiver. This is common practice when more than one member of a household requires input from district nursing teams. This will help to build a relationship with the person for whom the caregiver cares. However, they would not act as a case manager for the person requiring care and would only offer routine care. If the person for whom the caregiver cares for was to be admitted to hospital, they would be on-hand to advocate on behalf of the caregiver to support discharge in a suitable and timely manner. The case manager would also refer and signpost the caregiver to appropriate services when needs are identified outside of her clinical expertise.

6.2.6.17 Measurements

Core Outcome Sets (COS) such as those advocated by the COMET Initiative (https://www.comet-initiative.org/), are highly desirable within trial research to enhance comparative analysis between similar interventions and/or participant groups (Dodd et al., 2020). The use of COS within trial research standardises the process related to outcome measurement selection by dictating the minimum outcomes that researchers should implement. By doing this, researchers and clinicians can support more robust systematic reviews, clinical guidelines and quality indicators. I was unable to find COS specifically related to case management. However, caregiver outcomes are considered within some COS (including those still in development), such as COS for people living with dementia (Moniz-Cook et al., 2008b; Harding et al., 2019) and following stroke (Crocker et al., 2018). Furthermore, there is a COS for research related to older people (Akpan et al., 2018) and one in development related to frailty (Muscedere et al., 2019). The modified systematic review of caregiver outcomes also identified outcomes of interest specific to caregivers of people with life-limiting conditions.

Reilly et al (2015) carried out a review of case management for people living at home with dementia. They suggested that case management interventions collect and record data on which people had care plans, how often these were reviewed and updated, as well as visit schedules, and mode of follow-up support (phone vs home visit). These recommendations were made in the hope that future researchers will identify the level of active engagement that is required for case management to be successful. They also recommend that data is collected on hospital and/or care home admission, and length of stay.

It has been identified that caregivers are often unable to complete supportive interventions and research trials because of the unpredictability of their caring role. This intervention will work around the participant's caring responsibilities. Therefore, we do not anticipate that the caring role will directly cause a caregiver to leave the trial. However, there are a multitude of reasons why participants do not complete trials. We will analyse data obtained from participants who drop out. This will allow us to consider if there is a minimum intervention length where positive outcomes are established to help caregivers to complete subsequent trials and interventions.

At the end of the feasibility test, the district nurses who participated would be invited to a semi-structured interview that would last up to 90 minutes. This would help us to identify the feasibility and acceptability of the trial in relation to recruitment and retention, and logistical barriers experienced.

6.2.6.18 Caregiver Primary Outcome

Caregiver burden measured by the Zarit Burden Inventory

6.2.6.19 Caregiver Secondary Outcomes

1. Quality of Life measured by the SF-12
2. Number of district nurse encounters
3. Nature of district nurse encounters (telephone/in-person/electronic)
4. Number of unplanned care encounters
5. Nature of unplanned care encounters
6. Length of any hospital stays

6.2.6.20 District Nurse Outcomes

1. Source of case finding (GP, Accident and Emergency, self-referral, peer referral, hospital, community service)
2. Caseload size
3. Number of discharges

6.2.6.21 Interview Data

District nurses would be invited to a semi-structured interview, where an interview guide would be prepared in advance (Braun and Clarke, 2013; 2019). The interview guide would include open-ended questions related to how the district nurse felt about delivering the intervention and how it differed from the usual care they provide, as well as any barriers they experienced in implementing the intervention. Interviews would be carried out at the district nurse's place of work or at their homes at a time that is convenient to them. Interviews are recommended over focus groups when participants have a stake in the topic (Braun and Clarke, 2013). Therefore, as it has been suggested that district nurses have perhaps had changes happen to them rather than with them, it is hoped that an interview would allow them to share their experiences and feel fully supported at every stage of the intervention development.

6.2.6.22 Statistical Analysis

Quantitative data could be collected at four time points: pre-trial, 30 days, 60 days and 90 days (or at termination of the intervention). The quantitative outcomes will be collected face to face at the first meeting, then posted out thereafter. These provide data to undertake health economic analysis that will allow us to explore the financial feasibility of the intervention. Data collected from the in-depth interviews would be analysed with the Braun and Clarke thematic analysis framework (Braun and Clarke, 2013).

Findings would consider the impact of caregiver sex, age, ethnicity, and location on outcomes. The disaggregation of data by subgroups is advocated to ensure differential experiences are explored and considered (Mertens, 2008), which is of high importance when undertaking research as diverse as the Glasgow population.

6.2.6.23 Discussion

Case management is included in Ashworth's (2020) description of standard district nursing practice, and it is listed as an essential role within district nursing in the Transforming Nursing Roles district nursing report (Scottish Government, 2017). However, there are few trials that have investigated the effectiveness of case management within district nursing. Drennan et al. (2011) described the use of case management *techniques* within various community-based nursing roles. There is an important distinction to be made here as there is a difference between applying aspects and techniques of an intervention and implementing a full intervention with clear parameters and measured outcomes. The Transforming Nursing Roles report emphasises the importance of district nurses using evidence-based interventions that have been informed by research and evaluation. It could be suggested that some of the key components of case management are routinely used by district nurses. However, as a specific intervention, little is understood about its efficacy when delivered by district nurses. This further demonstrates the heterogeneity related to the term case management and how it is understood.

Beyond case management, to meet the increasing demands from ageing populations and multimorbidity, there have been trials of other models of nursing care led by district nursing teams across the UK. One such model is the Buurtzorg model (Kreitzer et al., 2015). This is person-centred care delivered by self-directed teams (Kreitzer et al., 2015). Each team is made up of district nurses, staff nurses and nursing assistants who plan, co-ordinate and deliver all the necessary care for people who would otherwise require community health and social care input (Kreitzer et al., 2015). This model has been shown to improve patients' perceptions of continuity of care and anticipatory care (Drennan et al., 2018). It was felt that this model allowed members of the district nursing team more time to undertake the necessary care (Lalani et al., 2019). This extra time not only benefitted the patients. District nurses in an Aberdeenshire trial stated that the model improved their feelings of autonomy and the quality of care they were able to deliver (Leask et al., 2020).

Another model of community nursing that was introduced to improve the care that people with life-limiting conditions receive in the community was the community matron role (Leighton et al., 2008). This role was used in England and is the closest role to what is described in this protocol. The community matron role blends case management and advanced clinical practice (Leighton et al., 2008). However, this role deviates from the district nurse because the district nurse has a more hands-on approach and has a recorded SPQDN qualification on the NMC register, which is not required of a community matron. An example would be where someone has chronic, highly exuding leg ulcers due to heart failure. The community matron would not be responsible for the wound management of the leg ulcers. Instead, they would liaise with the district nursing team regarding the wounds; whereas the district nurse would act as case manager for the person and regularly undertake the wound management.

The CAM intervention is influenced by both the Buurtzorg and community matron models of nursing. Like the Buurtzorg model, the CAM intervention offers the district nurse enhanced autonomy, the opportunity to maintain clinical skills that are fundamental to district nursing, along with the longevity of care that both clinicians and patients' value. Indeed, like the community matron model, it also offers the district nurse the ability to assess a person’s suitability against her knowledge and skills of a specific population. There is a feeling that by being generalists, district nurses’ expertise in complex areas such as palliative and end of life care are often overlooked (Burt et al., 2008). Therefore, having a clear admissions criterion, the patient and district nurse can be confident that they are a suitable match for one another. Furthermore, where district nurses are often self-described as “jack of all trades, master of none” (Gray et al., 2011), the CAM district nurse could be recognised at least as a master of one, caregivers.

6.2.6.24 Limitations

This intervention is adapted with the known benefits of Buurtzorg, case management, community matron and district nursing models that will increase its fidelity. However, barriers to recruitment and retention due to workload pressures from the Covid-19 pandemic might hinder its acceptability and feasibility within the district nursing teams.

6.3 Chapter Summary

Findings from the secondary analysis of caregiver needs assessments carried out by the Carers Support Team and the focus groups and interview with caregivers from Glasgow identified various issues in existing support that require attention. Consequently, a variety of interventions could be considered, from CBT-based interventions to improve their mental wellbeing and coping, to peer-support interventions that provide protected time to build a trusting support network, to case management that prioritises the relationship between a caregiver and a professional to improve their ability to prioritise their own health and wellbeing without compromising their caring role. However, it could also be a blend of these intervention groups, where the components of each that matter the most to caregivers are combined. Future research may be needed to make this decision.

Chapter 7: Discussion

7.1 Introduction

This doctoral project began with an idea to develop an intervention for caregivers of people with life-limiting conditions. However, the process of selecting an intervention that would meet the needs of the Glaswegian caregiver population was not clearly mapped out. The approach taken to developing or selecting an intervention was informed by Donna Mertens work on transformative interventions for marginalised groups. This doctoral project does not outline one specific intervention, as was originally intended. Instead, the previous chapters highlight that, contrary to what would reasonably be expected, professional groups such as nurses, social workers and medical staff often contribute to the psychological strain experienced by many caregivers, instead of alleviating it. Subsequently, many of the existing interventions do not address the aspects of the caring role that are most pertinent to caregivers. The poor communication and a lack of flexibility from professional groups working with caregivers requires urgent attention. Findings from this project suggest that if these issues are addressed, the need or demand for certain types of interventions for caregivers could be reduced because a significant source of their anxiety and stress would be removed. This would also be beneficial for health and social care services as better working relationships between caregivers and professional groups would improve the care that everyone involved can provide. Therefore, further enquiries are needed.

7.2 Novel and Overarching Findings

This project used a novel methodology to inform possible complex interventions that could enhance the wellbeing of caregivers in Glasgow. It draws on data from 813 caregivers from Glasgow who all used supportive services and/or interventions. Although there is a wealth of existing evidence in relation to the caring role, caregivers from Glasgow are a hard-to-reach population that are rarely the focus of research. However, with a deepening *political effect* in Glasgow, there is a growing need for researchers to centre the needs of groups most at risk of marginalisation (Cowley et al., 2016). The overarching findings from this project suggest that the caregiver population in Glasgow is a predominantly female population. Female and male caregiver groups have overlapping as well as distinct needs that require health and social care professionals to consider the age and sex (and how they might intersect) of those they are offering support to. Furthermore, existing support does not offer the necessary flexibility and continuity required to offer meaningful, person-centred help. In line with existing evidence (Peel and Harding, 2014), caregivers from Glasgow often experience fragmented help that can add to (rather than alleviate) the psychological burden that many caregivers experience. Alongside (or perhaps, instead of) caregiver services and interventions, professional groups require urgent training and education to understand that caregivers should be key allies when planning and delivering care to people with life-limiting conditions. Respectful practice that supports caregivers to have more autonomy over their time and values their expertise should be, but is not currently, routinely available to caregivers.

7.3 Chapter Overview

This chapter will outline how the overarching findings from this project can inform future interventions and support for caregivers. The structure has been adapted from questions posed by O'Cathain et al. (2019) in their systematic review of intervention methods. The authors suggest that intervention developers should ask themselves these questions to inform their future work. This will ensure that interventions suit the context, values, and needs from the evidence that they are building upon. By using these questions to structure this chapter, I can position the new and novel findings within the existing evidence whilst acknowledging that there are more questions that need to be answered to move this project on.

7.3.1 What should the intention of future interventions be?

This project evidenced the need for interventions for caregivers that seek to reduce the risk of psychological burden or mental ill-health associated with the role. Of the interventions that have been tested through trials, the modified systematic review described in Chapter Three demonstrated that this does tend to be the primary focus for researchers. However, there are discrepancies in what aspect of psychological burden requires attention and what type of intervention is most suited to improving psychological wellbeing. These issues support the need for future interventions to consider the unmet needs of caregivers, instead of expected outcomes based on assumptions like the diagnosis of the person requiring care. Reducing unmet needs is a major priority for caregivers and should therefore, be a priority for those developing or implementing interventions that seek to improve outcomes for caregivers (Mansfield et al., 2017).

For caregivers whose unmet needs are assessed, it is often an unstructured, small part of an assessment for the cared-for person (Aoun et al., 2015). However, assessing a person’s unmet needs can be a complex process. Ventura et al. (2016) grouped unmet needs into spiritual, psychosocial, communication, information, respite and isolation when reviewing studies on the unmet needs of people receiving palliative care and their caregivers. Although they were not setting out to review only advanced cancer studies, most of the retrieved studies were for this group. They suggest more research is required to understand the unmet needs of people caring for those with non-cancer diagnoses. Denham et al. (2022) grouped unmet needs into the themes of obtaining adequate information, taking care of oneself, service accessibility, emotional and psychological, and relationships. The broad scope of identified themes from these reviews demonstrates that understanding and seeking to address unmet needs requires a holistic, individualised approach. Subsequently, much of this research is qualitative and unmet needs are often described in terms of themes or domains (Denham et al., 2022; Ventura et al., 2016).

Chen and Zhang (2020) carried out a meta-review of systematic reviews and meta-analysis of non-pharmacological interventions, which included over 500 trials. They suggest that caregiver interventions would be more effective at achieving long-term improvements for caregivers if they prioritise unmet needs. They suggest one way of understanding caregivers’ unmet needs is by carefully screening potential participants. This would ensure caregivers are matched correctly to interventions, so a caregiver who does not display signs or symptoms of depression would not be the best fit for a cognitive behavioural therapy intervention. Conversely, a caregiver with signs or symptoms of depression might not be suitable for an education intervention until their depressive symptoms are managed. This approach might also help to reduce heterogeneity in outcomes because the pre and post screening tools used would be selected from a small pool that are clinically recognised, to support participant recruitment.

Mansfield et al. (2017) examined outcome measures that attempt to quantify (rather than describe or conceptualise) unmet needs. They argued that this is necessary because the pooling of data from standardised measures are vital for informing the development of interventions and resource allocation in research and clinical practice. Their critical review identified a lack of measures for unmet needs and suggest that those that do exist are methodologically flawed. The authors suggest that outcome measures could be used to measure unmet needs in future studies if caregivers are asked to prioritise the most common issues these tools try to evaluate against their impact on wellbeing. This has potentially important implications for the use of existing evidence from intervention trials and their outcome measures on future intervention studies, as most have not set out to test against unmet needs.

7.3.2 What is the context of future interventions?

This project called for an intervention that meets the needs of the Glaswegian population of caregivers. For any future interventions that are developed and/or tested in Glasgow because of this project, the contextual influence (including input from the PCPI volunteer, Charles) throughout the development process means that they would likely meet the definition of a place-based intervention. Place-based interventions have the potential to improve physical health outcomes, health behaviours and social determinants of health, including in areas with widening inequality and reduced local funding (McGowan et al., 2021). Because they tend to be developed by teams working near the intended individuals, they are attractive to community members, clinicians and policymakers (Foell and Pitzer, 2020). The proximity between researchers and communities that place-based interventions create increases perceived accountability and credibility. Place-based interventions appear to be welcome within Glasgow, as the City Council accepted £3.7 million from the Scottish Government in 2022 for interventions that aim to improve local communities (Glasgow City Council, 2021). This follows a successful run of such interventions being implemented in Glasgow in recent years. Examples of successful place-based interventions that have been tested include interventions to improve physical activity levels, reduce homelessness, and make intravenous drug use safer (Curl et al., 2018; Lowrie et al., 2021; Tweed et al., 2018).

Clark and Wright (2018) highlight the importance of long-term investment in place-based interventions. They described how the Gorbals area of Glasgow City has experienced cyclical improvements from interventions that have been followed by deterioration when interventions are not maintained. Furthermore, a systematic review of neighbourhood effects in health research by Arcaya et al. (2016) identified that researchers can simplify findings. The authors suggest that the accumulative effect of ageing on common outcome measures such as body mass index and mental health function can be overlooked. They note that there can also be a lack of attention given to the prevalence of early life exposures and their influence on the dominant characteristics of a population, as well as the impact that neighbouring areas have on a population. Researchers must also be clear about the boundaries of the areas they are focused on, with Macintyre et al. (2002) describing poorly demarcated places as “unspecified black box(es) of somewhat mystical influence” (p. 125). These are important factors that can help researchers understand how useful (or not) a place-based intervention really is (Graif, 2015).

The place-based influence in the development of this project was not only experienced through the research studies described in this thesis, but also from my clinical role working in the Glasgow City district nursing team. I was in constant contact with caregivers who were living with the socio-political fallout described by Schofield et al. (2021). This was evidenced in the high prevalence of mental ill-health among caregivers in the secondary analysis of needs assessments. It highlighted that researchers should continue to prioritise interventions that are concerned with the psychological wellbeing of caregivers. The focus groups and interview highlighted that caregivers require more respect and continuity from professional groups currently working in Glasgow health and social care services.

These highly contextualised findings and recommendations raise questions about the transferability of this project outside of Glaswegian caregivers. However, the benefits that flexibility and continuity create when offered by professionals to caregivers was described in interviews conducted by Prendergast et al. (2022) with caregivers of people living with dementia in Wales. Participants described their use of a specialist day service, which paired caregivers and the person for whom they care with a support worker. Although this was a professional relationship, there was an expectation that all involved would work together in a triad, which fostered a level of flexibility that often naturally occurs when people are allowed to build relationships over a period.

7.3.3 What values should inform intervention development?

The aim of this project was to develop or select one intervention for caregivers of people with life-limiting conditions from Glasgow. However, the data collected and the identified findings, suggested that there is a range of interventions that could be beneficial. Furthermore, findings from this project also suggest that improvements could be made to existing services that might mitigate the need for some of the caregiver-specific interventions. Better communication, more opportunities for collaboration and continuity of care could reduce the stress and burden experienced by caregivers that might reduce the need for interventions that are designed to address poor psychological wellbeing, such as cognitive behavioural therapy. Therefore, before any decisions are made about future intervention selection and testing, more training and education for all health and social care staff should be considered so they understand that respectful, person-centred care should be available to caregivers, not just the person or people they support who are living with life-limiting conditions.

The case management intervention described in Chapter Six suggests that district nurses could have a key role in supporting caregivers and the person for whom they care. This is because of their ability to carry out comprehensive assessments of needs and requirement to work collaboratively with the families of people they deliver care to. The importance of ongoing assessments and collaborative working for caregivers was echoed in an analysis of interviews and focus groups with caregivers supporting people at the end of their lives at home by Swan et al. (2022). Findings from this study suggest that members of the district nursing team are ideally positioned, but often fail, to identify when a caregiver's circumstances are changing. By ignoring obvious signs that a caregiver's circumstances have changed, they do not signpost to relevant services or act on mental ill-health. These failings often impact the grieving process. A reciprocal respect that caregivers expected from district nurses was also described in this study. Although some of the participants were from Glasgow, the overall pool of data was from 45 caregivers from across Scotland. This suggests that the issues identified in this project are not just experienced by caregivers who encounter health and social care professionals working in NHS Greater Glasgow and Clyde. It supports the need for further training and education for health and social care professionals about their role in supporting, and responsibility to, caregivers. Finally, it also suggests that the success or failure of future interventions, that expect respectful communication and relationship building between caregivers and professionals as key values within it, which are tested in Glasgow could have transferable findings for other areas where similar issues have been identified.

To build on the findings from this project, future research should continue with Patient, Caregiver and Public Involvement at all stages and consider co-designing studies with caregivers. Co-designed studies might result in findings that are perceived to be less innovative than what was originally planned (Latulippe et al., 2020). However, it will ensure that subsequent decisions made around interventions are shared and manage expectations while aligning with the values of those most affected (Slattery et al., 2020). This project was underpinned by Donna Mertens transformative paradigm. Intervention development research that is influenced by her theory, by its very nature, should be guided by the values of the communities the researchers are trying to help (Mertens, 2007; 2008). This is usually achievable because of the continuous community involvement expected of transformative researchers. Community involvement in research is described by Mertens as mutually beneficial. Research teams benefit because it can ease the funding process, support them with decision-making and help with logistical planning. This is especially helpful when researchers are recruiting people with disabilities or additional support requirements that might be difficult to predict or understand without lived or previous experience. Poor planning in relation to accessibility and communication issues could cause avoidable delays in studies. As was the case for this project, community involvement also gives researchers an opportunity to build relationships with people interested in their work who are outside the research team and offer an insider's perspective before any data is even collected.

However, community involvement in research is not without risk for the volunteers and many experience barriers to using their experiences as a PCPI volunteer. What is required of a volunteer will vary between studies because what it is understood to be, and how it is used, can vary significantly (Goodyear-Smith, 2021). For volunteers who are keen to build up different experiences, they will also have to adjust to different ways of working, and communication styles, terminology or jargon used within different teams, even if their area of interest appears to be the same (Slattery et al., 2020). Researchers can also become worried that their requests for support will add to a caregiver's burden, particularly people who care caring for someone receiving palliative or end of life care. This can create a situation where a researcher becomes a gatekeeper deciding who is suitable and for what, rather than trusting that a volunteer will articulate their feelings and availability (Chambers et al., 2019). These barriers can leave community volunteers feeling frustrated and confused, and risks further diminishing the caregiver's autonomy over how they use their time and energy (Chambers et al., 2019). Although these are not easy barriers to overcome, they are not unsurmountable. Researchers should spend time building and maintaining relationships with community members, which will allow volunteers to feel comfortable enough to articulate what level and type of involvement they want at a given time (Johnson et al., 2021).

7.3.4 What skills and experience are required?

This project sought to develop or identify an intervention for caregivers of people with life-limiting conditions from Glasgow. However, findings from this project suggest that caregivers would also benefit from a cultural shift among professionals in relation to how they work alongside caregivers that views caregivers as key collaborators when planning care for people with life-limiting conditions. This could be weaved into everyday practice. Such a shift in practice would alleviate some of the psychological burden experienced by caregivers that could mitigate the need for specialist psychological input, which is already stretched (Harrison et al., 2017). Professionals who have contact with caregivers have a duty to recognise that the caregiver is often the expert in the person for whom they care and should be central to any care planning, which involves regular, respectful communication. Effective communication has been described by caregivers as a way in which challenges associated with navigating the "well-intentioned but complicated and fallible system" (Luymes et al., 2021; p.4) of support available to them could be somewhat mitigated.

The high prevalence of mental ill-health among caregivers, which can be associated with, exacerbated by, or independent of, the caring role means that all professional groups should be monitoring caregivers for signs of depression, anxiety, isolation, and poverty (Hu et al., 2018; Joling et al., 2015; Riffin et al., 2019). Professionals and researchers working with caregivers have a duty to monitor their mental health and take appropriate action if they think they might be at risk (Harrison et al., 2017). This is because caregiver mental health is associated with significant risks for themselves and the person for whom they care. Risks include increased hospitalisation and a move into long-term care for the cared-for person and suicide (Guterman et al., 2019; Nunez, 2021; O'Dwyer et al., 2014). Even when these more extreme risks are not experienced, caregivers experiencing symptoms of mental ill-health can adopt dysfunctional coping strategies, which include disengagement, denial, substance use and poor communication (Lloyd et al., 2019). These risks further complicate the care that is required for the caregiver, patient dyad. However, many of the professional groups and researchers working alongside or with caregivers cannot be expected to have the expert knowledge to assess and manage psychological health and wellbeing (Harrison et al., 2017). Therefore, researchers planning on developing or testing interventions or services designed for caregivers should consider how their intervention could build networks with, or be integrated into, a multi-disciplinary team that includes professionals concerned with both physical and mental health and wellbeing (Sullivan and Miller, 2015).

7.3.5 Which approaches have resulted in interventions that are shown to be effective?

One of the challenges I faced was the volume of existing evidence on the caring role and interventions designed to either improve their ability to care or how they cope with the challenges they experience. For example, digital interventions (Finucane et al., 2021), creative arts interventions (Abrahamsen Grøndahl et al., 2017; Irons et al., 2020), support groups (Cheston and Ivanecka, 2017), psychosocial interventions (Rausch et al., 2017), multi-component interventions (Abrahams et al., 2018) and nurse-led interventions (Becqué et al., 2019) have all been systematically reviewed. These reviews, which collectively include a mix of qualitative and quantitative studies carried out by teams from many different clinical and research backgrounds (including medicine and psychology (Finucane et al., 2021), music therapy (Irons et al., 2020), public health (Rausch et al., 2017) and nursing (Becqué et al., 2019)) have demonstrated potentially positive effects on caregiver outcomes. Clearly, an array of approaches can be used to improve caregivers' knowledge, and their physical and mental wellbeing.

My awareness of positive results from existing evidence quickly developed into an unease around what I thought I could add. The challenges of the caring role, particularly for people in a caring relationship in Glasgow, seemed too big for a doctoral project to make a meaningful difference. However, my clinical role highlighted that despite a breadth of existing interventions and the legal right for caregivers to access timely needs assessments, what was available did not seem to be improving the long-term quality of life and reducing the psychological burden of caregivers. This is not to minimise short-term positive effects that existing interventions and services can demonstrate (Wiegelmann et al., 2021). Ideally, researchers should be able to demonstrate than an intervention has both short-term and long-term effects, especially those that seek to reduce burden (O'Cathain et al., 2019; Wiegelmann et al., 2021). The caregivers I met as a district nurse did not seem to be experiencing long-term benefits from accessing services and interventions that they were sign-posted to or referred to following their needs assessments.

One exception to the range of services and interventions available to caregivers that was described by caregivers as truly beneficial to them and was a high priority amongst their busy and unpredictable schedules was peer support. However, there are already several peer-support groups available to caregivers in Glasgow as all but one participant in Chapter Five described attending peer-support groups. Therefore, the primary reason why I was cautious about recommending peer-support as a stand-alone intervention based on the findings of this project was because researchers should be clear about what their intervention adds to what already exists. Peer support offers caregivers protected time away from their caring role. Participants in Chapter Five described a desire for more respite time away from caring and autonomy over that time, primarily wanting time to spend with friends. Similarly, a systematic narrative review of caregiver's needs identified that caregivers often express an increased need for psychosocial support, which was defined as their social, emotional, and spiritual needs (Doherty et al., 2016). Caregivers want more time off to themselves to preserve a feeling of normalcy and maintain a social life. Having a support group to attend is one way to meet these needs. More research is required to identify if it is the peer support group or the protected time with like-minded people that is what is beneficial.

7.3.6 What resources are available for the intervention development?

The Covid-19 pandemic and the adaptability of Capitalism will be the biggest challenge to adequate resource allocation that will enable future interventions to be developed and tested for marginalised groups, of which caregivers are one. However, challenges to adequate resource allocation from Capitalism has been a historical barrier faced by caregivers and people living with life-limiting conditions when attempting to access person-centred help and support through health and social care services and evidence-based interventions.

The secondary analysis of needs assessments carried out by the Carers Support Team were for women of working age. This suggests that this demographic is the most likely to be identified, or identify as, requiring help. This is unsurprising when we consider the work of Nancy Fraser, who has critiqued Capitalism and the "crisis of care" that it has created (Fraser, 2016). Fraser argued that Capitalism in its current form reinforces a care crisis, whereby women balance limited, feminised employment options with an increasing number of caring responsibilities. A key aspect of Fraser's arguments around Capitalism is in her definition of it. Fraser and Jaeggi (2018) suggested that most of the popular definitions of Capitalism held by economists and the public are limited. These definitions focus on the understanding of Capitalism as a purely economic system related to the ownership of private property, wage labour, commodity production, personal debt, and free markets. Even the most fervent critique of Capitalism, Marxism, focuses on class exploitation that occurs within each component of these definitions. However, Fraser and Jaeggi (2018) argued that Capitalism is an institutionalised social order, and that the narrow focus on an economic system overlooks some of the key components that are vital to Capitalism. Instead, an expanded definition focuses on the role of social reproduction ("people making") that makes Capitalism ("profit making") possible (Fraser and Jaeggi, 2018). This definition also considers the exploitation of the environment under Capitalism and the way natural resources are free or cheap inputs. This includes indigenous exploitation and under-waged workers, particularly in racialised societies. Finally, Fraser and Jaeggi (2018) highlighted that although Capitalism tends to resent the taxation that produces public goods and services, it depends on it. This is because it funds telecommunication, transport and environmental infrastructure, and education, police and healthcare services that support the enabling conditions of capital accumulation.

Understanding Capitalism by Fraser's definition helps us to understand the social infrastructure dependent on caregiver's exploitation and how difficult it may be to achieve change. This is highlighted for caregivers of people with life limiting conditions in the division of paid and unpaid labour between women and men all over the world. Ferrant (2014) identified that caring responsibilities are the reason for the pay gap between women and men, and an inequity in labour outcomes. They found that globally, women spend between two to ten times more on unpaid care than men, with the biggest difference found in developing countries. For example, in India, women spend an average of six hours a day on unpaid care work, compared to 36 minutes for men. This difference is not because women do not participate in paid employment. A woman in Ghana will spend 13 hours a day in work, 39% of which is paid work. The unequal division of unpaid care work is also negatively correlated with the wealth of the country, with men in higher income countries participating more in unpaid care work (Ferrant, 2014). This pay gap is biggest in countries with the most unequal division of unpaid care work.

Smith et al. (2019) examined male/female differences in the impact of caring for an older family member on labour market attachment, and the extent to which differences in labour market participation and employment relationships explained these differences. Their study covered a 19-year period and included over 5.8 million workers in Canada. They identified that this type of unpaid care work is directly associated with a change in working pattern that tended towards part time, unplanned time off and leaving the labour market altogether. All these outcomes affected women more than men, with women 73% more likely to stop work than men. Similar findings have been discussed in a study by Stanfors et al. (2019), which analysed time diary data from caregivers in Sweden, Canada and the UK. They identified that women have more caring responsibilities, do more housework, have less leisure time, and participate in paid employment less than men. However, the balance between female and male caregivers in Sweden, which has better social care infrastructure, is not as profound. Caregivers in Sweden are just as likely as non-caregivers to work full time. In all three countries, caring responsibilities reduced leisure time.

Therefore, it may not be the demands of caring, but the pressure to balance employment with care that heightens the need for support. A review by Greenwood and Smith (2016) identified some evidence that indicates that older caregivers might view their caring role more positively and cope better than younger, working age caregivers. Therefore, to reduce the risk of financial hardship and poverty, caregivers require flexible support that works around their caring responsibilities and employment. This, in turn, will not only benefit caregivers but their employers. It would enable caregivers to be more stable, dependable, and productive when working. The risks associated with financial pressure for caregivers is why Gardiner et al. (2016; 2020) recommended that services, professionals or researchers who work with caregivers, monitor and assess caregivers using evidence-based tools for financial burden, and signpost to appropriate support when necessary.

Feminist academics and activists have called for feminists to become more active in addressing the care crisis and aim for more than small adjustments to existing services, such as additional risk assessments to address specific risks or “tinkering with social policy” (Fraser, 2016). Arruzza et al. (2019) argued in their “Feminism for the 99: A manifesto” that addressing the subjugation of social reproduction should be central to feminist activism, which Fraser (2020) suggested has become somewhat distracted by neoliberalism and identity politics in recent years. It was suggested that some fractions of feminism have been tempted by neoliberalism (referred to as liberal feminism) and would rather lean into Capitalism rather than challenge it (Fraser et al., 2018; Arruzza et al., 2019; Fraser, 2020). Feminist activism that seeks to address the care crisis created by Capitalism would aim to transform the lives of the 99%. Confronting the care crisis would involve addressing access to healthcare and education, climate change, and adequate housing and transportation because their expropriation are intrinsically linked to one another (Arruzza et al., 2019).

Fraser (2016) is doubtful that any workable solution to the care crisis is compatible with Capitalism. Instead, she has championed a reordering of the social order centred on feminist socialism. This is partly because of the pragmatism that can often be found in feminism (Fraser, 2020). This vision is somewhat shared in Oxfam’s Time to Care report by Lawson et al. (2020) report, which outlined that a society that can effectively address climate change will be a feminist society. However, the compatibility of socialism and feminism has been debated. Barrett (1988) wrote that because feminism tends to focus on the female, and analysis primarily focuses on sex-class analysis, it does not pay enough attention to socio-economic class analysis and the treatment of working-class men. Although this argument was made in 1988, and feminist theory has developed significantly into something that is more sensitive to race, disability, and socio-economic class, this is still a prevailing argument among many Marxists. They argue that feminism is not compatible with their vision for the future because it is not necessary within class analysis. However, Goodman (2013) highlighted that this is an older view of class analysis that subordinated and ignored the struggles of women, and that it focused on white male privilege. Indeed, Fraser argued that Marxist analysis of Capitalism is too narrow because it overlooks the value of social reproduction. Fraser’s (2020) vision for the future is three-dimensional to address redistribution, recognition and representation that began during the second wave but has been side-lined by neoliberalism. A socialist feminist social order that includes and accounts for the value of social reproduction and the caring role might seem too aspirational. However, the Covid-19 pandemic has exacerbated the care crisis and brought such discussions back into public consciousness.

7.4 Caring and Covid-19

At the time of writing, the pandemic has lasted over two years. Understanding the true financial cost is unknown. Nevertheless, Deaton (2021) wrote in January 2021 that financial inequality had not been widened due to the pandemic. This was contrary to the zeitgeist of the time, which posited that the economic inequality gap had increased. He acknowledged that although poverty has increased, this was universal and does not add to global inequality. Furthermore, richer countries such as the UK and America had experienced more deaths compared to developing countries. However, devastating waves in countries such as the Philippines and India were still ahead. Moreover, Deaton (2021) did not discuss individual financial gains, which characterise our current institutionalised social order of neoliberal Capitalism.

Although the lives of caregivers during the pandemic have undoubtedly become harder, their enhanced role and responsibilities have not gone unnoticed. The first wave of the pandemic was characterised by the Clap for Carers weekly ritual that acknowledged both unpaid and paid people in caring roles (Wood and Skeggs, 2020). There was also a flurry of published literature that discussed the unequal division of labour, its impact on the caring role during the pandemic, as well as the sacrifices women will make in the longer term after the pandemic. In recognition of the far-reaching consequences that this will have, analyses and commentary have come from a variety of areas such as economics (Almudena and Smith, 2020), environmentalism (Power, 2020), feminism (Chatzidakis et al., 2020, Ceuterick, 2020), and sociology (Wood and Skeggs, 2020), all with interesting caveats. However, the recurring theme from these papers is that it is expected that progress to close the pay gap between women and men will slow or reverse, women will pay professional and academic penalties for reduced productivity and output, as well as experience an increased risk of physical and mental ill-health due to increased caring responsibilities with reduced professional support (Power, 2020; Almudena and Smith, 2020; Costa Dias et al., 2020). These risks are not just associated with women who earn or undertake less formal employment hours than their partners. Andrew et al. (2020) analysed patterns of working parents during the pandemic and identified that regardless of the income and employment status of the parents, women universally took on more housework, caring responsibilities and worked less compared to fathers. Although the focus of much of this literature is primarily on the care of children due to school and nursery closures, their considerations apply to caregivers of people with life-limiting conditions because many caregivers also work and have other caring responsibilities.

Chatzidakis et al. (2020) goes so far as to argue that care has become a buzzword. Nevertheless, these conversations have led to some wider discussion around addressing the care crisis following the pandemic. The Care Collective published their Care Manifesto (Chadzidakis et al., 2020). This text outlines a theory based on the appreciation for how natural and fundamental care is to society. Their manifesto highlights that the only way to effectively address the care crisis is with radical change. Their suggestion is a model of care called "promiscuous care" (p32), which is influenced by alternative caring arrangements outside of the nuclear family. Promiscuous care focuses on widening our social networks, and appreciating the importance of friendships, community and non-sexual relationships. They suggest that a society that acknowledges how common and important care is, that centres it within communities would have more people to undertake caring responsibilities. They wrote that "anyone can potentially care for, about and with, anyone" (p42). Wider social networks and the normalisation of care would have profound benefits for caregivers and the people for whom they care. Dowling (2021) suggested that this idea would encourage us to become more creative with our caring arrangements and foster longer lasting, interdependent relationships. These types of relationships and communities would be the antithesis to the instant, individualised transactional lives we now live in neoliberal Capitalist communities (Dowling, 2021). However, their model lacks nuance. It simplifies the complexity involved in caring for someone with a life-limiting condition and those requiring palliative and end of life care. Although they discuss the important role that friends have in palliative and end of life care, they do not consider the logistics involved, and the longevity associated with this type of care. Nor do they consider training and supporting multiple people to carry out common and complex tasks such as medication management, assistance with personal care, wound care etc. Nevertheless, any attempt to address the care crisis that considers palliative, and end of life care should be welcomed. While care is a buzzword there will be more opportunities for caregivers and/or health and social care advocates to become involved in those discussions. In doing so, possible solutions may eventually become more workable and realistic.

Ultimately, it is hoped from the dust of the Covid-19 pandemic, a fairer system of support will arise, much like the National Health Service followed World War Two. The Covid-19 pandemic has highlighted and amplified flaws in our current social care system (Wood and Skeggs, 2020). Because of this, an independent panel was set up in Scotland to review all adult social care in September 2020. The review included a wide array of services, including non-clinical support services, such as care homes, prisons, care at home, day services, and community support for people with disabilities, older people, people with mental health problems and those with drug and alcohol problems. The review also considered how these services support caregivers and wider families. The review identified that a strong social care system is the backbone of communities and society in Scotland. It contended that human rights should be at the centre of a future social care model and supports the idea of a National Care Service. Following the review, Nicola Sturgeon (First Minister for Scotland at the time of writing) pledged support for a National Care Service (Bol, 2021), and it was included in the Scottish Labour manifesto. However, Bottery (2020) suggested that the scale and complexity related to entitlement, geography and recruitment might render it practically impossible. For example, a National Care Service has been discussed in England for over ten years but has yet to materialise. However, a National Care Service was not included in the Scottish Conservative's manifesto and the UK Parliament has been ran by the Conservatives during this time. This could be why such a change to social care has not been implemented, rather than the logistical challenges.

There is no doubt that a National Care Service could be a radical step towards improving the lives of caregivers and those who receive care. However, the work of Klein (2007) suggests how (un)likely something like a National Care Service may be. Klein (2007) presented a historical overview of how neoliberal Capitalism has shaped and adapted to major social and financial shocks (termed disaster Capitalism). Unequivocally, following every major catastrophe, poor populations have become poorer; and the financial elite have become richer, widening the inequality gap.

Although it is still early in the pandemic, and long-term adjustments and outcomes have still to be understood, we have started to see some reactions and responses. There is a concern that Covid-19 will be used as a reason by Governments and local authorities to turn short term cuts to services into long term closures. Throughout the pandemic, 81% of caregivers have reported that they are doing more care (Carers UK, 2020a). Many caregivers found themselves adrift with limited support as services were cut (Giebel et al., 2020). To fill the gaps created by the loss of services, some caregivers made significant changes to their living and working arrangements, including moving in with the person for whom they care (Giebel et al., 2020). These cuts were framed as a short-term solution to reduce footfall in their homes, because services were temporarily closing or because staff were shielding. However, temporary closures to some public services in Glasgow will become long term (Suter, 2021). More than a year after services were stopped, even though all vulnerable groups have been vaccinated, 82% of caregivers in Scotland have not had access to any respite since March 2020 (Carers Trust Scotland, 2021).

Although the care crisis has been continuously discussed by feminists, improvements to caregivers of people with life-limiting conditions have stagnated. An increase in caregiver population statistics, and legislation that recognises the role, do go some way to improving the lives of some caregivers. However, these improvements are only experienced by people who can recognise themselves and the role they undertake as a caregiver. Even when they can recognise their caring role, they are often met with barriers to obtaining adequate support. This unfortunately highlights the complexity in addressing the care crisis.

7.5 Recommendations for Health and Social Care Practice

From the findings of this project, the following recommendations are made.

1. Health and social care services that purport to support caregivers should:
    - Be considerate of the unpredictability of the caring role.
    - Strive to be flexible and work around the availability of services such as respite, befrienders etc that enable caregivers to attend services and appointments.
    - Be mindful that caregivers are at increased risk of financial strain and poverty, and limit any increased costs incurred to caregivers related to their attendance at the service.

- Not assess caregivers and their need for help based on their personality traits or likeability.
- Understand that older caregivers may require additional adaptions and consider disabilities or health concerns they may have on their ability to attend the service.

2. Health and social care services that are designed for people with life-limiting conditions but where caregivers assist that person to attend:
    - Respect the caregiver's expert knowledge of the person for whom they care.
    - Consider any other responsibilities, such as paid employment and other caring responsibilities when developing care plans to ensure the caregiver does not need to compromise more of their time than necessary.
    - Work in collaboration with caregivers to ensure agreed care is achievable for the caregiver.
    - Have open, honest and non-judgemental discussions around the caregiver's expectations of their role.
    - Ask caregivers what they are willing to do.
    - Review care plans, including the caring role regularly, as the condition of the person for whom they care changes and adjust accordingly.
    - Evaluate the data they collect on caregivers to improve record keeping, audit and service evaluation.

7.6 Recommendations for Nursing Research

This project has identified the following recommendations for future research:

- Caregivers in this project were receptive when talking to a registered nurse, and sceptical about accepting help from social workers due to previous experiences. Future research should explore the influence of researcher profession on the recruitment and findings of interventions for caregivers of people with life-limiting conditions.
- There is a need for a caregiver-specific Core Outcome Set to allow for improved examinations of intervention efficacy.
- Patient, Carer and Public Involvement should be mandatory in all caregiver research.

- Improvements are required in relation to streamlining data that are collected in relation to caregivers. This will enhance the capacity for secondary analysis that does not cause disruption to caregivers and the support services available to them.
- Caregiver research should consider disaggregating data by sex, ethnicity, location and age depending on population and research aims and objectives.

7.7 Recommendations for Nursing Education

This project has identified the following recommendations for nursing education:

- Pre-registration and post-registration nurses should be encouraged to consider wider theoretical models and frameworks that impact on patient and caregiver populations. In doing so, they will develop a more nuanced understanding of the challenges faced by health and social care professionals, patients and caregivers to achieve measurable and equitable improvements.

7.8 Strengths

This project was primarily interested in understanding the mechanisms involved in caregiver support services to enable the development of a service, or intervention that meets the needs of the Glasgow caregiver population. I used data from a sample of caregivers from Glasgow to understand the typical demographics of caregivers who access supportive services and interventions. Through reviewing the literature, I identified the need for more theory-driven interventions drawing on a wider range of literature. From this I have developed an intervention that will improve caregivers’ access to a health service through flexibility, sensitivity and continuity.

The transformative paradigm is a novel paradigm that has not been used to this scale before in nursing research. This project has demonstrated that it is an effective paradigm that ensures that improving the lives of the population of interest, in this case caregivers of people with life-limiting conditions from Glasgow, remain central to all research activities. This paradigm encouraged me to actively prevent knowledge and power hierarchies developing between the caregivers and the researchers. Furthermore, the Covid-19 pandemic encouraged me to consider creative ways to stay aware of the challenges faced by caregivers. Early in the pandemic I identified that there was a risk with home-based working, a clinical job that was emotionally draining and increased caring responsibilities, I could become detached from my topic. However, this paradigm forced me to take steps to prevent this. Through social media I have developed relationships with caregivers who have not participated in this project or had PCPI input. These interactions helped me stay aware of the challenges they faced.

The commensurate theories of feminism, and more specifically, intersectionality have worked in partnership with the transformative paradigm. They helped me to develop a more nuanced approach to understanding the experiences of caregivers from Glasgow who require additional support. They have constantly encouraged me to explore the complex structures of oppression involved in caring and understand the experiences of caregivers from Glasgow within a wider socio-political and historical context. These approaches also encouraged me to consider theories that I would not normally have explored, and I am confident they have elicited interesting insights.

Working in a clinical setting so closely associated with the subject of this doctoral degree, I am confident in the fidelity of the intervention. I am assured that the CAM intervention is appropriately driven by theory but is also practical and realistic.

Patient, Caregiver and Public Involvement was added into this project at the start of second year. The primary PCPI volunteer, Charles, was involved in all aspects of the focus groups and interview study. These inputs were of considerable value to the development of the intervention. Patient, Caregiver and Public Involvement has enhanced community involvement in the project, which is a mandatory aspect of transformative research.

7.9 Limitations

There are several limitations to this project. The first is that the focus of this project has been on caregivers from Glasgow. This impacts on the generalisability outside of Glasgow. However, caregivers of people with life-limiting conditions from Glasgow are a hard-to-reach population that face many obstacles to research participation. Therefore, what is known about caregiver populations require targeted approaches to ensure caregivers from all areas and backgrounds are fairly represented. These findings contribute to a wider understanding of the Scottish, UK and worldwide population of people who care for people with life-limiting conditions.

This project also selected three exemplar conditions in stroke, heart failure and dementia. Within these conditions, caregivers of people with dementia feature most prominently. Therefore, this also affects the generalisability of findings.

When analysing or exploring the findings in this project, the characteristics of sex, age and the general location of Glasgow have been the focus. However, there are other characteristics, such as ethnicity, sexuality and culture that will likely intersect and impact on a person's caring role and experience. Therefore, a lack of postcode and ethnicity data from participants impacts on the generalisability of findings.

I am a registered nurse with 12 years clinical experience in community services. I accept and acknowledge that I entered and progressed through this project with a level of dogma and awareness of stereotypes from my clinical training and employment in relation to the care and management of life-limiting conditions. However, I have attempted to "un-learn" these aspects of my practice through the reflexivity required of transformative research and from my relationships with caregivers. Nevertheless, I accept that these issues will have some influence on this project.

The Covid-19 pandemic has changed community nursing health and social care services. All data collected from the included studies were collected prior to the Covid-19 pandemic. This impacts on the applicability of findings during and following the pandemic. For example, the development of the National Care Service will likely impact on the how viable the chosen intervention is, and what service could provide it. It is expected that the pandemic has exacerbated the need for such an intervention, and because of the integration of health and social care, I am confident that it would sit comfortably within either National Service.

7.10 Final Conclusions

This project used a novel combination of methodologies and methods to understand how supportive services for caregivers are used and experienced. From this, a list of interventions was suggested as possible considerations for future research. The selection of interventions balance theory with practice to maximise their potential to improve the lives of caregivers of people with life-limiting conditions post-Covid-19. Although there was a considerable body of evidence prior to this project related to caregivers of people with life-limiting conditions, caregivers from Glasgow have rarely been the focus of research. This project confirms that existing understandings of the challenges experienced by caregivers, and the typical demographics of people with caring responsibilities applies to the Glasgow population.

The caring role and experience have been researched from a variety of perspectives. Overall, this body of evidence seems to prioritise understanding and/or alleviating certain aspects related to the psychological burden associated with the role. From this, an array of interventions already exists. Yet, the caring role continues to pose a considerable risk to the mental health of those who undertake it. There is, therefore, a need for researchers and clinicians to carefully consider how they assess the efficacy of interventions to improve scope for meta-analyses/syntheses. These studies should consider PCPI involvement and qualitative analysis where possible. From this, more robust conclusions can be drawn.

The findings from this project demonstrate that the caring role and experience is influenced by the caregiver's socio-economic status, the socio-political climate of the time and gendered expectations of their age and sex. Yet, the risk of psychological burden seems to be universal. These risks and influences have all been further complicated by the Covid-19 pandemic. As the population of people with caring responsibilities has increased during the Covid-19 pandemic, so too has the population of "hidden caregivers". There is a need for practical steps to improve existing supportive services and interventions. Improvements to how services are delivered or accessed that prioritise flexibility and continuity for caregivers could be quickly implemented compared to designing and testing new interventions. This would be a cost-effective way at reducing the strain and burden experienced by many caregivers when they interact with professional groups.

There is also a need for improvements to how professionals communicate with caregivers. This is also associated with more discourse analysis around the caring role. Pragmatic discourse that recognises the need for appropriate terms and categorisations should involve caregivers and health and social care professionals, as well as theorists. Areas of academia and activism for other marginalised groups have made significant improvements to related discourse, but this has not been replicated in caregiver activism. We must strive to use language that is respectful and representative. This is the least we owe to one of the most valuable populations in society that we will likely all find ourselves part of at some point.

Finally, caregivers who require additional support require interventions that address specific challenges. They expect continuity, opportunities to build positive and trusting relationships, and require flexibility from that support. It is hoped that the suggested interventions can offer availability and reliability to caregivers of people with life-limiting conditions.

Appendix 1: CINAHL Search Syntax

Supplementary S1: CINAHL search syntax

S1 (MH "caregiver") OR (MH "caregiver burden") OR (MH "caregiver support")
S2 TI (caring or care*) OR AB (caring or care*)
S3 TI (parent* or relative* or partner* or "significant other*" or husband* or wife* or spouse* or child* or son* or daughter* or friend* or neighbo#r) OR AB (parent* or relative* or partner* or "significant other*" or husband* or wife* or spouse* or child* or son* or daughter* or friend* or neighbo#r)
S4 S1 OR S2 OR S3
S5 (MH "intervention") or (MH "early intervention") or (MH "intervention trials") or (MH "nursing interventions") or (MH "intervention scheme") or (MH "psychotherapeutic") or (MH "psychotherapy") or (MH "program") or (MH "education") or (MH "training") or (MH "support") or (MH "therapy") or (MH "Clinical Trials+") or (MH "Random Assignment") or (MH "Quantitative Studies")
S6 TX clinic* n1 trial*
S7 TX randomi* control* trial*
S8 TX random* allocat*
S9 TX allocat* random*
S10 S5 OR S6 OR S7 OR S8 OR S9
S11 S4 AND S10
S12 (MH "Dementia") OR (MH "Dementia, Multi-Infarct") OR (MH "Dementia, Vascular") OR (MH "Dementia, Senile") OR (MH "Lewy Body Disease") OR (MH "Dementia, Presenile") OR (MH "Frontotemporal Dementia")
S13 TI (dementia or alzheimers or cognitive* impair* or lewy body or vascular dementia or frontotemporal dementia) OR AB (dementia or alzheimers or cognitive* impair* or lewy body or vascular dementia or frontotemporal dementia)
S14 S12 OR S13
S15 (MH "Heart Failure") OR (MH "Pulmonary Heart Disease") OR (MH "Cardiovascular Diseases") OR (MH "Heart Hypertrophy") OR (MH "Myocardial Ischemia") OR (MH "Myocardial Diseases")
S16 TI ("heart failure" or "heart disease" or "pulmonary heart disease" or "cardiovascular disease*" or "heart hypertrophy" or "myocardial ischaemia" or "myocardial disease*") OR AB ("heart failure" or "heart disease" or "pulmonary heart disease" or "cardiovascular disease*" or "heart hypertrophy" or "myocardial ischaemia" or "myocardial disease*")
S17 S15 OR S16
S18 (MH "Stroke") OR (MH "Stroke Patients") OR (MH "Cerebrovascular Disorders")
S19 TI (stroke or "cerebrovascular accident" or cva or "cerebral vascular event" or cve) OR AB (stroke or "cerebrovascular accident" or cva or "cerebral vascular event" or cve)
V4
S20 S18 OR S19
S21 S14 OR S17 OR S20
S22 S11 AND S21 S23 S11 AND S21 (Jan ’15-Dec ’17)

Appendix 2: Trials of Interventions for Caregivers of People with Dementia

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Akkerman and Ostwald, 2004	Psychotherapy	3, 1	HADS, BAI, BDI	Sleep quality	Mood
Agar et al., 2017	case management	1, 0	EOLDS		Care quality
Au, 2015, Au et al., 2015	Psychotherapy +	1, 2	CES-D	RAS, DWSCE	Mood
Barnes et al., 2015	exercise	0, 4		CBI, NPI, QOL-AD, CG AD Coop Study-ADL	n/a
Basu et al., 2015, Graham-Phillips et al., 2016	education / training	1, 4	Perceived health (bespoke)	RMBPC, CES-D, PAOC, ZBI	General health
Beauchamp et al., 2005	education / training	1, 7	Stress (bespoke)	RWOCC (subscale), CSI (subscale), PAOC, CES-D, STAXI, Self-Efficacy (bespoke)	Mood
Blom et al., 2015, Pot et al., 2015	education / training	1, 5	CES-D	HADS, SPPFICS, RMBPC, SSOCQ, PMS	Mood

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Brijoux et al., 2016	education / training	1, 1	SF-12	Biza-D,	General health
Brown et al., 2016	Psychotherapy	0, 7		PSS, AAQ, PMS, SF-36, ZBI, FCI, Salivary cortisol	n/a
Burgio et al., 2003	education / training	0, 6		RMBPC (modified), PAOC, CES-D, LSNI, LTS, DTIS	n/a
Callaghan et al., 2006	case management	1, 3	NPI	PHQ-9, ADCS Resource Use, CG COOPS-ADL	Coping
Chang et al., 2004	Psychotherapy	0, 4		MCS, CAT, BSI, Global health (bespoke)	n/a
Charlesworth et al., 2016	support or alternative	1, 9	SF-12,	EQ-5D, VAS General Health, HADS, ELS, NPI (subscale), PANAS, COPE Index (subscale), PGI, QOPCR	n/a
Chen et al., 2015	education / training	3, 0	RMBPC, CBI, RWOCC		Coping
Cheng et al., 2016, Cheng et al., 2017	Psychotherapy	1, 4	HDRS	ZBI, ROS, PWBS, RSCSE	Mood
Chenoweth et al., 2016	education / training	0, 3		RSFCSE, CHS, SF-12	n/a

Reference	**Intervention Type**	**No. of Outcomes**	**Primary (Caregiver)**	**Secondary or Unspecified**	**Construct Measured (Primary)**
Cheung et al., 2015	education / training	0, 5		CES-D, ZBI, PAOC, RMBPC, Risk Appraisal Measure (bespoke)	n/a
Chien and Lee, 2011	Education or case management	0, 5		WHOQOL-BREF, SSQ6, NPI, FSSI, FCBI	n/a
Chiu et al., 2015	education / training	5, 0	CIFSS, SMS, ZBI, CCS, PSS		Coping
Chodosh et al., 2015	case management	2, 1	ZBI, PHQ-9	CGQOLI	Mood
Chu et al., 2000	case management	0, 4		CES-D, MBC, ZBI, use of social services	n/a
Coon et al., 2003	education/training	5, 1	STAXI (subscales), MAAC (subscales), BDI, WOCC-R, Perceived Health	RSFCSE	Mood
Cooper et al., 2016	Psychotherapy	1, 0	MCTS		Coping
Cristancho-Lacroix et al., 2015	education / training	1, 5	PSS	RSFCSE, ZBI, BDI, RMBPC, NHP	Mood
Danucalov et al., 2017	alternative	0, 4		WHOQOL-BREF, SVS, MAAS, SCS	n/a

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Dias et al., 2008	support +	1, 2	GHQ	ZBI, NPI (subscales)	Mood
Döpp et al., 2015	education / training	0, 3		SOCQ, COPM, DEMQOLI	n/a
Ducharme et al., 2015	education / training	0, 7		PFCS, RSFCSE, SES, PFFNS, CAOMI, SSB, PDI	n/a
Eloniemi-Sulkava et al., 2009	case management +	0, 3		ZBI, BI, NPI	n/a
Farran et al., 2004	education/training	1, 1	CES-D	Behaviour Management Scale-Revised	Mood
Farran et al., 2007	education/training	1, 1	RMPBC	Behaviour Management Scale-Revised	Coping
Farran et al., 2016	exercise	1, 1	CHAMPS (subscale)	SFT (subscales)	General health
Finkel et al., 2007	support +	0, 4		CES-D, RMBPC, CGHHBS, ISSB (subscales)	n/a
Gallagher-Thompson et al., 2015	education / training	2, 0	CES-D, RMBPC		Coping

Reference	**Intervention Type**	**No. of Outcomes**	**Primary (Caregiver)**	**Secondary or Unspecified**	**Construct Measured (Primary)**
Gallagher-Thompson et al., 2007	support +	3, 2	CES-D, PSS, RMBPC (subscale)	SES, SL-ASIA	Coping
Gant et al., 2007	education/training	1, 4	RMBPC	RSCSE, PANAS, TCI, BDI (subscale)	Coping
Gaugler et al., 2016	support	8, 0	GDS, weekly CG tasks, OARS, SSNL, RMBPC (subscales), Role overload, Role captivity, service utilisation		Coping
Gaugler et al., 2015	Psychotherapy	4, 0	CES-D, STAXI, NPI (subscale), RSFCSE		Coping
Gitlin et al., 2003	education/training	0, 8		Objective burden (bespoke), Upset with Memory-Related Behaviours (bespoke), Upset with Disruptive Behaviours (bespoke), Upset with ADL Assistance (bespoke), Upset with IADL Assistance, Perceived Change Index (bespoke), CMI, Task Management Strategy Index (bespoke)	n/a

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Glueckauf et al., 2007	Psychotherapy	6, 0	IS, IFS, ICS, CAI, CES-D, CSES		Coping
Gonyea et al., 2006	support +	2, 0	NPI, ZBI		Mood
Hattink et al., 2015	education / training	3, 4	ADKS, ADS, ATDQ	Burden (bespoke), SSOCQ, IRI, QOL (bespoke)	Disease knowledge
Hebert et al., 2003	education/training	1, 7	RMBPC	ZBI, STAXI, BRAS, IPSI, PES, Desire to institutionalise (bespoke)	Coping
Hepburn et al., 2006	education/training	1, 7	Distress (bespoke)	CSM, ZBI, CES-D, ASS, BACS, DCS, ABS	
Hirano et al., 2016	exercise	1, 4	ZBI	Plasma levels of cortisol, aldosterone and renin, Catecholamines	Mood
Ho et al., 2016	Psychotherapy	0, 6		CSAQ, PSS, CES-D, RSFCB, IOTGPL, FFMQ, Blood collection (biomarkers)	n/a
Huang et al., 2003	education/training	0, 1		AMSE (bespoke)	n/a
Jansen et al., 2011a	case management	4, 3	SOCQ (subscales), Impact of caregiving on	CES-D, SPPIC, SF-36	Coping

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
			personal life (bespoke), Satisfaction with caregiving performance (bespoke), satisfaction with care recipient (bespoke)		
Koivisto et al., 2016	support +	0, 4		GHQ, BDI, 15D, VAS	n/a
Korn et al., 2009	alternative	6, 0	PSS, CES-D, SF-36, QOL-AD, PSQI, PSWQ		Coping
Kuo et al., 2017	education / training	0, 5		CES-D, CMAI, FCI, SF-36, CCM	n/a
Laakkonen et al., 2016	support +	1, 1	SOCQ	PMS	Coping
Lam et al., 2010	case management	3, 1	ZBI, GHQ, PWIFA	Use of Social Support	Mood
Laporte Uribe et al., 2017a, Laporte Uribe et al., 2017b	support +	0, 2		BIZA-D, EQ-5D L	n/a

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Leach et al., 2015	alternative	2,2	AQoL-8D, WebNeuro (subscales)	WebNeuro (subscales), adverse events	Coping
Levy-Storms et al., 2017	education / training	0, 1	Safety survey (bespoke)		Disease knowledge
Llanque et al., 2015	education / training	0, 3		BCS, CCS, CBI (modified)	n/a
Lök and Bademli, 2017	education / training	0, 2		HLBSII, ZBI	n/a
Losada et al., 2015	Psychotherapy	1, 3	CES-D	DTACQ, LTSS, EAICQ	Mood
Mahdavi et al., 2017	alternative	1, 0	CSI		Coping
Marquez-Gonzalez et al., 2007	Psychotherapy	0, 3		CES-D, MBPC, DTACQ	n/a
Marriott et al., 2000	psychological therapy	0, 2		GHQ, BDI	n/a
Mavandadi et al., 2017	case management	2, 0	SF-12, ZBI	RMBPC	Coping

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Moniz-Cook et al., 2008a	Psychotherapy	1, 2	AGPC, HADS, GHQ-30		Coping
Nichols et al., 2017	education / training	1, 0	Annual healthcare expenditure		Financial implications
Nunez-Naveira et al., 2016	education / training	0, 3		CES-D, CCS, RCSC	n/a
Orgeta et al., 2015, Orrell et al., 2017	Psychotherapy	2, 3	EQ5D, SF-12	CES-D, RS	General health
Otero et al., 2015	Psychotherapy	0, 4		CES-D, GHQ-28, ZBI, RSES	n/a
Paller et al., 2015	Psychotherapy	2, 7	QOL-AD, GDS	PSQI, BAI, TMT, RBANS, RMBPC, SF-36, ALDQ	Coping
Prick et al., 2016, Prick et al., 2015	exercise +	1, 3	CES-D	Self-Perceived Pressure from Family Care, salivary cortisol, general health (bespoke)	Mood
Salamizadeh et al., 2017	alternative	1, 0	GSES		Coping

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Seike et al., 2016	education / training	0, 2		ZBI, TMS	n/a
Spector et al., 2015	psychological therapy	0, 3		HADS, QOL-AD, QOPCR	n/a
Steffen, 2000	Psychotherapy	0, 3		CAI, BDI, RSCSE	n/a
Steffen and Gant, 2016	Psychotherapy	2, 3	RMBPC, BDI-II	PANAS (subscale), MAAC-R (subscales), RSCSE (subscales)	Coping
Tanner et al., 2015	case management	1, 4	JHCNA	Objective burden (bespoke), ZBI, GDS, SF-12	Coping
Teri et al., 2005	Psychotherapy	0, 6		CES-D, HDRS, PSS, SFCB, CSQ, SSOCQ	n/a
Thyrian et al., 2017	case management	1, 0	BIZA-D		Mood
Tremont et al., 2008	education/training	2, 5	GDS, ZBI	ADKT, SF-36, FAD, SES, MDSFS	Mood
Tremont et al., 2017, Tremont et al., 2015,	education / training +	4, 4	ZBI, CES-D, RMBPC, Service and healthcare use and cost by PWD and/or CG	FAD, SEQ, PAOC, EQ5D	Coping

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Rodgers et al., 1999a			Questionnaire (bespoke)		
Tyack et al., 2017	alternative	0, 1		QOL-AD	n/a
Van Mierlo et al., 2015	education/training	0, 3		NPI, SSOCQ, EQ5D	n/a
Connor et al., 2008, Duru et al., 2009, Vickrey et al., 2006	case management	1, 9	Impact of intervention on CG costs	BRDSS, presence of a spouse (bespoke), MSFGHS, CDBQ, MOS-SSS, caregiver dementia knowledge (bespoke), UNIMOPB, EQ5D, MBRCCSI	Financial implications
Williams et al., 2016	Psychotherapy	6, 4	STAI, STAXI, PSS, CES-D, CMHS, BP	RSFCSE, PSQI, heart rate, salivary cortisol	Mood
Wilz et al., 2017, Wilz and Soellner, 2016	Psychotherapy	0, 5		CES-D, GBB-24, WHOQOL-BREF, wellbeing (bespoke), perceived health status (bespoke)	n/a
Winter and Gitlin, 2006/2007	support	3, 0	CES-D, ZBI, GTGIS (adapted)		Mood

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Woods et al., 2016	alternative	1, 6	GHQ-28	HADS, RSS, QOPCR, EQ5D-3L, EQVAS, Client Service Receipt Inventory (bespoke)	Mood
Xiao et al., 2016	alternative	1, 2	SSOCQ	SF-36v2, Quality of Care Through Patients Eyes	Coping
Fox et al., 2000, Miller et al., 1999, Newcomer et al., 1999b, Newcomer et al., 1999a, Shelton et al., 2001, Yordi et al., 1997	case management	0, 11		CG Hours Per Week, PRIM CG I/ADL (bespoke), SEC CG I/ADL (bespoke), formal providers assistance (bespoke), Unmet needs for assistance with I/ALD (bespoke), KATZ ADL, TLIADL, ZBI, GDS, Service Utilisation, ZSS (modified)	n/a
Zarit et al., 1987	Psychotherapy+	2, 2	ZBI, BSI	Social support assessment (bespoke), RMBPC	Mood
Zauszniewski et al., 2016,	education / training	0, 3		RS, PSS, CES-D	n/a

Reference	Intervention Type	No. of Outcomes	Primary (Caregiver)	Secondary or Unspecified	Construct Measured (Primary)
Zauszniewski et al., 2015					

Appendix 3: Trials of Interventions for Caregivers of Stroke Survivors

Reference	**Type of Intervention**	**Total Number of Outcomes**	**Primary Outcome(s)**	**Secondary Outcome(s)**	**Construct Measure (Primary)**
ATTEND Collaborative Group, 2017	education/training	0, 6		HADS, CBS, NEADLS, WHOQOL-BREF, EURO-QOL, indirect costs to family (bespoke)	n/a
Askim et al., 2004	support+	0, 1		CSI	n/a
Bakas et al., 2015, Bakas et al., 2016	support+	3, 0	PHQ-9, BCOS, UD (bespoke)		Coping
Bishop et al., 2014	support+	0, 5		FAI, GDS, FAD, PCS, Healthcare utilisation	
Cameron et al., 2015	support+	4, 3	CES-D, PAS, MOSSSS, MS	SKT, CIS, CAS,	Coping
Evans et al., 1988	psychotherapy	0, 3		SCIT, FAD, ESCROW	n/a
Forster et al., 2015	support+	0, 2		CBI, GHQ-12	n/a
Galvin et al., 2011	exercise	0, 1		CSI	n/a
Glass et al., 2004	psychotherapy	0, 2		BI, ISSB	n/a

Reference	Type of Intervention	Total Number of Outcomes	Primary Outcome(s)	Secondary Outcome(s)	Construct Measure (Primary)
Goldberg et al., 1997	case management	0, 4		CES-D, QORAS, OARS-SR, OARS-ER	n/a
Grant et al., 2002	education/training	0, 6		SF-36, SPSI-R, CSQ, CES-D, PFCS, CBS (subscale)	n/a
Hartke and King, 2003	education/training	0, 5		CES-D, UCLA-LS, CCS, BI, PPI	n/a
Hatice İnci and Bayik Temel, 2016	support+	0, 7		F Stressors I, FSI, TRAFSI, SSI, FCCI, FHI, FDI	n/a
Johnston et al., 2007	education/training+	0, 1		SF-36	n/a
Jokel and Meltzer, 2017	support+	0, 1		Spousal questionnaire (bespoke),	n/a
Kalra et al., 2004, Patel et al., 2004	education/training	0, 5	CBS, HADS, BI, FAI, EUROQOL		Coping
Kuo et al., 2016	education/training	0, 4		KOC (Bespoke), AOC, Self-E, BOC	n/a
Larson et al., 2005	education/training	0, 3		LSASATSEQ, QOL VAS (bespoke), EUROQOL	n/a

Reference	Type of Intervention	Total Number of Outcomes	Primary Outcome(s)	Secondary Outcome(s)	Construct Measure (Primary)
Lincoln et al., 2003	support+	0, 2		GHQ-12, CSI	n/a
Lomer and McLellan, 1987	education/training	0, 1		General stroke knowledge and utilised services questionnaire (bespoke)	n/a
Malini, 2015	support+	1, 0	FSSQ		Social support
Mant et al., 1998	education/training	0, 2		CSI, SF-36	n/a
Mant et al., 2000, Mant et al., 2005	support+	0, 6		Stroke knowledge and utilised services questionnaire (bespoke), FAI, GHQ-28, CSI, SF-36, DCOOPC	n/a
Pandian et al., 2015	education/training	0, 5		WHOQOL-BREF, NEQOL, EUROQOL, CBS, HADS	n/a
Pierce et al., 2007, Pierce et al., 2009	support+	0, 2		CES-D, SWLS	n/a
Rodgers et al., 1997	support+	1, 0	GHQ		Mood
Rodgers et al., 1999b	education/training	1, 2	SF-36	GHQ-30, stroke knowledge (bespoke)	General health

Reference	Type of Intervention	Total Number of Outcomes	Primary Outcome(s)	Secondary Outcome(s)	Construct Measure (Primary)
Smith et al., 2004	education/training	1, 2	Knowledge of stroke and stroke services (bespoke)	GHQ-28, Pound Scale (bespoke)	Disease Knowledge
Tielemans et al., 2015	education/training	0, 4		GSES, CSI, HADS, SER-P (subscales)	n/a
van den Berg et al., 2016	exercise	0, 5		HADS, GSES, FSS, C-QOL, ECSI	n/a
Wang et al., 2015	exercise	0, 1		CBS	n/a
Ward et al., 2016	psychotherapy	0, 4		BDI-II, HADSA, HADSD, OCBS	n/a

Appendix 4: Trials of Interventions for Caregivers of People with Heart Failure

Reference	**Type of Intervention**	**No. Of Outcomes**	**Primary Outcome Measure(s)**	**Secondary Outcome Measure(s)**	**Construct Measure (Primary**
Ågren et al., 2015	support+	3, 0	BDI, SF-36, PC		Coping
Bakitas et al., 2017	education/training	0, 5		BCOS, HADS, MBCB, PAOC, PROMIS	n/a
Cossette et al., 2016	support+	0, 2		FCCQ-P, FCCQ-F	n/a
Dunbar et al., 2016	education/training	0, 2		FAD, BDI-II	n/a
Hasanpour-Dehkordi et al., 2016	education/training	1, 0	SF-36		General health
Hu et al., 2016b	support+	1, 2	ZBI	CES-D, SF-36	Mood
Liljeroos et al., 2017	support+	0, 4		ZBI, BDI, CAS, SF-36	n/a
Piette et al., 2015a, Piette et al., 2015b	support+	0, 5		CSI, CG/PWHF relationship (bespoke), CES-D, Health and Retirement Survey (subscales), support given to PWHF (bespoke)	n/a

Reference	Type of Intervention	No. Of Outcomes	Primary Outcome Measure(s)	Secondary Outcome Measure(s)	Construct Measure (Primary
Shahriari et al., 2016	support+	1, 0	PSSQ (bespoke)		Social support
Srisuk et al., 2017	education/training	1, 2	CASR	DHFKS, SF-12	Coping
Stamp et al., 2016	support+ or education/training	0, 1		FAD	n/a

Appendix 5: List of Abbreviations

Abbreviation	**Name of outcome**
AAQ	Acceptance and Action Questionnaire II
ABS	Affect Balance Scale
ADCS	Alzheimer’s Disease Cooperative Study
ADKS	Alzheimer's Disease Knowledge Scale
ADKT	Alzheimer's Disease Knowledge Test
ADL	Secondary caregiver I/ADL
ADS	Alzheimer's Disease Survey
AGPC	Adapted-Gilleard Problem Checklist
ALDQ	Activities of Daily Living Questionnaire
AMSE	Caregiver Agitation Management Self-Efficacy Scale
AQOL-8D	Assessment of QOL
ASS	Anxiety Speilberger Scale
ATDQ	Approaches to Dementia Questionnaire
BACS	Beliefs About Caregiving Scale
BAI	Beck Anxiety Inventory
BAMDQ	Behaviour and Mood Disorder Questionnaire
BBS	Behaviour Bother Scale
BCOS	Bakas Caregiving Outcomes Scale
BCS	Brief COPE Scale
BDI	Beck Depression Inventory
BDI-II	Beck Depression Inventory-II
BI	Barthel Index
BIZA-D	Berlin Inventory of CG Burden with Dementia Patients
BOC	Behaviour of Oral Care questionnaire
BRAS	Bradburn Revised Affect Scale
BRDSS	Blessed Roth Dementia Severity Scale
BSI	Brief Symptom Inventory
CAI	Caregiver Anger Interview
CAOMI	Carers Assessment of Managing Index
CAS	CG Assistance Scale
CASR	Control Attitudes Scale-Revised

Abbreviation	Name of outcome
CAT	Caregiver Appraisal Tool
CBCAS	Communication between CG & SS
CBI	Caregiver Burden Index
CBS	Caregiver Burden Scale
CCM	Caregiver Competence Measure
CCS	CG Competence Scale
CDBQ	California Dementia Behavior Questionnaire
CES-D	Centre for Epidemiological Studies- Depression
CG COOPS-ADL	Alzheimer's Disease Cooperative Study-ADL (CG COOPS-ADL)
CGHHBS	Caregiver Health and Health Behaviour Scale
CGQOLI	CG Quality of Life Instrument
CHAMPS	Community Health Activities Model Program for Seniors
CHS	Caregiving Hassles Scale
CIFSS	Coping Inventory for Stressful Situations
CIS	Carer Impact Scale
CMAI	Cohen-Mansfield Agitation Inventory
CMHS	Cook Medley Hostility Scale
CMI	Caregiver Mastery Index
COPE INDEX	Carers of Older People in Europe Index
COPM	Canadian Occupational Performance Measure
C-QOL	Carer QOL
CSAQ	Caregiver Self-Assessment Questionnaire
CSES	Caregiver Self-Efficacy Scale
CSI	Caregiver Strain Index
CSM	Caregiver Stress Model
CSQ	Caregiver Satisfaction Questionnaire
CSQ	Caregiver Sleep Questionnaire
DCOOPC	Dartmouth Coop Chart
DCS	Decision Conflict Scale
DEMQOLI	Dementia QOL Instrument
DHFKS	Dutch HF Knowledge Scale

Abbreviation	Name of outcome
DTACQ	Dysfunctional Thoughts about CG Questionnaire
DTIS	Morycz desire to institutionalise Scale
DWSCE	Dealing with stressful CG events
EAICQ	Experimental Avoidance in CG Questionnaire
ECSI	Expanded Carer Strain Index
ELS	Emotional Loneliness Scale
EOLDS	End of Life in Dementia Scale
EQ5D	EuroQol EQ5D
EQVAS	EuroQol Visual Analogue Scale
ESCROW	ESCROW profile
F Stressors I	Family Stressors Index
FAD	Family Assessment Device Questionnaire
FAI	Frenchay Activity Index
FCBI	Family Caregiving Burden Inventory
FCCI	Family Coping Coherence Index
FCCQ-F	Family Care Climate Questionnaire-Family
FCCQ-P	Family Care Climate Questionnaire- Patient
FCI	Family Caregiver Inventory
FDI	Family Distress Index
FFMQ	Five Facet Mindfulness Questionnaire
FHI	Family Hardiness Index
FSI	Family Strain Index
FSS	Fatigue Severity Scale
FSSI	Family Support Services Index
FSSQ	Family Systems Strength-Stressor Questionnaire
GBB-24	GieBener Beschwerdebogen
GDS	Geriatric Depression Scale
GHQ	General Health Questionnaire
GHQ-12	General Health Questionnaire-12
GHQ-28	General Health Questionnaire-28
GHQ-30	General Health Questionnaire-30

Abbreviation	Name of outcome
GIS	Gleuckauf's Issue Severity
GSES	General Self-Efficacy Scale
GSKAUSQ	General stroke knowledge and utilised services questionnaire
GTGIS	Gains Through Group Involvement Scale
HADS	Hospital Anxiety and Depression Scale
HDRS	Hamilton Depression Rating Scale
HLBSII	Healthy Lifestyle Behaviour Scale II
ICS	Issue Change Scale
ICTF	indirect costs to family
IFS	Issue Frequency Scale
Index	CG Mastery Index
IOTGPL	Inventory of Traumatic Grief Pre-Loss
IPSI	Ilfeld Psychiatric Symptoms Index
IRI	Interpersonal Reactivity Index
ISS	Issue Severity Scale
ISSB	Inventory of Socially Supportive Behaviours
JHCNA	Johns Hopkins Care Needs Assessment
KATZ ADL	Katz Index of Independence in Activities of Daily Living
LSASATSEQ	Life Situation Among Spouses after the Stroke Event Questionnaire
LSNI	Lubben Social Network Index
LTS	Leisure Time Satisfaction scale
MAAC	Multiple Affect Adjective Checklist
MAACL-R	Multiple Affect Adjective Checklist-Revised
MAAS	Mindful Attention Awareness Scale
MBC	Memory and Behaviour Checklist
MBCB	Montgomery Borgatta CG Burden Scale
MBPC	Memory and Behavioural Problems Checklist
MBRCCSI	Margaret Blenkner Research Center Caregiver Strain Instrument
MCS	Moos Coping Scale
MCTS	Modified Conflict Tactic Scale

Abbreviation	Name of outcome
MDSFS	Multidimensional Scale of Perceived Social Support
MOSARA	Measure of Social and Recreational Activities
MOS-SS	Medical Outcome Study-Social Support Survey
MS	Pearlin Mastery Scale
MSFGHS	MOS Short form general health survey
NEADL	Nottingham Extended ADL
NHP	Nottingham Health Profile
NPI	Neuropsychiatric Index
OARS	Older Americans Resources and Services Scales
OARS-ER	Older Americans Resources and Services Scales- Economic Resources
OARS-SR	Older Americans Resources and Services Scales- Social Resources
OCBS	Oberst CG Burden Scale
PANAS	Positive And Negative Affects Schedule
PAOC	Positive Aspects of Caregiving Scale
PAS	Positive Affect Scale
PC	Perceived Control
PDI	Psychological Distress Index
PES	Personal Efficacy Scale
PFCS	Preparedness for Caregiving Scale
PFFNS	Planning for Future Needs Scale
PGI	Personal Growth Index
PHQ-9	Patient Health Questionnaire-9
PMS	Pearlin Mastery Scale
PMS	Profile of Mood States
PPI	Pressing Problem Index
PROMIS	Patient Reported Outcomes Measurement Information System
PSQI	Pittsburg sleep quality index
PSS	Perceived Stress Scale
PSS	Pound Satisfaction Scale
PSSQ	Perceived Social Support Questionnaire

Abbreviation	Name of outcome
PSWQ	Penn State Worry Questionnaire
PWBS	Psychological Well-Being Scale
PWIFA	Personal Wellbeing Index for Adults
QOCTPE	Quality of Care Through Patients Eyes
QOL	Quality of Life
QOL-AD	Quality of Life in Alzheimer’s Disease
QOLQ	Quality of Life Questionnaire
QOLVAS	Quality Of Life Visual Analogue Scale
QOPCR	Quality of C-P Relationship
QRS-F	Questionnaire on Resources and Stress
RAS	Relationship Assessment Scale
RBANS	Repeatable Battery for the Assessment of Neuropsychological Status
RCSC	Revised Caregiving Satisfaction Scale
RMBPC	Revised Memory and Behavioural Problem Checklist
ROS	Role Overload Scale
RS	Resilience Scale
RSCSE	Revised Scale for Caregiver Self-Efficacy
RSES	Rosenber Self-Esteem Scale
RSFCB	Revised Scale for Caregiver Burden
RSS	Relative Stress Scale
RSS	Revised Stress Scale
RWOCC	Revised Ways of Coping Checklist
SBS	Carer Burden Scale
SCS	Self-Compassion Scales
SELF-E	Family CG Self-Efficacy of Oral Care questionnaire
SEQ	Self-Efficacy Questionnaire
SER-P	SER-Participation subscales
SES	Self-Efficacy Scale
SF-12	Short Form-12
SF-36	Short Form-36
SF-36 V2	Short Form-36 V2

Abbreviation	Name of outcome
SFCB	Screen for Caregiver Burden
SFT	Senior Fitness Test
SK	Stroke Knowledge
SKIT	Stroke Care Information Test
SKT	Stroke Knowledge Test
SL-ASIA	Suinn-Lew Asian Self-Identity Acculturation Scale
SMS	Self-Mastery Scale
SOCQ	Sense of Competence Questionnaire
SPPFICS	Self-Perceived Pressure from Informal Care Scale
SPPIC	Self-Perceived Pressure by Informal Care
SPSI-R	Social Problem-Solving Inventory-Revised
SSNL	Stokes Social Network List
SQ	Spousal Questionnaire
SSB	Socially Supportive Behaviours
SSI	Social Support Index
SSOCQ	Short Sense of Competence Questionnaire
SSQ	Social Support Questionnaire
STAI	State Trait Anxiety Inventory
STAXI	State-Trait Anger Expression Inventory
SVS	Subjective Vitality Scales
SWSL	Satisfaction with Life Scale
TCI	Target Complaints Interview
TLIADL	The Lawton Instrumental Activities of Daily Living Scale
TMS	Temporary Mood Scale
TMT	Trail Making Tests
TRAFSI	The Relative and Friend Support Index
UCLA-LS	UCLA Loneliness Scale
UD	Unhealthy days
UNIMOPB	Unmet needs in management of problematic behaviours
utilisation	Service utilisation
VAS	Visual Analogue Scale

Abbreviation	Name of outcome
Wellbeing	Wellbeing
WHOQOL-BREF	World Health Organization Quality of Life-BREF
WOCC-R	Ways of Coping Checklist- Revised
ZBI	Zarit Burden Interview
ZSS	Zarit Stress Scale

Appendix 6: COREQ Checklist for Reporting Qualitative Studies

No	**Item**	**Guide questions/description**	**Location**
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Data collection section, page 130.
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Data collection section, page 130
3.	Occupation	What was their occupation at the time of the study?	Data collection section, page 130
4.	Gender	Was the researcher male or female?	Data collection section, page 130
5.	Experience and training	What experience or training did the researcher have?	Data collection section, page 130
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Participants section, page 130
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Data collection section, page 131
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator	Validity and reliability section,

		? e.g. *Bias, assumptions, reasons and interests in the research topic*	page 132. Reflexivity section,
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Design section, page 128
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Participant s section, page 129
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Participant s section, page 129
12.	Sample size	How many participants were in the study?	Table 19, page 135
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Findings section page 134
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Findings, table 20, page 136
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Data collection, page 130
16.	Description of sample	What are the important characteristics of the sample? *e.g.*	Finding table 19, page 135

		demographic data, date	
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Data collection table 18
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	no
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Data collection, page 130
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Data collection, page 130
21.	Duration	What was the duration of the interviews or focus group?	Findings, page 20 page 136
22.	Data saturation	Was data saturation discussed?	Findings, Covid impact, page 133
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Data analysis section, page 131
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Data analysis section, page 131
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Figure 5
26.	Derivation of themes	Were themes identified in advance	Data analysis

		or derived from the data?	section, page 131
27.	Software	What software, if applicable, was used to manage the data?	Data analysis page 131
28.	Participant checking	Did participants provide feedback on the findings?	Data analysis, page 131
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g. participant number*	Findings section page 137-150
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Findings section, page 137-150
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Findings section, page 137-150
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Findings section, page 137-150

Appendix 7: GRIPP 2 Short Form for Reporting Patient and Public Involvement

Section and topic	Item	Reported on page No
1: Aim	Report the aim of PPI in the study	114
2: Methods	Provide a clear description of the methods used for PPI in the study	116, 119
3: Study results	Outcomes—Report the results of PPI in the study, including both positive and negative outcomes	132
4: Discussion and conclusions	Outcomes—Comment on the extent to which PPI influenced the study overall. Describe positive and negative effects	148, 151
5: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience	148

PPI=patient and public involvement

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