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Psychosocial Interventions for Caregivers of Individuals with Dementia: A Scoping Review.

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Abstract

Dementia caregivers face increased risk for decreased health, physically, psychologically, and socially. Yet, informal caregivers globally provide the majority of care for people with dementia. While individualised interventions for caregivers have shown positive results, their implementation has been limited. This brings to question what are the content and nature of interventions and also possible barriers that prevent their use. It is therefore important to explore the literature surrounding this topic to determine what evidence there is for current psychosocial interventions for caregivers of individuals living with dementia. A comprehensive search of available literature on psychosocial interventions for dementia carers was conducted through Ebscohost, Google Scholar, Lancet, PubMed, and Wiley Online. A total of nineteen published articles were reviewed and analysed. Eighteen studies (94.7%) were based in high-income countries. Most studies utilised a quantitative methodology (n = 13; 68%) while the others utilised a qualitative (n = 3; 16%) or a mixed-methods approach (n = 3; 16%). Of the interventions utilised, 15 of the 19 studies (79%) incorporated the intervention into a known intervention while four developed a new intervention (21%). The thematic analysis of the data showed themes across the different approaches utilised by the interventions that include psychoeducation, therapeutic, and support. Caregiver burden and depression were the most predominant recorded outcomes across the 19 studies, with other health related aspects also measured, i.e. quality of life, distress, anxiety, self-efficacy, caregiver reaction to problem behaviour, utilisation of resources, and well-being. Caregiver burden was included as an outcome measure in 10 studies (53%), while depression was included as a target intervention measure in nine of the studies (47%). Current research on psychosocial interventions has shown a consistency in content focus. Most studies were conducted in high income countries, were quantitative, used known interventions, included informal caregivers, were professionally administered, and in-person. Comparing psychoeducational and therapeutic interventions, psychoeducational approaches seemed to demonstrate more improvements in outcomes of caregiver burden and depression.

Keywords: Dementia, caregivers, psychosocial interventions, caregiver burden, depression

Chapter 1: Introduction

Study Background

The elderly is a largely growing demographic worldwide. In 2019, there were one billion persons aged 60 and over. This is predicted only to rise, with estimates of 1.4 billion by 2030, followed by 2.1 billion in 2050 (WHO, 2019a). This corresponds to the trend that the World Health Organization (WHO, 2012) hypothesised would see an increase in the senior population from 12% in 2015 to 22% by 2050. Across Africa, the ageing population is growing significantly, estimated at 43 million in 2010 to 74 million in 2020, and predicted to triple by 2050 (He et al., 2020; WHO, 2012). South Africa had the largest elderly population at 5.4 million in 2020, and this is expected to increase over the decades, potentially reaching 12 million elderly persons by 2030 (Statistics South Africa [Stats SA], 2020). The health challenges faced by the elderly are exacerbated by population growth, putting strain on healthcare facilities, and are disproportionally worse for those in low- to middle-income countries (LMICs; Abudu-Birresborn et al., 2019). The age of this population presents them with different needs to the rest of the population, and the way societies are structured needs to adapt to the needs of this growing population.

Across the world, the Universal Declaration of Human Rights directs that acceptable standards of living and security in old age are a fundamental right for each individual (United Nations, 1948). While this standard of living and security is obtained through different means, such as housing, food security, and wealth, healthcare is crucial in the consideration of the elderly population (WHO, 2017). While the elderly encounters the same risk factors as the general population, their age adds risk factors such as a decline in physical abilities, bereavement, a change in socio-economics due to retirement, as well as experiencing multiple conditions at the same time (Pillemer et al., 2016).

Disability-adjusted life years (DALYs) is a measurement tool which expresses the degree of disease burden in populations, and the life years lost because of disability, illness, and premature death (Murray et al., 2012; Sassi, 2006). It is estimated that of the elderly population, over 20% suffer from a mental or neurological disorder (WHO, 2019a). The elderly population is at an increased risk for developing mental health problems such as depression, major or mild neurocognitive disorder (commonly referred to as dementia), substance use, and anxiety disorders (Takeda et al., 2020).

Dementia is a permanent, degenerative condition that is becoming more common among the elderly. The condition places great demands on the patient and necessitates intensive care in almost all facets of daily living. Dementia is commonly known and associated with the elderly population due to its prevalence in affecting people over the age of 60, however, it is not an inevitable part of ageing (Feast et al., 2016). It is, however, a crucial consideration when looking into the care of the elderly, as age is a prevalent risk factor in its development, and dementia is a leading cause in disability and dependency, having a large impact on the DALYs of the elderly population (Avan & Hachinski, 2021). Dementia affects an estimated 55 million individuals worldwide today, and by 2050 that figure is expected to triple (Werner et al., 2017). According to estimates, 60% of individuals with dementia reside in LMICs, and by 2050 that number is anticipated to rise to 71%, yet prevalence data in countries such as South Africa are limited (Avan & Hachinski, 2021). The World Alzheimer's Report (Gauthier et al., 2021) estimated that 55 million people over the age of 60 had some form of mild to major neurocognitive disease, while the South African 2011 census estimated approximately 2.2 million people had some form of dementia (Lehohla, 2015).

Dementia is described as a life-enduring illness once it has developed and is distinguished by the ongoing decline of the cognitive abilities of an individual (Shah, et al., 2016). Memory impairment is both the most noticeable and the most associated symptom of dementia (Lin & Lewis, 2015). Most commonly, the decline in memory starts slowly and is regarded as mild during the onset of dementia. However, over the course of dementia an individual's memory will gradually and continuously decline (Shah et al., 2016), until only the individual's earliest learnt information remains (Shah et al., 2016). While memory loss is the most apparent, other noticeable symptoms in dementia patients include lack of self-control, mood swings, personality changes, and behavioural fluctuations. Many dementia patients also find impairments in reasoning, thinking logically, and problem solving, while some may even experience hallucinations and delusions (Sadock & Sadock., 2007). The needs generated by dementia are the reason that most individuals with dementia require and rely on part- or full-time caregivers.

Informal caregivers, primarily family members, provide for a large portion of the care demands of individuals with dementia. This is estimated to be 40% of the total expense of dementia care demands in high-income countries, and up to a total of 70–90% in LMICs (Organisation for Economic Co-operation and Development [OECD], 2018). The rate of institution-based care versus in-home care differs based on a country's income levels, in that high-income counties have a lower level of in-home care, while lower-income countries have

a majority of in-home care (Wimo, 2018). A qualitative scoping review of caring for individuals with dementia in African countries, specifically Nigeria, South Africa, Egypt, and Tanzania, explored the methods and experience of caregiving. According to this study, the majority of carers are unpaid volunteers with limited education, no formal training, and a lack of support systems (Adedeji et al., 2022).

Dementia caregivers have an increased risk of adverse mental health affects (Ma et al., 2018). The overwhelming effects of caring for someone with dementia and the significance of proper support have been emphasised by the World Health Organization (WHO, 2012). Caring for individuals living with a neurological disorder is a significant stressor for caregivers and can affect caregivers' mental health, overall well-being, and ability to cope (Pirraglia et al., 2005). Studies such as those of Flaskerud and Lee (2001), Sörensen and Conwell (2011), and Kate and colleagues (2013) have explored the predictors of burden among caregivers across socio-economic statuses (SES).

The available research shows a diverse range of reasons for becoming a caregiver of an individual with dementia. People are motivated through factors such as gender roles, housing situations, socio-economic resources, and cultural and individual expectations (Erol et al., 2016). The study indicates that caregivers responded from a place of limited choice, to no choice, to take up the role of caregiving for their family member or loved one. These results also indicated other motivations for becoming a caregiver, such as the individual's wanting to protect the person, the desire to repay caring or love received in childhood, or as part of their role in a partnership, such as caring for a spouse (Erol et al., 2016). However, Doris and colleagues (2018) emphasised positive aspects of understanding a person's motivation to care, such as their personal sense of accomplishment, purpose and growth, improved family relations, and feelings of empathy in a relationship. While many circumstances may result in one becoming a caregiver, it is evident that individuals have different personal responses to the situation.

Fundamentally, many people volunteer to become an informal carer for a loved one. Due to the way in which dementia progresses, their role requirements increase over time, which increases the carer's overall burden and likelihood of developing health problems (Bullock, 2004). The informal caregiver's role results in challenges across various aspects, such as social, financial, physiological, and psychological health, yet across these areas mental health has a vital overall impact (Gilhooly et al., 2016). Within informal caregiving, studies showing that the high demand in dementia caregiving, such as longer hours required in a day and more daily activities requiring a caregiver's assistance, result in overall worse mental health indicators for

caregivers of those with dementia (Karg et al., 2018). The demands of caregiving have an increased risk of reported perceived burden, decreased quality of life (QoL), and an increase in levels of depression and anxiety symptoms. Ultimately, dementia caregiving results in some of the greatest impact on mental health (Karg et al., 2018; Kate et al., 2013). The health and well-being of caregivers is a vital consideration, and the successful implementation and use of psychosocial interventions aimed at caregivers' mental health is an essential part of dementia and caregiving research.

There are a number of studies available on psychosocial interventions for dementia carers, however, a gap is evident in their implementation. Studies, such as that by Gitlin and colleagues (2015), have shown as few as 3% of interventions proven to be effective progressed to translational stages necessary for their implementation. The study by Collins and colleagues (2011) explored factors which have contributed to the limited availability of interventions for mental health conditions worldwide, noting three contributing factors: a lack of understanding of mental health conditions, uneven distribution of resources across countries, and inaccessibility to healthcare. Numerous interventions are being developed and studied, and a focused understanding of what is available, beneficial, and the implementation thereof is vital to caregiver's mental healthcare.

Outline of Research Problem

In light of the background above, dementia is a chronic, progressive illness with an ever-increasing prevalence across a growing population group. The demands of the illness are high and require a large amount of care across most aspects of daily life. Dementia primarily affects the cognitive domains of learning and memory, language, complex attention, executive function, perceptual-motor abilities, and social cognition. Yet individuals with dementia worldwide most commonly receive their daily care from informal carers. According to the 2018 World Alzheimer Report, 60% of the global dementia population resides within LMICs, and an estimate of 60% to 96% reside and receive their care at home (Wimo et al., 2018). Dementia caregivers face higher risks for decreased QoL due to the demands of providing care for dementia patients. The burden of caregiving has evidently caused significant negative impacts on psychosocial outcomes, including decreasing the carer's QoL as well as causing psychological distress such as depression, anxiety, or drug use (Yu et al., 2015).

While individualised interventions for caregivers have shown positive results and the ability to adapt to varying cultural and educational backgrounds in research settings, their implementation on a broad scale is limited. This brings to question what the barriers are that

prevent their use. It is therefore important to explore the literature surrounding this topic in order to determine what evidence there is for current psychosocial interventions for the caregivers of individuals with dementia.

Research Aim

This study aims to explore psychosocial interventions which have been developed for caregivers of individuals living with dementia to inform the current content and nature of interventions in guiding future interventions and research in this field. The research will accomplish this by first exploring the content of current research focused on psychosocial interventions for caregivers of the elderly living with dementia. This will be followed by identifying the psychosocial interventions methods of delivery, and will then work to identify the outcomes of the psychosocial interventions among carers.

Research Objectives

- To explore the current content focus of psychosocial intervention research for caregivers of individuals living with dementia.
- To identify the methods of delivery utilised in the psychosocial interventions for caregivers of individuals living with dementia.
- To identify the outcomes of the psychosocial interventions for caregivers of individuals living dementia.

Research Questions

- What is the current content focus of psychosocial intervention research for caregivers of individuals living with dementia?
- What are the methods of delivery utilised in the psychosocial interventions for caregivers of individuals living with dementia?
- What are the outcomes of the psychosocial interventions for caregivers of individuals living dementia?

Chapter 2: Literature Review

Introduction

The goal of this chapter is to provide a brief overview of the body of research on the subject of psychosocial interventions for dementia caregivers as background to the in depth review that the study will focus on. The research scope touches on a variety of important factors, each of which will be important to review to guide the research further. Relevant literature on the following areas are vital to this study and will be discussed, namely, the ageing population and challenges faced by this population, a conceptualisation of dementia and its prevalence, dementia caregiving and the associated environments, the reason people become caregivers, and a conceptualisation of psychosocial interventions.

The Ageing Population

In looking at the global population, the elderly are a growing demographic. The term 'population ageing' describes the phenomenon universally experienced in which the elderly population is taking up a larger portion of the global population. This phenomenon is hypothesised to be due to lowered fertility rates and increased life expectancies, and to become a global health challenge (Chang et al., 2019; Suzman et al., 2015). The Alzheimer's Disease International Report shows that life expectancies have increased due to advancements and improvements in nutrition, sanitation and hygiene, healthcare, medication, and education (Gauthier et al., 2021). Studies further hypothesise that as development continues in all these spheres, more people worldwide will have increased life expectancies, and population ageing will continue (Chang et al., 2019). However, due to their advanced age, the elderly population poses a new set of complications, and population ageing has been classified as a global health challenge (Suzman et al., 2015).

Despite ageing being a fundamental biological process, the concept of an individual's age, and more so, ageing, is understood through socially determined ideas (Ameh et al., 2014; Mortimer et al., 2016). There is no universal understanding of what clearly defines someone as elderly. In the human body, the biological process of ageing is defined by a gradual increase in molecular collapse and cellular damage over time, which the body is unable to repair since its physiological capacity is at its maximum (Clegg et al., 2013; WHO, 2019a). While many countries acknowledge those aged 65 and older as elderly, the reality of this definition is

challenged by the individual's functionality, QoL, and environmental context in terms of life expectancies (Sabharwal et al., 2015). According to literature from the United Nations (2012), definition of the category of elderly includes several facets and is frequently adjusted for influential factors like chronology, social role dynamics, and changes in capabilities. According to Stats SA (Maluleke, 2023), in South Africa the term 'elderly' refers to persons 60 years of age and older.

Age-related issues are becoming increasingly prevalent worldwide. There were one billion persons aged 60 and over in 2019. Estimates have been made that by 2030 this will reach 1.4 billion, followed by an increase to 2.1 billion by 2050 (WHO, 2019b). The numbers presented correspond to the trend that WHO (2012) hypothesised would see an increase in the senior population from 12% in 2015 to 22% by 2050. This increase is considered a potential global health challenge due to the socio-economic and health challenges it will cause worldwide, and which will be disproportionally worse in LMICs (Parra et al., 2019). South Africa has one of the African continent's fastest ageing populations (Stats SA, 2020). The African Union Charter makes specific reference to the elderly population and has provisions on protecting the rights of the elderly (African Union, 2003). However, despite the efforts made by the Union, there is continued inequality, discrimination, and violations of the rights of the elderly population in Africa (Frisoli, 2016). The elderly are at increased risk of illnesses and non-communicable diseases such as dementia, and understanding this population is essential in order provide the correct support and care.

Prevalence of Dementia

The phenomenon of population ageing is having a notable effect in increasing the prevalence of dementia cases worldwide (WHO, 2022). While ageing does not necessarily guarantee the development of dementia, age is a significant risk factor for developing dementia. The current available data on the prevalence of dementia estimates that 55 million individuals have a form of dementia, and this estimate is expected to triple by 2050 (Gauthier et al., 2021; Werner et al., 2017). In addition, 60% of individuals with dementia are estimated to reside within LMICs and this percentage is similarly estimated to increase by 2050 to 71% (Avan & Hachinski, 2012). According to estimates from the 2011 census, 2.2 million South Africans suffer from dementia (Lehohla, 2015). Yet, while the estimates demonstrate elevated numbers within LMICs, prevalence data within LMICs is limited and outdated (Avan & Hachinski, 2012).

However, studies have shown that individuals can reduce their risk of developing dementia through a healthy lifestyle such as improved nutrition, avoiding smoking and drinking, remaining physically active, managing health concerns such as hearing loss, diabetes or depression, and improving general education on these topics (Livingston et al., 2017). Therefore, with measurable and accessible preventative interventions for dementia, policymakers and healthcare must be involved and work towards promoting prevention and overall well-being.

In response to the WHO's publication about making dementia a significant aspect of public health considerations, three unique concepts within the topic have emerged from countries' policies, namely dementia friendly, dementia capable, and dementia positive (Lin & Lewis, 2015). This study sought to compare and contrast these concepts through a review of the national dementia plans from 13 different developed countries, as they appear and are used by different governments. Further recommendations on their findings for policy, research, and practice were made. In participating in research on dementia, understanding and exploring such information is essential to guide the research. It provides insight into the impact of the WHO's publication discussed in the article, into policy being founded in different countries, and the resulting impact of these policies and concepts on future research.

In addition, the study by Shah and colleagues (2016) sought to understand the priorities around reducing the burden of dementia and to use this to guide future research, and in turn, policies and funding. The main research priorities were separated by completing a globally representative research priority and analysing 863 research questions from 201 participants. The primary priorities highlighted were related to prevention, identification and risk reduction, and quality of care for persons with dementia and their caregivers. In contrast, priorities highlighted as secondary were diagnosis, biomarkers, treatment, disease mechanisms, and public awareness (Shah et al., 2016). This information provides a practical understanding of future-focused priorities in dementia burden reduction. These priorities affect and guide dementia carers and are crucial to understand their impact and bearing on caregivers.

Conceptualising Dementia

Dementia is a chronic illness which is characterised by the steady decline in a person's cognitive abilities (Shah et al., 2016). The most prominent symptom of dementia is memory impairment. The decline in memory is typically slight in the early stages of dementia, however, as the condition continues to develop over time, the individual's memory will worsen to the point of only retaining their earliest gained information (Shah et al., 2016). While memory loss

is the most obvious, other symptoms are present such as poor impulse control, mood disturbances, personality and behaviour changes, and impaired reason, logic, and problem solving (Lin & Lewis, 2015; Sadock & Sadock, 2007). Some dementia sufferers may even experience hallucinations and delusions (Sadock & Sadock, 2007).

There are various types of dementia. The American Psychiatric Association (APA) and World Health Organization maintain that dementia is an acquired rather than developmental disorder that can be diagnosed through quantifiable cognitive deterioration measured in an individual (APA, 2013; Duthey, 2013; WHO, 2019b; WHO 2022).

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) has moved away from the term dementia and has adopted the term major neurocognitive disorder (MND; APA, 2013). The DSM-5 diagnostic criteria for MND encapsulate four criteria (APA, 2013). The first symptom is a marked reduction in performance from a previous level in one or more cognitive domains. The second is that the cognitive impairments make it difficult for a person to be independent in daily tasks. The last two criteria are that the deficits do not occur exclusively in the context of a delirium and that another disorder does not better explain the deficits. The DSM-5 further allows specifications of what the MND may be due to, the most common being Alzheimer's disease (Blazer, 2013).

According to the WHO (2019) classifications, there are various types of dementia with the primary dementias being Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia. Mixed dementia is also common, in which the individual has features of more than one type of dementia. The secondary types of dementia are those caused by, or somehow related to, another disease such as HIV, head injury, multiple sclerosis, thyroid disease, or vitamin B deficiency. While secondary types of dementia still present with the prominent symptom of impaired cognitive function and memory, the individual also suffers from other symptoms and their treatment is usually focused on the underlying cause (WHO, 2019b).

The risk factors for dementia are widely studied, and there is evidence for various risk factors. There are fundamental, non-modifiable risk factors for dementia, including genetics and family history, gender, age, and race (Arvanitakis et al., 2019). While age is seen as the leading risk factor, dementia is not an inevitability of ageing. More recent studies of the disease have shown the impact of modifiable risk factors for the disease, such as a diet, alcohol consumption, smoking, and physical activity. These studies have indicated that physical inactivity, tobacco smoking, excessive consumption of alcohol, and an unhealthy diet have an impact on increasing an individual's risk of developing dementia. For example, Bianchetti and

colleagues (2020) demonstrated that there are nine factors which increase the risk for dementia that potentially can be changed and prevented. These are physical inactivity, smoking, diabetes, obesity, hypertension, lower education levels, hearing impairment, and lower levels of social contact. This study added three more potentially modifiable risk factors to the list, namely: excessive consumption of alcohol, traumatic brain injury, and polluted air. This advancement in knowledge gives potential to risk factor reduction and intervention in the ever-increasing numbers of dementia cases.

When defining dementia, the APA emphasised the aspect of dementia being an acquired condition, which has been supported by the WHO (2021). The definitions presented demonstrate that dementia is a syndrome that can be identified by measured, cognitive deterioration rather than being understood as a linear, biological disorder (Duthey, 2013). It is therefore vital to consider the large variety of factors at play in dementia, and its course, when considering preventative interventions.

The experimental research design by Takeda and colleagues (2020) considered the effects of an intervention program which encouraged elderly individuals to participate in the management of their lifestyle in an attempt to reduce risk factors associated with cognitive decline. The study used the Geriatric Depression Scale (GDS) and Philadelphia Geriatric Centre Morale Scale (PGC) assessment tools. The study highlighted the associated risks of depression in the elderly, and the risk factor of depression on cognitive decline and the development of dementia (Takeda et al., 2020). This look into risk factors and assessing interventions in the elderly population shows the connection between dementia risk factors and further decline. Similarly, it emphasised the resulting importance of intervention and management of individuals with dementia to reduce dementia risk factors and further decline.

Dementia Caregiving

Being a caregiver comes with high levels of responsibility and resulting strain. The burden of caregiving incorporates elements such as decreased social, emotional, physical, and financial well-being. Studies such as Bullock (2004), Springate and Tremont (2014), and Van der Lee and colleagues (2014) emphasise the importance of minimising this burden's impact on the caregiver's mental health. The minimisation of caregiver burden and protecting the mental health of carers, simultaneously works to protect the individual receiving care (Van der Lee et al., 2014). Van der Lee and colleagues (2014) broadly reviewed models of caregiver burden while Bullock's (2004) review explores studies which utilise pharmacological interventions to increase the individual's cognitive and behavioural functioning. The reviews

similarly explore how better care and wellness of the patient has a positive mental health impact on the caregiver, which improves the long-term well-being of the individual with dementia. Understanding this relationship and the resulting cycle can inform interventions and the needs of carers and their recipients.

However, when considering caregiving for individuals with dementia and the concept of caregiver burden, as a control it is essential to compare caregivers' experiences against those not in a caregiving role. A quantitative review by Ma and colleagues (2018) compared literature regarding the mental health of dementia carers to those who are not caregivers. From the 18 studies reviewed, the study compared their experience of depression, anxiety, and psychological distress and showed the difference between these caregivers' lower reported mental health to that of the general population. A further review of literature by Sörensen and Conwell (2011) touched on multiple areas of caregiving and the caregiving experience. It explored caregiving costs, stressors, caregiving stress impact mediators, interventions available, and current gaps and problems in caregiver research. The findings about caregivers' mental, physical, and socio-economic health from these reviews highlight the risk to caregivers and, in turn, promote the importance of interventions and support.

Institution versus Home Care

In general, South Africa's healthcare system is facing multiple challenges that impede effective healthcare delivery to the population. The history and effect of Apartheid in South Africa can still be seen in the current socio-economic distributions, poverty, low education and unemployment (Foxcroft, 2004). These conditions cannot be ignored when considering South Africa's healthcare challenges. There are three fundamental challenges to consider when looking at South Africa's healthcare: financial challenges, supply challenges, and limited human resources (Coovadia et al., 2009; Maphumulo et al., 2019). Financial limitations lead to insufficient coverage of service costs, and healthcare providers are unable to provide sufficient or prolonged treatment (Coovadia et al., 2009). In the case of dementia care, this is seen in the limited available healthcare facilities for the elderly. Supply challenges are seen in the limited availability of clinical equipment and medications due to financial constraints and other challenges such as supply chains and delivery to remote or rural areas (Maphumulo et al., 2019). As a result, those in need may not receive adequate assessments, diagnoses, or medications for their conditions.

The third challenge is limited human resources within the South African healthcare context. A lack of human resources means an insufficient number of healthcare clinicians

benchmarked against the number of people living in South Africa. The World Health Organisation Global Health Observatory Data Repository (WHO, 2019c) keeps a detailed track of the number of healthcare professionals available within a country. In South Africa in 2019, there were 7.8 medical doctors per 10 000 people compared to a developed country such as the United Kingdom, which had 29.0 medical doctors per 10 000 people. In mental healthcare, there was a total of 1.5 psychiatrists per 100 000 people in South Africa in 2017, as opposed to the United States of America with 10.5 per 100 000. From this data, it is clear that there are not enough healthcare workers to provide the care that individuals need on a day-to-day basis.

Facilities intended for senior citizens, such as retirement homes or assisted care living spaces, are a common strategy for providing the care needed for the elderly. However, Makiwane and colleagues (2004), argued that such facilities within a South African context are outdated and employ inappropriate approaches. In this report from rural Mpumalanga, three concepts were focused on: ten essential socio-economic needs, the services available in the community to address the needs, and to recommend approaches by which the needs can be satisfied (Makiwane et al., 2004). While data from rural regions of South Africa is limited, similar findings were reported in the 2017 study conducted in Gauteng (Makiwane et al., 2022). The studies indicate that elderly care is informed mostly by western approaches in a South African community, such as old age care homes and facilities, rather than African approaches such as community-based care. The findings of these studies indicate that in a South African context more community or group-based care is needed.

In South Africa, the guidelines on aged care focus on ageing in the community setting rather than an institutionalised setting due to the high costs of institutionalised aged care (Kelly et al., 2019). While these policies could work for the cultural and socio-economic demands of the elderly in South Africa, currently, there are few resources available to address the health requirements of the elderly in communal settings. The South African elderly population relies heavily on free public healthcare as a limited number (23,3% in 2021; Maluleke, 2023), are members of medical aid schemes. Thus, access to healthcare is determined by the features of the individual seeking care, as well as the features of the healthcare system. Unfortunately, the elderly living in rural, community-based settings faces the largest of these challenges in accessing healthcare (Kowal et al., 2012).

Characteristics of the healthcare system which determine accessibility are elements such as the accessibility of medical apparatus, medications, medical professionals, as well as the implemented policies and processes (Hawthorne & Kwan, 2013). Studies of the public healthcare sector, such as Tsoka and Le Sueur (2004), show the many challenges that people

of all ages face when trying to access healthcare. South African healthcare systems are confronted with a lack of medical professionals, a lack of leadership, and a lack of resources. While South African policies look at community-based care approaches for the elderly, the healthcare systems are not prepared or structured to handle this approach appropriately. Kelly and colleagues' (2019) study recruited nine focus groups with a total of 64 participants, and compared the experiences of the elderly within high-income communities to those from low-income communities in South Africa. While those in high-income settings had few challenges receiving care, those in low-income settings faced multiple challenges and showed high mistrust of the healthcare system. These fundamental differences in experience within the same country show the discrepancies in how healthcare is being handled, and guide the research in considering community-driven approaches and interventions. These failures within the characteristics of the South African healthcare system have led to minimal accessibility of healthcare to all South Africans, not only the elderly.

However, over and above the limited characteristics of the elderly individual trying to access quality healthcare, these system failures result in the unmet health needs of the elderly. Individual characteristics which would assist an individual in receiving healthcare include finances, social capital, education levels, physical ability, and cognitive function (Carpentieri et al., 2020). Decreased physical and cognitive function is synonymous with ageing and is an undeniable challenge the elderly face. However, in South Africa as a low- to middle-income country, these challenges for the elderly are exacerbated by specific difficulties. Those with decreased mobility may have increased difficulties with transportation to clinics or hospitals, especially in more rural settings, (Tanser et al., 2006). Due to limited staff and mismanagement within the public healthcare systems, long waiting periods pose a significant challenge for the elderly. Similarly, many people living in South Africa face the challenge of having never been formally employed, living from month to month, and not having a self-funded pension fund (Tanser et al., 2006). Thus, most elderly patients would not be able to afford private healthcare and rely entirely on public healthcare and the care received from family members.

Reasons for Caregiving

It is clear that the duties of the family carer are crucial with regard to the management of dementia and require further understanding. A family carer is classified as someone, whether spouse, child, friend, or volunteer, who assists a sick relative through voluntary services (Eifert et al., 2015). The systematic review by Doris and colleagues (2018) sought to understand why and how caregivers experience the benefits of providing dementia care caring for a family

member. From 41 articles reviewed, the study explains four main aspects of positive family caregiving experiences: personal accomplishment, feeling they are supporting or fulfilling their role in a dual relationship, maintaining or bettering family functioning, and a personal sense of purpose. The discussions further posit the improvement of caregiver burden through developing and maintaining the positive experiences of caregiving (Doris et al., 2018; Kate et al., 2013). This take on positive experience and its role guides the understanding of caregivers' motivations and engagement in further caregiving activities and builds an understanding of optimising the caregiving experience.

As with many roles in healthcare, caregiving can be a gratifying job. Dementia is a growing concern globally, and the need for caregivers for individuals with dementia will grow. While most of the published research centres around caregiver burden and the adverse impact of caregiving, it remains vital to consider the positive to understand this role and the implications of family caregiving. (Carpenter et al., 2002). It is these experiences that will guide understanding of positive coping mechanisms and the resultant development of practical psychosocial interventions.

In exploring the literature on the positive caregiving experience, a study by Bauer and colleagues (2012) shows caregivers reporting increased self-confidence and inner strength and maturity. Statements from the study about the rewards of caregiving included: 'gratitude and affection from the patient', 'recognition and compassion', 'gladness and gratitude about treatment progression and healthy phases', and 'intensification of relationship with the patient'. Positive caregiving experiences as a coping mechanism imply that the caregiver relies on the good moments and successes to get them through the more challenging or stressful times. Bauer and colleagues (2012) demonstrated a unique insight into the rewarding and more positive caregiving experiences and what factors keep caregivers in this role. These themes correlate with Doris and colleagues' (2018) findings above, as well as findings in other studies on the topic (Carpenter et al., 2002). These results show the shared experience of caregivers across many capacities and illnesses and speak to caregivers' continued implications and coping skills.

In conceptualising and defining the topic of reward or the positive experience of caregiving, literature often turns to the concept of quality of life (QoL). The term QoL incorporates two factors, which are having the means to live a good life, and living a good life (Haraldstad et al., 2019). While such ideas are relatively subjective, a subset of understanding 'life-satisfaction' works to indicate the individual's apparent QoL through indications of physical and mental health, and the individual's experience of life satisfaction. In research conducted by Adelman and colleagues (2014) and Caldeira and colleagues (2017), caregivers'

life satisfaction regarding the amount of burden the caregiver had perceived was documented. Ultimately, life satisfaction is higher if the caregiver perceives less burden in their role, or lower if the amount of burden they perceive is higher (Fianco et al., 2015). The correlation between satisfaction and burden is fundamental in understanding the caregiver's experience, the impact of their role as a caregiver, and their subjective positive or negative experiences.

Impact of Caregiving

Deciding to become a caregiver can alter your life entirely. Adjusting to this new role and responsibilities can be an ongoing process for some, and the challenges require that the caregiver learns practical coping skills to get them through. Being a caregiver is a constantly changing role and frequently arouses emotional responses (Cantekin et al., 2016). In the WHO's (2012) report on dementia, the impact of caring for individuals with dementia was highlighted, and an emphasis was made on caregiver support. A concept of *caregiver burden* has been developing in literature over the years, although the definition and measurement of caregiver burden are currently inconsistent (Adelman et al., 2014). Currently, literature shows that when the demands of caregiving outweigh the caregiver's available resources and personal capacity to cope, caregiver burden may result (Chen et al., 2015). Chen and colleagues (2015) define caregiver burden as a multifaceted concept that shows the effects that providing care has on a caregiver's physiological, social, psychological, and financial aspects of life. These elements speak to the commonly considered concept of the QoL of an individual, and specifically in caregiving, how the QoL for both the caregiver and the care receiver is affected (Chen et al., 2015).

To consider the caregiver's QoL, the concept of caregiver burden is crucial in its development from feelings of distress and the inability of the caregiver to cope with the demands and strains of their roles and responsibility (Wiegelmann et al., 2021). Coping is conceptualised as the ability of the individual to adapt to and manage a stressful situation (Wiegelmann et al., 2021). Caregivers may endure significant physical, social, and emotional challenges through the continuous and intensive care they provide for the unwell individual and are prone to experience caregiver burden when there is insufficient social, familial, and governmental assistance (Adelman et al., 2014). The caregiver's experience of burden and how they evaluate their experiences have an impact on how they handle both providing care for the individual and in seeking assistance for themselves.

Further, certain risk factors can influence the chances of caregiver burden developing. The risk factors to caregiver burden are the caregiver's gender, with the female sex being more

at risk, lower levels of education, living with the individual in need of care, length of time spent caring per day, depression, social isolation, socio-economics, and their choice in becoming a caregiver (Adelman et al., 2014). If efficient coping strategies and interventions for caregivers were readily available, the caregiver could develop positive ways to handle their stress and ultimately reduce the burden they experience daily (Adelman et al., 2014). Caregivers are a crucial extension of the healthcare system, and understanding the risks and burden they face is vital to the development of interventions to improve their experience and ultimate continuation in their role.

While the study by Pirraglia and colleagues (2005) focused on caregivers of individuals with HIV, it was utilised for its informative look at the correlation between depression and caregiver burden. This cross-sectional study looked at 176 dyads of HIV patients and their informal caregivers, which utilised two assessment tools, the Beck Depression Inventory and the Caregiver Strain Index, and found a strong correlation between high caregiver burden and depression. Specifically, this correlation was notably high when the caregiver had more challenges or complications in their own life. This association between depression and burden, and the link to external life circumstances, guide the understanding of interventions and assistance caregivers may come to need.

In taking on the role of a caregiver for an individual with any illness, especially a mental illness, the caregiver may face stigma and prejudice around the presenting illness. Spittel and colleagues' (2019) study of individuals' perceptions reported that almost all illnesses associated with mental health, such as dementia, had a degree of stigma attached. Within South African communities, studies on attitudes, knowledge, and beliefs around dementia have shown continued stigmatisation and discrimination against those with dementia, with different beliefs around dementia being a myth or associated with witchcraft or spirituality (Borochowitz, 2011; Khonje et al., 2015; van Wezel et al., 2018). The negative appraisals the caregiver may face often results in distress or social isolation, which as a result reduces the physiological and psychological health of the caregiver (Tan et al., 2012). In considering these negative factors that caregivers may have to face, it speaks to the importance of the availability of support for the carer in order to protect their health.

Conceptualising Psychosocial Interventions

Psychosocial interventions are considered a non-pharmacological approach to treating individuals' mental health that concentrate rather on elements pertaining to psychology and social health (Walker, 2015). These interventions aim to improve the caregiver experience

through alleviating symptoms, increasing functionality, QoL, and the social inclusion of the individual. In addition, the aspect of a holistic approach to personal recovery, wherein living a gratifying and valued life is prioritised, is fundamental to psychosocial interventions (Asher et al., 2017). While psychosocial interventions are intended to be typically, administered by mental health professionals, the lack of accessibility and low number of professionals in some areas lead to their administration by non-specialists (Keynejad et al., 2018). This can be in the form of nurses, with or without specific training, lay-counsellors, or peer support workers.

Some studies have divided psychosocial interventions into subgroups in order to understand their effectiveness and availability as well as their specific evidence around the needs of varying socio-demographics (Dickinson et al., 2017). The most recognisable factors apparent in available literature are age, gender relation, family relation, housing situations, profession, ethnicity, and social environment (Wiegelmann et al., 2021). These factors show how the subgroup definitions have provided a more effective insight to interventions rather than looking at interventions in a broader, more general context.

The available literature shows an array of psychosocial interventions which have been developed and researched for their effectiveness in improving various mental health problems encountered by dementia caregivers. A study by Wiegelmann and colleagues (2021) systematically reviewed 48 published research studies within which 46 unique interventions were examined. Other published reviews have similarly demonstrated the development and research into the development of psychosocial interventions for dementia carers, reviewing between 14 to 40 unique interventions (Brodaty et al., 2003; Cooke et al., 2001; Laver et al., 2017; Tang et al., 2016). The reviews draw similar conclusions about the impact and resultant outcomes of the interventions reviewed, stating that intervention programmes show benefits and improvements in various mental health aspects of dementia caregivers' lives. However, these reviews similarly all conclude that there is a lack of robust, empirical evidence for the positive outcome effects of the intervention. The studies recommend further research in this field, such as studies with longer follow-up periods, larger sample sizes, exploring improvements in administration of interventions, and studies with robust systematic approaches to develop the understanding of intervention efficacy (Brodaty et al., 2003; Cooke et al., 2001; Laver et al., 2017; Tang et al., 2016; Wiegelmann et al., 2021).

The psychosocial interventions being developed and explored show variety within their content and their administration procedures. Yet, similarities can be drawn in the fundamental aspects of the intervention approach. The interventions have shown a tendency to incorporate elements of approaching support such as providing an education on topics such as dementia

and caregiving, supporting the caregiver, improving problem solving skills, and general or caregiver skills training (Cheng et al., 2019; Kales et al., 2015). Interventions also tend to be categorised in accordance with the principal concepts they apply in the development and implementation of the intervention. Categories commonly utilised are psychoeducation interventions, psychotherapy or counselling interventions, support interventions, physical interventions, and multicomponent interventions (Laver et al., 2017, Wiegelmann et al., 2021).

Conclusion

In the exploration and review of the broader literature, this chapter discussed the ageing population and challenges faced by this population, a conceptualisation of dementia and its prevalence, dementia caregiving and the associated environments, the reason people become caregivers, and a conceptualisation of psychosocial interventions. In this discussion, it has given an overview of the experience of caregiving for individuals with dementia, and the limits to psychosocial interventions available. By expanding on this field of knowledge, the understanding of psychosocial interventions can be expanded and can contribute to their effective implementation.

In the next chapter, a detailed exploration of the scoping review methodology will be discussed. This will include a discussion of the specific scoping review design and objectives of the study, the scoping review methodology, the search strategy utilised, the selection criteria, the data charting process, and the data analysis process. Further, the ethical considerations of the study will be explored.

Chapter 3: Research Methodology

Introduction

In the following chapter, a detailed exploration of the chosen methodology will be discussed. In detailing how, the review will be performed, the scoping review method will be described. This will include a discussion of the specific scoping review design and objectives of the study, the scoping review methodology, the search strategy utilised, the proposed selection criteria, the data charting process, and the data analysis process. Further, the ethical considerations of the study will be explored.

Research Methodology

Review Design and Objectives

The scoping review design has become increasingly popular due to the need to advance practice and research by evaluating available data (Colquhoun et al., 2014). Scoping reviews are used to integrate the available data surrounding a field and can be used to map the data according to found, specified characteristics (Peters et al., 2015). In conducting a scoping review, the purpose is to identify fundamental topics within literature surrounding a specific field, explore the methods utilised within the field, and analyse trends and or gaps within this literature (Munn et al., 2018). Therefore, scoping reviews offer a means to clarify working definitions as well as the conceptual boundaries of, a specific topic, field, or discipline. In considering psychosocial interventions, accurate and valuable recommendations would not be possible without a thorough or transparent summation of their effectiveness and present availability. Therefore, the research objectives of this review are to identify evidence of psychosocial interventions aimed at dementia carers and to identify further recommendations on knowledge gaps and future needs in the research.

In conceptualising this research, it is important to also consider the systematic review as a methodological approach. The study by Munn et al. (2018) compares the two approaches and guides researchers as to which methodology aligns with what research aims. A systematic review is defined as being conducted by a specialised review group aiming to identify the available research relevant to a particular question (Munn et al., 2018). The systematic review aims to appraise and synthesise the available research in a structured and rigorous process to inform or confirm practice or identify new practice, to guide policy and decision making, and to inform future research. This contrasts the scoping review aims of identifying types of

evidence or key characteristics of a concept within a field, clarifying concepts within a field of literature, identifying how research is conducted, and identifying knowledge gaps (Munn et al., 2018). Scoping reviews can also be used to guide future systematic reviews. It is important to consider the difference between the two methodologies as the current research looks at interventions and, with different research questions, could fall under a systematic review. In the proposed study, a scoping review approach is most applicable as the research aims to provide evidence to inform future practice rather than answering a clinically meaningful question.

In addition, a scoping review design has been selected due to its effective process of comprehensively examining, clarifying, and summarising relevant data (Colquhoun et al., 2014). The scoping review design is further strengthened in its incorporation of multiple study designs as well as both published and 'grey' literature (Colquhoun et al., 2014). This research technique will be applied to the objectives mentioned and will attempt to provide a more evident exploration of psychosocial interventions for caregivers of people with dementia.

Methodology of Scoping Review

The methodological framework of Arksey and O'Malley (2005), improved by Colquhoun and colleagues (2014), was used in this scoping review. They outline a five-step process for conducting a scoping review, which includes identifying the research topic, looking for pertinent studies, choosing studies, charting data, and reporting results (Arksey & O'Malley, 2005). Although the framework is described in steps, they encourage a non-linear approach to the research process. The researcher is advised to be reflexive throughout the research process, and is encouraged to repeat steps if it would advance the research.

In the methodology, the outcomes of the screening procedures are presented using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021). In addition, a request for ethical clearance was made to and approved by the University of KwaZulu-Natal (UKZN) Humanities and Social Sciences Research Ethics Committee (HSSREC).

Identify the Research Questions

To meet the aim of the research, the research questions posed were;

- What is the current content focus of psychosocial intervention research for caregivers of individuals living with dementia?
- What are the methods of delivery utilised in the psychosocial interventions?

- What are the outcomes of the psychosocial interventions for caregivers of individuals living dementia?

Search for Relevant Studies

According to Arksey and O'Malley's (2005) framework, in Stage Two multiple literature databases should be reviewed to provide comprehensive coverage of the literature available. A search for published articles was conducted electronically using the following search engines, available through the UKZN online library: Ebscohost, Google Scholar, Lancet, PubMed, and Wiley Online. This search allowed for the identification and analysis of the available literature relating to the scoping review. The databases considered in selection were those made available to the researcher through the university's resources. The database includes Academic Search Complete, APA PsycInfo, ERIC, Health Source, MasterFILE, and Medline.

Data was extracted by setting the initial criteria, year range and peer-reviewed, and then broadly searching using primary keywords. The year range was determined to be from 2013, when the DSM-5 (APA, 2013) was released, until 2022 when the electronic search was conducted. The primary keywords were identified based on an initial search and reading of available research (Green et al., 2006). The relevant keywords were: 'caregiver', 'caregiving', 'dementia', 'intervention', 'psychosocial intervention'. Based on the search results, a more specific search was done using the primary keywords in combination with the following words: 'burden', 'coping', 'informal', 'family'. To further the search, the researcher inspected the reference lists of the articles to identify any relevant research. A search of the abstracts and table of contents was done to determine which articles were included.

Selection of Studies

After conducting the study search, a large number of studies relevant to the research question and keywords were identified. In following Arksey and O'Malley's (2005) framework, the selection criteria were determined. Initial inclusion and exclusion criteria were proposed and further refined through the process of searching for studies.

The following are the inclusion criteria:

- Studies conducted between 2013 and 2022,
- Studies published in English,
- Both quantitative and qualitative studies,
- Studies and reviews published in peer-reviewed journals,

- Grey literature available on other databases,
- Studies which looked at least one successful psychosocial intervention aimed at the caregivers of individuals with dementia, and
- Study samples of carers delivering care directly for persons with dementia as their primary need.

Studies that did not meet the aforementioned requirements were excluded.

The following are the exclusion criteria:

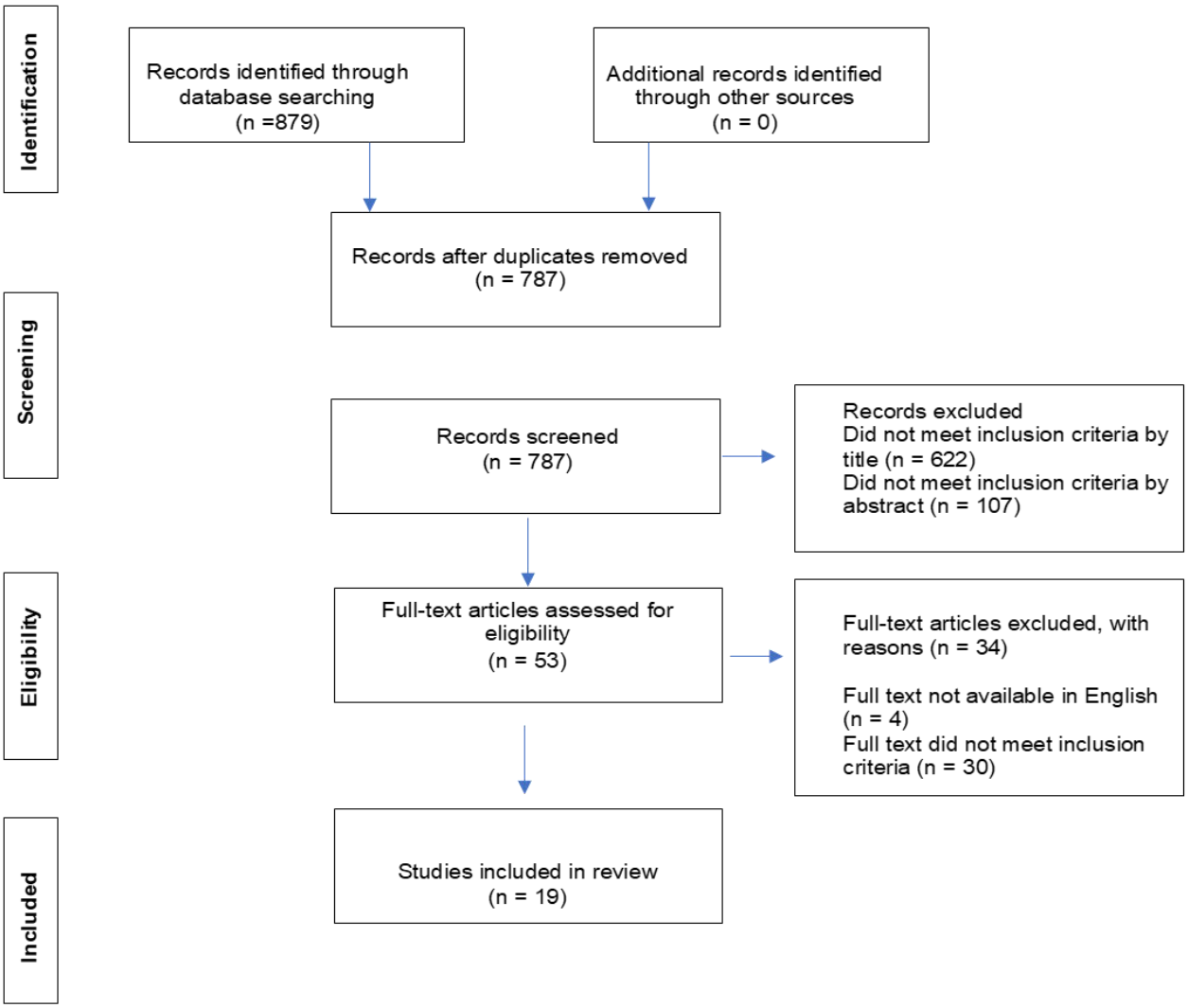
- Studies not translated into English nor available completely in an English version,
- Studies published before 2013,
- Studies in which non-psychosocial interventions are explored (such as pharmacological interventions), and
- Study samples of caregivers providing care for individuals with another physical or mental disorder.

Titles and abstracts were screened as part of the vast sample of data that had been gathered, and the inclusion and exclusion criteria were used to narrow down the studies that had been chosen. Once the articles were screened and selected, the process and selected articles were reviewed by the researcher's supervisor to ensure inclusion and exclusion criteria had been met.

From database searches conducted, 879 studies were located: Google Scholar (n = 369), EBSCOhost (n = 231), PubMed (n = 137), Wiley Online (n = 78), and The Lancet (n = 64). Once replicated studies were removed using EndNote (V.X9) software, 787 studies were initially inspected through a title review, and then by a review of abstracts to identify the studies which meet the initial inclusion criteria. A total of 622 studies were excluded through the initial title search as they failed to meet the requirements of inclusion and were unrelated to the questions stipulated in the research. A further 107 studies were excluded through the subsequent abstract search as they failed to meet the requirements of inclusion and were unrelated to the questions stipulated in the research. This left 53 studies for a full-text review, which were retrieved. Further studies were then excluded due to the full-text version being unavailable in English (n = 4) and due to further analysis of the studies revealing that they did not meet the inclusion criteria (n = 30). This left a total of 19 studies to be included in the review. The screening process findings were then conveyed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), as detailed in Figure 1.

Figure 1

PRISMA-ScR Flow Diagram of the Selection Process



Data Charting

In Step Four of Arksey and O'Malley's (2005) framework, a descriptive process of charting the data was utilised, wherein the data collection findings were summarised. A Microsoft Excel spreadsheet was used to extract and compile the data. A descriptive process was utilised in which the data was summarised according to relevant information of the literature selected, and simultaneously charts the data as a narrative review, as depicted in Table 1. The following descriptive markers were included: authors and date of publication, the study

location, the study's aims, the study design utilised, the number of participants in each study, the intervention method, setting and time frame, the intervention provider, and the intervention outcomes. The charting then focused on descriptive markers related to the current research aims, such as intervention type and content areas, the intervention duration, the method of intervention delivery, the intervention outcomes, and key findings.

Method of Synthesis and Results

The data was analysed using the thematic analysis technique as described by Braun and Clarke (2006) due to its method of organising and describing data so that it can be examined in detail. This analysis was used in this study to highlight the main themes and answers to the research question. To achieve this, a descriptive numerical summary was incorporated to describe the studies selected in terms of their characteristics. The researcher utilised the steps proposed by Levac and colleagues (2010) in creating a descriptive numerical summary of the data collected.

In order to start the process, the researcher first familiarised themselves with the data collected. To achieve this, a 'descriptive numerical summary' was utilised as discussed in Arksey and O'Malley (2005) to describe the studies selected in terms of their characteristics. The researcher incorporated the steps proposed by Levac and colleagues (2010) in which the following was suggested:

> (1) analysis including a numerical summary and qualitative thematic analysis, (2) reporting the results aligned to the research aim and objectives, and (3) assess the meaning of the findings in terms of the overall study aim and its relation to the purpose of the study, as well as to discuss the implications for further research, practise and policy when relevant (p. 4).

This summary included descriptions of the total number of studies included, the year of publication, the study design, the study location, the interventions used, and the study population. In following this approach the data collected underwent a descriptive numerical summary as well as a thematic analysis.

Once this descriptive summary was complete, and the researcher was familiar with the data, the thematic analysis was conducted. The researcher constructed data points using information extracted from the data that the researcher found relevant to the research (Braun & Clarke, 2006). The researcher methodically arranged the data into groupings that are meaningful to the research and its results.

In following Braun and Clarke's (2006) suggested methods, the researcher considered the groupings created and considered what themes apply in understanding the groupings. From this creation of the first themes, the themes identified underwent the same coding process and this final grouping produced the primary themes for the research.

The key theme findings of this review considered the study characteristics, the accessibility of interventions, the intervention approach, and the intervention outcomes. In the section below, the results of the study are detailed. In referencing the studies included and charted in Table 1, hard brackets with the depicted numbering from the table will be utilised.

Ethical Considerations

The researcher worked to ensure ethical practice was upheld throughout the research process by following the four principles of ethical research: autonomy, nonmaleficence, beneficence, and justice (Beauchamp & Childress, 2019). In pairing this with active reflexivity, it encouraged continued ethical research processes. Within the scoping review methodology, the research is done through secondary, desktop research, so the researcher did not directly work with people. While the ethical considerations in research reviews are not widely discussed, it does not mean there are no potential ethical implications for the researcher to consider (Suri, 2020). The researcher may produce a study that is published, read, and utilised in influential works (Suri, 2020). It is, therefore, still crucial for the researcher to take a reflexive approach to the research, be transparent in their methodology, and approach the research with informed subjectivity. The ethical considerations of a scoping review are strongly reflected in the selection criteria of a scoping review and the researcher's ethical obligation is to ensure the inclusion and exclusion criteria are purposefully informed and do not show any bias (Suri, 2020). Through reflective practice and awareness of these ethical concerns, the researcher worked to reduce bias. In addition, the research supervisor reviewed the research across all stages and provided constructive feedback throughout the research process. To ensure inclusion and exclusion criteria had been met by the articles, they were reviewed by the research supervisor. Similarly, in the final presentation of the research findings, it is crucial to take the researcher's prejudice into account. By maintaining subjectivity and complete transparency across the research, the researcher can demonstrate ethical practice (Suri, 2020). In disclosing all steps of the research process and processes in the full research text, the researcher has worked to maintain transparency across the research.

Chapter 4: Results

Introduction

In the following chapter, the results of the research are presented. The data obtained through a review of literature and thematic analysis are presented through both descriptive and narrative summaries. First, the charted data and the characteristics of the included data are presented in a table format in Table 1. The papers listed in Table 1 are subsequently referenced with the use of square brackets to correspond with the number allocated in the table. This is followed by summaries of the data analysed and results found. The analyses present data pertaining to study locations, design, and year of publication, and is then followed by data pertaining to the intervention characteristics, methods, measures, and outcomes. The chapter ends with Table 2 which demonstrates the intervention outcomes of the included studies.

Table 1

Characteristics of Included Studies

Study*	First Author (Year) Country	Aims	Methodology	Intervention Focus	Implementation Process Sessions, Duration, Time Frame	Study Measures	Outcome Measures	Results
[1]	Brown (2016) USA	To study the efficacy of an adapted, 8-week MBSR program relative to a Standard Social Support (SSS) control condition for reducing stress and enhancing the recipient-carer relationship	**Study design:** Quantitative pilot randomised controlled trial **Population target:** Family, informal caregivers **Sample size**: (n = 38)	**Intervention**: Mindfulness-based Stress Reduction (MBSR) program (Brown et al., 2015) **Control Group**: Standard Social Support (SSS)	In-person, delivered by masters educated and trained facilitators 8 weekly group classes of 1.5–2 hours, over 8 weeks Zarit Burden Interview (ZBI)	• Perceived Stress Scale • Acceptance and Action Questionnaire II • Profile of Mood States • Medical Outcomes Study Short-Form Health Survey • Zarit Burden Interview • Mutuality Scale of the Family Care Inventory	Perceived stress & stress via salivary cortisol Experiential avoidance Mood Mental and physical functioning Burden Carer-recipient relationship	MBSR participants reported sig. lower perceived stress and mood disturbance post-intervention relative to control SSS. No conditional difference between MBSR and SSS at 3 months follow up
[2]	Czaja (2013) USA	To evaluate the feasibility and efficacy of technology-based psychosocial intervention among minority family caregivers of dementia patients	**Study design:** Quantitative comparison group trial feasibility & efficacy trial **Population target:** Family, informal caregivers **Sample size**:(n = 110)	**Intervention**: Technology-based psychosocial intervention based on REACH II (Nichols et al., 2011) **Control 1**: Attention control **Control 2:** Information only	In-person & virtual, delivered by HCP & self-administered online One session per month of 1 hour, over 6 months, 2 in home and 4 online	• Risk Appraisal Questionnaire • Centre for Epidemiologic Studies Depression Scale • Revised Memory and Behaviour Problems Checklist • Positive Aspects of Caregiving Assessment • Social Support Scale	Depression Caregiver burden Social support Perception of caregiving experience	Reported decrease in burden, increased perceived social support & positive perceptions of caregiving experience. No effect for depression. Perceived improvement of caregiving skills.
[3]	Dichter (2020) Germany	To examine the effects of the telephone-based Talking Time intervention	**Study design:** Quantitative Medical Research Counsel Framework Phase 2 randomised controlled trial **Population target:** Informal caregivers **Sample size:** (n = 38)	**Intervention**: Telephone-based talking time intervention adapted by Berwig et al., (2017) **Control**: Usual, self-organised care	Virtual, delivered by psychologist 6 bi-weekly, 1-hour telephone-based support group sessions over 3 months	• General Health Survey Questionnaire Short Form • Perceived Social Support Caregiver • Caregiver reaction scale • Neuropsychiatric Inventory Questionnaire • General Practitioner Assessment of Cognition • Functional Activities Questionnaire • Social Conflict Scale	Psychological QoL Physical QoL Social support Social conflict	The Talking Time intervention shows increased health related QoL while the control shows a decrease Difference not statistically sig No results for social support yet

Study*	First Author (Year) Country	Aims	Methodology	Intervention Focus	Implementation Process Sessions, Duration, Time Frame	Study Measures	Outcome Measures	Results
[4]	Ploeg (2018) Canada	To describe how My Tools 4 Care (MT4C) helped dementia caregivers, which features of MT4C caregivers found beneficial, and what changes they recommend	**Study design:** Qualitative description from a mixed-methods pragmatic randomised controlled trial **Population target:** Family, informal caregivers **Sample size:** (*n* = 56)	**Intervention**: My Tools 4 Care Transition Toolkit by Duggleby et al. (2014) **Control**: Educational booklet	Virtual and self-administered Unrestricted, 3-month access to online toolkit No time restrictions	Qualitative interviews	Reflection Sharing Information and education Affirmation	Indicated benefit to self-administered psychosocial supportive web-based resources Helped caregivers identify support for caregiving role and for self.
[5]	Garand (2019) USA	To determine whether problem solving therapy (PST) would reduce levels of burden in dementia carers	**Study design:** Quantitative Randomised Control Group Design **Population target**: Family, informal caregivers **Sample size**: (*n* = 73)	**Intervention 1:** Problem solving therapy (PST) Garand et al. (2014) **Control Group**: Nutritional Training	In-person &Virtual delivered by HCP (nurses and social workers) 6 bi-weekly in-person sessions of 1.5 hours followed by 3 bi-weekly phone calls of 45 minutes, 18 weeks in total	• Montgomery's Objective Caregiver Burden Scale • Revised Memory and Behaviour Problem Checklist • Montgomery's Subjective Caregiver Burden Scale	Objective & subjective caregiver burden	PST improved subjective burden among caregivers compared to control Caregiver distress over dementia-related behaviours remained low in PST, and rose in control group.
[6]	Yoon (2019) South Korea	To develop & evaluate an intervention grounded on the caregiver empowerment model (CEM) for Korean caregivers	**Study Design**: Quantitative, quasi-experimental pre-test/post-test control group **Population target**: Family, informal caregivers **Sample size: (***n* = 115)	**Intervention**: Caregiver Empowerment Model (CEM by Jones et al., 2011) **Control Gr 1**: Usual service **Control Gr 2**: Psychoeducational handbook developed by researchers	In-person & Virtual delivered by licensed nurses 8 weekly in-person sessions of 1.5 hours followed by 4 weekly, 10-minute phone calls 12 weeks total	• Caregiving Appraisal Scale • Finding Meaning Through Caregiving Scale • Family Caregiver Self-efficacy Scale • Hogan Grief Reaction Checklist • Campbell's Subjective Well-being Scale	Caregiving appraisal Caregiving attitude Self-efficacy Personal growth Well-being	CEM showed significantly increased caregiving appraisal, attitudes, self-efficacy, & well-being
[7]	Hsu (2017) Taiwan	To provide further understanding of the relative efficacy of psychosocial interventions in the lessening of burden of caregivers	**Study design:** Quantitative, prospective, longitudinal, one-group pre-test/post-test **Population target:** Family, informal caregivers **Sample size: (***n* = 34)	**Intervention**: 32-hour Psychoeducation training program and support groups developed by the authors	In-person, delivered by HCP (nurses, social workers, psychologists, psychiatrists, neurologists) 4 weekly structured workshops of 8 hours over 4 weeks.	• Chinese Zarit Burden Interview • Chinese General Health Questionnaire • Medical Outcome Study • 36-item Short Health Survey	Perceived caregiver burden Psychological morbidity and distress Physical and psychological well-being	Significant improvements on perceived burden of care & overall mental health No significant improvement in physical health

Study*	First Author (Year) Country	Aims	Methodology	Intervention Focus	Implementation Process Sessions, Duration, Time Frame	Study Measures	Outcome Measures	Results
[8]	Jain (2014) United States of America	To assess the feasibility of Central Meditation and Imagery Therapy (CMIT-C) for dementia carers reporting stress	**Study design:** Qualitative open label feasibility study **Population target:** Family, informal caregivers **Sample size**: (n = 12)	**Intervention**: Central Meditation and Imagery Therapy for Caregivers (CMIT-C) developed by the authors In-person delivered by the researcher 8 weekly group sessions of 90 minutes	In-person delivered by the researcher 8 weekly group sessions of 90 minutes	• Centre for Epidemiologic Studies Depression Scale Zung Anxiety Scale • Quality of Life Enjoyment and Satisfaction Questionnaire – Short • Insomnia Severity Index • Five Factor Mindfulness Questionnaire	Depression Anxiety QoL Insomnia Mindfulness	Anxiety, depression, & insomnia symptoms decreased, mindfulness ratings improved
[9]	Kashimura (2018) Japan	To investigate the feasibility of applying START to Japanese family caregivers	**Study design**: Quantitative case study **Population target**: Family, informal caregiver **Sample size**: (n = 1)	**Intervention**: START (Strategies for relatives), adapted from START by Livingston et al. (2013)	In-person delivered by the researcher 8 weekly group sessions with no specified time frame	• Beck Depression Inventory – II • Hospital Anxiety and Depression Scale • Japanese Zarit Burden Interview • Kessley Psychological Distress Scale • Neuropsychiatric Inventory Questionnaire (NPIQ) • Short 8 Psychical & Mental Component Summary	Anxiety Depression Caregiver burden Distress Mental and physical QoL	Suggests Japanese START effective for improving mood, QoL, and subjective feelings of burden
[10]	Livingston (2020) United Kingdom	To assess clinical effectiveness over 6 years and the impact on costs and care of home admission	**Study design**: Quantitative randomised, parallel group, superiority trial **Population target**: Family, informal caregivers **Sample size**: (n = 260)	**Intervention**: START (Strategies for relatives), from US Coping with Caregiving Program (Gallagher-Thompson et al., 2002) **Control**: Treatment as usual	In-person, delivered by Psychology graduates with no clinical training 8 weekly sessions with no time frame specified	• Neuropsychiatric Inventory Questionnaire • Zarit Burden Interview • Hospital Anxiety and Depression Scale • Client Service Receipt Inventory	Anxiety Depression	Intervention group had improved HADS scores over 72 months compared to control. No sig. difference in patient or carer related costs, or care recipient hospitalisation

Study*	First Author (Year) Country	Aims	Methodology	Intervention Focus	Implementation Process Sessions, Duration, Time Frame	Study Measures	Outcome Measures	Results
[11]	Meichsner (2019) Germany	To evaluate the efficacy of an internet-delivered cognitive behavioural intervention for dementia carers and examined acceptance of program characteristics	**Study design**: Quantitative randomized control trial **Population target**: Family, informal caregivers **Sample size**: (n = 39)	**Intervention**: CBT online intervention translated form Tele.TAnDem (Wilz et al., 2018) **Control**: Wait-list	Virtual facilitated by therapist & self-administered online 10 online modules and one weekly message interaction with therapist over 8 weeks, no time frame specified	• Centre for Epidemiologic Studies Depression Scale • Caregiver Grief Scale • Psychosocial Resource Utilisation Questionnaire for Family Dementia Caregivers • Burden of Care Visual Analog Scale	Satisfaction with intervention Depression Caregiver grief Utilisation of resources Caregiver burden Emotional wellbeing	High treatment satisfaction and acceptance. Well-being increased. Improved coping with anticipated death & use of psychosocial resources. Effects not maintained. No treatment effects for depression, burden
[12]	Mittelman (2014) USA	To describe outcomes of the implementation of the evidence-based intervention (NYUCI) in a multisite program in Minnesota	**Study design**: Qualitative case study **Population target**: Family, informal caregivers **Sample size**: (n = 228)	**Intervention**: New York University Caregiver Intervention (NYUCI) adapted from (Mittelman et al., 2003)	In-person, delivered by HPC (Social workers, counsellors) 4 to 6 weekly sessions, of 1 hour	• Centre for Epidemiologic Studies Depression Scale • Revised Memory and Behaviour Problems Checklist • Older Americans Resources and Services Questionnaire • Stokes Social Network Questionnaire	Caregiver depression Caregiver reaction to problem behaviour Caregiver perceived health, caregiver satisfaction of support	Assessments showed decreased depression and distress and improved reactions. More sessions correlated to delayed hospitalisation or institutionalisation for dementia patient
[13]	Pihet (2018) Switzerland	To examine feasibility of implementing a psychoeducation group grogram in two regions, effects of the program, and participants' use of strategies	**Study design**: Mixed methods concurrent nested design, quasi-experimental **Population target**: Family, informal caregivers **Sample size**: (n = 26)	**Intervention**: Psychoeducation group program Based on the program Learning to feel better… and help better. (Levesque et al., 2002)	In-person, delivered by trained nurses 15 weekly group sessions of 2 hours	• Zarit Burden Interview • Revised Memory and Behaviour Problems Checklist • Ilfeld Psychiatric Symptoms Index • Self-efficacy Visual Analogue Scale • Qualitative Interviews	Caregiver burden, caregiver's memory and behaviour problem related distress, psychological distress, self-efficacy	High program acceptance. Sig. improvements in burden, distress, and self-efficacy Group format beneficial, reduced isolation and increased social support
[14]	Spalding-Wilson (2018) USA	To test whether a 2-day intervention improved psychological health in caregivers of individuals with dementia	**Study design**: Mixed-methods randomised control trial **Population target**: Family, informal caregivers **Sample size**: (n = 95)	**Intervention**: Manualised 2-day intervention developed by the authors **Control**: Waitlist	In-person, delivered by the researcher Manualised 2-day, group intervention, with no time frame specified	• Perceived Stress Scale • Caregiver Burden Inventory • Beck Depression Inventory – II • Beck Anxiety Inventory • • •	Caregiver burden Stress Anxiety Depression	Sig. reduced perceived stress (up to 6 months) Regarded as helpful by most for helping manage challenging behaviours

Study*	First Author (Year) Country	Aims	Methodology	Intervention Focus	Implementation Process Sessions, Duration, Time Frame	Study Measures	Outcome Measures	Results
[15]	Stockwell-Smith (2018) Australia	To evaluate the effect of targeted community-based psychosocial intervention on self-efficacy outcomes for recipient-carer dyads with early stage dementia	**Study design**: Explanatory sequential mixed method design **Population target**: Family, informal caregivers **Sample size**: (n = 88)	**Intervention**: Early Diagnosis Dyadic Intervention (EDDI) USA Whitlach et al. (2006) **Control**: Two information manuals	In-person, delivered by trained community practitioners 7 weekly meetings with caregiver and recipient for 60 to 90 minutes	• Self-Efficacy Questionnaire • Service use questionnaire • Qualitative interviews	Self-efficacy, Relationship, Wellbeing, Uptake & awareness of support services	Qualitative: acceptability of intervention structure, content, & delivery. Improved self-efficacy Quantitative: no sig. in self-efficacy
[16]	Tang (2018) Taiwan	To determine whether active psychoeducation intervention is more efficacious than passive intervention for improving caregiving skills	**Study design**: Quantitative prospective, single-blinded, controlled trial **Population target**: Family and formal caregivers **Sample size**: (n = 43)	**Intervention 1**: Active psychoeducation (AP) **Intervention 2:** Passive psychoeducation (PP)	In-person & virtual, delivered by HPC (occupational therapists, nurses) 6 visits and follow up phone calls for 60 minutes over 3 months	• Care Skill Inventory • Chinese Zarit Burden Interview • Neuropsychiatric Inventory Questionnaire • Chinese ADL Questionnaire	Caregiver competence, burden, distress	All three measures (competence, burden, and distress) showed sig. improved levels in AP intervention compared to PP intervention.
[17]	Tremont (2015) United States of America	To examine the effects of a telephone-based intervention on caregiver well-being	**Study design**: Quantitative randomised control trial **Population target**: Family, informal caregivers **Sample size**: (n = 250)	**Intervention**: Family InterventionTelephone tracking-caregiver (FITT-C) developed by the authors **Control**: Telephone Support (TS)	Virtual, delivered by trained therapists 16 telephone sessions over 6 months with no time frame specified	Zarit Burden Interview Centre for Epidemiologic Studies Depression Scale Revised Memory and Behaviour Problems Checklist Family Assessment Device Self-efficacy Questionnaire Positive Aspects of Caregiving Scale EuroQoL	Caregiver burden, depression, reaction to problem behaviours, other areas of caregiver functioning	FITT-C sig improved depressive symptoms Reduced reactions to recipient-carer depressive behaviours compared to control
[18]	Werner (2020) Israel	To evaluate NYUCI efficacy in reducing depressive symptoms and discuss insights associated with translation of an evidence-based intervention to a new environment.	**Study design**: Quantitative hybrid community implementation study & randomised controlled trial **Population target**: Family, informal caregivers **Sample size**: (n = 100)	**Intervention**: NYUCI (Mittelman et al., 2003) **Control**: Support groups (usual care approach)	In-person, delivered by trained counsellors and social service providers 4 to 6 weekly sessions of 1 hour	Geriatric Depression Scale (GDS)	Depression	Israeli adaptation of NYUCI effective, reduced depressive symptoms reported compared to control

Study*	First Author (Year) Country	Aims	Methodology	Intervention Focus	Implementation Process Sessions, Duration, Time Frame	Study Measures	Outcome Measures	Results
[19]	Zhang (2020) China	To examine the feasibility of a caregiving self-management support program developed for caregivers of relatives with dementia in Shanghai	**Study design**: Quantitative quasi-experimental and evaluated control group **Population target**: Family, informal caregivers **Sample size**: (n = 41)	**Intervention**: C-SMS Program (Caregiving self-management support) Rong et al. (2019) **Control**: 3 monthly telephone instructions All received baseline psychoeducation	In-person, delivered by trained facilitators 6 bi-weekly social support groups of 1 hour and 3 educational presentations of 1 hour over 3 months	Chinese 36-item Short Form Health Survey Self-Efficacy Questionnaire for Chinese Family Caregivers Disability Assessment in Dementia Neuropsychiatric Inventory Questionnaire	Health Related QoL & caregiver self-efficacy Neuropsychiatric Inventory Questionnaire (NPIQ)	Both perceived stronger self-efficacy in gathering information than baseline. Intervention report better health-related QoL, improved responses to behavioural disturbances, and stress management

HCP: Health Care Professionals

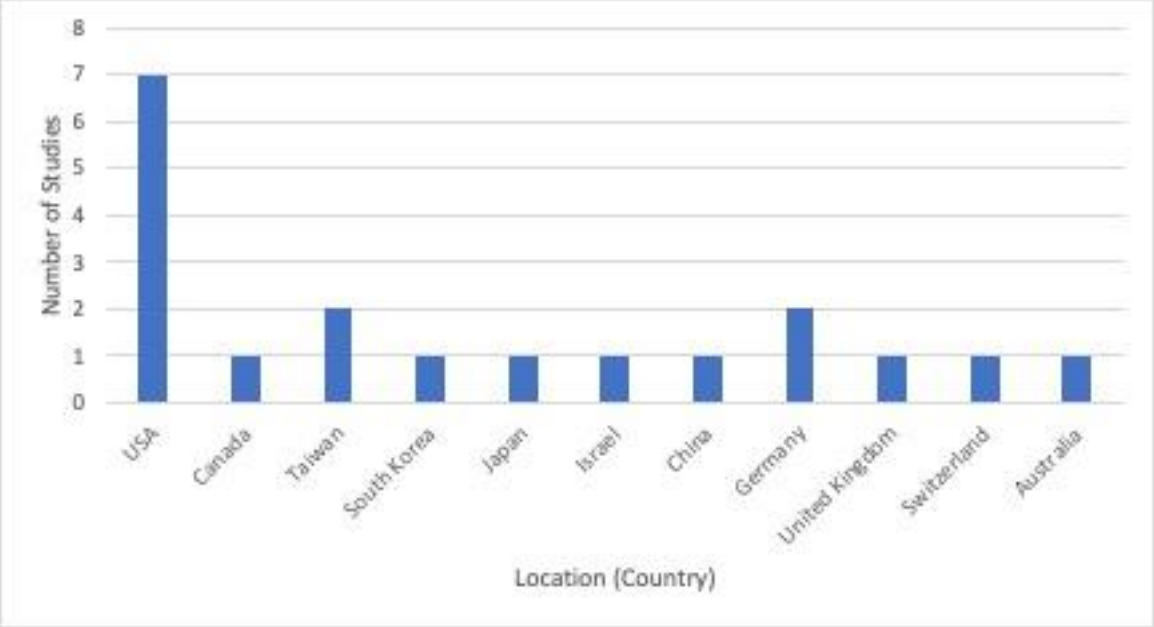
*As numbered and depicted in text below

Location

The studies were primarily carried out in high-income countries (HICs; *n* = 18) with only one study being conducted in a country considered upper-middle income [19]. Figure 1 illustrates the countries of focus. Forty two percent of the studies were conducted in North America, primarily in the USA, 31.5% were located in Asia, 44% were located in Europe, and 0.5% were located in Oceania. The study's inclusion criteria were not met by any studies from a Low to Middle Income Country, nor any country in South America or Africa.

Figure 1

Location of Included Studies by Country



Study Design of Included Studies

From the 19 studies that fulfilled the listed criteria for inclusion, most studies (*n* = 13) utilised a quantitative methodology while the others utilised a qualitative approach (*n* = 3) [4, 8, 12] or a mixed-methods approach (*n* = 3) [13, 14, 15]. Of the 19 studies, the most popular experimental design was a randomised controlled trial (*n* = 8) [1, 3, 4, 5, 11, 14, 17, 18].

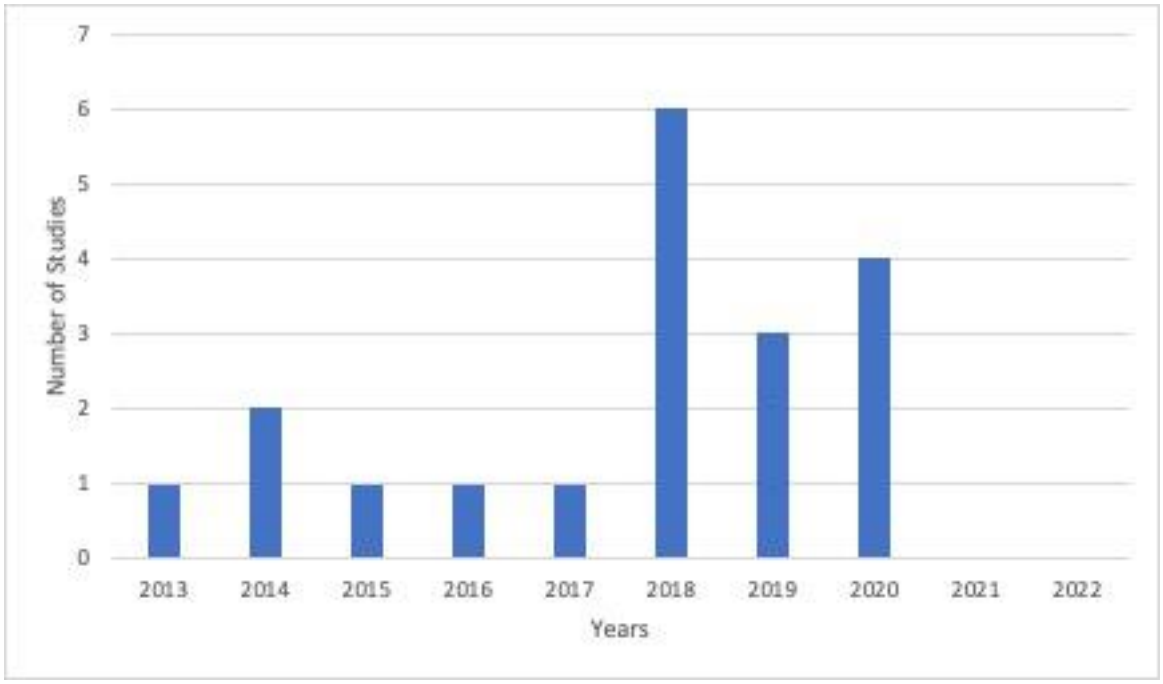
Number of Publications per Year

The inclusion criteria described the year range of 2013 to 2022, and the number of publications within this range is illustrated in Figure 2 below. The number of articles published between 2013 and 2017 was consistent at one to two per year. There was a notable rise in

publications from 2018 to 2020 which accounts for the majority of the research found in this review. There was, however, a very prominent drop in publications after 2020. Of the studies published in 2020, it is noted that the research was typically conducted in 2019 and published in 2020 after peer-revision and publication processes. From that, it is apparent that the research done in the field diminishes from the start of 2020, and no publications that met the inclusion criteria were found from 2021 or the beginning of 2022 (when this review's search was conducted). Taking the COVID-19 pandemic into consideration, research focus is likely to have shifted from 2020 onwards.

Figure 2

Number of Studies Published per Year



Characteristics of Interventions

The majority of the studies focused on informal dementia carers (*n* = 17) [1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 17, 18, 19], with only one study [16] that included both formal and informal caregivers in their interventions. Depending on the study's methodology and design, different numbers of individuals were included in different investigations. Most of the studies had a sample size range of one to 40 participants (*n* = 7) [1, 3, 7, 8, 9, 11, 13], followed by 80 to 120 participants (*n* = 5) [2, 6, 14, 15, 18] and 41 to 80 participants (*n* = 4) [4, 5, 16, 19], while the remaining had over 200 participants (*n* = 3) [10, 12, 17]. In addition, the majority of the studies utilised in-person participation in their intervention design (*n* = 13) [1, 6, 7, 8, 9,

10, 12, 13, 14, 15, 16, 18, 19], while a few utilised virtual only participation (n = 4) [3, 4, 11, 17], whether online or telephonic, or a combination of in-person and virtual (n = 2) [2, 5]. The use of telephone-based interventions by some studies was explored to increase the availability and reach of interventions while also reducing costs. The studies showed positive outcomes such as improved well-being, increased utilisation of psychosocial resources, and decreased burden [2, 3, 17]. The web-based studies similarly showed positive outcomes in perceived support, increased utilisation of psychosocial resources, and improved well-being [4, 11]. In addition, the majority of the studies used a trained professional to deliver the intervention (n = 14) [1, 3, 5, 6, 7, 11, 12, 13, 14, 15, 16, 17, 18, 19], while few were self-administered (n = 2) [2, 4], administered by the key researcher (n = 2) [8, 9], or administered by graduate students (n = 1) [10].

The time frames of the interventions can be considered from three perspectives, namely: the number of weeks over which the intervention took place, the number of sessions the intervention consisted of, and the amount of time taken per session. The number of weeks over which the interventions took place varied, with the majority being eight-week interventions (n = 5) [1, 8, 9, 10, 11] and 13-week interventions (n = 4) [3, 4, 16, 19]. The shortest intervention was a two-day intervention [14] and the longest was a six-month (26 week) intervention [2]. Within the eight-week interventions, the interventions typically consisted of eight sessions with one consisting of 10 sessions, and varied between unspecified time frames (n = 3); a one and a half-hour time frame (n = 1) and a two-hour time frame (n = 1) [1, 8, 9, 10, 11]. Of these five interventions, improvements were seen across measures such as perceived stress, anxiety, depression, QoL, and burden. Within the 13-week interventions, the interventions consisted of six sessions, nine sessions, or unrestricted online access and utilised a one-hour time frame (n = 3) and an unspecified time frame (n = 1) [3, 4, 16, 19]. Of these four interventions, improvements were seen across measures such as QoL, utilisation of resources, burden, distress, and self-efficacy.

Within these varied time frames, the number of sessions per intervention and the length of time per session also varied. To deduce the total number of sessions per intervention, the entirety of the intervention was taken into consideration, in that sessions per section of intervention were tallied. If the intervention considered a range with optional sessions, only the compulsory sessions were tallied. Eight sessions per intervention were most frequently used in the studies (n = 4) [1, 8, 9, 10], followed by four sessions (n = 3) [7, 12, 18], and nine sessions (n = 3) [5, 16, 19]. There was an even spread between the number of studies which did not specify a time frame (n = 6) [4, 9, 10, 11, 14, 17], those which took up to an hour (n = 6) [2,

3, 12, 16, 18, 19], and those that took between one and two hours (*n* = 6) [1, 5, 6, 8, 13, 15], which one study having the greatest length of time of eight hours per session (*n* = 1) [7].

Intervention Method

In considering the methods of delivery for the psychosocial intervention utilised, the majority of researchers utilised or adapted a known intervention (*n* = 15) [1, 2, 3, 4, 5, 6, 9, 10, 11, 12, 13, 15, 16, 18, 19] while a few developed a new intervention for their study (*n* = 4) [7, 8, 14, 17]. The interventions utilised can be grouped according to the intervention approach, namely, psychoeducational, therapeutic, and peer support. Notably, this differentiation in characteristics is meant to highlight the fundamental approach of the interventions, such as whether it was a mostly therapeutic approach, psychoeducational, or peer support based. Thus, for example, if an approach was largely based on a therapeutic intervention which utilised psychoeducation in part, it would be characterised as a therapeutic based approach.

More interventions used therapeutic based approaches (*n* = 10) [1, 5, 8, 9, 10, 11, 12, 14, 15, 18] than psychoeducational based approaches (*n* = 7) [2, 4, 6, 7, 13, 16, 17]. Only two of the studies reported a peer support-based approach (*n* = 2) [3, 19].

The aims of the psychoeducational approaches in this review varied between providing education, providing skills training, and addressing and improving risk areas (such as QoL, self-efficacy, burden, distress, ability to cope, and depression). The psycho-educative role of these interventions was approached in various ways. The studies made use of virtual (*n* = 2), in-person (*n* = 2), and both virtual and in-person settings (*n* = 3). In delivering the intervention, studies utilised one-on-one sessions either online or in person, online toolkits, in-person workshops, group sessions, and telephone contact sessions.

However, as stated previously, this classification used in this review highlights the fundamental approach of the intervention. Many of the interventions utilised elements of other approaches to enhance the intervention. Within the psychoeducational approaches, some studies incorporated support group sessions (*n* = 2) [2, 7] or therapeutic approaches (*n* = 1) [17], while some therapeutic approaches incorporated peer support (*n* = 2) [12, 18], and some included psychoeducation (*n* = 5) [9, 10, 11, 14, 15].

The studies in this review that were classified under a therapeutic approach include interventions which were grounded in therapeutic-based theories and incorporated a therapeutic approach in the implementation of their intervention. Due to the variability of therapeutic approaches in general, the interventions characterised as therapeutic tended to have greater differences in their implementation than the psychoeducational or peer support

approaches. The difference across therapeutic interventions depended on the fundamental therapeutic approach being used. From this, the therapeutic approaches could be further categorised into counselling and psychotherapy approaches, combined approaches, and mindfulness-based approaches.

The counselling and psychotherapy approaches incorporated the interventions which primarily used a form of psychotherapy to target the intervention measures. Within this review they included problem solving therapy (n = 1) [5], cognitive behavioural therapy (n = 1) [11], and dyadic counselling (n = 1) [15]. The combined approaches consider those interventions which utilised more than one approach in their intervention. In the New York University Caregiver Intervention (NYUCI), individual support, family support, and support groups are combined (n = 2) [12, 18]; whereas the START intervention combined psychoeducation and individual counselling (n = 2) [9, 10], and a manualised two-day intervention which utilised therapeutic interventions, mindfulness approaches, behaviour management training, and validation therapy (n = 1) [14]. The mindfulness-based approaches (n = 2) incorporated interventions which focused on mindfulness-based practices which, in this review, included the Mindfulness-Based Stress Reduction Program [1] and the Central Meditation and Imagery Therapy for Caregivers [8].

The peer support approaches were the smallest category in this review, with only two studies that fell under peer support [3, 19]. However, many of the studies which predominantly fall in the psychoeducational or therapeutic approaches incorporated an element of peer support in their intervention design, such as structured or unstructured support groups.

Study Measures and Outcomes

The papers reviewed support a number of strategies in their selected methodologies, samples, interventions, and outcome measures. Intervention outcome measures are utilised to understand the impact of the chosen intervention on the caregivers. Some studies measure multiple constructs, as noted in Table 1. However, in most studies, measured caregiver burden (n = 10) and depression (n = 10) are notably the most common constructs, thus outcomes measured across the studies. The following mental health related constructs were also investigated, namely QoL (n = 5), distress (n = 5), anxiety (n = 4), self-efficacy (n = 4), caregiver reaction to problem behaviour (n = 4), well-being (n = 3), and utilisation of resources (n = 3).

The different studies used various scales and psychometric measures. In looking at the construct of burden, the most common scale used across the studies is the Zarit Burden

Interview (ZBI) and updated versions for different target audiences such as the Chinese ZBI. The ZBI is a 22-item, self-report scale, utilising a 5-point Likert scale, which measures a caregiver's perceived burden (Yap, 2010). This measure was used in six studies [1, 7, 9, 13, 16, 17] to measure caregivers' experience of burden. Ultimately, from ten studies which included a measure of burden, six utilised the same scale to deduce the measure's outcome. Within the measure of burden, other scales utilised were the Revised Memory and Behaviour Problems Checklist [2], the Montgomery's Objective and/or Subjective Caregiver Burden Scale [5], a visual analogue scale [11], and the Caregiver Burden Inventory [14].

Similarly, in looking at the construct of depression, there was a wide variety of scales utilised, with the most common scale used being the Centre for Epidemiologic Studies Depression Scale (CES-D; n = 5) [2, 8, 11, 12, 17]. This scale is a 20-item self-report scale, with a 10-item short version, and utilises a 4-point Likert scale to assess the individual's reported experience of depressive symptoms (Eaton et al., 2004). Other scales utilised to measure depression were the Beck Depression Inventory II (n = 2) [9, 14], the Hospital Anxiety and Depression Scale (n = 2) [9, 10], and the Geriatric Depression Scale (n = 1) [18]. The Hospital Anxiety and Depression scale was also utilised in scoring and reporting caregiver anxiety in the same studies (n = 2) [9, 10].

Despite the fact that numerous constructs were evaluated throughout the research, there were limited similarities across the measures used. In the less common constructs, such as QoL, distress, and anxiety, a variety of measures were seen. In order to gauge QoL, researchers utilised scales such as the General Health Survey Questionnaire Short Form (n = 2) [3, 7] and the Medical Outcome Study 36-item Short-Form Health Survey (n = 2) [1, 7]. The Neuropsychiatric Inventory Questionnaire (n = 3) [3, 9, 16] was used to measure distress and behaviour tolerance, and the Hospital Anxiety and Depression Scale (n = 2) [9, 10] or Beck Anxiety Inventory (n = 1) [14] were used to measure anxiety, alongside all other scales used across the various studies.

To analyse the intervention outcomes for this report, the range of intervention results on mental health outcomes were considered and tabulated, as seen in Table 1. While the studies vary, similarities in the outcomes measured were noted. Due to some studies considering multiple mental health outcomes, Table 1 reflects each reported outcome. As mentioned above, predominant recorded outcomes are caregiver burden and depression. These are presented below in terms of the intervention characteristics i.e. psychoeducational, therapeutic, and peer-support based approaches.

Caregiver Burden

Of all 19 studies, 10 included caregiver burden as a target intervention measure (53%).

In the therapeutic based studies (n = 10), five included caregiver burden as a target intervention measure [1, 5, 9, 11, 14], and two studies found an improvement in caregiver burden [5, 9] while three reported no significant change in caregiver burden or no reportable treatment effect [1, 11, 14].

Within the studies that utilised a psychoeducational based approach (n = 7), five included caregiver burden as a target intervention measure [2, 7, 13, 16, 17]. In three of these investigations (60%), caregiver burden was significantly reduced [7, 13, 16], one reported a decrease in burden but did not report on significance [2], and one study showed no significant difference in levels of burden levels among the intervention participants [17].

Of the studies that utilised a peer support approach (n = 2), neither included caregiver burden as a target intervention measure [3, 19].

Depression

Nine studies (47%) included depression as a target intervention measure.

From the studies which utilised a therapeutic based approach (n = 10), six included depression as an intervention outcome measure [8, 9, 11, 12, 14, 18]. Of the six studies, three (50%) showed significant improvements in levels of depression [8, 12, 18], one suggested improved levels of depression but did not mention whether or not it was significant [9] while two studies reported no significant difference in depression levels after the intervention [11, 14].

With regards to the studies that used a psychoeducational based approach (n = 7), three included depression as an intervention outcome measure [2, 10, 17]. Two studies (66.6%) out of the three revealed substantial variations in the levels of depression [10, 17] while one reported no significance or treatment effect on depression [2].

Of the studies which utilised a peer support approach (n = 2), neither included depression as a target intervention measure [3, 19].

Other Intervention Outcomes in terms of General Intervention Approach

The following mental health related constructs were also investigated in multiple studies, namely, utilisation of resources and support (n = 6), distress (n = 5), general mood and well-being (n = 5), anxiety (n = 4), self-efficacy (n = 4), QoL (n = 4), stress (n = 2), and caregiver reaction to problem behaviour (n = 2). Additionally, the following constructs were

measured and reported positive outcomes in singular studies (n = 1): experiential avoidance, perception of caregiving experience, caregiver appraisal, caregiver attitude, insomnia, mindfulness, intervention satisfaction, caregiver grief, and competence.

Utilisation of Resources and Support

Six studies considered the caregiver's utilisation of resources and social support as an intervention outcome. Of the six, two were psychoeducational and reported improved utilisation of resources [2, 4], three were therapeutic based interventions and all reported improved resource utilisation [11, 12, 15], and one was a peer-support based intervention which did not report results on social support outcomes [3].

Distress

Five studies included distress as a target intervention measure (26%). Of the five studies, three utilised a psychoeducational approach [7, 13, 16], one used a therapeutic approach [9], and one used a peer-support approach [19]. All five reported significant improvements in distress outcomes.

General Mood and Well-Being

Five of the studies included considered the general mood and well-being of the caregiver as an intervention outcome. Of the five studies, three were a therapeutic based intervention [1, 11, 15], and two were a psychoeducation-based intervention [6, 7]. Within the outcomes, improvements were seen in three of the studies [1, 6, 11], while one study found significant improvements in mental health aspects of well-being but not in physical well-being [7], and one study showed no significant improvements [15].

Anxiety

Anxiety was considered by four of the studies as an intervention outcome, of which all were therapeutic based approaches [8, 9, 10, 14]. Of the four studies, three found significant improvements in levels of anxiety [8, 9, 10], while one found no significant improvement in anxiety outcomes [14].

Self-Efficacy

Four studies considered self-efficacy as a target intervention measure. Of the four, two were psychoeducational interventions and both found significant improvements to self-efficacy measures [6, 13], one was a therapeutic intervention and showed no significant improvements

to self-efficacy findings [15], and one was a peer-support based intervention which reported improved self-efficacy [19].

Quality of Life (QoL)

Quality of life was considered by four studies as an intervention outcome, of which two studies utilised a peer support approach [3, 19] and two studies utilised a therapeutic approach [8, 9]. All four reported improvements across QoL measures.

Stress

Two studies considered stress levels, perceived and actual, as an intervention outcome, of which both studies utilised a therapeutic approach [1, 14]. Of the studies, both reported lower levels of perceived stress by the caregivers, but no change in actual stress measured through neuroendocrine stress markers was noted.

Caregiver Reaction to Problem Behaviour

Two of the studies considered caregiver reactions to problem behaviours as an intervention outcome, of which one study utilised a therapeutic approach [12] and the other study utilised a psychoeducational approach [17]. Of the studies, both reported improvements in caregiver reactions.

Other Outcomes

There were a number of singular outcomes that were measured and reported upon, that only appeared in single studies. Those which reported improvements through the intervention were experiential avoidance [1], perception of caregiving experience [2], caregiver appraisal [6], caregiver attitude [6], insomnia [8], mindfulness [8], intervention satisfaction [11], caregiver grief [11], and competence [16].

Table 2

Intervention Outcomes of Included Studies

Study*	Intervention Content	Intervention Type	Desired Outcome Stated	Impact
[1]	Mindfulness-based Stress Reduction (MBSR) program	Therapeutic	Reduce psychological and neuroendocrine markers of stress, improve psychological morbidity & carer-recipient relationship	Participants reported lower levels of perceived stress, tension, & anger that were sig. lower post-intervention compared to control. Control had better impact on caregiver burden. No change in neuroendocrine markers
[2]	Technology-based psychosocial intervention (based on REACH II)	Psycho-educational	Provide education & skills training. Virtually address 5 carer risk areas (safety, social, support, problem behaviours, depression, carer health)	Reported improvements in burden, perceived social support, & positive perceptions. No effect observed for depression. Perceived improvement of caregiving skills.
[3]	Telephone-based Talking Time intervention	Peer-support	The effect factors from "universality of suffering" and "interpersonal learning" may influence and improve their HRQoL.	Increased HRQoL (Not statistically significant difference compared to control)
[4]	My Tools 4 Care (MT4C)	Psycho-educational	Virtual use of MT4C impacts HRQoL, hope, & self-efficacy	Indicated benefit to self-administered psychosocial supportive web-based resources Helped caregivers identify support for caregiving role and for self.
[5]	Problem solving therapy (PST)	Therapeutic	Enhanced problem solving skill training learned early in the caring process would improve burden levels	Improved subjective burden levels among caregivers
[6]	Caregiver Empowerment Model (CEM)	Psycho-educational	Improve carer appraisal, attitude, self-efficacy, personal growth, & well-being	Significantly increased caregiving appraisal, caregiving attitude, self-efficacy, and well-being
[7]	32-hour psycho-education training program and optional support groups	Psycho-educational	Reduced burden & psychological distress, enhance QoL	Sig. improved appraisal, attitude, self-efficacy, & well-being
[8]	Central Meditation and Imagery Therapy for Caregivers (CMIT-C)	Therapeutic	Reduce psychological distress	Psychological distress, anxiety, depression, and insomnia reduces

Study*	Intervention Content	Intervention Type	Desired Outcome Stated	Impact
[9]	START (Strategies for relatives)	Therapeutic	Improves caregivers' moods and QoL	Improved mood, QoL, & subjective burden
[10]	START (Strategies for relatives)	Therapeutic	Clinical effectiveness (anxiety, depression, QoL) and cost-effectiveness	Improved depression and anxiety over 72 months and were cost neutral
[11]	CBT online intervention	Therapeutic	Reduce depressive symptoms, decrease caregiver burden, cope better with predeath grief, & utilise psychosocial resources	Well-being increased. Improved coping with anticipated death. Increased use of psychosocial resources
[12]	New York University Caregiver Intervention (NYUCI)	Therapeutic	Increased ability to withstand difficulties, prevent need for institutionalisation of dementia patient	Decreased depression and distress in caregivers. More sessions correlated to delayed nursing home placement.
[13]	Psychoeducation group program	Psycho-educational	Improve carer coping with stress & demands of caring	Sig improved burden, psychological distress & self-efficacy. Group format beneficial, reduced isolation and increased social support
[14]	Manualised 2-day intervention	Therapeutic	Reduce depressive symptoms, anxiety, perceived stress, & burden	Sig reduced perceive stress Reported helpful in managing problem behaviours
[15]	Early Diagnosis Dyadic Intervention (EDDI) USA	Therapeutic	Improve self-efficacy outcomes to increase positive outcomes for individual with dementia	Quantitative data showed no significance in self-efficacy findings
[16]	Active psychoeducation (AP)	Psycho-educational	AP more efficacious than passive psychoeducation, improved competence, skills, reduced burden & distress about problem behaviours	All three measures (competence, burden, and distress) showed significantly better levels in active psychoeducation
[17]	Family InterventionTele-phone tracking-caregiver (FITT-C)	Psycho-educational	Decreased depression & burden. Improved reaction to problem behaviours, self-efficacy, family functioning, & HRQoL	Sig improved depression & reaction to problem behaviours
[18]	New York University Caregiver Intervention (NYUCI)	Therapeutic	Better social support improves carer ability to withstand difficulties and delay need for institutionalisation of dementia patient	Depressive symptoms reportedly reduced
[19]	C-SMS Program (Caregiving self-management support)	Peer-support	Improve HRQoL & self-efficacy of caregivers	Reported stronger self-efficacy, improved HRQoL, improved efficacy in stress management

*As numbered and depicted in Table 1 and text above

Chapter 5: Discussion and Conclusions

Introduction

In the following chapter, the results of the research are discussed and the limitations, recommendations and conclusion of the research are drawn. An overview of the topic and findings is briefly conferred, followed by a structured approach to discussing the research findings. The characteristics of the studies are discussed, including the study designs, publications per year, the target caregivers, and the interventions used. Following this, aspects impacting the accessibility of interventions are discussed, such as the location of the studies, the setting, administration requirements, and timeframes of the interventions. To complete the discussion, the intervention approaches and the intervention outcomes are discussed. The chapter ends on the presentation of the research limitations and recommendations, and a conclusion is drawn.

Discussion

In consideration of the chronic, progressive nature of dementia and the increasing prevalence of the disease, it is understandable that the demands the disease creates are large. Those caring for individuals with dementia face intense daily challenges in their role and are at a significant disadvantage through risking their personal health, both physiological and psychological (Gilhooly et al., 2016; Ma et al., 2018). It should be noted that worldwide it is informal caregivers, mostly family members, who are taking on this role and risking their health (Nay et al., 2015; Wimo et al., 2018). Not only are the physical demands high, but the psychological and social challenges are also especially increased when it is a loved one who is experiencing a progressive illness. While care demands increase, the support usually received from the loved one, whether social, financial, physical, or otherwise, will decrease because of the progressive development of dementia (Cheng, 2017; Prince et al., 2015).

These caregivers face increased burden of care, heightened levels of depression, an impaired quality of life, psychological distress, and various other mental and physical health impacts (Prince et al., 2015). Previous reviews have shown a range of psychosocial interventions that have been created and studies for their efficacy in addressing different mental health issues faced by dementia caregivers (Laver et al., 2017; Tang et al., 2016). The reviews have drawn conclusions in support of the available psychosocial interventions and the impact that they have on varying mental health aspects of dementia carers. In order to better grasp the present evidence about psychosocial therapies for dementia carers, it is crucial to examine the

published studies on this subject. This review's objective was to examine psychosocial interventions designed for those who provide care for people with dementia. In meeting these objectives, three concepts were focused on: the content of current intervention research, the approach to the delivery of an intervention, and the outcomes of the respective psychosocial interventions among carers.

The present scoping review entailed a comprehensive search of electronic databases which resulted in the selection and analysis of 19 articles exploring psychosocial interventions for dementia carers. Within this review, four key themes were identified: the study characteristics, the accessibility of interventions, the intervention approach, and the intervention outcomes.

Study Characteristics

The first theme that was identified in the current review was how each of the studies approached the fundamentals of research. The approaches were categorised as study design, publication year, target caregivers, and interventions.

Study Design

The studies included in this review tended towards a quantitative methodology (68%), with three using a mixed-methods approach and three studies using a qualitative methodology. The focus on quantitative study designs has produced robust research based on numerical values and controlled designs to examine a phenomenon (Rutberg & Bouikidis, 2018). Through terms such as caregiver burden and depression, the quantitative research has shown correlations between the use of psychosocial interventions and the intervention's favourable or unfavourable effects on the carer. There is, however, a limit to quantitative research which does not explore the lived experiences and human perceptions of the relationship demonstrated (Mey, 2022). The qualitative research design focuses on the lived experiences and human perspectives which influence the relationship between two variables, such as psychosocial interventions and their outcomes (Mey, 2022; Rutberg & Bouikidis, 2018). Additionally, mixed method study designs reviewed worked to both demonstrate the relationship between the variables as well as to explore the human contextual factors which influence the relationship (Rutberg & Bouikidis, 2018). The incorporation of qualitative data supplements the numerical and statistical results of quantitative studies which works to enhance the findings and resultant understandings of a field of study (Mey, 2022). The field of research would be enhanced by an increase in qualitative and mixed methods studies to compliment the qualitative data.

Publications Per Year

From the results, there was a notable trend in the publication of research relating to the field of caregivers for individuals with dementia. Studies in the field were being published at a moderate rate from 2013 to 2017, and then increased from 2018 to 2020, which demonstrates the increased awareness of the need surrounding concerns of a growing elderly population, of growing dementia numbers, and of growing demands in dementia care (Cheng, 2017). In 2017, the World Health Organisation published *The Global Action Plan on the Public Health Response to Dementia* which provided a directed and researched approach to improving the global approach to dementia patients, caregivers, and families while also addressing the impact of the growth of the individuals with dementia population (WHO, 2017). Publications at this time tended to focus on the global rise of dementia, the impact on global healthcare facilities, costs, and importantly the skewed impact on LMICs, which face higher numbers of dementia (Abudu-Birresborn et al., 2019; Werner et al., 2017; WHO, 2012).

Population ageing and the continued increase in dementia evidently was, and continues to be, a global concern (Chang et al., 2019; Suzman et al., 2015). The field of research in areas of dementia and Alzheimer's disease is expansive, with continued research in both biomedical and lifestyle approaches to the disease (Demurtas et al., 2020; Rashid et al., 2021). There is evidence of a current focus on the integration of medical, lifestyle, and psychosocial approaches in the prevention, treatment, and management of dementia (Vernooij-Dassen et al., 2019; Livingston et al., 2020a). The statistics predicting the prevalence of dementia to triple by 2050 (Werner et al., 2017) is a notable concern which could explain both the continued publications in 2013 to 2017 and the raised number of research publications between 2018 and 2020. However, in 2021 and the beginning of 2022 (when this review search was conducted), there was an evident decrease in articles being published after the trends seen in 2018, 2019, and 2020. From a closer look at the articles published in 2020, and which is commonly seen in research processes, the research tends to have been completed in 2019 and published in 2020 after review and publication processes. It can be hypothesised that the reduction in research being conducted and published from 2020 onwards was related to the global outcomes and effect of the COVID-19 pandemic rather than a loss of interest in the prevalence of dementia.

Target Caregivers

Due to the significant care requirements that dementia produces (Lin & Lewis, 2015; Shah et al., 2016), the majority of those with dementia depend on part-time or full-time care (Wimo, 2018). As background research has shown, the majority of dementia caregiving is done

by informal caregivers who tend to be either the partner or a family member of the dementia patient (OECD, 2018; Prince et al., 2015). Of the 19 research papers utilised in this review, all implemented a psychosocial intervention for informal dementia carers. Only one study considered formal caregivers, and they were included with a majority of informal caregiver participants rather than being the focus of a psychosocial intervention. This study by Tang and colleagues (2018) explored active compared to passive psychoeducation as an intervention, and included a substantial group of formal caregivers who were hired to perform caregiving tasks. However, of the hired caregivers, all were related to the individual with dementia, and were still considered a family caregiver. While the difference between an informal and formal caregiver stem from their received training and employment to perform their role, in considering dementia caregiving, the vast majority of caregiving is evidently done by family caregivers (Adedeji et al., 2022; OECD, 2018).

In considering the demanding, near 24 hours a day work performed by unpaid, informal caregivers, the burden is further increased by the fact that informal caregivers are in the majority family members or friends of the individual with dementia (Nay et al., 2015; Prince et al., 2015). Dementia presents with neuropsychiatric symptoms, disruptive behaviours, and mood disturbances, all of which are demanding to manage from a caregiving perspective and from the perspective of witnessing a loved one's progressive deterioration in normal functioning (Cheng, 2017). The combined challenges of caregiving as well as a personal connection to the care recipient increase the risk factors to the caregiver's health, QoL, well-being, and the carer-recipient relationship. This is a clear indication of the importance of support being made available to informal caregivers, and that continued support can impact the areas of QoL, well-being, and caregiver recipient relationships.

In addition to the challenges currently being faced by caregivers (Wimo, 2018; Adedeji et al., 2022), is the consideration of the growth in dementia worldwide (WHO, 2022). From a global evaluation, informal caregivers take on a large share of the expenses which come as a result of caring for someone with dementia (OECD, 2018). An estimate of the proportion of individuals with dementia receiving care at home is 84%, as opposed to those receiving care from other institutions (Wimo et al., 2018). The difference in percentage costs across HICs and LMICs is significant, where 40% of the expenses associated with dementia care are paid for by the informal caregivers in HICs while 70% to 90% of the expenses associated with dementia care are paid for by informal caregivers in LMICs. In considering this large proportion, the content focus on informal caregivers is considerable and necessary to advance the research and

contextual understanding of dementia care. Furthermore, from a LMIC perspective, this focus on informal caregivers is vital as it accounts for the overwhelming majority of care.

Interventions

According to the review, the majority of the studies used an already developed intervention (n = 15). The researchers either replicated an established intervention or adapted such an intervention for an altered context such as a different location, different language, or a different setting of delivery. Of the few studies that developed a new intervention for the study (n = 4), the interventions were grounded in theory and developed from a knowledge of evidence-based practices, such as imaginal self-modelling, imagery rehearsal, and mental contrasting, to develop the CMIT-C intervention [8]. By applying the empirical evidence and theory of established interventions as a foundation, it can allow for the sound development of interventions as demonstrated in Intervention Mapping frameworks by Bartholomew and colleagues (1998). Intervention Mapping demonstrated the process of intervention development through a stepped process of identifying general principles and procedures, utilising theory-based methods, and developing an intervention based off of this, with specified adaptations and evaluations (Kok et al., 2016).

Accessibility of Interventions

The second theme identified in this review was the importance of accessibility of the interventions. Various elements of an intervention can work to make the intervention more accessible across a variety of populations, such as the location of the study, the setting of the intervention, the administering requirements, and the time frames of the intervention. For an intervention to be accessible to the population, adaptations are required which are tailored to the needs of the target population (Kenning et al., 2017). Research shows that adaptations at a service level only, such as directly translating current information, is not adequate and targeted adaptations need to be incorporated, in which information is restructured in socially and culturally acceptable ways (Kenning et al., 2017). Additionally, current literature is exploring virtual access to interventions, such as online or telephone based interventions, in attempts to increase accessibility for individuals in remote or rural areas, with limited transportation, or time constraints [2, 11, 17].

Study Location

It is evident that the ageing population is growing worldwide, and this population is expected to continue in an exponential growth rate in coming years. The reported statistics have

shown the exponentially increasing elderly population within African countries as well as the high rates of dementia diagnoses within African countries (WHO, 2012; Wan et al., 2020; Stats SA 2020). The research further shows concerns around the impact of an increase in dementia on individual's DALYs and the demand on healthcare resources (Avan & Hachinski, 2021). Yet, despite the predicted growth, inadequate attention has been paid to research in LMICs, particularly across the African continent.

The absence of studies which relate to LMICs and the African context could be due to factors such as a lack of resources, unemployment, and poverty, which limit the general availability of research in the continent (Tirupakuzhi Vijayaraghavan et al., 2022). Additionally, studies which focus on other areas of need within the countries may be prioritised. Currently within South Africa, the WHO Co-operation Strategy prioritises health concerns around communicable diseases such as tuberculosis, HIV, influenza, and pneumonia, as well as non-communicable diseases, such as hypertension, cardiovascular disease, and diabetes (WHO, 2018). Consideration of these focus points and recommendations from the WHO encourage the continued prioritisation of other studies. The need for dementia carers will, however, rise rapidly as a result of the exponentially fast-growing elderly population in African nations and the rising incidence of the disease.

In considering how cultures and norms vary across populations, it is crucial to explore and understand how a population might experience and respond to different constructs and interventions due to cultural differences. The current literature argues that an intervention developed for and tested on one population may not be effective when applied across other cultures, yet the costs and time needed to develop studies across all populations and cultures would be high (Day et al., 2023). The study by Chen and colleagues (2015), however, discusses the existing evidence of psychosocial interventions for dementia caregivers being successfully adapted for other cultures and educational backgrounds. As a country, South Africa has a uniquely diverse population with a variety of cultures which influence experiences in different ways. While Western cultures tend to emphasise biological and intrapersonal considerations, African cultures tend to emphasise environmental and interpersonal considerations (Chentsova-Dutton & Lyons, 2016). Concepts, interventions, and outcomes cannot always be generalised as universally accepted across countries, as the variations across populations and cultures influence the individual's lived experiences and can impact how concepts and interventions are received as well as possible outcomes (Barrera & Castro, 2019; Cardemil, 2015). It is therefore important to promote location-specific research as the lack of availability

of research around the elderly, dementia, and dementia care in Africa can limit the accessibility of interventions for the population.

Within this review, the only study which met inclusion criteria and was not conducted in a High Income Country was based in China, which is considered an Upper-Middle Income Country. The study in China utilised support groups for caregivers, which showed positive outcomes in measures of self-efficacy and QoL and was an appropriate intervention to the population [19]. In addition, a study by Czaja and colleagues (2013), included in this review, attempted to target disparities within a lower income context as well as individuals from an ethnic or cultural minority. The study was based within the United States of America, which is a high income, well-resourced country, but it focused on a sample from a lower socio-economic class and on minority caregivers [2]. The study adapted an intervention to overcome disparities in accessibility that caregivers in a lower socio-economic class face, and produced successful results in implementation and outcome measures [2]. This study shows the possibility of adaptability of the intervention to a context such as South Africa, but cannot alone account for the generalisability of an intervention. It does, however, support further research into this intervention in a LMIC context.

Intervention Settings

The majority of studies in this review demonstrated an intervention conducted in an in-person setting in which the intervention administrator and the recipients, in this case the caregivers, meet in a face-to-face setting. There was variation in that the in-person location was at the caregiver's home, the home of the person with dementia, at the researcher's university campus, at community centres, or at dementia support centres. The location specific setting is an important consideration when developing and implementing an intervention. Previous studies have shown that, irrespective of whether a caregiver had accessed a psychosocial intervention or not, the perceived ease of accessibility of psychosocial interventions is very low, with most caregivers portraying a negative appraisal for ease of access (Teles et al., 2021). Many factors, such as limited means of transport, physical restrictions, rural areas, and the role requirements in providing care, make accessing an in-person intervention difficult (Tremont et al., 2015). Notable in a LMIC context such as South Africa, the same barriers would be faced by the caregiver along with the barriers created by limited resources in healthcare (Maphumulo et al., 2019). A few of the studies included in this review considered virtual approaches to psychosocial interventions as a means to increase accessibility and reach of interventions to dementia caregivers. The use of telephone-based counselling by some studies was explored to

increase the availability and reach of interventions while also reducing costs, and showed positive outcomes regarding well-being, utilisation of psychosocial resources, and burden [2, 3, 17]. Other virtual studies made use of web-based approaches to address barriers of intervention accessibility in terms of transportation and time restraints, which similarly showed positive outcomes in perceived support, increased utilisation of psychosocial resources, and improved well-being [4, 11].

Intervention Administering Requirements

Of the identified studies, all were administered by trained professionals, except for two studies which utilised a self-administered intervention. This means that in considering the use of the intervention and replicating results, administrators would need to be health professionals, trained professionals, or receive adequate training before being able to deliver the intervention. Similarly, this is an important consideration with regard to the accessibility and feasibility of an intervention, especially in LMICs where healthcare and human resources are limited (Maphumulo et al., 2019).

Typically, psychosocial interventions have been developed on the basis that they will be administered by mental health professionals. This ensures best practice, professional and appropriate implementation, and is considered an application of high-quality care (Jack et al., 2014). Realistically however, there are not enough resources available in healthcare systems to promote the continued application of interventions by advanced mental health professionals (Livingston et al., 2013; Mendenhall et al., 2014). The limitations of, and demands on, human resources and financial resources, increases difficulty with accessing psychosocial interventions in healthcare (Javadi et al., 2017). The reduced access to human resources leads to the need for interventions to be administered by individuals with less training, including lay-counsellors or peer-support workers (Keynejad et al., 2018) or even students as noted in this review.

The study by Livingston and colleagues (2013) addressed the demand in the United Kingdom (UK) context where typically only clinical psychologists were providing effective therapies and interventions. Policies within the UK describe a stepped care approach which works to increase access to mental healthcare by allowing graduates under supervision to provide less intense therapeutic interventions (Livingston et al., 2013). Within this review, the study by Livingston and colleagues (2020b) [10] utilised a stepped care approach and the intervention was administered, reportedly successfully, by graduates without specific clinical training. This study shows that the administration of a successful intervention potentially does

not have to rely on a highly trained mental health professional, and that the utilisation of a stepped care approach may work to increase the accessibility of interventions.

However, these students were still to an extent highly trained in that they were university graduates with a degree in psychology. In a LMIC where access to tertiary education and healthcare resources are limited while demand is high, a level of training requiring a university degree is still a large barrier to the accessibility of an intervention. From the studies in this review, accessibility in a LMIC such as South Africa could be increased through interventions which are self-administered such as the technology adapted REACH II intervention [2] or the My Tools 4 Care intervention [4]. Self-administered interventions can work to counter the limited physical and human resources within the healthcare system, but they do not address the limited resources faced by individuals within these contexts, such as limited access to technology, limited technological literacy, electricity, and time (Kruse et al., 2019).

In South Africa, a task-shifting approach has been encouraged with regard to managing healthcare demands. Much like the stepped care response utilised in the UK, a task-shifting approach works similarly to reassign clinical roles by moving the tasks to different divisions of healthcare workers (Javadi et al., 2017). Systematic reviews of literature across task-sharing support this as a valid approach to positive healthcare outcomes where tasks have been shifted to nurses, lay counsellors, or community-based healthcare workers (Daniels et al., 2019; Lewin et al., 2005; 2010). This approach has been successfully implemented in the healthcare approach to HIV treatment and was effective in counteracting the shortages of human resources in healthcare (Callaghan et al., 2010). Within the context of South Africa, self-administrated interventions may be a viable approach in increasing accessibility to some extent. However, by incorporating a task-shifting approach and training lay counsellors or community workers, it could address the limitations of technology inaccessibility.

Time Frames

In further considering the methods of delivery of the studies aligned with accessibility and feasibility, the time frame of administration is a crucial consideration. There are three time-frame considerations, the length of time per session, the number of sessions, and the number of weeks or months over which the intervention takes place. In considering accessibility from a resource perspective, a study with positive outcomes from fewer sessions over the shortest length of time would reduce burden and demand on the administrators of the intervention, as well as reduce costs (Rice et al., 2020; Perlini et al., 2020). Previous studies have similarly

found that time constraints faced by the caregiver was a primary barrier to accessing an intervention (Qui et al., 2019). Within this review, eight-week interventions were the most common (n = 5), followed by 13-week interventions (n = 4). The interventions with an eight-week time frame reported improvements across outcomes of perceived stress, anxiety, depression, QoL, and burden. The interventions with a 13-week time frame similarly reported improvements across outcomes of QoL, competence, burden, distress, and self-efficacy. While different outcome improvements are noted, the difference is seen in the outcomes targeted and measured by the study, and not necessarily due to the impact of the time frame.

In considering accessibility and feasibility, it would be beneficial to understand what amount of time in terms of hours, days, or weeks, would be the most viable to result in a successful intervention (Qui et al., 2019). Further studies which explore as well as quantify the impact on outcomes and differences experienced across interventions with shorter to longer administration periods could provide an understanding which impacts the development and most beneficial implementation of interventions.

However, in considering outcomes from the perspective of time frames, accessibility would channel considerations towards the most effective interventions in the shortest time frame. Another consideration is the importance of on-going support and its impact on caregivers. In this review, one of the means by which caregivers were provided with support was via informational handbooks or websites with information on dementia, dementia caregiving, and coping skills [2, 3, 4, 6, 11, 13, 15, 19]. The outcomes of these interventions suggest the impact that support, and the continuation of support, for caregivers can have on their quality of life, well-being, and self-efficacy

Intervention Approaches

In reviewing the studies, a theme emerged pertaining to the categorisation of interventions in accordance with the principal concepts they apply in the development and implementation of the intervention. Aligned with the data collated in the literature review (Chapter 2) the interventions included in this review were diverse in their content, procedures, and implementation. Based on the core concepts of the intervention, such as the theoretical or practical approach of the intervention, they were divided into subgroups, namely, psychoeducational, therapeutic, and peer support.

The psychoeducational approaches include psychosocial interventions which prioritise the use of psychoeducation for the caregiver in their understanding and application of the intervention [2, 4, 6, 7, 13, 16, 17]. An intervention based on psychoeducation would typically

include a structured programme which aims to provide the participants with education and informational material, and some include an element of advice about target problems (Ghosh et al., 2022). Within caregiving, the psychoeducational intervention typically incorporates an aspect of working to improve the caregiver's coping strategies and help-seeking behaviours for future problems they may encounter (Cheng et al., 2019).

Psychoeducational based approaches are among the most commonly used methods in interventions and have continued to produce promising results (Zabalegui et al., 2014). Previous study results have shown improvements in caregiving abilities, improvements in depression, and reduced caregiver burden (Zabalegui et al., 2014). As seen in this review, the psychoeducational interventions reported improvements in outcomes for depression, caregiver burden, caregiver's utilisation of resources and social support, distress, mood and well-being, self-efficacy, reactions to problem behaviours, perception of caregiving experience, caregiver appraisal, caregiver attitude, and competence [2, 4, 6, 7, 13, 16, 17]. The aspect of psychoeducation has been continually presented as a crucial part of psychosocial intervention for dementia carers. Through the provision of education about dementia, how to care for someone with dementia, and incorporating the psychological aspects that target caregiver health concerns such as burden, depression, and distress, a comprehensive form of intervention is provided.

As stated above, psychoeducation-based interventions have tended to be the most popular approach to providing support to caregivers of individuals with dementia (Zabalegui et al., 2014). However, this approach is limited in that providing standard information can only account for partial areas of support, while the utilisation of intervention approaches based on therapeutic theory and intervention allows for the emotional needs of the caregivers (Cheng et al., 2019). As can be seen in the results of this review, a large variety of outcomes were measured and reported on to reflect the success or limitations of an intervention. The impact of the interventions on the outcome measures varied across intervention approaches.

Therapeutic approaches are at a relatively early stage of their development and use (Cheng et al., 2019). The therapeutic approaches include psychosocial interventions which align with therapeutic theories and practices in their implementation. Therapeutic approaches, in general, vary largely in theory and approach, and therefore the therapeutic based interventions are more variable than other approaches which further complicates and prolongs their development and study (Cheng et al., 2019). Further research on the mechanisms of therapeutic approaches is needed to further refine the therapeutic element of psychosocial interventions.

The therapeutic-based approaches were further categorised into counselling and psychotherapy approaches, combined approaches, and mindfulness-based approaches due to their variability. Previous studies have shown improvements in caregiver distress and depression through counselling and psychotherapy and combined approaches, while mindfulness-based approaches tend towards reducing depression, rumination, stress, and anxiety (Cheng et al., 2019; Dickinson et al., 2017). As seen in this review, the therapeutic interventions reported improvements in outcomes for depression, caregiver burden, caregiver's utilisation of resources and social support, distress, mood and well-being, anxiety, self-efficacy, QoL, stress, reactions to problem behaviours, experiential avoidance, insomnia, mindfulness, intervention satisfaction, and caregiver grief [1, 5, 8, 9, 10, 11, 12, 14, 15, 18]. It can be argued that the element of emotional support and psychological health promotion that therapeutic interventions provide are crucial for psychosocial interventions for dementia caregivers.

The peer support interventions encompass a small category of this review with only two studies utilising peer support as their primary approach. Notably, while the two peer support interventions had variability in their outcome measures, both interventions measured the quality of life for caregivers and reported improvements across QoL measures [3, 19]. Improved outcomes were singularly reported for distress and self-efficacy. However, other studies, both psychoeducational and therapeutic, incorporated peer support in their intervention approach, and the element of support for caregivers is crucial. Peer support-based approaches present an intervention which have shown positive impacts on areas of psychosocial outcomes and providing support, while also being accessible through limited long-term reliance on healthcare professionals and medical insurances or medical expenses (Dichter et al., 2020).

Intervention Outcomes

The fourth theme that emerged from the review pertained to the outcomes reported from the interventions explored within this research. This research review followed a scoping review methodology, and thus no meta-analyses were conducted on the statistical significance of findings and outcomes of the reviewed studies' interventions. Caution therefore should be used when considering the statistical significance of the results discussed and comparisons made. Studies with reported positive outcomes, such as in qualitative designs, as well as reported statistically significant positive outcomes are considered further.

Most of the interventions included in this review are complex and their processes are multifaceted. This complexity makes it difficult to compare the interventions to each other or

to compare the impact of their outcomes (Higgins et al., 2019). A component that further complicated comparison is the different instruments the studies used to measure outcomes. Two scales which were more frequently utilised were the ZBI to measure caregiver burden (*n* = 6) and the CES-D to measure depression in caregivers (*n* = 6). Other than these two measures, a large variety of scales were used to measure outcome. As there is no common scale across the outcomes, the comparison between reported outcomes is inconsistent and unstandardised. The use of different measuring constructs poses a challenge determining programme efficacy in the endeavour to establish best practice (Higgins et al., 2019; Schünemann et al., 2019). Studies to compare such outcomes, such as in meta-analyses, within which different scales have been used to measure the same construct require alternative methods to standardise a mean difference, utilise a ration of means, or alternative effect measures (Schünemann et al., 2019). Future studies which compare the outcomes of various interventions from the measurements of the same scales would benefit a future analysis comparing the outcomes of the various interventions.

Similarly, analysing the outcomes of these studies is further complicated by the number of outcomes considered, as well as the variability in outcomes considered across the studies. Whether therapeutic, psychoeducational, or peer support interventions were used, the outcomes varied and were not consistent within intervention type. The diversity of intervention focus points may stem from the complexity of the job of providing care for an individual with dementia. The job of caregiving is psychologically as well as mentally demanding, due to a lack of knowledge about the condition, how it impacts the elderly, what to expect and how to manage it all (Cantekin et al., 2016; Cheng, 2017).

There is evidence of the development of psychosocial intervention for dementia carers which have had successful results, as can be seen in this review as well as previous studies in the field (Wiegelmann et al., 2021). However, it is also evident that there is a paucity in the implementation and accessibility of psychosocial interventions for current caregivers, where studies have shown as few as 3% of developed interventions were implemented among caregivers (Gitlin et al., 2015). It can be reasoned that the limited availability of interventions can be due to factors such as a lack of understanding of mental health conditions, uneven distribution of resources across countries, and healthcare inaccessibility (Collin et al., 2011). However, uncertainty around the availability, real world benefits, and demands required in their implementation can all be considered an added barrier.

From the outcomes of the studies included in this review, it is evident that there is uncertainty about the outcomes and related benefits to the recipients of the interventions. with

regard to Table 2 in this study, an overview of the desired outcome pursued by the interventions and the actual impact of the intervention does, however, show positive results. Each study reported at least one positive outcome as a result of the intervention such as decreased burden, or increased health-related QoL. From this it can be deduced that there are effective interventions available which have shown positive improvements on some areas of mental health for dementia caregivers. However, most of the included interventions aimed to improve multiple areas of the caregivers' experience, but many were only able to reflect improvements in some areas. Furthermore, many of the studies report a lack of statistically significant differences in their comparisons of intervention outcomes to the control group or baseline group. Future studies, such as a meta-analysis of the data, would provide the basis to develop an in-depth understanding and valid comparison of intervention outcomes and their effectiveness. This would allow researchers to draw a more accurate and valid conclusion around the benefit and impact of the psychosocial interventions being produces.

In deliberating all of the constructs considered across the interventions, the most prominent constructs measured were that of caregiver burden and depression and, as outlined earlier, most studies reported significant, or some level of, improvements in this regard. The psychoeducational interventions more frequently considered the outcome of caregiver burden and showed greater improvements in this regard. The therapeutic based studies considered and showed improvements in measures of depression in caregivers. The peer-support based interventions tended to measure and show improvements in measures of QoL [3, 19].

Conclusion, Limitations, and Recommendations

In this final section, a conclusion of the result findings and discussion will be presented. There were four themes which emerged from the thematic analysis of the studies reviewed which related to the research questions presented. This will be followed by a reflection on the limitations of the presented scoping review and the recommendations that follow. In addition, the ethical considerations of conducting a scoping review are discussed.

Conclusion

The scoping review presented aimed to explore psychosocial interventions for dementia carers. To achieve this, the research first explored the content of current research focused on psychosocial interventions for dementia carers. Following this, the methods of delivery utilised in the intervention and the resultant outcomes reported by the intervention were similarly explored. Of articles searched, 19 articles satisfied the inclusion criteria of the present review,

and were analysed for themes relating to the current research aims and research questions. Four themes were identified, reported on, and discussed in this study, namely; the study characteristics, the accessibility of interventions, the intervention approach, and the intervention outcomes.

The first theme considered the design of the studies included, and found trends in quantitative based research being more common, in research in the field growing prominently from 2013 and then declining drastically from 2020, in informal, and predominantly family, caregivers being the target of most interventions, and in most interventions explored being based on previously developed interventions. The second theme considered the accessibility of interventions, wherein the overwhelming majority of interventions were based in high-income countries with none based on the African continent, most were conducted in an in-person setting, all were administered by trained professionals, and tended towards eight- to thirteen-week long interventions requiring one to two hours per session. This theme showed the trend in accessibility to be more suited towards high-income countries due to the need for physical and human resources.

The third theme reflected the approaches of the interventions based on the principle concepts they utilise in the development and implementation of the intervention. The interventions could be categorised into subgroups, namely psychoeducational, therapeutic, and peer support. The fourth theme considered the outcomes of the interventions explored and reported in the studies. The scales and measures used to report outcomes varied greatly across the interventions, and limited the comparison of outcomes between interventions. Yet, across the interventions, the most prominent constructs measured and reported on were that of caregiver burden and depression.

This review demonstrates how intervention programmes are able to enhance the mental health of informal carers of dementia patients. In summary, it seems that psychoeducational interventions had better outcomes in caregiver burden while the therapeutic based studies impacted on depression in caregivers. Elements of peer-support showed improvements in caregiver quality of life and well-being. These findings suggest that a hybrid, holistic approach of therapeutic based interventions which incorporate psychoeducation and on-going peer-support would better be able to address the wide range of mental health and education needs faced by dementia caregivers.

Limitations

The following limitations were considered in this review;

- The goal of this study was to assess psychosocial treatments for dementia carers, hence literature on interventions from other perspectives, such occupational therapy and pharmaceuticals, was omitted.
- Only studies published in English were included in this review.
- Databases that were made available to the researcher through the university resources were utilised, and some important health databases might therefore not have been incorporated as they were not readily available to the researcher.
- This review gave a summary of the available research on psychosocial interventions for dementia carers which does not include a statistical appraisal of the literature, nor assessment of risk of bias. It is recommended that future research be conducted in the form of a systematic review and meta-analysis as the results would allow for a more rigorous comparison across the interventions.

Recommendations

Based on the growth of dementia and the demands of dementia caregiving, it is important that research in this domain is regularly updated and improved. This scoping review has identified key themes relating to the area of research within psychosocial interventions for dementia caregivers. In utilising the aims stated in this research, and the key themes identified, further recommendations can be made.

Future research should endeavour to supplement quantitative data with qualitative data. By incorporating more qualitative data, it would strengthen the numerical data gathered and enhances the findings and understandings of the field of study. Additionally, there is a notable need for studies to be conducted in LMICs, and a heightened need for research across the African continent. With the exponentially growing elderly population and dementia in the African continent, interventions that have been studied within the context of the target caregivers will be vital. If the fields of study around the elderly, dementia, and dementia care in Africa are neglected, it can have a disadvantageous impact on the population and efforts to make any interventions accessible. Some studies have shown the adaptability of interventions to a varying context, but cannot alone account for the generalisability of an intervention to a country like South Africa. It does, however, support further research into this intervention in a LMIC context.

Previous studies have shown the negative perception caregivers have around the accessibility of psychosocial interventions. Further research into the accessibility of support and related interventions for caregivers is needed aligned to their respective needs and

contextual realities, for example, to explore virtual study settings (for example web-based or telephonic interventions). In addition, the accessibility of interventions is further limited by the current trend of needing highly trained professionals to administer psychosocial interventions for caregivers. Studies which explore self-administered interventions can work to counter the limited physical and human resources within the healthcare system. Similarly, a task-shifting approach could be considered, as outlined earlier. The task-shifting approach proved successful in other areas healthcare, such as the HIV epidemic. By promoting research that explore the effectiveness of a task-shifting approach, especially in a South African context, may lead to better understanding of improving accessibility of psychosocial interventions for a population in dire need of such, without the limitations of technology.

In considering further accessibility and feasibility of interventions for caregivers, it would be beneficial to understand the optimal delivery mode in terms of best times in a day and the number of hours, days, or weeks for an intervention to be successful among this population. Future studies that explore these aspects across interventions could improve the understanding of feasibility and efficiency over different duration.

Finally, from the current research available, and the research done in this review, a generalised comparison cannot be drawn from the intervention outcomes due to the abovementioned variability between the outcome focus measured and the instruments utilised in this regard. This limits definite conclusions about which type of intervention and mode of delivery has the best treatment outcome for dementia caregivers. Within this field, further research is still needed, for example, studies that conduct more detailed analyses across the outcomes.

It is evident that the phenomenon of population aging will lead to an increase in dementia populations globally resulting in an increase in caring responsibilities and adoption of caregiver roles. This task, demanding both physically and psychologically, will continue to fall on informal volunteers, usually family members of the individual with dementia. Without the proper implementation of evidence-based, psychosocial interventions for those who take on a caregiving role for individuals with dementia, a large population of individuals will face negative physical and mental consequences. Psychosocial interventions which provide psychoeducation, therapeutic support, or peer-support are a crucial to protect and support the caregiver's health and wellbeing. As seen in this review, psychoeducation on the topic of dementia, caring for an individual with dementia, and caring for the self through this role in addition to therapeutic support in the form of counselling and mindfulness, and peer-based support such as support groups, show success in improving the health-related outcomes in

caregivers. This study reviewed and presented such psychosocial interventions, and demonstrated their positive impact across a variety of outcomes, such as improved caregiver burden, depression, QoL, distress, anxiety, and more. This review highlights the importance of not only providing support resources to the caregivers of individuals with dementia, but also the need for quality, evidence-based interventions that are accessible to a large audience of carers.

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Appendix

Confirmation of Exemption from Ethics Review

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

14 September 2022

Mrs Kelsey Nightingale (219039842)
School Of Applied Human Sc
Howard College

Dear Mrs Kelsey Nightingale,

Original application number: 00018844
Project title: Psychosocial Interventions for Caregivers of Individuals with Dementia: A Scoping Review

Exemption from Ethics Review

In response to your application received on 06 Sept 2022 , your school has indicated that the protocol has been granted **EXEMPTION FROM ETHICS REVIEW.**

Any alteration/s to the exempted research protocol, e.g., Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through an amendment/modification prior to its implementation. The original exemption number must be cited.

For any changes that could result in potential risk, an ethics application including the proposed amendments must be submitted to the relevant UKZN Research Ethics Committee. The original exemption number must be cited.

In case you have further queries, please quote the above reference number.

PLEASE NOTE:
Research data should be securely stored in the discipline/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours sincerely,

[redacted]

Prof Johanna Hendrina Buitendach
Academic Leader Research
School Of Applied Human Sciences