ADAPTING AND EVALUATING NAMASTE CARE FOR HOME USE

ADAPTING AND EVALUATING THE NAMASTE CARE PROGRAM DELIVERED BY CAREGIVERS OF COMMUNITY-DWELLING OLDER ADULTS WITH MODERATE TO ADVANCED DEMENTIA: A MIXED METHODS STUDY

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TITLE: Adapting and Evaluating the Namaste Care Program Delivered by Caregivers of Community-Dwelling Older Adults with Moderate to Advanced Dementia: A Mixed Methods Study

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LAY ABSTRACT

With the growing numbers of family and friend caregivers across Canada supporting people living with dementia at home, there is a need to better prepare caregivers for their role. The aim of this study is to adapt, implement and evaluate a sense-based, skill-building program called Namaste Care delivered by caregivers of older adults living with moderate to advanced dementia. First, workshops for caregivers were held to adapt the Namaste Care program for home use. Afterwards, 12 caregivers received training in using the adapted program and delivered the program for three months. Caregivers used the program at least twice a week as intended and delivered a variety of activities. The program improved relationships with persons with dementia. No significant changes for caregiver quality of life, positive beliefs of caregiving, burden, and confidence were found. Next steps are to further test the effects of the program in a larger trial.

ABSTRACT

Introduction: More than half a million Canadians are living with dementia and 260,000 of these individuals live at home. As dementia progresses, persons with dementia require more assistance from caregivers to meet their daily needs including stimulation and emotional support. However, caregivers receive little training in this role. Namaste Care is a program originally developed for use in long-term care homes promoting a structured routine, a slow pace of care, and multisensorial activities for persons with advanced dementia. The program has not yet been adapted or evaluated for use by caregivers of community-dwelling older adults with moderate to advanced dementia. The objective of this study is to explore the feasibility, acceptability and preliminary effectiveness of a version of Namaste Care adapted by caregivers.

Methods: A multiphase mixed methods design was used. In the adaptation phase, six caregivers participated in workshop sessions to adapt Namaste Care for home use. In the evaluation phase, 12 caregivers received training to use the adapted program. Surveys were used to collect data on caregiver quality of life, perceptions of caregiving, self-efficacy, and burden at baseline and 3-month follow-up. Qualitative interviews at 3-month follow-up were also completed to assess the acceptability of the program and implementation facilitators and barriers.

Findings: All caregivers used the program for a minimum of twice a week as planned and used a variety of program activities. The retention rate was 83%. Caregivers perceived that the program improved their relationships with persons with dementia. Implementation facilitators were receiving a Namaste Care Toolbox and written resources about Namaste Care. No statistically significant effects were found with regards to the outcome measures listed above.

Conclusions: The adapted Namaste Care program was feasible and acceptable for use by caregivers. There is a need to conduct a larger trial to determine the extent of its effects.

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LIST OF ABBREVIATIONS

ALC	Alternate Level of Care
C-DEMQOL	Carers-DEMentia Quality of Life scale
CI	Confidence Interval
LTC	Long-Term Care
PAC	Positive Aspects of Caregiving scale
QOL	Quality of Life
RN	Registered Nurse
RIS-SE	Relational, Instrumental, Self-soothing Eldercare Self-Efficacy scale
SD	Standard deviation
SMD	Standard Mean Difference
ZBI-12	Short form Zarit Burden Interview scale

DECLARATION OF ACADEMIC ACHEIVEMENT

This thesis is composed of four manuscripts presenting original research that have been published or submitted for publication. The manuscripts presented in Chapters 3 through 6 are co-authored. Marie-Lee Yous (PhD student) is the first author and contributed to the conception and design of the study, data collection and analysis of qualitative and quantitative data, mixed methods interpretation, and writing and revising of each manuscript. Dr. Jenny Ploeg (supervisor) contributed to the conception and design of the study, review of workshop session and interview transcripts, qualitative analysis process, and critical revisions of each manuscript. Two supervisory committee members, Drs. Sharon Kaasalainen and Carrie McAiney, contributed to the conception and design of the study, review of workshop session and interview transcripts, review of the analyses, and critical revisions of the manuscripts. Dr. Kathryn Fisher contributed to the review of the analyses and critical revisions of Chapter 6. The results of this thesis have been presented at 3 national and international conferences:

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CHAPTER 1: INTRODUCTION

More than 55 million individuals were living with dementia worldwide in 2021 (World Health Organization, 2021). The number of people affected by dementia is expected to double every two decades due to a growing global aging population with projections increasing to 75 million by 2030 (Alzheimer's Disease International, 2019). Age is a leading risk factor for dementia with a twofold increase in risk of acquiring dementia every five years following the age of 65 (Fiest et al., 2016). Dementia is an umbrella term used to define a group of symptoms caused by neurodegenerative diseases such as Alzheimer's disease, Lewy Body disease, Vascular Dementia, and Frontotemporal dementia (Alzheimer Society of Canada, 2018a). The symptoms affecting people living with dementia vary by stage and can include memory loss, difficulties with problem-solving, poor language comprehension, and loss of communicative abilities. Such symptoms have a significant impact on the ability of individuals to perform their daily activities. Dementia is a leading cause of disability worldwide and many older adults with dementia require support from others (World Health Organization, 2021).

In Canada, as in other parts of the world, dementia is a growing health concern with over half a million Canadians living with dementia (Alzheimer Society of Canada, 2018b). More than 260,000 Canadians with dementia are currently living at home (i.e., private residence in the community) (Canadian Institute for Health Information (CIHI), 2019a). In Canada, over 90% of people with mild dementia, 50% of those with moderate dementia, and 14% of those with advanced dementia are living at home compared to an institution (Chambers, Bancej, & McDowell, 2016). These proportions are not likely to change in the next few years due to long wait times for long-term care (LTC), the rising costs of LTC, and the desire of most families to care for people with dementia at home for as long as possible (McCurry et al., 2017). Older adults living in the community, either alone or with family, have many complex care needs. Approximately 20% of older adults with dementia living at home have severe cognitive impairment, 28% are dependent on others to help them meet their activities of daily living, 25% experience responsive behaviours, and 25% display symptoms of depression (CIHI, 2019a). Responsive behaviours may be exhibited by people with dementia who experience difficulties with language and communication. Responsive behaviours are defined as words, sounds, behaviours, or actions used to make a person's needs or concerns known to others (e.g., yelling, hitting, repetitive questioning) (Alzheimer Society of Canada, 2017; Draper, Finkel, & Tune, 2015). See Appendix A for a list of terms and definitions.

Many older adults with dementia living at home are dependent on their family and friend caregivers (hereafter referred to as caregivers) for support and care. Caregivers typically consist of individuals aged 18 years or older who provide help or care for an individual with a chronic health condition, physical or cognitive disability, and/or age-related problems (Turcotte, 2013). In Ontario, Canada over three million caregivers provide support and care for a family member or friend who is aging or has a chronic illness or disability (The Change Foundation, 2019). The type of help or care provided includes helping with personal care, providing emotional support, and providing medical care (Turcotte, 2013). The amount of care and support required to meet the needs of people with dementia can lead to burden for caregivers and increased costs for healthcare organizations (Etters, Goodall, & Harrison, 2008).

Despite the growing numbers of caregivers caring for older adults with dementia at home, most caregivers receive very little preparation and support in assuming the role of a caregiver. As a result, caregivers experience burden, depression, poor physical health and wellbeing, and low confidence levels in caring for older adults with dementia (Brodaty & Donkin, 2009). Caregivers have been found to resort to poor coping strategies when caring for people with dementia such as high use of medications for care recipients (Grace et al., 2016). This is due to greater functional impartment of care recipients as persons with dementia in the later stages experience greater emotional distress and responsive behaviours that are challenging to address. The features of advanced dementia include significant memory loss, minimal speech, loss of independent ambulation, and inability to complete activities of daily living (Mitchell, 2015).

There are very few psychosocial and educational interventions (e.g., leisure activities and exercise programs) that can be used by caregivers in the community to support those with more advanced forms of dementia (Clarkson et al., 2018). Many interventions target caregivers caring for people with early to moderate forms of dementia (Jensen, Agbata, Canavan, & McCarthy, 2015). Other interventions target caregivers caring for people with dementia across all stages of the illness (Clarkson et al., 2018). The needs of people at different stages of dementia vary and their caregivers therefore require tailored interventions (see Appendix A for a definition of stages of dementia).

In most studies, caregivers are not typically involved in the development of caregiver interventions for people with dementia, thus limiting the relevance of interventions (Burgio et al., 2009; Huang et al., 2013; Liddle et al., 2012; Llanque et al., 2015). There is also a need for interventions that measure positive aspects of caregiving such as improved relationships with others and confidence in providing care (Tarlow et al., 2004). These aspects lead to better quality of life (QOL), self-efficacy or competency, and mental health for caregivers (Quinn & Toms, 2018). There is a growing international recognition that Namaste Care is a program that may be suitable to be delivered by caregivers of people with advanced dementia living in their homes (Simard, 2013).

Namaste Care Intervention for Older Adults with Advanced Dementia

Namaste Care is a psychosocial, multisensory program that was developed in a LTC home in the United States to improve the QOL of individuals with advanced dementia, their families and friends, and healthcare providers (Simard, 2013). The principles of Namaste Care consist of improving QOL through a comfortable environment and an unhurried, loving touch approach (Simard, 2013). Namaste Care combines different modalities including creating a comfortable environment through music, massage, socialization, aromatherapy, and snacks (see Appendix B for an overview of Namaste Care). The program provides practical skills for families and healthcare providers to meaningfully engage people with dementia in activities.

Namaste Care sessions are offered in a private room with soft lighting and no interruptions. In LTC settings, the sessions are provided daily in the morning and afternoon and typically last about two hours at a time. Residents with dementia are brought to a room where relaxing music is playing and soothing scents (e.g., lavender, seasonal scents) are diffused. Care providers offer one activity at a time for each resident. Namaste Care incorporates principles of touch to provide stimulation for persons with dementia and healthcare providers provide tactile activities throughout the session such as hand/foot massages, applying moisturizing cream, and brushing hair. Depending on the preferences of residents, they may show photo albums, sports games on a computer tablet, or sing with the resident. Family members and healthcare providers are expected to share life stories related to the care recipient and speak to the person with dementia throughout the session. Persons with dementia are provided with a Namaste Care sensory box that has unique items based on preferences such as lotions, life-like dolls, plush animals, and balls to provide sensory stimulation. Throughout the Namaste Care program persons with dementia are being monitored by caregivers and healthcare providers for signs of pain and discomfort (Simard, 2013).

Namaste Care has now been used internationally in various settings including LTC, hospice, acute care, and home settings (Simard, 2013). Namaste Care has resulted in positive changes such as reduced use of antianxiety medications and psychotropic medications, lower risk of delirium, lessened pain symptoms, and reduced responsive behaviours while improving QOL for persons with advanced dementia and relationships with staff (McNiel & Westphal, 2018; Nicholls, Chang, Johnson, & Edenborough, 2013; Simard & Volicer, 2010; Stacpoole, Thompsell, Hockley, Simard, & Volicer, 2013). Family members feel more comfortable and confident when interacting with persons with dementia as a result of Namaste Care (Simard & Volicer, 2010). In acute care settings, Namaste Care has been perceived by healthcare providers as a way to reduce agitated behaviour, promote communication between persons with dementia and staff, and make persons with dementia feel valued (St. John & Koffman, 2017).

There is only one study that explores the use of Namaste Care in a home setting (Dalkin, Lhussier, Kendall, Atkinson, & Tollman, 2020). In this study, Namaste Care was delivered by volunteers working for a hospice in England who went into the homes of persons with dementia. The program was found to increase socialization for persons with dementia (Dalkin et al., 2020). Although the program has been implemented in a home setting, caregivers had little participation in the program and lacked confidence in delivering the program. This may be attributed to the lack of involvement of caregivers in the design of the program and lack of formal training.

Purpose of the Study

This research aims to address the gaps in the current literature related to lack of psychosocial and educational interventions for caregivers of older adults with moderate to advanced dementia for use in community settings and collaboration of caregivers in adapting interventions. The purposes of this mixed methods study are to: (a) develop an adapted version of the multisensory, psychosocial intervention called Namaste Care through consultation with caregivers of persons with moderate to advanced dementia to be used in the community setting and (b) determine the feasibility, acceptability, and preliminary effectiveness of the adapted Namaste Care program in supporting caregivers in the community. The outcomes of this research are the development of a feasible intervention that is practical and simple to use by caregivers of people with dementia and strategies to train caregivers to implement the approach at home.

PROBLEM STATEMENT

There are currently few community programs that can be delivered by caregivers for people with moderate to advanced dementia. There is a pressing need for research to guide and support the development of skills-based educational and support programs for family caregivers caring for older adults with moderate to advanced dementia living at home. Caregivers require education in caring for older adults with dementia and the unique needs of caregivers should be addressed at different stages of the care recipient’s illness (van der Steen et al., 2014). Most programs target individuals in the earlier stages of dementia, suggesting that the complex needs of people with moderate to advanced dementia and their caregivers are not being met. Many studies evaluating educational and psychosocial programs include people with dementia of all stages from mild to severe and authors do not report on outcomes based on the severity of dementia (Elliott, Burgio, & DeCoster, 2010; Huang et al., 2013; Kales et al., 2018). Including people of all stages of dementia in studies makes it difficult to determine the effectiveness of specific interventions or programs for people with moderate to advanced dementia.

Namaste Care, a multisensory program focused on meaningful engagement, holds promise in improving the QOL of caregivers of people with advanced dementia (Simard, 2013). Namaste Care warrants further investigation in relation to whether it can be delivered by caregivers in home settings and the effects of the program on the QOL of caregivers of older adults with moderate to advanced dementia. To date, there are no quantitative studies exploring Namaste Care that have included outcome measures related to family members/caregivers' QOL and self-efficacy. Only one quantitative study measured perceived gains in dementia caregiving (El Alili et al., 2020). While qualitative studies indicate that Namaste Care has benefits for families, positive experiences of caregiving before and after program implementation have rarely been measured.

Namaste Care has also been predominantly used in institutional settings. Prior to implementing the program in home settings, Namaste Care would have to be adapted and tailored. In this research, adaptation of Namaste Care was achieved through active engagement of family caregivers of people with moderate to advanced dementia. In the present study, caregivers were not only involved in designing an adaptation of Namaste Care, but they were also responsible for delivering the program to older adults with moderate to advanced dementia after receiving educational training and support. This approach promoted capacity building of caregivers to deliver the program in their own homes through structured support provided by a Registered Nurse (RN) with guidance from a research team composed of experts in dementia care.

An important issue related to the evaluation of programs for caregivers is that some studies implement a trial to evaluate interventions without first conducting feasibility studies (Liddle et al., 2012; Teri, Logsdon, McCurry, Pike, & McGough, 2020). Feasibility studies are used to determine whether an intervention can be implemented, should be implemented, and how it should be implemented (Eldridge et al., 2016). It is essential to assess feasibility of interventions for caregivers to determine the interest of caregivers in participating in intervention studies, caregiver satisfaction with programs, and fidelity with the intervention. Assessing feasibility was of particular significance in the current research because Namaste Care has not yet been implemented in a home setting by caregivers and it was unknown how the program would be accepted by participants.

RESEARCH OBJECTIVES

The research objectives of this study are to: (a) describe and explain adaptations recommended by caregivers for the Namaste Care program and training procedures (See Chapter 4); (b) explore the experiences of caregivers of community-dwelling older persons with moderate to advanced dementia in adapting the Namaste Care program for home use through workshop sessions (See Chapter 5); and (c) explore the feasibility, acceptability and preliminary effectiveness of the adapted Namaste Care program in supporting caregivers (See Chapter 6).

BACKGROUND AND CONTEXT

In this section an overview of relevant concepts and supporting literature is provided. QOL of older adults with dementia is presented first, followed by QOL of caregivers of older adults with dementia. The benefits of psychosocial and education interventions for caregivers are discussed next as well as important considerations. The final concept discussed consists of the need to develop interventions with the involvement of caregivers of older adults with dementia.

Quality of Life of Older Adults with Dementia

The World Health Organization (2019) defines QOL as a person's perception of their position in life that is affected by the complexity of one's physical health, mental wellbeing, personal beliefs, social relationships, and relationships with the broader cultural environment. For older adults with advanced dementia, their QOL can be enhanced by providing comfort care, decreasing agitation, reducing pain, and providing meaningful activities. QOL for older adults with moderate to advanced dementia can be achieved through activities that stimulate the senses such as touch, smell, vision, hearing and reminiscence (Alzheimer Society of Canada, 2016). These types of activities promote social engagement and lead to a reduction in agitation and depression (Bray, Brooker, & Garabedian, 2019a). Caregivers have been found to engage older adults with dementia in activities such as arts and crafts and day trips during the early stages of dementia, but not during the more advanced stages of dementia (Moore, Ozanne, Ames, & Dow, 2013). Persons with dementia may not be able to participate in such activities as dementia progresses and this finding also suggests that there is a lack of support for caregivers to implement meaningful activities for those in more advanced stages of dementia. In the more advanced stages of dementia, caregivers have been found to spend most of their time and energy on completing tasks, such as providing personal care or assisting the person with dementia with meals, rather than providing meaningful activities (Dalkin et al., 2020).

Pain is prevalent among 50% of community-dwelling older adults with dementia and is more challenging to detect in those with advanced dementia (Pieper et al., 2018). Older adults with advanced dementia may not be able to verbalize pain and discomfort and pain may be expressed through other means such as responsive behaviours. Poor pain and symptom management may occur due to poor understanding of the progression of dementia (Mitchell et al., 2009). Family or friend caregivers may misinterpret responsive behaviours in relation to pain and address the behaviours by administering antipsychotic or antianxiety medications rather than pain medications. Antianxiety medications have been used by caregivers so that responsive behaviours of persons with dementia were more ‘manageable’ at home (Grace et al., 2016). This approach has been used by caregivers who feel the need to be constantly vigilant in case their family member required their attention (Grace et al., 2016). Caregivers likely administer these medications due to a lack of knowledge of dementia and alternative approaches to care (Grace et al., 2016).

Inappropriate use of medications by caregivers in the community is concerning as this may lead to further poor health outcomes of care recipients with dementia. Current clinical recommendations for healthcare providers suggest administering chemical restraints such as antianxiety and antipsychotic medications only when responsive behaviours are severe, non-pharmacological approaches have been exhausted, and when there is a high safety risk and severe agitation (Conn, Gibson, & McCabe, 2014; Registered Nurses’ Association of Ontario, 2016). Improper use of chemical restraints among older adults leads to an increased risk for delirium, excessive sedation, and harmful interactions with other medications (Conn et al., 2014; Inouye, Westendorp, & Saczynski, 2014). Caregivers who report greater confidence in addressing responsive behaviours in care recipients living at home are less likely to administer chemical restraints (Grace et al., 2016).

Black et al. (2013) conducted a cross-sectional study in Maryland, United States, of unmet needs of persons with dementia and their family caregivers. The authors found that 90% of community-dwelling persons with dementia have unmet safety needs and over 50% had unmet needs related to meaningful activities. These alarming findings reveal that people with dementia living at home are not receiving high quality care that promotes their QOL. Higher unmet needs of persons with dementia and their caregivers are associated with greater symptoms of depression for both groups (Black et al., 2013). The high percentage of unmet needs of community-dwelling persons with dementia is likely related to the finding that more than 85% of caregivers had unmet needs related to referrals to community resources and caregiver education (Black et al., 2013). The QOL of family caregivers is associated with the QOL of older adults with dementia receiving care at home. When caregivers experience poor QOL, this also leads to poor QOL and cognitive decline among care recipients (Thomas et al., 2006). Educating caregivers to use evidence-based non-pharmacological approaches to care for older adults with dementia is necessary to lead to improvements in health and social outcomes for care recipients with dementia and their caregivers. Namaste Care is a personalized program that can help meet the needs of older adults with advanced dementia and their caregivers (Simard, 2013). Recognizing that the QOL of older adults is dependent on the QOL of caregivers, QOL of caregivers is discussed next.

Quality of Life of Caregivers of Older Adults with Dementia

There is a high level of complexity in being a caregiver in the community and caregivers of older adults with dementia may experience many impacts on their QOL. Caregivers are highly involved in supporting or caring for older adults with dementia, placing their own health and wellbeing at jeopardy. Caregivers spend on average 26 hours a week providing care to meet the complex care needs of older adults with dementia, which is nine hours more than caregivers caring for older adults without dementia (CIHI, 2019b). Caregiving responsibilities could stretch over several years leading to negative effects on their psychological, emotional, social, and physical wellbeing (Mansfield, Boyes, Bryant, & Sanson-Fisher, 2017). Caregivers of people with dementia experience high rates of caregiver burden, social isolation, poor physical health, depressive symptoms and depression, and financial burden (Brodaty & Donkin, 2009).

Although the literature focuses heavily on the negative effects of caregiving, there are also positive effects of being a caregiver for older adults with dementia. Some of these positive aspects are gaining a sense of personal accomplishment and reward, building stronger relationships within a family unit, and feeling a sense of purpose in life (Brodaty & Donkin, 2009; Doris, Cheng, & Wang, 2018). In taking on the role of a caregiver, caregivers feel that their support is crucial to help meet the needs of family members or friends living with dementia. The perceptions of caregivers on caregiving therefore influence the QOL of people with dementia and can delay the need for institutional care (Brodaty & Donkin, 2009). Optimising positive experiences of caregiving through programs such as Namaste Care can lead to better QOL for caregivers and care recipients. In the next section a description of psychosocial and educational programs like Namaste Care and its benefits is provided.

Psychosocial and Educational Interventions for Caregivers of Older Adults with Dementia

Psychosocial and educational programs implemented in the community for caregivers of persons with dementia have been found to reduce caregiver burden and depression and increase caregiver self-efficacy in addressing responsive behaviours and physical health of caregivers (DiZazzo-Miller, Winston, Winkler, & Donovan, 2017; Jensen et al., 2015; McCurry et al., 2017). A psychosocial intervention is intended to reduce or prevent a decline in mental and/or physical health of caregivers and/or care recipients by targeting activities, skills, competence, and/or relationships (Van’t Leven et al., 2013). Dementia education for caregivers provides them with knowledge and skills required to provide care at home such as effective communication, assistance with activities of daily living, and nutrition for the person with dementia (DiZazzo-Miller et al., 2017).

Despite the interventions that exist to help caregivers support community-dwelling older adults with dementia, most are specific for care recipients who have early or mild to moderate dementia (Chien & Lee, 2011; Kunik et al., 2017; Law & Kwok, 2019; Prick, de Lange, Scherder, Twisk, & Pot, 2016). For example, training programs for caregivers caring for persons with dementia in the early to moderate stages of dementia are often focused on memory recall, advanced cognitive stimulation through word and card games, and verbal fluency (Milders, Bell, Lorimer, MacEwan, & McBain, 2013; Orrell et al., 2017). These types of educational programs are not suitable for older adults with more advanced forms of dementia due to greater cognitive and physical limitations. In creating suitable programs for people with advanced forms of dementia, there is a need to collaborate with caregivers who are most familiar with their preferences and wishes as explored next.

Developing Interventions in Collaboration with Caregivers of Older Adults with Dementia

There has been an emerging trend where researchers aim to empower people in early to middle stages of dementia to be active participants in designing interventions to promote social engagement and wellbeing (Niedderer, Coleston-Shields, Craven, Gosling, & Salter, 2017; Rodgers, 2018). People with dementia and their caregivers have lived experience and can share valuable insight in designing programs to meet their needs. Active consultation with people with dementia and caregivers ensures that they are able to make and influence decisions that impact their lives such as decisions related to program planning, intervention design, or policies (Health Quality Ontario, 2017). It has been argued that the development of educational and psychosocial programs should involve both community-dwelling caregivers and persons with dementia as this would result in more positive outcomes than focusing only on people with dementia (Thinnes & Padilla, 2011). An example where caregivers were involved in developing such interventions was to create playful objects (e.g., stuffed animals that can provide hugs, steering wheels, fidget jewelry) for people with advanced dementia to support their wellbeing and meet their emotional and psychological needs (Treadaway, Taylor, & Fennell, 2018).

Older adults in the more advanced stages of dementia may not be able to participate in designing interventions; however, family members may be suitable participants in collaborating with researchers to develop and refine programs (Treadaway et al., 2018). There is a need to involve caregivers in developing interventions for home use to care for people with moderate to advanced dementia so that interventions are tailored to their needs and abilities and reflect the voices of care recipients. When adapting programs, contextual modifications may be made to deliver an intervention in a new setting and have a different type of person deliver the intervention (Stirman, Miller, Toder, & Calloway, 2013). Programs that were developed for use in LTC settings, such as Namaste Care, would require further adaptation with the collaboration of caregivers prior to being implemented in the community. Involving caregivers can help to ensure that the program will be relevant and feasible.

REFLECTIVE STATEMENT OF DISCIPLINARY ORIENTATION

This section explores how I came to pursue research in supporting caregivers of community-dwelling older adults with dementia. My interest in conducting the present study originated from my clinical experience as a RN caring for older adults with dementia and their family members. I have worked as a RN on an Alternate Level of Care (ALC) unit located within a large teaching hospital for over eight years. Many older adults with dementia receive care on the ALC unit once their medical conditions have stabilized and they are waiting to transition to a different setting. Many are waiting to transition to a LTC facility or retirement home. Some older adults with dementia are waiting to be discharged home to receive support from family members and home care services. I have cared for many older adults living with moderate to advanced dementia on my unit who have been discharged home to live with family members, only to return to the hospital within a few weeks. Older adults with dementia are sometimes readmitted to the hospital because family members do not have adequate skills and knowledge to care for their loved ones at home. Family members receive very little education and support in helping them prepare for the caregiver role. As a result, they become fatigued and stressed.

On the ALC unit I had the privilege of learning about the life stories of older adults with dementia and their caregivers. I have listened to the stories of many caregivers and the common theme that emerges is that they wish they could have continued to care for their family member with dementia at home. I have witnessed caregivers in tears as they share their frustration when caring for persons with advanced dementia at home and the hopelessness they feel in not knowing how to help their loved one anymore. Oftentimes caregivers feel that their loved one is no longer the same person they once knew.

When family members visit older adults with dementia in hospital, they sometimes sit in silence within the small hospital rooms and are unsure of how to interact with their family members. My experience in caring for persons with dementia has helped me to understand that caregivers need support and education on how to continue to provide comfort for their family members based on their unique preferences. Education can help them better understand the needs of persons with dementia such as meaningful social interaction and activities. Caregivers are in the best position to provide person-centred care because they have the most knowledge about the preferences, routines, abilities, behaviours, and stories of persons with dementia. I believe that there is a need to support caregivers caring for persons with advanced dementia at home by providing them with simple yet valuable skills that they could apply during the day-to-day care of their family member. Building the capacities of caregivers can be achieved through Namaste Care. I have attended a Namaste Care session at a local LTC residence to learn about the program, observe how it was delivered, and discuss the program with an experienced Namaste Care facilitator. I recognize the value that this program brings for caregivers and was interested in working with caregivers to adapt the program for use in home settings with older persons with moderate to severe dementia.

THESIS CONTENT

This thesis has been prepared as a sandwich thesis with seven chapters. Four of the chapters consist of manuscripts that were developed for publication. Chapter 1 (introduction) offers a description of the current issues that require the need for research supported with background and contextual information, a purpose for the study, a problem statement, research objectives, and a disciplinary orientation. Chapter 2 (literature review) consists of two separate literature reviews. The first literature review describes the current state of knowledge of the effects of supportive skills-based psychosocial and educational programs on health and social outcomes for caregivers of older adults with moderate to advanced dementia. The second literature review describes the effects of Namaste Care for persons living with dementia, family members, and healthcare providers and how it can be and has been implemented.

Chapter 3 (study protocol) consists of a published, peer-reviewed paper providing a comprehensive description of the methodology applied in the thesis (Yous, Ploeg, Kaasalainen, & McAiney, 2020). Chapters 4, 5, and 6 (study results) are manuscripts that describe the results of the quantitative and qualitative strands of the mixed methods research thesis. Chapter 4 (adaptation of Namaste Care) is an in-press, peer-reviewed manuscript describing and explaining suggested adaptations for the Namaste Care program and training procedures in collaboration with caregivers so that the approach was feasible to be delivered in a home setting (Yous, Ploeg, Kaasalainen, & McAiney, in press). Chapter 5 (adaptation experience) is a manuscript submitted to a peer-reviewed journal that describes the experiences of caregivers who participated in virtual workshop sessions to adapt Namaste Care for community-dwelling older persons with moderate to advanced dementia. Chapter 6 (evaluation of the adapted Namaste Care program) is submitted to a peer-reviewed journal and provides a discussion of findings related to the feasibility, acceptability and preliminary effectiveness of the adapted Namaste Care program. In Chapter 6, a mixed methods interpretation is provided.

Chapter 7 (discussion and conclusion) summarizes the thesis findings within the current state of knowledge, highlights novel findings, and provides an overview of practice, education, policy, and research implications with regards to the findings. Across Chapters 3, 4, 5, and 6 some of the content overlaps due to being part of the same program of research. Overlaps can be found in the following sections: (a) introductions of manuscripts with regards to the rationale for research and background information about community-dwelling older adults with dementia and caregivers; (b) description of the study design, frameworks, and methodology; and (c) ethical considerations. Furthermore, the results chapters also provide an overview of study implications, strengths, and limitations that are also discussed in Chapter 7.

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CHAPTER 2: LITERATURE REVIEW

This chapter begins with a summary of the current state of understanding about the effects of supportive skills-based psychosocial and educational programs on health and social outcomes for caregivers of older adults with advanced forms of dementia. Second, the effects of Namaste Care and how it can be and has been implemented was explored. Following an overview of studies included in the literature review, findings were synthesized. The strengths and limitations of studies were evaluated and summarized prior to a discussion of the gaps in the current literature.

Search Strategies

Two literature searches were conducted: (a) the effects of supportive skills-based psychosocial and educational programs on health and social outcomes for caregivers of community-dwelling older adults with moderate to severe dementia and (b) Namaste Care for caregivers and older adults with moderate to severe dementia. For the purpose of this literature review, health and social outcomes were broadly defined as a variety of outcomes related to QOL such as physical and mental health and relationships with others. I consulted with a health sciences librarian at McMaster University to review and refine the search strategies used.

Critical Appraisal of Studies

Once relevant studies were located, they were critically appraised using the Critical Appraisal Skills Programme (CASP) (2018) checklists for qualitative studies, randomized controlled trials (RCT), economic evaluations, and systematic reviews. For studies including non-RCTs or before-after trials, irrelevant criteria were omitted from the RCT checklist during the appraisal of such studies (e.g., blinding and randomization). For review papers other than systematic reviews such as scoping reviews and literature reviews, irrelevant criteria were also omitted during the appraisal of reviews (e.g., meta-analysis). The CASP (2018) checklists are organized into three main sections that consider the validity of results, the actual results of the study, and whether the results can lead to local improvements. The Mixed Methods Appraisal Tool (MMAT) was used to critically appraise mixed methods studies (Hong et al., 2018). The tool is composed of five different categories (i.e., qualitative, quantitative – RCT, quantitative – non-RCT, quantitative descriptive, and mixed methods) that can be used to assess the quality of a study and the appraiser is expected to answer the screening questions of the most relevant categories.

Each study was assigned a quality score of one to three based on whether the authors considered appraisal criteria from the CASP checklists and the MMAT (CASP, 2018; Hong et al., 2018). I assigned a score of one to low quality studies that met 50% or less of quality criteria, a score of two to moderate quality studies that met 51% to 75% of quality criteria, and a score of three to high quality studies that met 76% or greater of quality criteria. Most of the studies included in the review were deemed to be of moderate quality with very few studies determined to be of high quality. See Appendix C for the quality score of studies included in the literature review.

Literature Search 1: Skills-Based Psychosocial and Educational Programs

First search strategy. For the first search, the following electronic databases were accessed: AgeLine, CINAHL, EMBASE, MEDLINE, PsycInfo, and PubMed. The key search terms used were: *skill*-based educational program*, skill*-based support program*, skill* training, family caregiver*, informal caregiver*, community, living at home,* and *dementia*. The search terms were combined using AND/OR where applicable. I did not specify the severity of dementia (e.g., mild, moderate, severe) in order to capture studies that may have included all stages of dementia. I also hand searched reference lists and sought expert recommendations on relevant papers.

Studies were included if they met the following criteria: (a) explored the effectiveness of a psychosocial or educational program to support caregivers of older adults with moderate to severe dementia living in a home setting; (b) focused on an intervention that targeted the building of skills of family caregivers related to dementia care; (c) considered health and/or social outcomes for family caregivers of older adults with moderate to severe dementia; (d) published between January 1, 2009 and December 27, 2021; and (e) written in English. Some studies included caregivers of people with dementia in mild, moderate, and advanced stages of dementia in a single study. We included those studies that combined all stages of dementia as there were few studies targeting only people with advanced dementia at home. Systematic reviews, mixed methods, quantitative and qualitative research studies were included. Clinical commentaries, guidelines, protocol studies, and editorials were excluded from the review.

Some studies included both community and institutional settings. Studies were excluded if they did not analyze findings related to community and institutional settings separately. Studies were excluded if they: (a) were not an intervention study; (b) focused on adult day care, respite, and/or peer-support group programs; (c) did not include caregivers of people with moderate to severe dementia; (d) did not define the stage of dementia or report cognitive assessment scores of older adults; and (e) did not provide support or education focused on skills training for caregivers. I located six papers that were included in the review by hand searching reference lists and through expert recommendations. A total of 918 articles were retrieved from all six databases. Once duplicated articles were removed and 107 full-text articles were assessed for eligibility, 24 articles remained. See Appendix D for the Preferred Reporting Items of

Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of the search strategy (Moher, Liberati, Tetzlaff, Altman, & the PRISMA Group, 2010).

Overview of studies of interventions. Through the first search, 24 relevant studies were found including eight reviews (Brasure et al., 2016; Braun et al., 2019; Brodaty & Arasaratnam, 2012; Clarkson et al., 2018; Jensen, Agbata, Canavan, & McCarthy, 2015; Trivedi et al., 2019; Vandepitte et al., 2016; Van't Leven et al., 2013) and 16 primary studies (Bass et al., 2019; Birkenhäger-Gillesse, Achterberg, Janus, Kollen, & Zuidema, 2020; Burgio et al., 2009; Drossel, Fisher, & Mercer, 2011; Elliott, Burgio, & DeCoster, 2010; Gitlin et al., 2021; Horvath et al., 2013; Huang et al., 2013; Hum et al., 2020; Kales et al., 2018; Kwok et al., 2013; Lee, Cjaza, & Schulz., 2010; Liddle et al., 2012; Llanque et al., 2015; Simpson & Carter, 2010; Teri, Logsdon, McCurry, Pike, & McGough, 2018). There was duplication of the primary studies included across review papers. I decided to include primary studies that were also included in the review papers because most of the review papers did not provide an in-depth discussion of a variety of outcomes (e.g., caregiver QOL, positive aspects of caregiving) that are relevant to the present literature review. Most of the review papers did not report on statistical results of primary studies and few review papers included meta-analyses of outcomes. The study conducted by Liddle et al. (2012) was included in the review by Vandepitte et al. (2016), the study conducted by Huang et al. (2013) was included in the review by Brasure et al. (2016), and two studies (Horvath et al., 2013; Kwok et al., 2013) were included in the review by Clarkson et al. (2018). Only four primary authors included more than half of people with dementia living at home with moderate to severe dementia in their study sample (Drossel et al., 2011; Huang et al., 2013; Liddle et al., 2012; Llanque et al., 2015). Hum et al. (2020) only included persons living with advanced dementia in their sample.

Skill-building interventions for caregivers exploring health and social outcomes. The eight reviews located explored the effectiveness of supportive psychosocial and educational interventions including non-pharmacological interventions delivered by caregivers, home support interventions for older adults with dementia and/or their caregivers, and psychosocial programs targeting dyads consisting of caregivers and persons with dementia (Brasure et al., 2016; Braun et al., 2019; Brodaty & Arasaratnam, 2012; Clarkson et al., 2018; Jensen et al., 2015; Trivedi et al., 2019; Vandepitte et al., 2016; Van't Leven et al., 2013). All eight reviews included studies conducted in at least seven different countries, including a few conducted in Canada.

Brodaty and Arasaratnam (2012), Jensen et al. (2015), and Van't Leven et al. (2013) performed meta-analyses to evaluate the effects of interventions. Four reviews included RCTs only (Brasure et al., 2016; Jensen et al., 2015; Trivedi et al., 2019; Van't Leven et al., 2013). Two reviews included both RCT and non-RCT studies (Brodaty & Arasaratnam, 2012; Vandepitte et al., 2016). Only Clarkson et al. (2018) included both quantitative and qualitative studies in their systematic review. Braun et al. (2019) included only qualitative studies in their systematic review. Various health and social outcomes were considered in the included studies for both persons with dementia and caregivers, however only caregiver outcomes will be reported in the current literature review. Jensen et al. (2015) only explored outcomes for caregivers. The authors of the reviews included studies that explored all stages of dementia. Although the papers used different methodologies to analyze the literature, the findings were similar across the papers (See below). See Table C1 in Appendix C for a detailed summary of each review.

A total of 16 primary studies were located that explored the effects of psychosocial, and educational interventions for caregivers of community-dwelling older adults with dementia and/or their care recipients (Bass et al., 2019; Birkenhäger-Gillesse, Achterberg, Janus, Kollen, & Zuidema, 2020; Burgio et al., 2009; Drossel, Fisher, & Mercer, 2011; Elliott et al., 2010; Gitlin et al., 2021; Horvath et al., 2013; Huang et al., 2013; Hum et al., 2020; Kales et al., 2018; Kwok et al., 2013; Lee, Cjaza, & Schulz., 2010; Liddle et al., 2012; Llanque et al., 2015; Simpson & Carter, 2010; Teri et al., 2018). More than half of the primary studies were conducted in the United States (n=11). The rest were conducted in the Netherlands (n=1), Hong Kong (n=1), Taiwan (n=1), Singapore (n=1), and Australia (n=1). The study designs used were an RCT (n=8), before-after design with no control group (n=4), a pre-test/post-test design (n=1), a pre-test/post-test controlled trial (n=1), a prospective cohort study (n=1), and a translation study (n=1). See Table C2 in Appendix C for detailed descriptions of the primary studies.

Three studies (Burgio et al., 2009; Elliott et al., 2010; Lee et al., 2010) examined the effects of a multicomponent psychosocial intervention called the REACH (Resources for Enhancing Alzheimer’s Caregiver Health) program which aimed at improving the wellbeing of caregivers through self-care education and telephone support. Many of the studies involved healthcare providers to deliver the intervention for caregivers. One study included a web-based tool to help caregivers assess, address, and track responsive behaviours (Kales et al., 2018). Most studies explored outcomes for caregivers and people with dementia. Four studies only included outcomes for caregivers of people with dementia (Drossel, et al., 2011; Kwok et al., 2013; Llanque et al., 2015; Simpson & Carter, 2010). Although the primary studies used different methodologies, the findings were similar across the studies (See below).

Most educational interventions included in the studies were multicomponent ones. Interventions that included education, social support, and behaviour management were found to be effective in supporting caregivers (Clarkson et al., 2018). Two primary studies included only caregivers of people with moderate to severe dementia (Drossel et al., 2011; Liddle et al., 2012). Hum et al. (2020) only included caregivers of people with severe dementia. Only two studies involved caregivers in developing interventions (Kales et al., 2018; Liddle et al., 2012). Kales et al. (2018) involved caregivers in the first stage of designing their web-based tool for caregivers. Liddle et al. (2012) sought input from caregivers in developing memory and communication strategies for caring for persons with dementia. The next sections describe the synthesis of the findings of these reviews and studies, followed by a critique, and identification of the gaps in the current literature. Many authors included similar outcomes in their studies. Common findings following the delivery of interventions were synthesized and grouped together.

Outcomes for Caregivers. Results supported by multiple studies in terms of outcomes for caregivers were: (a) improved QOL of caregivers; (b) decreased caregiver burden; (c) improved positive experiences and perceptions of caregiving; and (d) increased self-efficacy of caregivers. Each of these are described below.

Improved QOL of caregivers. A total of six reviews examined the impact of psychosocial, support, and educational interventions on QOL of caregivers (Brasure et al., 2016; Brodaty & Arasaratnam, 2012; Clarkson et al., 2018; Jensen et al., 2015; Vandepitte et al., 2016; Van't Leven et al., 2013). Only one of the 16 primary studies directly explored QOL of caregivers (Birkenhäger-Gillesse et al., 2020). A few studies included caregiver outcomes such as wellbeing, sleep, and mood instead (Drossel et al., 2011; Elliott et al., 2010; Gitlin et al., 2021; Simpson & Carter, 2010).

The reviews showed that supportive strategies for caregivers including psychosocial interventions and education and training for caregivers improve QOL of caregivers (Brodaty & Arasaratnam, 2012; Vandepitte et al; 2016; Van't Leven et al., 2013). In their meta-analysis, Brodaty and Arasaratnam (2012) found that non-pharmacological interventions including programs focusing on skills training and education of caregivers led to significant improvement in the QOL and general wellbeing of caregivers. The authors did not measure the effect size of QOL improvements for caregivers.

Van't Leven et al. (2013) and Vandepitte et al. (2016) conducted systematic reviews and similarly found positive findings related to improvements in QOL of caregivers. For caregiver QOL outcomes, only three studies included in the review by Van't Leven et al., (2013) showed statistically significant results in terms of standardized mean differences following the delivery of dyadic interventions (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010a; Gitlin et al., 2010b; Graff et al., 2007). Following the delivery of dyadic interventions, a standardized mean difference (favoring the experimental group) of 0.36 (95% CI= 0.09, 0.64) was found by Gitlin et al. (2010a), 0.71 ((95% Confidence Interval (CI) = 0.45, 0.97) by Gitlin et al. (2010b), and 0.92 (95% CI= 0.56, 1.28) by Graff et al. (2007). Vandepitte et al. (2016) found that psychoeducational programs, focused on enhanced coping skills and combining education and training for caregivers, improved QOL of caregivers and this positive effect lasted two years. The authors also found that occupational therapy interventions, defined as programs that focus on supporting the activities of daily living of care recipients and maintaining function through meaningful activities, have positive impact on QOL of caregivers.

In their review, Clarkson et al. (2018) explored the types of outcomes reported when implementing home support interventions for older adults with dementia and/or their caregivers.

The authors found most qualitative studies were focused on the QOL of caregivers and older adults with dementia, with a strong emphasis on caregiver burden. Two other reviews showed inconclusive evidence to support a change in QOL of caregivers following the delivery of an educational or psychosocial intervention (Brasure et al., 2016; Jensen et al., 2015). Jensen et al. (2015) conducted a systematic review and meta-analysis but were not able to determine the effects of educational programs on caregiver QOL. Meta-analysis of QOL was not possible given high amounts of variation in how QOL was reported and different scales used. In terms of QOL of caregivers following the delivery of caregiver-level non-pharmacological interventions, Brasure et al. (2016) conducted a review of RCTs addressing agitation and aggression in people with dementia and found insufficient evidence to support the effects of interventions on QOL of caregivers due to moderate risk of bias and imprecise analysis and reporting of results in most studies.

Birkenhäger-Gillesse et al. (2020) conducted a RCT to evaluate a multicomponent community-based group training program and measured QOL of caregivers at baseline and at the 3- and 6-month follow-up using the Care-Related Quality of Life-7 dimensions (CarerQol-7D) (Hoefman, van Exel, Foets, & Brouwer, 2011). Data were not analyzed at the 6-month follow-up period due to high loss of participants. There were no statistically significant differences found for caregiver QOL from baseline to 3-month follow-up.

Decreased caregiver burden. Seven reviews examined the impact of psychosocial, support, and educational interventions on caregiver burden (Brasure et al., 2016; Brodaty & Arasaratnam, 2012; Clarkson et al., 2018; Jensen et al., 2015; Trivedi et al., 2019; Vandepitte et al., 2016; Van't Leven et al., 2013). Nine primary quantitative studies explored the effects of interventions on caregiver burden (Birkenhäger-Gillesse et al., 2020; Burgio et al., 2009; Drossel et al., 2011; Elliott et al., 2010; Horvath et al., 2013; Kales et al., 2018; Kwok et al., 2013; Lee et al., 2010; Llanque et al., 2015). The findings of the reviews were generally positive with significant decreases in caregiver burden post-intervention. Meta-analysis of five trials revealed that educational programs for caregivers of people with dementia have a moderate effect on caregiver burden (Standardized Mean Difference (SMD) = -0.52; 95% CI = -0.79, - 0.26; p<0.0001) (Jensen et al., 2015).

In their reviews, Clarkson et al. (2018) and Vandepitte et al. (2016) found that multicomponent home support interventions for caregivers combining education and behaviour management were most effective at reducing caregiver burden compared to single component interventions. Educational programs and structured activity programs aimed at addressing responsive behaviours can also reduce family caregiver burden (Trivedi et al., 2019). Brodaty and Arasaratnam (2012) similarly found that one study included in their meta-analysis evaluating a non-pharmacological intervention to help caregivers address responsive behaviours (Gavrilova et al., 2009) led to a decrease in caregiver burden. In their RCT, Gavrilova et al. (2009) found that from pre- to 6-month post-intervention, the intervention group had a statistically significant decrease in caregiver burden measured using the Zarit Burden Interview scale (Zarit, Reever, & Bach-Peterson, 1980) with a mean difference of -2.6 (standard deviation (SD)=7.7) and the control group had a statistically significant increase in burden with a mean difference of 2.8 (SD=7.7). The adjusted effect size was 0.64 (p=0.03). No effect sizes for the impact of interventions on caregiver burden were reported in three reviews (Brodaty & Arasaratnam, 2012; Clarkson et al., 2018; Vandepitte et al., 2016).

Two systematic reviews (Brasure et al., 2016; Van’t Leven et al., 2013) found no statistically significant impacts on caregiver burden as a result of psychosocial and other non-pharmacological interventions. Van't Leven et al. (2013) found that benefits in reducing caregiver burden following psychosocial interventions were not always statistically significant at different study timepoints. In their review, Brasure et al. (2016) concluded that low-strength evidence of RCTs showed that interventions aimed at the skills and behaviours of caregivers had similar effects on caregiver burden compared to no intervention.

Four primary quantitative studies found positive effects of psychosocial and educational programs on caregiver burden. Burgio et al. (2009) found that the REACH intervention led to a small decrease in caregiver burden at the four-month follow-up period (pre-mean= 2.40, (SD=0.74]); post-mean= 2.23 (SD=0.65); p =0.0001). Caregiver burden was measured using the 12-item modified Zarit Subjective Burden Inventory (Bédard et al., 2001) and scores can range from 0 to 48 with higher scores reflecting greater burden. Elliott et al. (2010) also found that the REACH intervention led to varying decreases in caregiver burden based on race measured using the 12-item modified Zarit Subjective Burden Inventory (Bédard et al., 2001).

Kwok et al. (2013) conducted a RCT and found that caregivers in the intervention group who received a telephone-delivered psychosocial intervention had a decrease in caregiver burden with a mean change of -1.83 (SD=5.26) and those in the control group had an increase in burden from baseline to 3-month follow-up with a mean change of 2.25 (SD=7.09) (p=0.0002). Horvath et al. (2013) similarly found that a self-directed educational intervention on caregiver competence to promote a safer home environment led to reduced caregiver strain with an effect size of 0.22 ($p < 0.001$). Hum et al. (2020) did not measure caregiver burden before and after the implementation of an integrated palliative home care program for persons with advanced dementia, however they found that caregivers had statistically significantly reduced caregiver distress scores with a mean of 3.6 (SD=4.9) at baseline and 1.8 (SD=3.6) at the 1-year follow-up

($p<0.05$). Caregiver distress was measured using the Neuropsychiatric Inventory Questionnaire (NPI-Q) distress scale with scores ranging from 0 to 60 and reduced scores indicating improvement in distress (Kaufer et al., 2000).

Four primary studies found no impact on burden as a result of four interventions (Drossel et al., 2011; Kales et al., 2018; Llanque et al., 2015; Birkenhäger-Gillesse et al., 2020). Drossel et al. (2011) did not find any significant differences in caregiver burden following the delivery of the dialectical behavioural therapy skills training group program for caregivers caring for people with moderate to severe dementia. Following the implementation of a web-based resource tool for caregivers, Kales et al. (2018) also did not find significant differences in caregiver burden between the intervention and control group in their RCT. Llanque et al. (2015) defined caregiver burden as stress to better reflect the strain and frustration associated with caregiving for people with dementia and found no significant improvement following the community-based psychoeducational program compared to baseline. Birkenhäger-Gillesse et al. (2020) reported non-statistically significant changes in caregiver burden from baseline to 3-month follow-up after the implementation of a community-based training program for caregivers and persons living with dementia.

Improved positive experiences and perceptions of caregiving. One review (Clarkson et al., 2018) and two quantitative primary studies (Burgio et al., 2009; Liddle et al., 2012) explored the perceptions and experiences of caregivers following the delivery of an intervention to support caregivers. The findings suggested that caregivers had more positive perceptions associated with caregiving following an intervention. In the qualitative component of the systematic review conducted by Clarkson et al. (2018), the authors found that most qualitative studies considered the impact of interventions to improve the relationships between caregivers and care recipients.

Clarkson et al. (2018) did not report on the actual impact of interventions on relationships. These studies revealed the need to support caregivers in regulating their feelings and behaviours as doing so impacts the care of persons with dementia. Changing the perceptions of caregivers was found to help them recognize that they should be changing their behaviours when caring for older adults with dementia (Clarkson et al., 2018).

Two primary studies found positive changes in terms of experiences and perceptions of caregiving (Burgio et al., 2009; Liddle et al., 2012). Both studies included the Positive Aspects of Caregiving (PAC) scale; this scale has a maximum score of 45 with higher scores reflecting greater satisfaction in caregiving (Tarlow et al., 2004). Liddle et al. (2012) conducted a pre-test/post-test control trial and found that a DVD-based training program to support caregivers in using strategies for communication and memory for people with moderate to severe dementia led to increased beliefs associated with positive aspects of caregiving (p=0.039). Almost half of the intervention group (46%) showed improvements in positive aspects of caregiving compared to 13% in the control group. Positive aspects of caregiving were related to satisfaction in the caregiving role and relationship with the care recipient (Tarlow et al., 2004). Burgio et al. (2009) also examined positive aspects of caregiving following the delivery of the REACH program using a pre-post treatment design with no control group and found an improvement in positive aspects of caregiving score with a baseline mean score of 3.94 (SD=1.07) and 4.17 post-intervention (SD=1.01) (p=0.001).

Increased self-efficacy of caregivers. Three reviews (Braun et al., 2019; Trievedi et al., 2019; Vandepitte et al., 2016) and six primary quantitative studies (Birkenhäger-Gillesse et al., 2020; Gitlin et al., 2021; Horvath et al., 2013; Huang et al., 2013; Kwok et al., 2013; Liddle et al., 2012) examined the effect of supportive psychosocial and educational interventions in improving the self-efficacy of caregivers. The main finding was that these interventions helped to increase the self-efficacy of caregivers in caring for older adults with dementia. Vandepitte et al. (2016) found that multicomponent psychoeducational and occupational therapy interventions improved self-efficacy of caregivers in caring for people with dementia but did not report any statistical results to support this finding. Braun et al. (2019) found that educational interventions targeting the skills of family caregivers in addressing responsive behaviours can be helpful in providing care, dealing with sudden changes among persons with dementia, and prioritizing caregiving responsibilities. Findings from high quality studies suggest that psychoeducational programs aimed at supporting caregivers through problem-solving techniques and skills in addressing responsive behaviours can enhance their behaviour management skills while decreasing emotional distress related to presentation of agitation by persons with dementia. Caregivers who were part of multicomponent interventions combining behaviour management, stress-coping techniques, telephone support, and skills training were found to be less bothered by responsive behaviours (Trivedi et al., 2019).

Six primary studies showed positive results in terms of increased knowledge, skills, and self-efficacy of caregivers as a result of three interventions (Bass et al., 2019; Birkenhäger-Gillesse et al., 2020; Gitlin et al., 2021; Horvath et al., 2013; Huang et al., 2013; Liddle et al., 2012). Liddle et al. (2012) found that a DVD-based training program led to significant improvement in caregivers' knowledge of strategies in the training group (median=9.0) compared to the control group (median=5.75) (p=0.0011). In their RCT, Horvath et al. (2013) evaluated a program to promote home safety and found that caregivers in the intervention group had significant improvements compared to those in the control group in terms of self-efficacy with an effect size of 0.29 (p=0.002). Self-efficacy was measured using the Revised Scale for

Caregiving Self-Efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002). Huang et al. (2013) similarly found in their RCT that a home-based training program improved the skills of caregivers in addressing responsive behaviours. At six months post-intervention the intervention group had a mean self-efficacy score in addressing behavioural problems of 177.33 (SD=30.85) and the control group had a mean of 151.83 (SD=37.43) ($p< 0.001$). Self-efficacy was measured using the Agitation Management Self-Efficacy Scale with scores ranging from 42 to 210 and higher scores reflect greater caregiver self-efficacy (Huang, Shyu, Chen, Chen, & Lin, 2003).

Only one study consisting of an RCT showed that a telephone-delivered psychoeducational program led to no significant changes in self-efficacy in responding to disruptive behaviours or controlling upsetting thoughts post-intervention (Kwok et al., 2013). Bass et al. (2019) conducted a translation study to test Partners in Dementia Care, an intervention aimed at providing a professional consultant for persons with dementia and caregivers to help address their problems, and found that with regards to the outcome of lack of caregiving confidence there was a statistically significant 0.32 decrease from baseline (mean=4.77; SD=2.24) to the 12-month follow-up (mean=4.45; SD=2.02) indicating greater confidence in caregiving at follow-up ($p = 0.01$). Gitlin et al. (2021) evaluated the Tailored Activity Program (TAP), a home-based intervention tailored to the interests and capabilities of persons with dementia with the aim of training families to use activities (e.g., gardening, walking, puzzles, exercises) as part of care routines. They found that caregivers in the intervention versus control group had greater confidence in delivering activities at the 3-month period with a mean difference between groups of 3.46 (95% CI: 0.42, 6.50) ($p=0.03$). This was measured using a 5-item scale with scores ranging from 0 to 50 with higher scores indicating greater confidence

(Gitlin et al., 2009). Birkenhäger-Gillesse et al. (2020) conducted interviews with 38 dyads following the completion of a community-based training program and found that some caregivers perceived that they had better coping skills, improved skills to address responsive behaviours, and used the knowledge gained through the program.

Critique of the studies. In terms of the strengths of the review papers, most of the authors addressed the CASP criteria for systematic reviews consisting of searching for the most suitable type of papers and assessing the methodological quality of papers (CASP, 2018c). The reviews included anywhere from 20 to 70 relevant studies and these studies were organized based on the type of interventions examined (Brasure et al., 2016; Braun et al., 2019; Brodaty & Arasaratnam, 2012; Clarkson et al., 2018; Jensen et al., 2015; Trivedi et al., 2019; Vandepitte et al., 2016; Van't Leven et al., 2013). All authors used one or more critical appraisal tool to assess the methodological quality of studies included in the review. Some of the limitations of the review papers based on the CASP criteria were that not all suitable papers may have been included in the reviews and some of the authors combined results even though this may not have been reasonable. For example, only Clarkson et al. (2018) included both quantitative and qualitative studies and synthesized these findings separately.

Brodaty and Arasratnam (2012) conducted a meta-analysis and this may not have been ideal due to heterogeneity among studies. The studies included in the review by Brodaty and Arasaratnam (2012) were different in terms of scales used to measure responsive behaviours, type of intervention evaluated, and outcomes being explored. Large variation between studies may have had an impact on the reliability of results of the meta-analysis. Different outcome measures were used in the studies making it difficult to summarize findings across studies.

The strengths of the primary quantitative studies included in the present literature review based on CASP criteria for trials (2018b) were that all trials addressed a clearly focused question and most clinically important outcomes for caregivers were considered. Some of the limitations of the studies based on CASP criteria were in the lack of discussion on randomization and blinding when implementing RCTs. For example, Elliott et al. (2010) did not describe the process for randomizing participants, blinding of study personnel, and the process for determining sample size. Huang et al. (2013) similarly did not state whether outcome assessors were blinded to the treatment group of participants and the same nurse who administered the intervention was responsible for evaluating outcomes in the intervention group.

Gaps in the literature related to interventions. There are few psychosocial and educational programs that exist to support caregivers caring for older adults with moderate to severe dementia living at home (Drossel et al., 2011; Huang et al., 2013; Liddle et al., 2012; Llanque et al., 2015). Only Drossel et al. (2011) and Liddle et al. (2012) exclusively included older adults with moderate to severe dementia and Hum et al. (2020) included only those with severe dementia. The other studies did not analyze data separately for moderate to severe dementia. Many studies also do not specify the stage of dementia of care recipients and it is difficult to establish which educational interventions are most effective at which stage in the illness (Clarkson et al., 2018). Oftentimes educational interventions are targeted for people with mild or moderate dementia in the community (Braun et al., 2019; Jensen et al., 2015; Trivedi et al., 2019).

Although the REACH program was evaluated by three different studies (Burgio et al., 2009; Elliott et al., 2010; Lee et al., 2010), most of the studies evaluated unique educational programs that are often not standardized. These unique programs are very different in terms of components, method of delivery, objectives, and length of training sessions. There is also varied length of follow-up across studies ranging from five weeks to 18 months.

Only two studies included in this literature review were created in collaboration with caregivers who would be expected to benefit from the programs (Kales et al., 2018; Liddle et al., 2012). The lack of input and feedback sought from caregivers in developing psychosocial and educational programs may therefore impact the relevance and potential impact of the programs. Considering these gaps, there is a need to study the effects of a formalized educational program such as Namaste Care for older adults with advanced dementia living at home and their caregivers. There is also a need to adapt Namaste Care in collaboration with caregivers to potentially lead to positive and meaningful impacts for caregivers and people with dementia.

Literature Search 2: Namaste Care

In this section, I will describe the search strategy used to locate literature exploring Namaste Care, the results of the search, a critique of results, and gaps in the current literature. The second literature search was focused on the Namaste Care program for older adults with advanced dementia regardless of the setting where they lived.

Second search strategy. The following databases were accessed: AgeLine, CINAHL, EMBASE, MEDLINE, and PsycInfo. The key search terms used were the following: *Namaste Care*, *family caregivers, informal caregivers, older adults, moderate dementia, severe dementia, advanced dementia, late-stage dementia,* and *end-stage dementia.* The search terms were combined using AND/OR where applicable as was done in the first search. A search limit was applied so that *Namaste Care* appeared in the abstract of the paper. This was done to ensure that Namaste Care was discussed in detail in the paper. I did not limit the search to older adults with moderate to severe dementia living at home given that there is currently only one available study exploring Namaste Care in the community (Dalkin, Lhussier, Kendall, Atkinson, & Tollman, 2020). I also conducted a hand search of reference lists and contacted experts to locate papers.

Studies were included if they met the following criteria: (a) focused on Namaste Care; (b) consisted of an intervention study; (c) targeted older adults with moderate to severe dementia regardless of the care setting; (d) consisted of a review, mixed methods, economic evaluation, quantitative, or qualitative study; (e) published between January 1, 2009 and December 27, 2021; and (f) written in English. Studies were included that did not explore the perspectives of informal caregivers or the effects of Namaste Care on families and friends due to the limited number of available studies. Clinical commentaries, guidelines, protocol studies, letters to editors, and editorials were excluded from the review. I located 10 papers by hand searching reference lists and through expert recommendations. A total of 123 studies were located from all five databases. After duplicated studies were eliminated and 45 full-text articles were assessed for eligibility, 30 studies remained. See Appendix E for the PRISMA flow diagram of the search strategy (Moher et al., 2010).

Overview of studies of Namaste Care. The literature search on Namaste Care yielded 30 studies consisting of seven reviews (Backhaus et al., 2020; Backman, Demery-Varin, Cho-Young, Crick, & Squires, 2021; Bray et al., 2019a; Bunn et al., 2018; Camacho-Montaño et al., 2021; Karacsony & Abela, 2021; Volicer, 2019) and 23 primary studies (Ali et al., 2020; Bray, Atkinson, Latham, & Brooker, 2018; Bray, Brooker, Latham, & Baines, 2021; Bray, Brooker, Latham, Wray, & Baines, 2019b; Dalkin et al., 2020; El Alili et al., 2020; Froggatt et al., 2020; Hunter et al., 2017; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Kohne et al., 2021; Latham, Brooker, Bray, Jacobson-Wright, & Frost, 2020; Magee, McCorkell, Guille, & Coates, 2017; Manzar & Volicer, 2015; McNiel & Westphal, 2018; Nicholls, Chang, Johnson, &

Edenborough, 2013, 2013; Rezapour-Nasrabad, 2021; Simard & Volicer, 2010; St. John & Koffman, 2017; Stacpoole, Hockley, Thompsell, Simard, & Volicer, 2015; Stacpoole, Hockley, Thompsell, Simard, & Volicer, 2017; Tasseron-Dries, Smaling, Doncker, Achterberg, & van der Steen, 2021; Walshe et al., 2019). Six reviews on Namaste Care included both papers on Namaste Care and other multisensory programs for people with dementia (Backhaus et al., 2020; Backman et al., 2021; Bunn et al., 2018; Camacho-Montaño et al., 2021; Karacsony & Abela, 2021; Volicer, 2019). The review led by Bray et al. (2019a) only included papers that provided evidence for the activities that are delivered through Namaste Care (e.g., aromatherapy, music).

I decided to include primary studies that were also included in the reviews because relevant outcomes were not comprehensively discussed, and statistical results were often not reported in the review papers. The reviews captured primary studies that were also included in the current literature review. For example, Volicer et al. (2019) included five primary studies (Magee et al., 2017; Manzar & Volicer, 2015; McNiel & Westphal, 2018; Simard & Volicer, 2010; Stacpoole et al., 2015) and Bunn et al. (2018) included seven studies (Magee et al., 2017; McNiel & Westphal, 2018; Nicholls et al., 2013; Simard & Volicer, 2010; St. John & Koffman, 2017; Stacpoole et al., 2015, 2017) that were included in the literature review. In the current literature review on Namaste Care, both caregiver outcomes and outcomes for people with dementia are included given the limited number of studies that consider caregiver outcomes.

Description of reviews. Seven reviews that included studies on Namaste Care or studies that supported the activities delivered through Namaste Care were included in the literature review (Backhaus et al., 2020; Backman et al., 2021; Bray et al., 2019a; Bunn et al., 2018; Camacho-Montaño et al., 2021; Karacsony & Abela, 2021; Volicer, 2019). The types of studies included in the reviews were systematic reviews, meta-analyses, quantitative, and qualitative studies. The studies included were conducted in four or more different countries including Canada. Each of the reviews had a different aim and explored Namaste Care from different perspectives (e.g., healthcare providers, families). In the present literature review only findings from the reviews specific to Namaste Care will be described.

Bray et al. (2019a) conducted a rapid assessment review to examine the quality of research evidence behind different activities provided during the delivery of Namaste Care for LTC residents with advanced dementia. They reviewed studies on interventions that make up Namaste Care. The authors assessed evidence related to Namaste Care activities such as aromatherapy, animal therapy, doll therapy, music therapy, and touch, which have been found to have positive effects on QOL for people with advanced dementia (Bray et al., 2019a). Bunn et al. (2018) conducted a realist review to explain how Namaste Care can be implemented in LTC and what outcomes should be considered in program evaluation. A key finding was the need to implement activities that lead to meaningful connections between older adults with advanced dementia, family members, and staff (Bunn et al., 2018).

Volicer (2019) conducted a literature review to describe four types of non-pharmacological programs that maintain the QOL of people with advanced stages of dementia in LTC settings. The programs explored in the review included Snoezelen therapy (Sánchez et al., 2016), multisensory and motor-based group activity programs, garden experience, and Namaste Care (Simard, 2013). Snoezelen therapy provides multisensory stimulation for residents using colorful objects, sound systems, and scent diffusers to target sight, touch, smell, sound, and movement (Sanchez et al., 2016). Multisensory and motor-based group activity programs are similar to Snoezelen therapy, but also focus on stimulating taste (Cruz, Marques, Barbosa, Figueiredo, & Sousa, 2011; Trudeau, 1999). A third program included in the review was garden experience focusing on providing indoor or outdoor gardening activities for residents (Goto, Kumal, Puzio, Kobylarz, & Herrup, 2014; Spring, Viera, Bowen, & Marsh, 2014). Volicer (2019) found that although these three programs led to positive benefits in QOL of people with advanced dementia, they involved short, infrequent sessions, which did not lead to lasting results. In contrast, the fourth program, Namaste Care, is offered several hours a day and can lead to longer lasting benefits.

Backhaus et al. (2020) conducted a systematic review of studies of interventions that promote family involvement in LTC and included two studies on Namaste Care (McNiel & Westphal, 2018; Stacpoole et al., 2017). Backman et al. (2021) completed a scoping review of the impact of sensory interventions on the quality of life (QOL) of residents living in LTC and included two studies on Namaste Care (Magee et al., 2017; Simard & Volicer, 2010). In their systematic review of qualitative studies, Camacho-Montaño et al. (2021) explored how healthcare providers of clients living with advanced dementia perceive the need for spirituality and interventions to provide spiritual care and included two studies on Namaste Care (Bray et al., 2018; Stacpoole et al., 2017). Karacsony and Abela (2021) conducted a literature review of qualitative findings of studies on Namaste Care to explore the potential for sense memories to be triggered by sensory stimulation. See Table C3 in Appendix C for a description of reviews.

Description of primary studies. A total of 23 primary studies including quantitative, qualitative, mixed methods, intervention design, and economic evaluation studies exploring Namaste Care were included in this literature review (Ali et al., 2020; Bray et al., 2018; Bray et al., 2021; Bray et al., 2019b; Dalkin et al., 2020; El Alili et al., 2020; Froggatt et al., 2020; Hunter et al., 2017; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Kohne et al., 2021; Latham et al., 2020; Magee et al., 2017; Manzar & Volicer, 2015; McNiel & Westphal, 2018;

Nicholls et al., 2013; Rezapour-Nasrabad, 2021; Simard & Volicer, 2010; St. John & Koffman, 2017; Stacpoole, et al., 2015; Stacpoole et al., 2017; Tasseron-Dries et al., 2021; Walshe et al., 2019). More than half of the studies were conducted in the United Kingdom (n=12). The remainder were conducted in Canada (n=3), the United States (n=2), the Netherlands (n=2), Iran (n=2), Singapore (n=1), and Australia (n=1). Most of the studies took place in LTC settings (n=19), two were conducted in a hospital setting (Ali et al., 2020; St. John & Koffman, 2017), one was conducted in a home setting (Dalkin et al., 2020), and one study included staff who worked in a variety of settings such as LTC settings, hospitals, hospices, and private homes (Bray et al., 2018). Bray et al. (2018) included healthcare providers who delivered care in the homes of people with dementia but did not analyze findings separately for home settings. Participants included in the studies were family members and friends of residents with advanced dementia, volunteers, students, healthcare and non-healthcare staff, and managers.

The study designs used were mostly a qualitative design (Dalkin et al., 2020; Hunter et al., 2017; Magee et al., 2017; McNiel & Westphal, 2018; Nicholls et al., 2013; St. John & Koffman, 2017; Tasseron-Dries et al., 2021) followed by a mixed methods design (Ali et al., 2020; Bray et al., 2018; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Latham et al., 2020; Manzar & Volicer, 2015). Other studies used the following designs: a cluster RCT design (El Alili et al., 2020; Froggatt et al., 2020), an action research design (Stacpoole et al., 2015, 2017), a pre-test/post-test design (Simard & Volicer, 2010), a cost model design (Bray et al., 2019b; Bray et al., 2021), a feasibility design (Rezapour-Nasrabad, 2021), a pilot study (Kohne et al., 2021) and an intervention co-design (Walshe et al., 2019). The objectives of the studies varied and were to understand: (a) the perceptions of staff and family members on Namaste Care; (b) the effects of the program on QOL of persons with dementia; (c) how best to implement the program; and (d) barriers and facilitators to program delivery. See Table C4 in Appendix C for descriptions of the primary studies. Findings across reviews and primary studies were similar and synthesized below.

Synthesis of findings of Namaste Care. The synthesis of findings of Namaste Care was separated into three main sections. The first summary explored findings related to the effects of Namaste Care for family members/caregivers of older adults with advanced dementia and the second explored the effects of the program for older adults with advanced dementia. The third summary explored the implementation of Namaste Care.

Effects of Namaste Care for family members/caregivers. Findings related to outcomes for family members/caregivers were: (a) increased empowerment and engagement in caring for older adults with advanced dementia and (b) improved connections when communicating with older adults with advanced dementia.

Increased empowerment and engagement in caring for older adults with advanced dementia. One of the reviews addressed the outcome of empowerment and engagement of family members/caregivers in caring for persons with dementia. In their systematic review, Backhaus et al. (2020) found that Namaste Care provided opportunities for family members to engage with their family members living with dementia and other family members present in the Namaste Care room during the delivery of the intervention. Family members and friends were also involved in the Namaste Care intervention by participating in meetings organized by LTC homes to determine how best to tailor the program to the preferences and stories of residents (Backhaus et al., 2020).

Five mixed methods studies (Ali et al., 2020; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Latham et al., 2020; Manzar & Volicer, 2015) and one action research study (Stacpoole et al., 2017) found that Namaste Care increased empowerment and engagement of family members in delivering care for older adults with advanced dementia. The studies included qualitative findings and suggested that family members perceived that time spent with older adults with dementia was more enjoyable following the implementation of Namaste Care as older adults were less agitated and better able to interact during the visits (Manzar & Volicer, 2015). Family members reported greater involvement in providing meaningful activities for older adults with advanced dementia and experienced joy in helping their loved ones (Ali et al., 2020; Kaasalainen et al., 2019; Kaasalainen et al., 2020). The program was found to improve relationships between family members and residents through family engagement in delivering Namaste Care (Latham et al., 2020).

Stacpoole et al. (2017) found that family members had more skills in engaging older adults with advanced dementia during their visits through sensory stimulation. Family members would perform activities that make up Namaste Care with confidence such as providing hand massages, offering snacks, and brushing the hair of family members. By learning ways to support loved ones with dementia through Namaste Care, family members perceived that visits were positive and helped them feel that they made a difference in the lives of their loved ones (Stacpoole et al., 2017).

In a qualitative realist study, Dalkin et al. (2020) did not find that family caregivers were more engaged in caring for older adults with dementia in terms of implementing meaningful activities in the home setting following the delivery of the Namaste Care program. Namaste Care was delivered two hours a week by trained volunteers from a community hospice center and family caregivers did not receive formal training on how to use the program. Caregivers reported not feeling confident to participate in Namaste Care activities and preferred that volunteers delivered the program without their involvement (Dalkin et al., 2020). This finding may be related to the lack of education provided to caregivers and few opportunities to practice using Namaste Care on their own as the Namaste Care sensory box was not left in the homes of older adults with dementia. Family caregivers were found to be task-focused on meeting the physical care needs of their family member and perceived that they were unable to impact the QOL of their family member (Dalkin et al., 2020).

Improved connections when communicating with older adults with advanced dementia. Five primary studies suggested that Namaste Care led to improved connections between family members and older adults with advanced dementia (Ali et al., 2020; Manzar & Volicer, 2015; McNiel & Westphal, 2018; Stacpoole et al., 2017; Tasseron-Dries et al., 2021). Namaste Care was found to help families create connections with older adults with advanced dementia through meaningful activities that they could both participate in together (McNiel & Westphal, 2018; Tasseron-Dries et al., 2021). In their mixed methods study, Manzar and Volicer (2015) found that among older adults with advanced dementia who still maintained verbal abilities in communication, family members perceived that the length and quality of conversations between family members and older adults with advanced dementia improved following Namaste Care. During the Namaste Care sessions, family members were better able to lead conversations on a wide variety of topics that were of interest to their loved ones. Namaste Care increased alertness among older adults with advanced dementia and increased their communication abilities (Manzar & Volicer, 2015). Caregivers were found to have formed stronger relationships with persons with advanced dementia through the use of touch to encourage communication (Ali et al., 2020).

Namaste Care was also found to help caregivers forge new connections or re-connections with older adults with advanced dementia. Namaste Care provided support for family members to find alternative ways of connecting with their loved ones and made them feel that they still had a meaningful role in the lives of their family members with dementia (Stacpoole et al., 2017). Stacpoole et al. (2017) reported on how touch was found to be a powerful phenomenon that led to stronger bonds between families and older adults with advanced dementia. One study found that even after Namaste Care was implemented caregivers still found it challenging to interact and communicate with their family member with dementia (Dalkin et al., 2020). This may be due to the lack of involvement of caregivers in participating in the delivery of Namaste Care in the home setting with volunteers. Dalkin et al. (2020) found an unintended outcome of Namaste Care which was that caregivers would often use the time that volunteers delivered Namaste Care as respite rather than building on their skills as a caregiver.

Effects of Namaste Care for older adults with advanced dementia. With regards to the effects of the Namaste Care program on outcomes for older adults with advanced dementia, findings were: (a) increased social interaction and meaningful engagement; (b) improved QOL for older adults with advanced dementia; (c) enhanced person-centred care for older adults with advanced dementia; (d) decreased pain for older adults with advanced dementia; and (e) reduced responsive behaviours.

Increased social interaction and meaningful engagement. Five reviews found that Namaste Care and/or interventions that make up Namaste Care led to better social interaction between older adults with advanced dementia, families, and LTC staff (Bray et al., 2019a; Bunn et al., 2018; Camacho- Montaño et al., 2021; Karacsony & Abela, 2021; Volicer, 2019). In their rapid review of evidence supporting activities delivered through Namaste Care, Bray et al. (2019a) found that sensory stimulation had a positive effect on the level of engagement of people living with dementia and made them more aware of their environment. Following the delivery of

Namaste Care and provision of interventions such as doll and animal therapy (i.e., live, plush, or robotic dog), older adults with advanced dementia had improved abilities to communicate with family members and staff (Bray et al., 2019a; Volicer, 2019).

Bunn et al. (2018) similarly found that one of the key components of Namaste Care consisting of ‘loving touch’ was perceived as leading to greater physical engagement between older adults with advanced dementia and staff. Physical contact such as hand massaging that combines one-to-one social interaction and sensory stimulation was found to enable meaningful relationships between staff and older adults with advanced dementia. Camacho-Montaño et al. (2021) found that Namaste Care was perceived by healthcare providers in LTC as leading to greater social interactions between residents and increased communication. Karacsony and Abela (2021) found that Namaste Care helped persons with dementia be more engaged with their environment and aware of other people in the Namaste Care room. Multiple expressions of touch (e.g., massages, hugs, hair brushing) used in Namaste Care were found to increase communication in people with dementia

The effectiveness of meaningful activities to enhance connections and social interactions was found to be dependent on the skills of staff (Bunn et al., 2018), and perhaps those of family members as well. Bunn et al. (2018) found that Namaste Care would work best by taking into consideration that everyone responds differently to the same stimuli. Staff and family members should be aware of the music being played, how people with dementia are touched, and the aromas being used.

Ten primary studies (Bray et al., 2018; Dalkin et al., 2020; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Latham et al., 2020; Manzar & Volicer, 2015; McNiel & Westphal, 2018; Nicholls et al., 2013; St. John & Koffman, 2017; Stacpoole et al., 2017) explored the effects of Namaste Care on social interaction and meaningful engagement. The main findings were that Namaste Care improved interactions between staff, volunteers, families and persons with advanced dementia and increased meaningful engagement. These findings were supported by qualitative data.

Six mixed methods studies found that LTC staff and family members perceived that older adults with advanced dementia were more engaged and alert during and after the implementation of Namaste Care (Bray et al., 2018; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Latham et al., 2020; Manzar & Volicer, 2015; Nicholls et al., 2013). Residents were found to be speaking, interacting and smiling more often post-Namaste Care implementation (Kaasalainen et al., 2019). Namaste Care was perceived by staff as increasing social inclusion for older adults with advanced dementia and communication between older adults with advanced dementia, families, and staff (Bray et al., 2018). Nicholls et al. (2013) found that Namaste Care helped staff understand the emotional needs of older adults with advanced dementia and opportunities for emotional engagement such as when providing physical care. Namaste Care helped residents to connect with others in the home and increased their verbal communication (Latham et al., 2020).

Four qualitative studies found that multisensory activities used in Namaste Care helped staff and/or families engage and connect with older adults with advanced dementia through sensory stimulation in home, LTC, and hospital settings (Dalkin et al., 2020; McNiel & Westphal, 2018; St. John & Koffman, 2017; Stacpoole et al., 2017). Dalkin et al. (2020) found that there was greater social interaction and engagement between volunteers and people with dementia when Namaste Care was delivered in a home setting. The one-on-one interaction between volunteers and people with dementia was perceived as beneficial by volunteers and family caregivers to focus on the interests of people with dementia. Using an action research design, Stacpoole et al. (2017) found that Namaste Care changed the care routine by providing LTC staff and families with more one-on-one time to engage with older adults with advanced dementia and slowing the pace of interactions. Namaste Care provided family members with skills to engage and stimulate older adults with advanced dementia during their visits. The program created awareness among families and staff that persons with advanced dementia were not passive care recipients as they could actively engage in care. In their qualitative descriptive study, McNiel and Westphal (2018) found that LTC staff perceived that Namaste Care promoted meaningful interaction and strengthened relationships between residents, staff, and families through verbal and non-verbal cues expressed by residents. Families received support by staff to connect with residents and used alternative ways to communicate with them through Namaste Care.

Improved QOL for older adults with advanced dementia. Two reviews found that interventions used in Namaste Care led to an improvement in QOL of older adults with dementia (Bray et al., 2019a; Volicer, 2019). Bray et al. (2019a) and Volicer (2019) narratively concluded that Namaste Care and its interventions such as music therapy, animal therapy, and touch led to improved QOL of residents with advanced dementia in LTC. None of the authors conducted a meta-analysis.

Nine primary studies (Ali et al., 2020; Bray et al., 2018; El Alili et al., 2020; Kohne et al., 2021; Latham et al., 2020; Manzar & Volicer, 2015; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Stacpoole et al., 2017) examined the impact that Namaste Care had on the QOL of older adults with advanced dementia. Most studies showed that Namaste Care led to improved QOL for people with advanced dementia. Four mixed methods studies showed that Namaste Care improved the QOL of people with advanced dementia and created a sense of wellbeing for residents (Bray et al., 2018; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Manzar & Volicer, 2015). Namaste Care was perceived by families and staff as improving the wellbeing and QOL for people with dementia in all facets of their lives (e.g., emotional, physical, and social) (Bray et al., 2018) and ensured that QOL continues to be upheld in residents regardless of how far their dementia progresses (Kaasalainen et al. (2019).

QOL of people with advanced dementia was measured in six studies (Ali et al., 2020; El Alili et al., 2020; Kaasalainen et al., 2020; Kohne et al., 2021; Latham et al., 2020; Manzar & Volicer, 2015) using the Quality of Life in Late Stage Dementia (QUALID) or a translated version of the scale to fit unique cultural contexts (Weiner et al., 2000). The QUALID scale is composed of 11 items and scores can range from 11 to 55 with higher scores indicating poorer QOL (Weiner et al., 2000). Manzar and Volicer (2015) found statically significant improvements in QOL at week three and seven of the implementation of Namaste Care intervention. The mean QUALID score decreased from a score of 23 (SD=7.9) to 15 (SD=6.4) at week 3 (p=0.008) and to 13 (SD=4.7) at week 7 (p=0.001). In their pilot study, Kohne et al. (2021) found that Namaste Care improved the QOL scores for Iranian women living with advanced dementia in LTC homes from baseline (mean=25.64; SD=1.64) to 6-month Namaste Care program implementation (mean=18.72; SD=1.01). This finding was statistically significant with a p-value of < 0.001. Even after controlling for demographic variables (e.g., age, marital status, education, occupation) and comorbidities, statistically significant improvement in scores were revealed. Latham et al. (2020) found that out of 31 residents with complete data, QOL scores improved with a mean difference of -4.29 from baseline (mean=25.81; SD=10.03) to 12-week follow-up (mean=21.00; SD=6.99) (p=0.01).

Kaasalainen et al. (2020) also found a small improvement in mean QUALID score following the implementation of Namaste Care, but the mean difference between baseline and six-month post-intervention of -1.7 (SD=10.9) was not statistically significant. El Alili et al. (2020) found that the mean difference from baseline to 12-month follow-up in QOL scores between the intervention group who received the Namaste Care Family Programme in Dutch LTC homes and usual care group improved over time, however this was not statistically significant at -0.06 (95% CI: -0.42; 0.30). Although Ali et al. (2020) found a positive improvement in QOL scores for persons with advanced dementia receiving Namaste Care in hospital with a baseline mean of 29.0 (SD=7.4) and 24.0 (SD=4.3) at follow-up, the significance of this finding was unknown because p-values and length of follow-up were not reported and only 4 patients were included in the study.

Enhanced person-centred care for older adults with advanced dementia. In their review, Karacsony and Abela (2021) found that Namaste Care promoted person-centred care by encouraging staff to get to know persons with dementia more intimately and support family members in focusing on what persons with dementia are still able to do. Eight primary studies (Ali et al., 2020; Dalkin et al., 2020; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Magee et al., 2017, McNiel & Westphal, 2018; St. John & Koffman, 2017; Stacpoole et al., 2017) explored the influence of Namaste Care on person-centred or individualized care for people with advanced dementia. The main finding was that Namaste Care encouraged person-centred care and the program was most effective when individualizing care.

Using a qualitative realist approach, Dalkin et al. (2020) found that Namaste Care promoted personalized care delivered by volunteers in a home setting based on sensory interactions for older adults with dementia. Three mixed methods studies revealed that Namaste

Care encouraged hospital and LTC staff to implement individualized care for residents (Ali et al., 2020; Kaasalainen et al., 2019; Kaasalainen et al., 2020). In their action research study, Stacpoole et al. (2017) reported that care routines were transformed following the implementation of Namaste Care. The program helped staff and families recognize the importance of upholding the dignity of residents with advanced dementia and engaging residents to become active participants in their own care. Staff in hospital similarly reported that Namaste Care provided a means to help people with dementia feel valued (St. John & Koffman, 2017). In their qualitative studies, Magee et al. (2017) and McNiel and Westphal (2018) found that staff in LTC perceived that individualizing care for residents post-Namaste Care was important. The program enhanced creativity among staff to personalize care offered during the sessions to help residents feel more comfortable in participating in activities. For example, staff provided different music and movies, dolls, wedding dresses, and farming tools based on the interest of residents (McNiel & Westphal, 2018).

Decreased pain for older adults with advanced dementia. Three reviews showed that Namaste Care and the interventions used in Namaste Care led to a reduction in pain and complaints associated with pain in older adults with advanced dementia (Bray et al., 2019a; Karacsony & Abela, 2021; Volicer, 2019). In their rapid review, Bray et al. (2019a) found that music therapy, which is an intervention used in Namaste Care, led to a reduction in pain in people with dementia. The authors found that two RCTs (Fung & Tsang, 2018; Kapoor & Orr, 2017) that evaluated the effects of massage for older adults with advanced dementia did not report any statistically significant findings in terms of pain reduction.

Four mixed methods studies (Bray et al., 2018; Kaasalainen et al., 2020; Manzar & Volicer, 2015; Stacpoole et al., 2015) assessed pain among people with advanced dementia and two found that pain decreased following Namaste Care implementation (Bray et al., 2018; Manzar & Volicer, 2015). Manzar and Volicer (2015) found that older adults with advanced dementia who participated in Namaste Care received decreased doses of acetaminophen and eventually stopped taking acetaminophen as they no longer had pain symptoms. The quantitative data were inconclusive to support whether the decrease in pain was significant, however engagement and massage provided in Namaste Care led to a decreased perception and complaints of pain among residents (Stacpoole et al., 2015; Manzar & Volicer, 2015).

Kaasalainen et al. (2020) and Stacpoole et al. (2015) did not find statistically significant reductions in pain following Namaste Care implementation. From baseline to six-month post-intervention, Kaasalainen et al. (2020) reported a non-significant mean difference in pain of -0.7 (SD=4.3) on the Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II), which has a range of scores from 0 to 31 with higher scores reflecting greater pain (Chan, Hadjistavropoulos, Williams, & Lints-Martindale, 2014).

Reduced responsive behaviours. Four reviews found that Namaste Care and/or interventions used in Namaste Care led to a reduction in responsive behaviours in older adults with advanced dementia (Bray et al., 2019a; Bunn et al., 2018; Karacsony & Abela, 2021; Volicer, 2019). Elements used in the Namaste Care sessions including scents of lavender, doll therapy, music therapy, and touch decreased agitation and responsive behaviours (Bray et al., 2019a; Volicer, 2019). Bunn et al. (2018) found that touch such as hand massages can reduce responsive behaviours in people with dementia. The authors also found that responsive behaviours are complex in nature and best addressed using a multifaceted approach. Bunn et al. (2018) suggested that people with advanced dementia require routine access to social and physical stimulation provided by considering personal preferences in order to lead to a reduction in responsive behaviours. The Namaste Care program was found to have a positive effect on agitation for persons with dementia by providing familiar stimuli such as hymns (Karacsony & Abela, 2021). Backman et al. (2021) did not report statistically significant findings following the implementation of Namaste Care in terms of agitation among residents in their scoping review. Seven primary studies (Manzar & Volicer, 2015; McNiel & Westphal, 2018; Simard & Volicer, 2010; St. John & Koffman, 2017; Stacpoole et al., 2015; Stacpoole et al., 2017) explored the impact of Namaste Care on responsive behaviours. The general finding was that Namaste Care led to a reduction in responsive behaviours. Only two studies actually measured changes in responsive behaviours following Namaste Care implementation (Simard & Volicer, 2010; Stacpoole et al., 2015). In their pre-post test study, Simard and Volicer (2010) found that residents who had baseline social withdrawal or decreased social interaction experienced a significant decrease in responsive behaviours after enrolling in Namaste Care with a mean challenging behaviour score of 3.27 (SD=0.30) at baseline and 2.00 (SD=0.47) post-intervention (p=0.046). Stacpoole et al. (2015) found that the severity of behavioural symptoms and occupational disruptiveness were significantly decreased following the launch of Namaste Care ($p<0.001$) and after the second interval (i.e., two to three months after the Namaste Care launch) (p=0.003).

Qualitative findings of four studies (Latham et al., 2020; McNiel & Westphal, 2018; St. John & Koffman, 2017; Stacpoole et al., 2017) suggested a perceived reduction in behavioural symptoms following the implementation of Namaste Care by staff and family members. Namaste Care created dialogue among staff regarding the suitability of the program for residents with behavioural symptoms (McNiel & Westphal., 2018). The program was perceived by staff as reducing agitated behaviours among older adults with dementia (St. John & Koffman, 2017).

Namaste Care led to a reduction in anxiety and responsive behaviours among residents, including behaviours of a physical nature (Latham et al., 2020).

Implementation of Namaste Care. The findings related to the implementation of Namaste Care were: (a) Namaste Care is feasible; (b) co-design with stakeholders leads to better intervention adaptation; and (c) multiple facilitators and barriers exist for implementing Namaste Care.

Namaste Care is feasible. Six primary studies included in the present review explored the feasibility of the Namaste Care program. Namaste Care was found to be a feasible program to be implemented for older adults with advanced dementia in LTC and hospital settings (Bray et al., 2021; Bray et al., 2019b; Froggatt et al., 2020; Kaasalainen et al., 2020; Rezapour-Nasrabad, 2020; St. John & Koffman, 2017). Although Dalkin et al. (2020) did not explore the feasibility of Namaste Care in the home setting, findings (e.g., change in frequency from 4 hours a day, 7 days a week to 2 hours, once a week) suggest that with modifications to the Namaste Care program it may be suitable for delivery in the home setting. In their mixed methods study, Kaasalainen et al. (2020) found that the participation rate for residents with advanced dementia in LTC was 88.6% and this result met the pre-set criteria for success of feasibility consisting of 80% or greater. Despite the high participation rate, residents only received 72% of the Namaste Care sessions and this may be due to the staff ability to provide the sessions as prescribed. Family members, residents, and staff were mostly satisfied with the program (Kaasalainen et al., 2020). Rezapour-Nasrabad (2020) explored the feasibility of implementing Namaste Care in LTC homes in Iran and administered surveys to 20 LTC staff. On a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) staff perceived that they would have enough human resources to provide

Namaste Care (mean=4.18) and the average feasibility score was 3.95 (SD=0.22). The statistical significance of the findings was unknown as p-values were not reported for feasibility.

Froggatt et al. (2020) used a cluster RCT design with a process and cost evaluation to similarly explore the feasibility of Namaste Care in LTC. The authors found that out of 32 residents enrolled in the study and receiving Namaste Care sessions, only one resident withdrew because he or she relocated to another facility. The authors therefore met their target criterion of the attrition rate of no more than two residents per care home withdrawing from the intervention based on practical or preference reasons. The target criterion of 80% completion of QOL questionnaires was met for residents with 94% being completed at 24 weeks. The indicators for number of sessions delivered per week (i.e., 7 out of 14 or 50%) and the length of the sessions (i.e., 1.5 hours) were not met. Only 30% of possible sessions were held and the average length of sessions ranged from 0.87 to 1.91 hours. Family caregivers found questionnaires to be easy to complete and their engagement in the study supported recruitment of residents. Some nursing homes incurred no additional costs to deliver Namaste Care while others incurred an average cost of 222 euros per resident across a 4-week period (Froggatt et al., 2020).

In a hospital setting, St. John and Koffman (2017) conducted a pilot qualitative study and found that the program was perceived as acceptable by staff as well as having the potential to improve QOL of people with dementia. In order to implement Namaste Care in a different setting such as within the homes of older adults with advanced dementia, findings from the current review suggest that there is a need to pay attention to the ability of caregivers to deliver the program.

In an economic evaluation study, Bray et al. (2019b) described the full cost model to implement Namaste Care in the United Kingdom. The authors based their cost model on staff costs related to job roles, capital costs associated with room hire in LTC, and consumable costs related to equipment and materials required to run the Namaste Care sessions (e.g., comfortable chairs, soap). Bray et al. (2019b) found that the program costs about eight to 10 euros more for every two-hour session compared to usual care. The cost of staffing (e.g., care staff, kitchen staff, director of nursing, housekeeping staff) to run a Namaste Care session was on average 100.09 euros. In a follow-up to the study conducted by Bray et al. (2019b), Bray et al. (2021) used data from five care homes to develop a costing model for the implementation of Namaste Care and found that costs were greater than what was predicted in the earlier study. Bray et al. (2021) found that the average Namaste Care group session costs 220.53 euros, which was valued at 22% more than usual care. The average cost per session per resident was 38.01 euros, 7.24 euros more than usual care. The positive effects of the program on resident wellbeing (e.g., decreased pain and responsive behaviours) and staff wellbeing (e.g., increased job satisfaction, decreased staff turnover) may have their own benefits which could negate the additional cost of the program. Most of the equipment and supplies were already available in LTC homes and this led to some offset of costs. (Bray et al., 2021).

When considering the implications of these findings related to implementing Namaste Care in a community setting, the cost of the program may be much less. Namaste Care could conveniently be offered within the homes of older adults with advanced dementia and family members or friends could deliver the program instead. Many supplies such as chairs, lotions, and soaps are often already found in the homes of older adults with advanced dementia and additional purchases may not be necessary.

Co-design with stakeholders leads to better intervention adaptation. One study included in the present literature review explored the process and experiences of co-designing the

Namaste Care intervention for LTC with multiple stakeholders (Walshe et al., 2019). In this qualitative workshop co-design study, Walshe et al. (2019) included 18 nursing care home staff, one family caregiver, one volunteer, and five members of the public involvement panel to support the co-design of Namaste Care. Engaging stakeholders in reviewing the Namaste Care training guide and altering the program based on real-time feedback was found to be an effective approach to ensure that the program would be acceptable in a LTC context. This was determined by adapting Namaste Care so that it was created based on research evidence and expertise of current users of Namaste Care while maintaining some flexibility on how care homes implement the program. Walshe et al. (2019) developed a 16-page booklet to support implementation at the end of the study that included flow charts, graphics, and colour for more appeal and ease of navigation. Participants in the study suggested that the booklet be labelled as a ‘guide’ rather than a ‘manual’ to reflect flexible boundaries in the Namaste Care intervention.

Multiple facilitators and barriers exist for implementing Namaste Care. Five primary studies explored the facilitators and barriers to implementing Namaste Care (Bray et al., 2018; Hunter et al., 2017; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Tasseron-Dries et al., 2021). There are many facilitators that can improve the uptake of Namaste Care and numerous barriers that impact the delivery of Namaste Care. Some of the findings are relevant to consider when planning to implement Namaste Care in a community setting and have the program delivered by caregivers.

In their mixed methods study, Kaasalainen et al. (2019) found that facilitators to support Namaste Care implementation were strong support from LTC administration and good communication between LTC administration and staff. Nurses and managers acting as champions or staff leads for Namaste Care were effective facilitators in ensuring that Namaste

Care took place daily as planned (Bray et al., 2018; Kaasalainen et al., 2019). Staff attitudes should be targeted through clear communication of what Namaste Care entails and training and education. Bray et al. (2018) found that staff would need to have prior knowledge of person-centred care to appreciate Namaste Care’s philosophy. In Dutch LTC homes caregivers perceived facilitators for their involvement in the Namaste Care Family program were witnessing and experiencing the benefits of the program for residents and matching activities to the preferences of both caregivers and residents (Tasseron-Dries et al., 2021).

In a qualitative interpretive study, Hunter et al. (2017) found that facilitators to implementing Namaste Care were perceived by family and staff as potential positive benefits, need for the program, and fit with a person-centred or end-of-life approach to care. The authors suggested that the minimal reliance on advanced technologies and equipment when delivering Namaste Care can help ease implementation of the program. These findings suggest that in a community setting, the success of Namaste Care would also depend on having a knowledgeable facilitator check-in with caregivers who will be delivering the program at home and address their concerns. It would be helpful to explore with caregivers their understanding of person-centred care and how this can be achieved through Namaste Care.

Two mixed methods studies found barriers to implementing the program such as greater work burden on staff related to having the sessions during busy morning routines, the length of the program, and reported adverse events related to skin breakdown (Kaasalainen et al., 2019; Kaasalainen et al., 2020). Hunter et al. (2017) found that the barriers to implementing Namaste Care were low financial and human resources available in LTC and the need to disrupt structured routines to fit the program. Family members were especially aware of low government funding to support LTC initiatives.

Bray et al. (2018) identified similar barriers to Namaste Care implementation in their study such as lack of time, resources, and negative attitudes of staff due to changing their routines and busy schedules. The authors reported that families and staff with limited knowledge of Namaste Care were also perceived as limiting success of the program by not knowing what kind of changes the program could bring. Staff were concerned that families would perceive that having their loved ones with advanced dementia participate in Namaste Care meant that they were nearing imminent death (Bray et al., 2018). Tasseron-Dries et al. (2021) reported some barriers for family caregivers to engage in Namaste Care including unclear communication from staff about their role in delivering Namaste Care and caregivers feeling uncomfortable in delivering unfamiliar activities. For example, hand massages were perceived as too intimate to provide for their relatives. Caregivers perceived that they lacked knowledge and skills in delivering Namaste Care activities and were not certain how to address responsive behaviours during group sessions. Not having enough time to participate in Namaste Care was a barrier as caregivers were working and/or had a family with children.

These findings suggest that it would be important to negotiate with caregivers when and for how long Namaste Care should be delivered at home and what activities they would feel comfortable in delivering. Caregivers would also require education on how to assess their friends or family members with moderate to advanced dementia during sessions for signs of discomfort and when responsive behaviours occur. In order to address skeptical attitudes of some caregivers of the Namaste Care program, it would be helpful to ensure that caregivers have a clear understanding of what the program entails and potential benefits prior to training.

Critique of the studies. The strengths of the seven reviews included in the present literature review (Backhaus et al., 2020; Backman et al., 2021; Bray et al., 2019a; Bunn et al., 2018; Camacho- Montaño et al., 2021; Karacsony & Abela, 2021; Volicer, 2019) were that they addressed the CASP (2019c) criteria for reviews consisting of searching for the 'right' type of papers, considered all important outcomes, and reasonably combined the results in their review. In terms of the limitations of the reviews, the authors of most reviews did not do enough to assess the methodological quality of the papers that they decided to include in their review. Bray et al. (2019a) and Volicer (2019) did not discuss critically appraising the studies. Bunn et al. (2018) mentioned that they included papers based on whether they were 'good enough' or 'relevant enough' and did not use a tool to assess studies. This makes it challenging to determine the trustworthiness of findings. None of the reviews were based on meta-analyses and the authors were not able to make strong conclusions regarding results.

The strengths of most of the mixed method studies (Bray et al., 2018; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Latham et al., 2020; Manzar & Volicer, 2015) included in the present review based on the MMAT (Hong et al., 2018) were that the qualitative and quantitative components were effectively integrated and inconsistencies between the quantitative and qualitative outputs were usually discussed. The limitations of the mixed methods studies were that for each study it was unclear whether the authors adhered to quality criteria of each tradition. The strengths of the qualitative studies (Hunter et al., 2017; Magee et al., 2017; McNiel & Westphal, 2018; Nicholls et al., 2013; St. John & Koffman, 2017; Tasseron-Dries et al., 2021) were that they included a clear statement of findings and a qualitative methodology was appropriate for each study (CASP, 2018a). A limitation was that a few studies did not specify the type of qualitative design used in their study (Magee et al., 2017; St. John & Koffman, 2017).

Other limitations of the studies were the lack of RCT design used and limited quantitative data related to outcomes and impacts associated with Namaste Care. Not many studies measured outcomes before and after the implementation of Namaste Care for older adults with advanced dementia and family members. Although some of the qualitative studies reported on the experiences or effects of Namaste Care for family members, only one of the quantitative studies included outcome measures for family members/caregivers consisting of perceived gains in dementia caregiving (El Alili et al., 2020). None of the studies considered whether Namaste Care led to a change in QOL of caregivers and none measured the positive experiences of caregiving. The gaps in the Namaste Care literature will be explored next.

Gaps in the literature related to Namaste Care. The current gap in the literature is that the feasibility of implementing Namaste Care in the community by caregivers is unknown. Only one study explored Namaste Care in the home setting, however the program was delivered by volunteers and not caregivers; further, people with mild to severe dementia were included in the study (Dalkin et al., 2020). Although Namaste Care has been shown to have a moderate effect on the wellbeing of family members and good feasibility in a community setting, particularly supported by qualitative findings, outcomes measures for family members/caregivers have not yet been evaluated. There are few studies that measure outcomes before and after the implementation of Namaste Care for older adults with advanced dementia and their caregivers. In most studies families are invited to participate in Namaste Care, but many family members do not receive formal training in using the program. There is only a single study that explored the adaptation of Namaste Care through collaboration with stakeholders prior to implementation in LTC (Walshe et al., 2019). There are also currently no community-based studies evaluating Namaste Care and its delivery by caregivers of older adults with advanced dementia at home. I will address these gaps by adapting a program intended for people with moderate to advanced dementia in the community and collaborating with key stakeholders to revise the Namaste Care program. I will also assess the feasibility of implementing Namaste Care in the community and preliminary outcomes for caregivers.

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CHAPTER 3

TITLE: Namaste Care Delivered by Caregivers of Community-Dwelling Older Adults with Moderate to Advanced Dementia: A Mixed Methods Study Protocol[1]

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ABSTRACT

A**im:** The aim of this study is to adapt and evaluate the feasibility, acceptability and preliminary effectiveness of a multisensory, psychosocial intervention called Namaste Care delivered by family and friend caregivers of community-dwelling older adults with moderate to advanced dementia.

Design: A multiphase mixed methods design combining quantitative and qualitative methods will be used.

Methods: This study is composed of two phases. Phase 1 is guided by a qualitative description approach. Small group workshop sessions with 8-10 caregivers of community-dwelling older adults with moderate to advanced dementia will be conducted to adapt Namaste Care. In Phase 2, 10-20 caregivers will receive training and implement the adapted Namaste Care approach at home. A one group, before-after design will be used to evaluate feasibility, acceptability and preliminary effectiveness of the approach over three months. Feasibility will be assessed using quantitative measures and acceptability will be explored using qualitative methods. Outcomes to evaluate preliminary effectiveness include quality of life, positive perceptions of caregiving, self-efficacy and caregiver burden.

Discussion: There are currently few skill-building interventions that can be delivered by caregivers of people with moderate to advanced dementia at home. Caregivers should be involved in developing programs to enhance program relevance. This research will be the first to explore the feasibility of implementing the Namaste Care approach at home by caregivers.

Impact: Study results will provide important information about the feasibility and preliminary effects of an adapted form of Namaste Care. This program has the potential to improve the quality of life of caregivers and may prevent hospitalization or long-term care placement of older persons with moderate to advanced dementia. The revised Namaste Care program supports building the skills of caregivers so that their needs and the needs of older persons with dementia living at home are being addressed.

Key Words: nurses, nursing, dementia, quality of life, mixed methods, community-dwelling older adults, caregivers, namaste care and psychosocial skill-building intervention

INTRODUCTION

In 2016, close to 50 million individuals were living with dementia worldwide (Nichols et al., 2019). Approximately 10 million people are diagnosed with dementia yearly and this number is expected to increase due to a growing global aging population (World Health Organization, 2019). Over 260,000 Canadians with dementia are living at home (i.e., private residence in the community) (Canadian Institute for Health Information (CIHI), 2019). In Canada, over 90% of people with mild dementia, 50% of those with moderate dementia and 14% of those with advanced dementia are living at home compared with an institution (Chambers, Bancej, & McDowell, 2016). This trend is not likely to change soon due to long wait times for long-term care (LTC), the rising costs of LTC and the desire of most families to care for people with dementia at home (McCurry et al., 2017).

Older adults living with dementia in the community have many complex care needs. Approximately 20% of older adults with dementia living at home have severe cognitive impairment, 28% depend on others to complete their activities of daily living and 25% have symptoms of depression (CIHI, 2019). Many older adults with dementia living at home are dependent on their family and friend caregivers (hereafter referred to as caregivers) for support and care. Despite the growing numbers of caregivers, most caregivers receive very little preparation and support in assuming the role of a caregiver (Black et al., 2013). As a result, caregivers experience burden, depression, poor physical health and well-being and low confidence levels in caring for older adults with dementia (Brodaty & Donkin, 2009).

Background

There are very few tested psychosocial and educational interventions specifically designed for caregivers of individuals with more advanced forms of dementia in the community

(Clarkson et al., 2018). The features of advanced dementia, leading to a need for greater support, include significant memory loss and impaired communication, loss of independent ambulation and inability to complete activities of daily living (Mitchell, 2015). Many interventions target caregivers of people with early to moderate dementia (Jensen, Agbata, Canavan, & McCarthy, 2015). Interventions for caregivers of persons with dementia in the early to moderate stages of dementia are focused on memory recall, advanced cognitive stimulation (e.g., word and card games) and verbal fluency (Milders, Bell, Lorimer, MacEwan, & McBain, 2013; Orrell et al., 2017). These types of programs are not suitable for older adults with more advanced forms of dementia due to greater cognitive and physical limitations. The needs of people with dementia at different stages vary and their caregivers require tailored interventions (Gaugler et al., 2019). Some interventions do not specify what stages of dementia the interventions are best suited for (Clarkson et al., 2018). Nurses are well-positioned to implement caregiver support interventions and reduce the wait time for caregivers to receive services and assistance from health systems (Shepherd-Banigan et al., 2020).

In most studies, caregivers are not involved in the development of caregiver interventions for people with dementia, limiting the relevance of interventions (Burgio et al., 2009; Huang et al., 2013; Liddle et al., 2012; Llanque et al., 2015). There is also a need for studies of interventions that measure positive outcomes of caregiving such as positive aspects of caregiving and confidence in providing care (Tarlow et al., 2004). Enhancing the positive outlook on caregiving leads to better quality of life (QOL), self-efficacy and mental health for caregivers (Quinn & Toms, 2018). The perceptions of caregivers on caregiving influence the QOL of people with dementia and can delay the need for institutional care (Brodaty & Donkin, 2009). Optimising positive experiences through programs such as Namaste Care can lead to better QOL for caregivers and care recipients (Kaasalainen et al., 2019; Kaasalainen et al., 2020; Manzar & Volicer, 2012, Stacpoole, Hockley, Thompsell, Simard, & Volicer, 2017). There is a growing international recognition that Namaste Care may be suitable to be adapted and delivered by caregivers of people with advanced dementia living in their homes (Bray, Atkinson, Latham, & Brooker, 2018; Dalkin, Lhussier, Kendall, Atkinson, & Tollman, 2020; Simard, 2013).

Namaste Care intervention. Namaste Care is a psychosocial, multisensory program developed in a LTC setting in the United States to improve the QOL of those with advanced dementia (Simard, 2013). Its principles consist of improving QOL through a comfortable environment and an unhurried, loving touch approach (Simard, 2013). Namaste Care combines different multisensory modalities including music, massage, socialization, aromatherapy and snacks. The program provides practical skills related to the modalities for healthcare providers to meaningfully engage people with dementia in activities.

Namaste Care sessions are typically delivered by a healthcare provider in a quiet room with low lighting and no distractions. In LTC settings, the sessions are delivered daily in the morning and afternoon. People with dementia are welcomed into a room where relaxing music is being played and scents (e.g., lavender, seasonal scents) are diffused. Namaste Care incorporates principles of touch by providing hand/foot massages, applying moisturizing cream and brushing hair. Healthcare providers may show photo albums, sports games on a computer tablet, or sing with the resident. Residents are provided with a Namaste Care toolkit that has unique items such as lotions, life-like dolls, plush animals and balls to provide sensory stimulation. Throughout the program persons with dementia are being monitored by healthcare providers for signs of pain and discomfort (Simard, 2013).

Namaste Care has been used internationally in various settings including LTC, hospice, acute care and home settings (Simard, 2013). Namaste Care has led to reduced use of antianxiety medications and psychotropic medications, lower risk of delirium, lessened pain symptoms and improved QOL for people with dementia (McNiel & Westphal, 2018; Nicholls, Chang, Johnson, & Edenborough, 2013; Simard & Volicer, 2010; Stacpoole, Thompsell, Hockley, Simard, & Volicer, 2013). Family members feel more comfortable and relaxed when interacting with persons with dementia when engaging in Namaste Care (Simard & Volicer, 2010). Only one study explored use of Namaste Care in a home setting (Dalkin et al., 2020). In this study, Namaste Care was delivered by hospice volunteers in England who visited persons with dementia at home. The program increased socialization for persons with dementia (Dalkin et al., 2020). Caregivers however were not involved in delivering the program. Assessing feasibility is of particular significance in the proposed research because Namaste Care has not yet been delivered by caregivers at home.

THE STUDY

Aim

The purpose of this study is to: (a) develop an adapted version of Namaste Care through meaningful engagement of caregivers of persons with moderate to advanced dementia to be used in the community setting; and (b) determine the feasibility, acceptability and preliminary effectiveness of the adapted Namaste Care approach in supporting caregivers.

Research questions

The research question for Phase 1 (qualitative) is: (a) How do caregivers envision the adaptation of the Namaste Care program for use by caregivers of community-dwelling older adults with moderate to advanced dementia? Phase 2 (quantitative and qualitative) is guided by the following questions: (a) What is the feasibility of the revised Namaste Care program? (b) What is the acceptability of the revised program? (c) What are the experiences of caregivers in implementing the revised program at home? and (d) What are the preliminary effects of the revised program on QOL, positive aspects of caregiving, self-efficacy and burden for caregivers? The overarching mixed methods research question is: To what extent and in what ways do qualitative themes of the adaptation of the Namaste Care program and its implementation serve to contribute to a more comprehensive understanding of the quantitative results related to feasibility, acceptability and preliminary effectiveness of the program?

Methodology

Multiphase mixed methods design. The study design that will be used is a multiphase mixed methods design that combines sequential and concurrent strands over time to address an overall program objective (Creswell & Plano Clark, 2018). In this study the overall program objective is to support caregivers of community-dwelling older adults with moderate to advanced dementia through adaptation and evaluation of Namaste Care. The multiphase design is used to inform the development, adaptation and evaluation of programs by combining quantitative and qualitative approaches (Creswell & Plano Clark, 2018). The notation of the proposed study design is QUAL —> [quan + QUAL] meaning that we will start with a qualitative strand to adapt Namaste Care and then evaluate the revised program using quantitative and qualitative methods. The qualitative strands will be given greater priority. See Figure 1 for the study flow diagram.

Phase 1: Adaptation of Namaste Care. The research design guiding Phase 1 consists of qualitative description (Sandelowski, 2000). Qualitative description was selected as it provides direct descriptions of phenomena while still encouraging some level of interpretation of data

(Sandelowski, 2000, 2010). For Phase 1 it is important to use a research design such as qualitative description to produce themes that remain close to the words of participants (Sandelowski, 2010). The Namaste Care program will be adapted in terms of content, care activities and implementation process. Adaptation will occur by conducting small group workshop sessions with caregivers. A training guide will be created, and caregiver feedback will be sought. We will use the System for Classifying Modifications to Evidence-Based Programs or Interventions (Stirman, Miller, Toder, & Calloway, 2013) in the adaptation phase. It will be used to guide the adaptation process of Namaste Care, document changes made to the original Namaste Care program to assess fidelity and as a coding framework. The System for Classifying Modifications to Evidence-Based Programs or Interventions framework (Stirman et al., 2013) is composed of five categories that consider the following: (a) By whom are modifications made?, (b) What is modified?, (c) At what level of delivery (for whom/what are the modifications made)?, (d) Context modifications are made to which of the following? and (e) What is the nature of the content modification?

Phase 2: Assessing feasibility, acceptability and preliminary effects of Namaste Care. In Phase 2 participants will receive a 60-minute in-person or virtual training session on implementing the revised Namaste Care approach at home. MY will be providing weekly check-ins with caregivers to assess their needs. As this study aims to evaluate feasibility, acceptability and preliminary effectiveness of Namaste Care under real-world conditions, a one group, before-after design will be used in Phase 2 (Feeley et al., 2009; Thabane et al., 2010). Feasibility will be evaluated by comparing the research activity log to pre-set target criteria; a similar approach was used in another study of Namaste Care (Kaasalainen et al., 2020): (a) number of days the Namaste Care approach is used across weeks (target: at least 5 out of 7 days per week for at least

8 out of 12 weeks); (b) retention rate (target: 75% have 3 months of data collection completed); and (c) percentage of adverse events reported (target: 0%). Caregivers will be asked to complete a brief Namaste Care Activities Checklist on the days they deliver the program. The type of adverse event that may be reported is skin breakdown as found by Kaasalainen et al. (2019). The criterion consisting of number of days the Namaste Care approach is used is subject to change based on the input of caregivers at the workshops.

Qualitative description will be used to explore the acceptability of the program among caregivers and to help explain potential effects of the program. It will be used to explore the experiences of caregivers following the implementation of the revised Namaste care program (Sandelowski, 2000). The acceptability of Namaste Care will be explored through individual interviews with caregivers in person, by phone, or by videoconference at the end of the study period (i.e., at three-month follow-up). These interviews will explore the following in terms of acceptability: (a) benefits and disadvantages of the program; (b) satisfaction with the process of implementation; (c) barriers and facilitators to implementation; and (d) recommendations to improve the program.

Preliminary effectiveness of the program will be assessed using primary and secondary outcome measures. The primary outcome for this study is QOL score for caregivers obtained from the Carers-DEMentia Quality of Life (C-DEMQOL) scale exploring the QOL of caregivers of people with dementia (Brown et al., 2019). Subdomains of the scale will be used in the proposed study (i.e., carer well-being and carer role). The secondary outcomes include caregivers': (a) positive perceptions score obtained using the Positive Aspects of Caregiving (PAC) scale (Tarlow et al., 2004); (b) self-efficacy score obtained using the Relational, Instrumental, Self-soothing (RIS) Eldercare Self-Efficacy scale (Gottlieb & Rooney, 2003); and

(c) caregiver burden score obtained using the short form Zarit Burden Interview scale (ZBI-12) (Bédard et al., 2001). QOL was selected as an outcome because it has not yet been measured in Namaste Care studies for caregivers. Namaste Care focuses on creating positive perceptions in caring and requires measurement. The program aims at building skills of caregivers with the potential to affect self-efficacy. There is a need to determine whether asking caregivers to deliver the program over three months affects caregiver burden.

Setting, participants and recruitment

Setting. The setting for the study will consist of Southern Ontario, Canada. The workshops with caregivers will take place in Alzheimer Society offices in private meeting rooms or virtually using an encrypted videoconferencing platform (i.e., Zoom). Individual training will take place in the homes of caregivers and persons with dementia or virtually using videoconferencing. Data collection of baseline and follow-up data will occur in the homes of caregivers, by telephone, or by videoconference.

Participants. Participants sought for Phase 1 and Phase 2 consist of family or friend caregivers of older adults with moderate to advanced dementia. In this study caregivers are defined as unpaid caregivers who provide support or physical care for a relative with moderate to advanced dementia for at least four hours a week. For Phase 1 caregivers must be currently or have experience in the last five years caring for older adults, 65 years and older, who are living with dementia. Caregivers must be currently caring for older adults with dementia to be eligible for Phase 2. Computer tablets and access to the internet will be provided for caregivers who do not have access to these.

The types of purposive sampling to be used to select caregivers are criterion, maximum variation and snowball sampling (Patton, 1990). Criterion sampling will be used to seek participants who meet the study inclusion criteria for each of the study phases. Maximum variation sampling will be used to seek diverse caregivers in terms of sex, relationship to the person living with dementia, ethnicity and level of education. Snowball sampling will also be used by asking caregivers to share study and researcher contact information with other caregivers who may be interested in participating in the study (Patton, 1990). The sample size sought for Phase 1 of the study is 8-10 caregivers. Four to 5 caregivers will be included in each workshop session to ensure that participants can actively participate in discussions. The sample size is not only based on the total number of participants included in the study, but the number of interviews or observations (Sandelowski, 1995). In the proposed study caregivers will attend two workshop sessions and data will therefore be collected on two occasions.

For Phase 2 a total of 10-20 caregivers will be included in the sample. Thabane et al. (2010) report that sample size calculation may not be necessary for pilot studies. The authors emphasize the importance of ensuring that the sample for a pilot study is adequate to provide relevant information to assess feasibility of the study. The total number of caregivers was determined based on previous studies that explored Namaste Care which included anywhere from 8 to 15 caregivers (Dalkin et al., 2020; Froggatt et al., 2020; Hunter et al., 2017; Kaasalainen et al., 2020; Magee et al., 2017, Nicholls et al., 2013).

Recruitment. Caregivers will be recruited from the local Alzheimer Society, adult day centers, the Local Health Integration Network and Behavioural Supports Ontario. MY will present the study at in-person and virtual dementia education events for caregivers. Information about the study will be shared in electronic newsletters distributed to caregivers by the Alzheimer Society via email. The Alzheimer Society community program educators will refer potential participants to the study by providing them with a study flyer (hard copy or by email).

Data Collection

Demographic data to be collected using questionnaires will include information such as age, sex, education level, relationship to care recipient, ethnicity and chronic conditions. Qualitative data will be collected in Phase 1 during in-person or virtual (i.e., videoconference) workshop discussion sessions with caregivers. Individual face-to-face or non-face-to-face (i.e., by telephone or videoconference) semi-structured interviews lasting approximately 30 minutes will be conducted with caregivers at the end of the workshops. The follow-up interview will be used to explore patient engagement experiences of caregivers. The interview guide is based on the targeted outcomes of the Strategy for Patient-Oriented Research (SPOR) patient engagement framework: (a) inclusive mechanisms and processes created, (b) respectful collaboration between researchers and caregivers and (c) experiential knowledge of caregivers is valued as evidence for research (Canadian Institutes of Health Research, 2019).

In Phase 2 of the study both quantitative and qualitative data collection will be completed. Survey data will be collected at baseline and at the three-month follow-up. The C-DEMQOL scale consists of 30 items (Brown et al., 2019). For the two subdomains that will be used in the proposed study, carer well-being had a Cronbach alpha of 0.91 and care-patient relationship/carer role had a Cronbach alpha 0.82. Scores range from 30-150 with higher scores reflecting better QOL (Brown et al., 2019). For the PAC nine-item measure the Cronbach alpha for the scale was 0.89 (Tarlow et al., 2004). Scores range from 9-45 with higher scores reflecting greater positive feelings towards caregiving.

The RIS Eldercare Self-Efficacy scale is a 10-item tool (Gottlieb & Rooney, 2003). Internal consistency was established for relational self-efficacy with a Cronbach alpha of 0.73, 0.78 for instrumental self-efficacy and 0.72 for self-soothing self-efficacy. The validity of the instrument was established with the ability to explain 61.2% of total variance using a principal component factor analysis. Scores range from 10-50 with higher scores reflecting greater self-efficacy. The ZBI-12 (Bédard et al., 2001) is a short version adapted from the 22-item scale and the original 29-item scale created by Zarit et al. (1980). Internal consistency was established with a Cronbach alpha value of 0.88 found for the ZBI-12 scale. Scores range from 0 to 48 with higher values representing greater burden. Data on feasibility will be collected by completing the research activity log. MY will be updating the log based on information obtained from caregivers (e.g., completed Namaste Care Activities Checklist) during the telephone or virtual check-ins.

Qualitative data will be collected at the three-month follow-up and will consist of a 45-60-minute individual face-to-face or non-face-to face (i.e., by telephone or by videoconference) semi-structured interview with caregivers to explore their experiences in implementing the revised program. The interview guide will be used to explore experiences with the program and acceptability. The interview guide was developed based on the Bowen Feasibility Framework (Bowen et al., 2009), semi-structured qualitative research methods (DiCicco-Bloom & Crabtree, 2006), recommendations by research team members and dementia literature. It includes open-ended and focused questions directed at the central phenomenon (Creswell, 2013). Reflective field notes made immediately after the interviews will be used to capture actions and to highlight personal reactions by bringing important elements to light such as emotions experienced by participants (Thorne, 2016). Both workshop sessions and interviews will audio-recorded and transcribed by an experienced transcriptionist. See supplementary files for interview guides.

Data Analysis

Qualitative data obtained from the workshop sessions and interviews will be analyzed separately using thematic analysis, a method that is used to identify themes and patterns within data (Braun & Clarke, 2006). Specifically, experiential thematic analysis will be used. This type of analysis is suitable for the proposed study as it focuses on the experiences of participants and how they understand their world (Braun & Clarke, 2013). Analysis will be both inductive and deductive in nature. We will follow the six phases of Braun and Clarke's (2006) thematic analysis: (a) gaining familiarity with the data; (b) conducting coding; (c) locating themes; (d) reviewing themes, (e) developing a definition for themes and naming them; and (f) developing a report. The research team will read transcripts and review coding structures, themes and interpretations initially developed by MY. The research team will analyze data concurrently as interviews are being completed. The System for Classifying Modifications to Evidence-Based Programs or Interventions (Stirman et al., 2013) framework (for Phase 1) and the Bowen Feasibility framework (for Phase 2) will serve as coding frameworks. Consistent with qualitative description (Sandelowski, 2000), constant comparative analysis will be used to identify similarities and differences across participants. The final report will also include a comparison of study findings to the current literature surrounding the phenomenon of interest (Braun & Clarke, 2006). NVivo version 12 software will be used for data management.

Demographic characteristics of participants will be analyzed using descriptive statistics. Means and standard deviations will be reported for continuous variables and counts or percentages will be reported for categorical variables. Normalcy will be assessed to determine whether the sample is normally distributed before deciding to conduct parametric or non-parametric tests. Based on the findings, paired t-tests or non-parametric tests (i.e., the Wilcoxon's Signed Rank Test) will be used to examine the change in score in outcomes for caregivers from baseline to post-intervention. Data analyses will be conducted using SPSS version 25 and statistical significance will be set at $\alpha=0.05$ using two-tailed tests.

Once data analysis for both the quantitative and qualitative strands are completed, the findings of both analyses will be compared with develop the mixed methods interpretation (Creswell & Plano Clark, 2018). Inferences will be made based on the separate findings from the quantitative and qualitative strands at the end of each phase (Onwuegbuzie & Johnson, 2006). Meta-inferences will be made at the end of the study by combining the inferences from separate strands to provide a broader interpretation (Creswell & Plano Clark, 2018). We will connect the strands when using the quantitative strand to evaluate the effectiveness and feasibility of the revised Namaste Care program which was adapted based on a qualitative strand. In terms of merging the strands, both quantitative and qualitative methods will be used to examine the feasibility and acceptability of the revised program. The mixed methods discussion will also focus on how the quantitative, qualitative and mixed methods questions were addressed at the end of the study. A joint display will be used to show the connection between quantitative results and qualitative findings that either support or diverge from one another (Creswell & Plano Clark, 2018). Another aim of the mixed methods interpretation is to further refine the program based on the results and experiences of caregivers.

Ethical Considerations

Ethics approval was received from the Hamilton Integrated Research Ethics Board (#10526). The three core principles, respect for persons, concerns for welfare and justice, of the Tri-Council Policy Statement will be applied throughout the study (CIHR, Natural Sciences and Engineering Research Council of Canada (NSERC), & Social Sciences and Humanities Research Council (SSHRC), 2018). All caregivers will receive a written introduction to the study and an informed consent form written in lay language. An incentive in the form of a $25 gift card will be offered to caregivers after completing Phase 1 or Phase 2.

Validity and reliability/Rigour

Quantitative validity. When choosing the instruments included in the study we considered content validity to ensure that the instruments measure salient aspects of a phenomenon and face validity to ensure that the measurement and number of items included appear reasonable (Hulley, Cummings, Browner, Grady, & Newman, 2013). We also carefully selected the instruments based on whether they were specific for caregivers of people with dementia and can be used in a home setting. The outcomes that were selected were explored in previous studies that focused on community-dwelling older adults with dementia and their caregivers.

Qualitative validity. MY will maintain a reflexive journal to document reactions and experiences potentially having an impact on the study process (Finlay, 2002). We will implement strategies to meet Lincoln and Guba’s (1985) trustworthiness criteria consisting of credibility, transferability, dependability and confirmability. We will promote credibility through investigator triangulation by seeking feedback from members of the research team as they hold research expertise in the areas of caregivers, people with dementia and/or community support programs. This process will promote credibility and complementarity as well as validating data (Lincoln & Guba, 1985). To increase the transferability of the study findings, rich thick descriptions will be used to describe the setting and sample of the study (Lincoln & Guba, 1985). MY will conduct a study audit to meet the criteria of dependability and confirmability to ensure that the process for collecting data and analyzing data is systematic and findings are supported by data.

Mixed methods study validity. We will be implementing strategies to minimize threats related to data collection, data analysis and interpretation of both quantitative and qualitative findings. We will be selecting samples and using data collection methods as appropriate for both phases of the study (Creswell & Plano Clark, 2018). We will ensure that we adequately interpret the quantitative and qualitative findings appropriately to address the mixed methods research question (Creswell & Plano Clark, 2018). We will ensure validity by integrating quantitative and qualitative strands to answer the mixed methods research question and revealing divergencies between the findings of both strands in a joint display. The Mixed Methods Appraisal Tool (MMAT) will be used to ensure validity of the mixed methods study (Hong et al., 2018).

DISCUSSION

When caregivers are unable to meet the demands of caregiving and lack supports to effectively care for people with dementia at home, they are faced with having to place people with dementia in LTC or admit them to hospital. In Canada in 2016, 56,000 individuals with dementia received care in hospitals (Chambers et al., 2016), with some receiving care due to caregivers no longer being able to support their care needs at home. Limited resources (e.g., healthcare personnel with limited knowledge of dementia, equipment and recreational activities) are available in hospitals, LTC and home care to adequately support people with dementia leading to poor outcomes for this population such as delirium, dehydration and falls. Unnecessary admittance of persons with dementia to healthcare facilities can be prevented by providing caregivers with knowledge and skills to care for persons with moderate to advanced dementia at home. QOL of caregivers can be improved by providing tailored education and meeting their needs for support.

With very few psychosocial and educational interventions that can be used by caregivers in the community to support those with more advanced forms of dementia (Clarkson et al., 2018), there is a need for a tailored program. The study intervention will help caregivers build skills by supporting them to use the adapted Namaste Care approach when assisting people with dementia with activities of daily living and offering meaningful social activities. Through Namaste Care, care provision has the potential to be more effective for caregivers while reducing the need for hospitalization and LTC admission.

This study will allow nurses to gain a more active role in supporting and educating caregivers of people with advanced dementia in a community setting. This study will reveal the impact and lessons learned of translating dementia care skills and knowledge to members of the public and partnering with organizations such as the Alzheimer Society to create positive change. Nurses with a clinical background in dementia care can be effective educators in supporting caregivers of persons with moderate to advanced dementia in home settings. In some studies, nurses were responsible for training caregivers on implementing psychosocial and educational interventions at home (Dahlrup, Nordell, Andrén, & Elmståhl, 2011; Huang et al., 2013).

Strengths and Limitations

The strengths of the study include: (a) adapting an intervention for caregivers of community-dwelling older adults with moderate to advanced dementia by meaningfully engaging caregivers; (b) providing formal training for caregivers and support in using the adapted Namaste Care program; and (c) including both quantitative and qualitative methods to provide a deep understanding of the feasibility, acceptability and preliminary effects of the newly adapted program. This study will be the first to assess feasibility of Namaste Care delivered by caregivers in the home setting.

The limitations of the study include the small sample size which limits our ability to conduct further statistical tests such as regression analyses and using a pre-test/post-test design with no control. Given that this study will assess the feasibility of a version of Namaste Care to be delivered by caregivers, this study may later inform a more rigorous trial such as a randomized controlled trial with a larger sample size.

CONCLUSION

With most programs targeting those with early stages of dementia, this suggests that the complex needs of people with moderate to advanced dementia and their caregivers are not being met. There is a need to involve caregivers in developing interventions so that interventions are tailored to their needs and abilities and reflect the voices of care recipients. When adapting programs, contextual modifications may be made to deliver an intervention in a new setting and have a different type of person deliver the intervention (Stirman et al., 2013).

Namaste Care holds promise in improving the QOL of caregivers of people with moderate to advanced dementia. Namaste Care warrants further investigation in relation to whether it can be used in home settings and delivered by caregivers and the effects of the program on the QOL of caregivers of older adults with moderate to advanced dementia. There is no existing study exploring feasibility of Namaste Care in a home setting delivered by caregivers. The potential outcomes of this research are the development of a feasible supportive intervention that is practical and simple to use by caregivers of people with dementia and strategies to train caregivers to implement the approach at home.

CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

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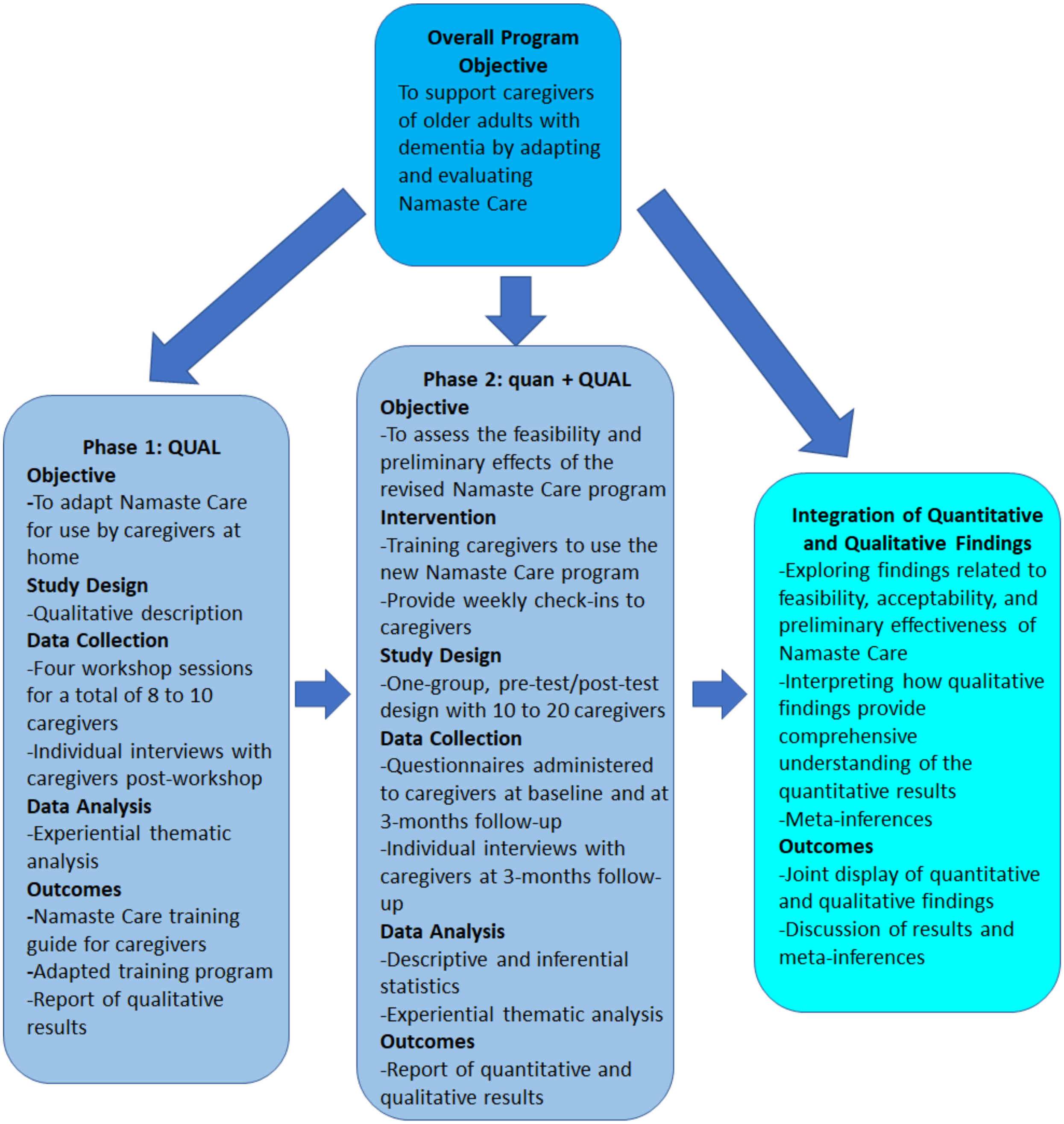

Overall Program Objective
To support caregivers of older adults with dementia by adapting and evaluating Namaste Care

Phase 1: QUAL
Objective
-To adapt Namaste Care for use by caregivers at home
Study Design
-Qualitative description
Data Collection
-Four workshop sessions for a total of 8 to 10 caregivers
-Individual interviews with caregivers post-workshop
Data Analysis
-Experiential thematic analysis
Outcomes
-Namaste Care training guide for caregivers
-Adapted training program
-Report of qualitative results

Phase 2: quan + QUAL
Objective
-To assess the feasibility and preliminary effects of the revised Namaste Care program
Intervention
-Training caregivers to use the new Namaste Care program
-Provide weekly check-ins to caregivers
Study Design
-One-group, pre-test/post-test design with 10 to 20 caregivers
Data Collection
-Questionnaires administered to caregivers at baseline and at 3-months follow-up
-Individual interviews with caregivers at 3-months follow-up
Data Analysis
-Descriptive and inferential statistics
-Experiential thematic analysis
Outcomes
-Report of quantitative and qualitative results

Integration of Quantitative and Qualitative Findings
-Exploring findings related to feasibility, acceptability, and preliminary effectiveness of Namaste Care
-Interpreting how qualitative findings provide comprehensive understanding of the quantitative results
-Meta-inferences
Outcomes
-Joint display of quantitative and qualitative findings
-Discussion of results and meta-inferences

Figure 1. Study Flow diagram

Supplementary files for online publication only

Table 1. Discussion and interview guide for Phase 1

Phase 1

First Workshop Session Discussion Guide

1. What is it like to care for a family member or friend living with mid to late-stage dementia at home?
2. What are some principles that should be reflected in the design of Namaste Care?
3. How often and for how long should Namaste Care be implemented?
4. When is the best time to deliver Namaste Care for you and your loved one or friend?
5. What kind of training would you need to be able to use Namaste Care at home?
    a. What kind of resources would be most helpful?
6. What are your thoughts on considering unique preferences, routines, strengths, and abilities when using Namaste Care for your loved one?
    a. Do you feel you have enough knowledge (e.g., preferences, life story, routines, health history) of your friend or family member to meet his or her needs?
7. What activities (e.g., massaging, feeding, playing music, aromatherapy) would you be comfortable and confident in doing during the Namaste Care sessions?
8. What would make it easy for you to use Namaste Care in a home setting?
9. What would make it hard for you to use Namaste Care in a home setting?

Second Workshop Sessions Discussion Guide

Training Guide

1. What are your thoughts on the training guide?
2. Does the training guide capture your ideas and suggestions? If not, what should be added to the guide?
3. Do you feel that the training guide would be useful in helping you deliver Namaste Care in your own home? Why or why not.
    a. What are your suggestions to help make the training guide more useful?
4. Are there certain words or ideas that need to be better defined? Which ones?
5. What are your thoughts on the length of the training guide (i.e., too long or too short)?

Training session and implementation

6. In addition to the training guide, what kind of one-on-one Namaste Care training would you be interested in receiving at home?
7. How long should the Namaste Care training session be?
8. What kind of materials would you like to have in a Namaste Care toolkit (e.g., scents, lotions, soaps, balls, etc.)?
9. How often should someone follow-up with you by phone to support you in using Namaste Care?

Post-Workshop Interview Guide

1. What did you think about the workshop sessions?
2. How did you feel about participating in discussions?
3. Did you feel included in discussions? Why or why not?
4. How comfortable were you in sharing your ideas in adapting the program?
5. Did you feel that your ideas and experiences were being respected during the workshops? Why or why not?

6. Did you feel that your ideas were reflected in the training guide? Why or why not?
7. What could have been done differently to make this experience better for you?
8. Would you participate in a similar workshop for a research project in the future?

Note. The post-workshop interview guide was inspired by the targeted outcomes of the SPOR Patient Engagement framework (CIHR, 2009).

Table 2. Interview Guide for Phase 2

Phase 2
Interview Guide for the 3-Month Follow-Up
Delivering Namaste Care: 1. What were your experiences in delivering Namaste Care at home? 2. How did you feel about the resources provided to you to use Namaste Care at home? 3. How confident and comfortable did you feel in using Namaste Care at home? 4. How supported did you feel in implementing Namaste Care at home? 5. How often and over what length of time were you able to deliver Namaste Care? 6. What kind of activities did you provide for the person you are caring for? 7. What made it difficult to use the program? 8. What made it easy to use the program? 9. How did you personalize care activities for your family member or friend? **Satisfaction with Namaste Care:** 10. Would you continue to use the Namaste Care at home after this study is done? Why or why not? 11. How satisfied were you in using the program? 12. What changes would you recommend to improve the program? **Effects of Namaste Care:** 13. What impact did Namaste Care have for you? 14. What impact did Namaste Care have for your family member or friend? 15. Has Namaste Care created any changes in how you see your role as a caregiver? If so, what kind of changes? 16. What impact did Namaste Care have on your connection and relationship with your family member or friend? 17. Did you feel like delivering Namaste Care made a difference for you and/or your family member or friend? In what ways?

Note. Some of the questions included in the Phase 2 interview guide were inspired by the Bowen Feasibility Framework (Bowen et al., 2009).

CHAPTER 4

TITLE: Adapting the Namaste Care Program for Use with Caregivers of Community-Dwelling Older Adults with Moderate to Advanced Dementia: A Qualitative Descriptive Study[2]

AUTHORS: Yous, M., Ploeg, J., Kaasalainen, S., & McAiney, C.

JOURNAL: Canadian Journal on Aging/ La Revue canadienne du vieillissement

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Abstract

Family/friend caregivers are highly involved in supporting older adults with dementia with daily activities, especially when older adults with dementia are living at home. There is a need for psychosocial interventions for caregivers of older adults with moderate to advanced dementia as most interventions focus on persons at earlier stages. Namaste Care is a psychosocial, multisensory program intended to enhance quality of life for people with advanced dementia and their caregivers, however it has not yet been adapted for use in a home setting. In this study caregivers collaborated in adapting Namaste Care during workshops so that it could be delivered by caregivers of older adults with moderate to advanced dementia at home. Key findings were that Namaste Care resonated with the daily activities of caregivers, but the intervention required modifications to ensure that it can be tailored to the needs and realities of caregivers and persons with dementia.

Résumé

Les proches-aidants sont très impliqués dans le soutien des personnes âgées atteintes de démence, surtout si ces personnes habitent à la maison. Des interventions psychosociales sont nécessaires pour les proches-aidants des personnes âgées atteintes de démence modérée à avancée, car la plupart des interventions sont pour les personnes aux stades précoces. Namaste Care, un programme psychosocial et multisensoriel, peut améliorer la qualité de vie des personnes atteintes de démence avancée et leurs familles, mais il n'a pas encore été adapté pour usage à domicile. Dans cette étude, les proches-aidants ont collaboré à l’adaptation de Namaste Care afin qu'il puisse être utilisé par des proches-aidants des personnes âgées atteints de démence modérée à avancée à domicile. Les résultats étaient que Namaste Care s’intègre bien avec les activités quotidiennes, mais l'intervention nécessitait des modifications pour qu'elle puisse être adaptée aux besoins et aux réalités des proches-aidants et des personnes atteintes de démence.

Keywords: Caregivers, community-dwelling older adults, dementia, adaptation, intervention, qualitative

Background

Globally, 50 million individuals are currently living with dementia and 10 million individuals are diagnosed with dementia every year (World Health Organization, 2020). Older adults are more likely than other age groups to be diagnosed with dementia with a twofold increased risk every five years after the age of 65 (Fiest et al., 2016). Persons with dementia experience significant symptoms impacting their abilities to complete daily activities including memory loss, difficulties with decision-making, poor language comprehension, and loss of communicative abilities (World Health Organization, 2020).

In Canada alone, over half a million individuals are living with dementia (Alzheimer Society of Canada, 2021), with more than 260,000 individuals living at home in the community (Canadian Institute for Health Information, 2019). Over 90% of Canadians with early dementia, 50% of those with moderate dementia, and 14% of those with advanced dementia live at home in the community rather than in an institution such as a long-term care (LTC) home (Chambers, Bancej, & McDowell, 2016). Many persons with dementia are staying at home due to long wait times for LTC, the high costs of LTC, and the preferences of many people with dementia and their families to have the person with dementia remain at home for as long as possible (McCurry et al., 2017).

With the progressive decline in social, cognitive, and physical abilities associated with dementia many older adults with dementia living at home increasingly depend on family and friend caregivers (hereafter referred to as caregivers) for support and care. The common definition of a caregiver is a person 18 years or older who provides support or care for an individual with a chronic health condition, physical or cognitive limitation, and/or age-related issues (Turcotte, 2013). Caregivers are highly involved in the care of older adults with dementia;

however, caregivers often report unmet needs for caregiver education and community support (Black et al., 2013). As a result, caregivers experience poor outcomes such as stress, depression, a decline in physical and mental health, and a lack of confidence in caring for older adults with dementia (Brodaty & Donkin, 2009).

There is a need to support caregivers of community-dwelling persons with dementia through psychosocial interventions (e.g., sensory activities, cognitive stimulation, physical activities, art therapy). These have been found to reduce caregiver burden and depression while improving caregiver well-being, quality of life, knowledge about dementia, resilience, and skills for care delivery (DiZazzo-Miller, Winston, Winkler, & Donovan, 2017; Jensen, Agbata, Canavan, & McCarthy, 2015; McCurry et al., 2017; Vedel et al., 2020). A psychosocial intervention is defined as having the aim of reducing or preventing a decline in mental and physical health of caregivers and/or care recipients by targeting activities, skills, competence, and/or relationships (Van't Leven et al., 2013).

There are currently few psychosocial interventions intended for use by caregivers in the community to support persons with moderate to advanced dementia (Clarkson et al., 2018). Many psychosocial interventions are designed for caregivers of persons with early to moderate dementia (Jensen et al., 2015). Other interventions are created for caregivers supporting persons with dementia with little consideration given to differences between stages of dementia and the abilities of persons with dementia (Clarkson et al., 2018). This limits the relevance and usefulness of caregiver interventions as the needs of persons with dementia vary from stage to stage.

Namaste Care is a psychosocial, multisensory program originally created for use in LTC in the United States to improve the quality of life of persons with advanced dementia and their families and friends (Simard, 2013). Its principles consist of providing a comfortable environment and interacting with persons with dementia through an unhurried, loving touch approach (Simard, 2013). Different modalities are combined within the Namaste Care program including music, massage, socialization, aromatherapy, and snacks. Through this approach, family members and healthcare providers are equipped with practical skills to meaningfully engage people with dementia.

Namaste Care sessions are typically delivered daily by care providers in a quiet room with soft lighting and no interruptions (Simard, 2013). In LTC settings, sessions generally last two hours and are offered in the morning and afternoon. Family members can join sessions if they wish. Inside the Namaste Care room, relaxing music is played and scents such as lavender or seasonal scents are diffused. Activities are provided one at a time by care providers. Touch is used through approaches such as hand/foot massages, applying lotions, and hair brushing. A Namaste Care box or cart is used to store items. The included items are based on the individual’s preferences such as lotions, life-like dolls, plush animals, photos, and sensory balls. Throughout the sessions, persons with dementia are monitored by healthcare providers for signs of pain and discomfort (Simard, 2013).

Namaste Care has been implemented worldwide and within various settings including LTC, hospice, acute care, and home settings (Simard, 2013). The program has led to favorable outcomes such as reduced use of antianxiety and psychotropic medications, lower risk of delirium, decreased pain symptoms, and improvement in quality of life for persons with dementia and relationships with staff (Bunn et al., 2018; Karacsony & Abela, 2021; McNiel & Westphal, 2018; Nicholls, Chang, Johnson, & Edenborough, 2013; Simard & Volicer, 2010; Stacpoole, Thompsell, Hockley, Simard, & Volicer, 2013). Family members are more relaxed during interactions with persons with dementia following Namaste Care (Simard & Volicer, 2010). To date only one study explored Namaste Care delivery in a home setting, and it was delivered by volunteers from a hospice organization (Dalkin, Lhussier, Kendall, Atkinson, & Tollman, 2020). Dalkin et al. (2020) found that Namaste Care led to increased socialization for persons with dementia. Caregivers however had little participation in the intervention, as the focus was on volunteers (Dalkin et al., 2020).

Most studies have not involved caregivers in the development or adaptation of caregiver interventions for persons with dementia, thus limiting the practicality and usefulness of interventions (Burgio et al., 2009; Huang et al., 2013; Liddle et al., 2012; Llanque et al., 2015). Partnering with persons with dementia and caregivers ensures that they can make and influence decisions that impact their lives such as decisions related to program planning, intervention design, or policies (Health Quality Ontario, 2017). Older adults with advanced dementia may not be able to participate in designing interventions; however, family members have valuable insights that should be shared when collaborating with researchers to develop and refine programs (Treadaway, Taylor, & Fennell, 2018). There is a need to involve caregivers in developing interventions for home use to support people with moderate to advanced dementia so that interventions are tailored to their needs and abilities and reflect the voices of care recipients. When adapting programs, contextual modifications may be made to deliver an intervention in a new setting and have a different type of person deliver the intervention (Stirman, Miller, Toder, & Calloway, 2013). Programs that were developed for use in LTC settings, such as Namaste Care, would require further adaptation with the collaboration of caregivers prior to being implemented in individual residences.

Prior to implementing the program in home settings, Namaste Care (Simard, 2013) would have to be adapted while ensuring that modifications maintain fidelity. The purpose of this study is to describe and explain suggested adaptations for the Namaste Care program and training procedures in collaboration with caregivers so that the approach is feasible to be delivered in a home setting. The research question is: How do caregivers envision the adaptation of Namaste Care for use by caregivers of community-dwelling older adults with moderate to advanced dementia?

Methods

Study Design

The research design for the present study consists of qualitative description (Sandelowski 2000, 2010). Qualitative description allows for direct descriptions of phenomena with some room for interpretation of data (Sandelowski, 2000, 2010). By incorporating direct suggestions of caregivers in revising Namaste Care, this can help ensure that the program will meet the needs and expectations of caregivers. The present study is one component of a larger study that uses a multiphase mixed methods design combining both sequential and concurrent qualitative and quantitative strands over time to address a program objective (Creswell & Plano-Clark, 2018). As a follow-up to the present study caregivers will receive training to deliver the adapted version of Namaste Care at home for persons with moderate to advanced dementia over three months and its feasibility, acceptability, and specific outcomes for caregivers will be evaluated. The protocol for the mixed methods study is published elsewhere (Yous, Ploeg, Kaasalainen, & McAiney, 2020).

Core Components of Namaste Care

The full structured Namaste Care program (Simard, 2013) is expected to be delivered twice a day, two hours at a time in the morning and afternoon in a designated LTC room with the following core components: (a) using a person-centred approach, (b) incorporating comfort and pain management, (c) scenting a room, (d) playing relaxing/upbeat music, (e) providing touch activities, (f) offering beverages and snacks, (g) encouraging range of motion activities, and (h) providing reminiscence activities (e.g., photo albums, conversations about life stories) (Kendall, 2019). With the original program, Namaste Care providers are often providing the program as a group therapeutic session for persons with dementia in LTC. A proposed alternative to the full structured Namaste Care program is an adapted Namaste Care program for caregivers at home. The adapted program will retain the original program's core components and principles (Simard, 2013), but provides flexibility for when it is used, how long it is delivered, and what key activities are being offered as seen in a study by Dalkin et al. (2020).

In this present study it is proposed that caregivers use the adapted Namaste Care program rather than the full structured program designed for use in LTC. Rather than trying to reserve a dedicated time and place for delivering Namaste Care, caregivers are encouraged to creatively integrate the program into their day. The decision was made to use the adapted program rather than the full program as caregivers in the home setting may not have the time and energy to deliver the program daily, two-hours at a time, as it is intended in LTC settings. Instead, it is likely that caregivers would find ways to incorporate the adapted Namaste Care program in routine care activities such as when assisting with personal grooming and providing snacks and beverages in between mealtimes. The main principles of the adapted program that will continue to be upheld are creating a comfortable environment and providing an unhurried, loving touch approach (Simard, 2013).

Framework for Namaste Care Adaptation

The System for Classifying Modifications to Evidence-Based Programs or Interventions (Stirman et al., 2013) was used to guide the adaptation process of Namaste Care (Simard, 2013). The framework was used to document modifications for the original Namaste Care program and as a coding framework. Stirman's et al. (2013) framework was created to provide a coding scheme to be able to categorize modifications to pre-existing evidence-based interventions when they are implemented in different contexts or with populations that differ from the ones that were originally targeted. The framework also considers modifications to the processes for training individuals responsible for delivering the intervention. These training modifications are separate from content and context modifications as training procedures do not typically impact the content of an intervention or the context in which it will be delivered (Stirman et al., 2013).

In the present study modifications to training is considered as an implementation strategy that has the potential to increase the successful delivery of the intervention. The framework has been used in previous studies to provide a coding framework for modifications to an evidence-based psychotherapy program (Stirman et al., 2015) and pediatric weight management program (Simione et al., 2020). It has also been used to inform the development of a questionnaire to assess adaptations to evidence-based practices by community healthcare providers offering children's mental health services (Lau et al., 2017). The use of a classification system helps to address the tension between fidelity and modifications related to maintaining fidelity of interventions without compromising effectiveness through modifications (Scheirer & Dearing, 2011).

The System for Classifying Modifications to Evidence-Based Programs or Interventions framework (Stirman et al., 2013) is composed of five categories: (a) By whom are modifications made?, (b) What is modified?, (c) At what level of delivery (for whom/what are modifications made)?, (d) Context modifications are made to which of the following?, and (e) What is the nature of the content modification? The framework was used in the present study to ensure that modifications for Namaste Care do not result in a dramatic departure from the original program while keeping intact the core elements.

Setting

The setting for the study consisted of urban areas in Ontario, Canada. The lead author met with caregivers individually prior to the workshop sessions to support them in preparing for the sessions using a method (i.e., by phone or Zoom) of their choice that adhered to Public Health Covid-19 restrictions at the time of the study.

Sample

Participants consisted of six family caregivers of older adults with moderate to severe dementia. Four small group workshops were held with two to four caregivers present at each workshop. Each caregiver attended two workshop sessions and met with the same group of caregivers each time. Purposive sampling was used including criterion and snowball sampling (Patton, 1990). The study inclusion criteria were: (a) aged 18 years or older with experience providing physical, emotional, and/or psychological support for a family member or friend aged 65 years or older with moderate to advanced dementia within the last five years at home for at least four hours a week, (b) able to speak, write, and understand English, (c) currently living in Ontario, and (d) able to provide informed consent. Caregivers who were no longer caring for a family member or friend at home (i.e., care recipient is living in a LTC setting or passed away) were also eligible to participate in the study. One participant in the study was a former caregiver who was last caring for a family member two years ago. Persons who were no longer caring for someone at home were invited to participate in the study because they could reflect on their recent home care experiences to inform the adaptation of Namaste Care and may still identify strongly with the caregiver role (Corey & McCurry, 2018). Former caregivers often seek to fulfill this role by helping other caregivers of people with dementia through sharing their experiences and lessons learned (Kim, 2009; Larkin, 2009). They may also have more time and are interested in participating in activities such as research. Snowball sampling was used by asking caregivers to share contact information of the researcher with other caregivers who may be interested in participating in the study.

Recruitment

Caregivers were recruited from the Alzheimer Society of Canada, local Alzheimer Societies, and Dementia Advocacy Canada through social media, online advertising, and newsletters. The lead author discussed the study at virtual dementia education courses and offered staff and client presentations at the Alzheimer Society. Alzheimer Society community program educators and counsellors were asked to refer potential participants to the study by providing them with a study flyer.

Namaste Care Adaptation Workshops

Each caregiver participated in a total of two workshops, an initial and follow-up session. A total of four workshop sessions with caregivers of community-dwelling older adults with moderate to advanced dementia were held. The workshop sessions occurred over a period of 60-90 minutes. All of the caregivers participated by videoconference except for one caregiver who participated by phone. The purpose of the initial workshop was to present the Namaste Care program to caregivers, provide an opportunity to discuss the program, and learn about their insights regarding adaptations needed for the program so that it can be used at home. The purpose of the second workshop was to present the draft training manual (developed based on results of the first workshop sessions with caregivers) to caregivers, obtain their feedback in the manual and training procedures, and further refine the Namaste Care program. During the first workshop session, the lead author provided caregivers with a 20-minute educational presentation of Namaste Care. As most of the caregivers were actively caring for a family member at home, they were interested in learning about Namaste Care so that they could apply new knowledge to support them in caring for persons with dementia at home. The content presented included: (a) the history of the creation of Namaste Care; (b) how it has been used in LTC; (c) the main principles and components of the program; (d) the benefits of the program supported by research evidence; (e) recommended steps in using the program; and (f) examples of items that can be found in a Namaste Care toolbox. Following the presentation of Namaste Care, the lead author facilitated interactive workshop discussions on caregivers' suggestions for adaptation of Namaste Care for home use. After the first workshop, the research team developed a draft version of the Namaste Care training guide based on what was shared at the first workshop sessions. This guide was shared by email with participants before the second workshop session for their review.

At the second workshop caregivers were provided with another 20-minute educational presentation on Namaste Care. The educational content presented at the second workshop included: (a) examples of Namaste Care sessions; (b) key considerations and strategies for delivering and selecting Namaste Care activities (e.g., music, aromatherapy, massages, snacks and beverages, range of motion/exercises, reminiscence activities); (c) how to perform observational assessments of mood, alertness, and pain for persons with dementia before, during, and after Namaste Care; (d) examples of responses of persons with dementia to activities; and (e) strategies to optimize the delivery of Namaste Care. A discussion to seek feedback and further adaptations required for Namaste Care and training procedures including the training guide was facilitated following the educational presentation.

Data Collection

Data collection occurred from October 2020 to January 2021. Demographic data were collected including age, sex, education level, relationship to the person with dementia, length of time as a caregiver, and type of support provided. Workshop discussion guides were developed based on a review of the literature, expert recommendations, and the Stirman et al. (2013) framework. See Table 1 for a sample of workshop discussion questions. Notes were taken following the workshop sessions. Workshop discussions were audio-recorded and transcribed by an experienced transcriptionist. In terms of the adaptation process, the experiences and recommendations shared during the workshop sessions were used to inform the adaptation of Namaste Care and the training procedures.

Data Analysis

Qualitative data obtained from the workshop sessions and researcher notes of the sessions were analyzed using thematic analysis, a method that is used to identify themes and patterns within data (Braun & Clarke, 2006). Specifically, experiential thematic analysis was used as it is suitable for the current study which focuses on participants' experiences and how they view their world (Braun & Clarke, 2013). Analysis was both inductive and deductive in nature. Inductive coding was used to reveal unique codes that arose from the workshop discussions with caregivers and deductive coding was conducted by using the Stirman et al. (2013) framework as an a priori template for codes (Freeday & Muir-Cochrane, 2006). The six phases of thematic analysis as described by Braun and Clarke (2006) were followed: (a) gaining familiarity with the data, (b) conducting coding, (c) locating themes, (d) reviewing themes, (e) developing a definition for themes and naming them, and (f) developing a report.

The lead author reviewed the transcripts twice before beginning to code to gain familiarity with the data and made reflexive notes about initial thoughts (Damayanthi, 2019). Initial reactions to the data were documented. During the process of coding, the research team analyzed data concurrently as interviews were being completed. Data-driven inductive themes were found to complement coding framework themes and shed light on rationale for why Namaste Care adaptation is needed. The lead author sought feedback from co-authors to ensure that the coding process was sound. Consistent with qualitative description (Sandelowski, 2000), constant comparative analysis was used to identify similarities and differences across participants and participant groups. Themes were developed from the codes to highlight meaningful patterns within the data while reflecting the research question. Themes were developed based on similarities between codes and the data (Braun & Clarke, 2006). NVivo version 12 software was used for data management.

Rigour and Trustworthiness

In terms of maintaining rigour and trustworthiness in qualitative research, a reflexive journal was kept by the lead author to document personal reactions and past experiences that could impact the study process (Finlay, 2002). Lincoln and Guba’s (1985) trustworthiness criteria were applied throughout the study (i.e., credibility, transferability, dependability, and confirmability). Credibility was upheld through investigator triangulation by seeking feedback from co-authors as they hold expertise in research areas including caregivers, people with dementia, community support programs, and/or Namaste Care. This process not only ensured credibility and complementarity, but helped to validate data (Lincoln & Guba, 1985). To increase the transferability of the study findings, rich thick descriptions were used to describe the study's setting and sample (Lincoln & Guba, 1985). The research team ensured that the proposed project followed clear logic by conducting a comprehensive review of the current literature to highlight the gaps in existing research.

Ethical Considerations

Ethics approval was granted from the local Research Ethics Board (#10526). All caregivers received a written introduction to the study and an informed consent form written in lay language. To protect anonymity of the responses of participants in the data set, study IDs were provided for each participant. All information collected in this study was confidential. Caregivers were invited to share only their first names during the workshops. Transcripts were shared between the lead author and the transcriptionist over a password protected encrypted folder. Participation in the study was voluntary. Caregivers were asked to only share what they felt comfortable disclosing and none of them experienced emotional distress during the study. The three core principles, respect for persons, concerns for welfare, and justice, of the Tri-Council Policy Statement were enacted throughout the study (Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), & Social Sciences and Humanities Research Council (SSHRC), 2018). An incentive in the form of a $25 gift card was provided to caregivers who participated in the study.

Findings

Demographic Characteristics

There was variation in caregiver characteristics such as sex, age, level of education and years of being a caregiver. See Table 2 for the demographic characteristics of caregivers and persons with dementia. There were equal numbers of male and female caregivers (50%). The mean age of caregivers was 56.5 years with a standard deviation (SD) of 12.1. Most of the caregivers were caring for a parent (66.7%). The sample was Caucasian, except for one participant. All except one participant were currently caring for a family member. All caregivers had completed post-secondary education with half of them having completed a bachelor's degree (50%). More than half of the caregivers were working part-time or full-time (66.7%). Caregivers reported few chronic conditions (e.g., chronic musculoskeletal pain, osteopenia, gastrointestinal issues) with most of them reporting 1 to 2 chronic conditions (66.7%). Most caregivers had been in the role for many years with the mean number of years in the caregiver role being 4.9 years (SD=3.2). All caregivers reported providing support for persons with dementia in the form of advice or emotional support and assistance with daily activities such as household chores, transportation, and banking. All except one caregiver reported providing assistance with personal care such as assistance with mobility, providing nutrition, dressing, and bathing. In terms of demographics characteristics of the persons with dementia being cared for, the mean age was 78.3 years (SD=7.6). Persons with dementia had on average 3 to 5 chronic conditions (e.g., depression/anxiety, hypertension, cardiovascular disease, stroke, osteoporosis, chronic musculoskeletal pain) (85.8%).

Themes

In this section themes that arose from analysis of the notes and transcripts from the workshop sessions are presented. First, codes and themes that emerged from the data were grouped under: Perceived need for adapting the Namaste Care approach for home use. Next, themes for suggested adaptations for the Namaste Care intervention based on the Stirman et al. (2013) framework are presented: (a) Modifications for the implementation of Namaste Care sessions; (b) Contextual modifications for delivering Namaste Care; and (c) Nature of Namaste Care content modifications. The framework category regarding who was responsible for suggesting modifications has been explored by describing the caregivers in the demographic characteristics section. Finally, codes and themes for adapting training as an implementation strategy based on the Stirman et al. (2013) framework were categorized under: Modifications for training in Namaste Care. See Table 3 for an overview of categories and themes. Quotes are labelled with CG for caregiver. Table 4 provides a comparison of the similarities and differences between the original Namaste Care program intended for LTC use and how caregivers in the current study envisioned the adaptation of Namaste Care for home use.

Perceived need for adapting Namaste Care for home use. Caregivers were optimistic that Namaste Care could lead to positive impacts for persons with dementia. They recognized the value of adapting Namaste Care so that it could be used in a home setting. Caregivers involved in adapting Namaste Care perceived that it could: (a) Help to relieve frustration during interactions; (b) Enhance daily activities through creative ideas; and (c) Increase connections between persons with dementia and caregivers.

Help to relieve frustration during interactions. Caregivers reported feeling frustrated at times when interacting with family members. "*But when she is in that very stubborn kind of framework, it just makes it so much more harder and frustrating and tiring, for sure*" (CG-102). Namaste Care was perceived as an approach to allow both persons with dementia and caregivers to take time to enjoy an activity together such as completing a puzzle. The approach was perceived as having the potential to improve interactions. *I could try doing the puzzle with mom with like CBC radio in the background and making it nice and calm. This is a really nice way to interact with her.* (CG-102)

Enhance daily activities through creative ideas. The core elements of Namaste Care resonated with caregivers and most reported doing some of the activities (e.g., dancing, singing, holding hands) already but wanted to learn how to implement more activities through creative means. "*I do a little bit, but I would like to do more"* (CG-104). One caregiver suggested using a heating pad as a way to provide comfort for her mother and other caregivers agreed with the idea. *"I know that [heat pad] works very well for my mom if she has pain on her back or on her leg. So that would probably be part of the comfort thing"* (CG-102). Caregivers had an understanding of preferences of their family members which in turn informed their selection of comforting activities.

Increase connections between persons with dementia and caregivers. Caregivers perceived that Namaste Care could be used to increase meaningful connections between persons with dementia and caregivers. The program was viewed as a way to strengthen familial relationships and also decrease agitation for persons with dementia.

> *I think it does make a difference for so many reasons. Like even to keep them less agitated, sort of a connection as well. I'm always holding my dad's hand...And it seems he is much more calm.* (CG-104)

Modifications to the implementation of Namaste Care sessions. Modifications were suggested for the implementation of Namaste Care sessions for caregivers and for persons with dementia. Themes were: (a) Gradually increasing Namaste Care sessions and (b) Using shorter and less frequent sessions to the fit the realities of caregiving.

Gradually increasing Namaste Care sessions. Caregivers were concerned about how interested their family members might be in participating in Namaste Care sessions. Some were hesitant to use the adapted program more frequently at the start due to the fear of persons with dementia not liking certain activities. This hesitancy could also be due to the initial comfort level of caregivers in using the approach. Caregivers who had been in the role for a number of years were more inclined to suggest using the adapted Namaste Care program daily, however some felt more cautious and suggested starting the adapted program twice a week.

> *I think for me. It's just depending on how interested my mum would be. I think I could probably try a minimum of two times a week and maybe do it for like an hour, an hour and a half and see how it goes.* (CG-102)

Using shorter and less frequent sessions to fit the realities of caregiving. Caregivers perceived that implementing Namaste Care for one to two hours at a time was not practical. Many of the caregivers were working and responsible for most if not all household activities. Caregivers also reported that their family members' attention span may not last for one hour, their period of alertness may be brief, or they may not be able to sit still for long periods. Caregivers perceived that for the adapted Namaste Care program to work for them they needed more flexibility in terms of how often and for how long they should use the adapted program.

> *It really depends on the situation at hand. If, my mom is having a good week with no falls or no reaction to medications then three times a week could be workable, but if she is falling twice a week and if she is having problems with medication even once a week may be stretching it. So, it really depends right. I think for my scenario at least it has to be more flexible than you would have to do it two times a week or three times a week.* (CG-106)

The changes in persons with dementia could be unpredictable from week-to-week, and even day-to-day so flexibility in delivering Namaste Care was perceived as key. Setting together a proposed minimum number of sessions of two times a week and a minimum length of session of 20 to 30 minutes were perceived as suitable for most caregivers. "*...but I wouldn't see it being much longer than 20 to 30 minutes"* (CG-103).

Contextual modifications for delivering Namaste Care. The adapted version of Namaste Care underwent a few context modifications (i.e., personnel, population, and setting) so that it better reflects the needs of caregivers in a home setting. In the adapted version: (a) persons delivering Namaste Care were family and friend caregivers rather than LTC healthcare providers; (b) recipients included older adults with moderate dementia in addition to those with advanced dementia; and (c) Namaste Care is delivered in any room of the home. The themes were: (a) Caregivers are highly involved in supporting persons with dementia daily; (b) Older adults with moderate dementia can also benefit from Namaste Care by tailoring activities; and (c) Namaste Care is delivered wherever it is convenient.

Caregivers are highly involved in supporting persons with dementia daily. Compared to care providers who are responsible for delivering Namaste Care in LTC at set times, family caregivers in the community are taking on multiple different tasks throughout the day to support persons with dementia. "*I have just been slowly taking on tasks. I live with her and so we formalized that term caregiver with her and the physicians in June. You know, I've been a caregiver for a long time, but officially since June*" (CG-102). Bearing in mind that caregivers are responsible for providing assistance with daily activities, the suggested adaptations for Namaste Care were intended to increase the likelihood for caregivers to adopt the program.

Older adults with moderate dementia can also benefit from Namaste Care by tailoring Namaste Care activities. Although the original Namaste Care program was designed to help fill a gap in programs for persons with advanced dementia, caregivers perceived that older adults with moderate dementia could also be positively impacted through the approach. Caregivers perceived that tailoring activities for each individual with dementia was key in delivering Namaste Care. Caregivers perceived that it is essential to have room for flexibility in tailoring activities for different stages of dementia, abilities, preferences, and needs. *"I think that's important because what will work for one [person] won't work for another"* (CG-104).

Namaste Care is delivered wherever it is convenient. Rather than have a designated room for Namaste Care sessions such as would be done in LTC, caregivers perceived that the adapted Namaste Care program should be taken to their family members. This was perceived as a way to minimize disruptions of routines and reduce the burden of transferring less mobile or resistant family members from one room to another. Caregivers recommended flexibility in selecting where Namaste Care would take place in the home.

> *I wouldn't have a particular room, but I would either use the living room, where we sit after a nap. I would use that as one spot and the other spot might be in the family room where we go to sit and watch TV. I could do something there. Or the bedroom, often I'm doing a massage on his feet and legs before he even gets out of bed in the mornings. So I could do something in that room as well with the diffuser.* (CG-101)

Nature of Namaste Care content modifications. Regarding content modifications to Namaste Care, suggested changes were adding activities and being flexible with how Namaste Care is used. Specific themes were: (a) Asking persons with dementia to reciprocate an activity; and (b) Integrating Namaste Care into daily care routines.

Asking persons with dementia to reciprocate an activity. Caregivers recommended that persons with dementia be encouraged to engage in the adapted Namaste Care program by performing activities in return for caregivers. This ensured that persons with dementia were still being perceived as able to provide valuable contributions and reminds them of their identity within the family.

> *I think that's important to kind of be two-fold. Like my dad likes to help out. So I was thinking for the hand massage like I do it for him, but then I'll say "ok dad do it for me too", right? Because he's always wanting to help out and do something. So kind of gives him something to do but also soothes him at the same time. So that's what I'm hoping that that could be a possibility.* (CG-104)

This idea also provided a reflection of the nature of the adapted version of Namaste Care which focuses on impacts for both caregivers and persons with dementia.

Integrating Namaste Care into daily care routines. Caregivers did not perceive Namaste Care as being an approach completely separate from what they were already doing with their family members. Rather than view Namaste Care as a new activity, it was perceived as a way to enrich daily interactions and an opportunity to turn it into a routine.

> *The other thing that I wanted to mention is that, for me, an integrated solution is ideal. Meaning that instead of spending a block of time and it also depends on what those... Namaste Care pieces are...But for the other pieces, like touch, aromatherapy and massage, all those other things, if you are doing as direct service, you can probably integrate that in, weave it into your other daily activities.* (CG-105)

Integrating Namaste Care into daily activities was perceived as being a more effective strategy to enable caregivers to use the adapted program as this is more realistic than trying to find additional time to implement it.

Modifications for training in Namaste Care. Modifications were also suggested for the training content and format. Caregivers recommended the incorporation of additional specific information on Namaste Care activities in the training content, a more practical training format, and an informal assessment of caregivers to support uptake of the adapted Namaste care program. Themes were: (a) Wanting to know how persons with dementia may respond to Namaste Care activities; (b) Identifying videos demonstrating hands-on activities; (c) Using Zoom as a good alternative to in-person training; (d) Limiting repetition through a shorter training session; and (e) Maximizing uptake of Namaste Care by exploring caregivers' understanding of dementia.

Wanting to know how persons with dementia may respond to Namaste Care activities. Caregivers sought written information about signs that Namaste Care activities are comforting for persons with dementia so they can be reassured *"whether it's working or not working"* (CG-104). Responses to activities, especially non-verbal responses, were perceived by caregivers as important indicators that demonstrate their success in connecting with their family members. *"Just to know or understand that you're actually managing to get through to her"* (CG-103). Caregivers of persons with dementia in the moderate stages were concerned about reactions to activities being too simple and sought clear guidance on tailoring activities.

> *I think also some instructions of what to expect in terms of how typically people with Alzheimer's or dementia will react to an activity or what would be too complicated or maybe too simple. Like maybe ways to break down an activity so it is a little more digestible. So I had tried a puzzle last year with my mum because we used to do puzzles all the time, but it was too complicated. So this weekend I picked up a 500-piece puzzle and it seems to be just the right complication.* (CG-102)

Identifying videos demonstrating hands-on activities. For activities requiring manipulation such as hand or foot massages and range of motion exercises caregivers recommended integrating videos during Namaste Care training. These activities were perceived as requiring skilled movements learned through audiovisual means. *"And if you are able to provide those [step-by step sheets] and/or video for that massage piece or any of the other things, but clearly with massage that's technical in nature that would really, really be great"* (CG-105).

Using Zoom as a good alternative to in-person training. Due to the unpredictable course of the COVID-19 pandemic, caregivers perceived that Zoom was a good option for Namaste Care training as it provided an audiovisual component. "*I think Zoom probably because you could visualize*" (CG-104). Videoconferencing was perceived as providing the best simulation to an in-person Namaste Care training session and *"you can demonstrate certain things"* (CG-102).

Limiting repetition through a shorter training session. Caregivers perceived that many of the Namaste Care activities were familiar to them and recommended a shorter training session than the original full day training session done in LTC. *"The people that are starting the program, new people to this, I think an hour is probably plenty. Now, I don't know if I would* *need that much time. Just because I do some of the stuff already"* (CG-101). Caregivers involved in adapting Namaste Care were also looking forward to implementing the adapted program in the next part of the study and felt that some information would be repetitive if brought up again during training. Some caregivers perceived that the length of the training session should depend on the learning needs of caregivers and that it would be difficult to set a fixed timeline for all. *"I will have questions and especially just relating to my mom's situation and my own personal context. Sixty minutes is great, if longer even better"* (CG-106).

Maximizing uptake of Namaste Care by exploring caregivers' understanding of dementia. Caregivers perceived the need to ensure that training is tailored to learning needs by exploring caregivers' overall understanding of dementia. *"I think maybe the better approach would be before starting any Namaste Care program with any pre-conceived notions or approaches, the family is assessed"* (CG-105). Assessing families prior to starting Namaste Care training was seen as a way of ensuring that they understand the value of sensorial activities and encouraging them to implement the approach.

Discussion

This study is the first to present detailed descriptions and explanations of suggested adaptations for the Namaste Care intervention for use by caregivers of community-dwelling older adults with moderate to advanced dementia and suggested training procedures. Dalkin et al. (2020) explored the use of Namaste Care in home settings but did not provide a comprehensive description of how Namaste Care was adapted from a LTC context for a home setting. The authors did state that the dose of the intervention was modified from the original Namaste Care program as it was delivered weekly by volunteers for two hours at a time (Dalkin et al., 2020). Due to the lack of studies focused on home-based interventions for caregivers of older adults with moderate to advanced dementia, this group of caregivers was targeted to ensure that modifications would reflect their unique realities of caregiving.

By using a recognized framework for modifications (Stirman et al., 2013) to guide the adaptation process recommended adaptations to Namaste Care were identified while keeping intact the core components of the program: (a) using a person-centred approach, (b) incorporating comfort and pain management, (c) scenting a room, (d) playing relaxing/upbeat music, (e) providing touch activities, (f) offering beverages and snacks, (g) encouraging range of motion activities, and (h) providing reminiscence activities (e.g., photo albums, conversations about life stories) (Kendall, 2019). These components were left intact as caregivers perceived that all of them were important in supporting the quality of life of persons with moderate to advanced dementia. Caregivers perceived that the successful implementation of these components depended on flexibility in the program in tailoring the components to the unique preferences and abilities of persons with dementia. The suggested changes to the original Namaste Care program were therefore considered as being minor such as adding activities and including older adults with moderate or advanced dementia. Suggested changes for Namaste Care training were also minor. Providing training virtually was seen as necessary when implementing Namaste Care during the COVID-19 pandemic and may be a feasible approach for the future as well.

Key findings of the study were that caregivers felt fully engaged in the adaptation process because the core components of Namaste Care were not perceived by caregivers as being completely unknown to them and they recognized the value of Namaste Care in making meaningful connections. With previous experience in implementing sensorial activities at home, this helped to ease the way for caregivers in understanding what adaptations were needed to ensure the intervention was appropriate for caregivers in the home setting. They felt comfortable and confident in making recommendations to improve the program as well as share their experiences in terms of what activities worked for them. Findings revealed that caregivers were receptive to delivering Namaste Care at home, but modifications would need to be made to ensure flexibility in delivery and that activities can be tailored to the needs of each person and the realities of the caregiver's situation. Caregivers perceived the need to be flexible in when, how long, and where Namaste Care should be used. Providing room for caregivers to tailor the Namaste Care activities was perceived as important as not all persons with dementia will respond to activities in the same manner.

The present study actively engaged caregivers to adapt Namaste Care for home use to ensure that it would fit within a new context. Findings related to the strategies and process used to meaningfully engage caregivers in adapting the Namaste Care program are reported elsewhere. Walshe et al. (2019) found similar findings when they explored the process and experiences of co-designing the Namaste Care intervention and its training procedures for LTC with multiple stakeholders including healthcare providers, members of a public involvement panel, and caregivers. The program was to be delivered within nursing care homes in the United Kingdom and adaptations were perceived as necessary to reflect the language and culture of the new context. Engaging stakeholders in reviewing the Namaste Care training guide and altering the program based on direct feedback was found to be an effective approach to ensure that the program would be acceptable in a LTC context. Compared to the present study however, Walshe et al. (2019) had only one family caregiver from a LTC home with prior knowledge of Namaste Care participate in workshops to co-design Namaste Care. In addition, five members of a patient and public involvement panel, which may have included some family members, were asked to discuss and comment on the final refinement of Namaste Care program resources. The limited involvement of family caregivers in co-design may prevent them from taking on a more active role in participating in Namaste Care sessions in LTC. They may not view Namaste Care as applicable or feasible for them.

In the present study caregivers emphasized the importance of tailoring the adapted Namaste Care program for older adults with dementia and caregivers based on their unique situations. Tailoring also applied to Namaste Care training as not all caregivers have the same understanding of dementia and therefore may have different learning needs. Duggleby and Williams (2016) suggest that when selecting interventions to adapt, it is important to ensure that the interventions could be tailored on an individual level. One of the important attributes of Namaste Care is that activities can be tailored to individuals based on unique life stories, likes, dislikes, abilities, and needs (Simard, 2013). It is important to ensure that interventions can meet the needs of diverse caregivers and older adults with dementia while still maintaining its original effectiveness when transferred to a home setting. Tailoring can also ensure that interventions can be used in a flexible manner while taking into consideration personal values and choices (Collado, McPherson, Risco, & Lejuez, 2013).

Furthermore, using meticulous planning in qualitative research when making adaptations to interventions has been found to ensure that interventions are feasible, acceptable, and have the potential for positive impacts for a new population (Duggleby et al., 2020). In the present study the use of qualitative research combined with careful planning (Card, Solomon, & Cunningham, 2011) provided rich descriptions and explanations of why caregivers proposed specific adaptations. Such detailed information may not have been found if the Stirman et al. (2013) framework was simply used to classify modifications without the use of inductive analysis to reveal themes that can support the rationale for adaptation. A better understanding of the current context of caregiving was gained through qualitative research and how interventions can be used to support caregivers.

A comprehensive process in adapting Namaste Care for home use by caregivers was selected to enhance the uptake of the intervention and its effectiveness in the next part of the study which consists of a pre-test/post-test feasibility study. Using the Stirman et al. (2013) framework in the current study helped to ensure that suggestions for modifications to the Namaste Care program provided by caregivers were documented in detail to inform the adapted program and that all aspects of an intervention was considered including its training processes. This type of approach to adapt interventions has been found to be successful in another study in meeting key objectives for adapting the intervention such as improving the fit for stakeholders, engaging intended providers of an intervention, and increasing intervention effectiveness in a trial (Chlebowski, Hurwich-Reiss, Wright, & Brookman-Frazee, 2019).

Moreover, the workshop sessions in the current study provided an opportunity for caregivers to reflect on their caregiving experience in making recommendations for adapting Namaste Care. Caregivers were encouraged to think about how they feel about the caregiving role and how Namaste Care can bring a positive approach to care. Carbonneau, Caron, and Desrosiers (2011) found that the perceptions of caregivers who participated in a leisure education program adapted for persons with dementia evolved to help them perceive their role as a positive opportunity rather than a burden. Although caregivers in the current study did not yet participate in the implementation of the adapted version of Namaste Care, talking about sensorial activities and learning about ideas discussed in the group gave them hope that there are still things that they could do to support the quality of life of their family members.

Including both men and women in the current study sample ensured that perspectives were diverse in terms of perceived gender roles and caregiving activities. Male caregivers have been found to assume a more task-oriented approach when providing care compared to women and male caregivers may require more support to adjust to the caregiving role as it has been traditionally regarded as feminine work (Robinson, Bottorff, Pesut, Olfie, & Tomlinson, 2014). Learning about the perspectives of male participants regarding how to adapt Namaste Care provided a better understanding of their perceptions of meaningful leisure activities for persons with dementia and how the training should be conducted to best support them in delivering the adapted program. Participants were also of various ages. Including participants of different ages provided a better understanding of the experiences and unique challenges of younger and older caregivers in supporting older adults with moderate to advanced dementia and how they perceived the delivery of Namaste Care. Older caregivers are often of similar age to persons with dementia and experience greater limitations in providing hands-on care compared to younger caregivers due to lower energy levels and potential presence of chronic conditions (Greenwood, Pound, Brearly, & Smith, 2019). In the present study younger caregivers were still working while caregiving. When compared to older caregivers they experience more mental health distress related to addressing responsive behaviours such as yelling, hitting, restlessness expressed due to feelings of boredom, hunger, or thirst (Koyama et al., 2016).

This present study highlights important policy and research implications for designing interventions. Many ideas suggested by caregivers in adapting Namaste Care were unique and valuable, and the research team alone would not have been able to come up with such recommendations. In terms of policy implications there is a need to ensure that the input and feedback of persons with lived experience are sought when developing or adapting interventions.

This should be a mandatory requirement when designing or modifying interventions as patient or family involvement is a growing area of health services research with many advantages. For example, involving caregivers of persons with dementia in developing interventions provides a comprehensive understanding of the perspectives of end-users and their ideas and experiences inform the tailoring of intervention materials while providing a more accurate representation of the needs of caregivers (Hales & Fossey, 2018). It is essential for researchers and policymakers to listen to and incorporate what caregivers are sharing in terms of what they need because the ultimate goal of creating these interventions in the first place is to support them as best as possible.

From a research perspective many interventions are being adapted in the middle of implementation leading to negative repercussions for intervention fidelity and favorable outcomes (Escoffery et al., 2019). Findings of the present study have research implications in terms of saving time for researchers by adapting interventions with caregivers prior to their implementation. Potential funders of intervention studies should be recommending that this type of research involve stakeholders in some capacity whether it is in creating, adapting, reviewing, or testing an intervention prior to its implementation to enhance its relevance. The next steps for the current program of research are to further adapt the Namaste Care program based on the suggested modifications provided by caregivers and test the new intervention with caregivers of community-dwelling older persons with moderate to advanced dementia living at home. Prior to implementing the program further modifications to fit the unique context of caregivers will be made by considering the relationship between caregivers and persons with dementia, ethnic and cultural values, and areas where further training is required.

Study Strengths and Limitations

Study limitations include a small sample size, lack of ethnically diverse participants, and inclusion of only participants residing in Ontario, Canada. With the small sample size and lack of ethnic and cultural diversity within the sample further adaptations to the Namaste Care program may be required to suit the unique values and context of multicultural groups. One of the key suggestions shared by participants was to ensure flexibility in how to deliver the adapted program. This may be an area to acknowledge when offering the program to diverse groups as well as providing training for caregivers. Despite the lack of ethnic and geographical diversity in the study sample there were an equal number of women and men who participated in the workshops and the ages of participants varied making findings more transferrable. Another limitation was that this study was not truly a ‘co-design’ study as caregivers were not involved in developing research questions, study design, establishing study outcomes, or designing an entirely new intervention. Nevertheless, caregivers were actively engaged in making recommendations for how Namaste Care could be adapted for their use in home settings and in the training.

Conclusion

This study provided a comprehensive description and explanation for suggested adaptations for Namaste Care in collaboration with caregivers of community-dwelling older adults with moderate to advanced dementia. Findings revealed that caregivers perceived Namaste Care as fitting in to their usual interactions and activities and as an approach to strengthen relationships between persons with dementia and family members. Caregivers stressed the importance of tailoring activities and training to individual needs and situations in order to maximize the use of the adapted Namaste Care program in a home setting. An output of the adaptation process consisted of a training guide for delivering the adapted version of Namaste Care at home which reflected the ideas and suggestions provided at the workshop sessions. One of the top 10 research priorities for dementia research in Canada is caregiver support (Bethell et al., 2018). Evaluating family-centered interventions that are adaptive to conditions, needs, and stages of a health condition was similarly identified as a top 10 research priority during a summit on research priorities in caregiving (Harvath et al., 2020). In responding to these priorities, the next steps for the study are to implement and evaluate the adapted Namaste Care program for caregivers at home which can be tailored when delivered by caregivers in a home setting through a feasibility study. Further adaptations to the adapted Namaste Care program may also be recommended by caregivers following the feasibility study based on real-world experiences in implementing the approach. The adapted Namaste Care program has the potential to support older adults with dementia to remain at home by enhancing the skills of caregivers and delaying the need for LTC.

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Table 1. Sample of Workshop Discussion Questions

First Workshop Session
1. What is it like to support or care for a family member or friend with moderate to advanced dementia at home? 2. How often and for how long should Namaste Care be implemented? 3. What kind of training would you need? 4. What activities (e.g., massaging, providing nutrition, playing music, aromatherapy) would you be comfortable in doing during the Namaste Care sessions? 5. What would make it easy for you to use Namaste Care at home? 6. What would make it hard for you to use Namaste Care at home? 7. How do you envision how you would use Namaste Care?
Second Workshop Session
1. What do you think of the training guide? 2. What are your suggestions to make the training guide more useful? 3. Are there certain words or ideas that are unclear? Which ones? 4. What are your thoughts on the length of the training guide (i.e., too long or too short)? 5. What kind of Namaste Care training would you be interested in receiving at home? 6. How long should the Namaste Care training session be? 7. What kind of materials would you like to have in a Namaste Care sensory box? 8. How often should someone follow-up with you by phone or video to support you in using Namaste Care?

Note. See the protocol paper for the full workshop discussion guide (Yous et al., 2020).

Table 2. Demographic Characteristics of Caregivers (N=6)

Category	n (%)
Caregiver demographics	
Age in years (Mean [SD])	56.5 [12.1]
30-49	1 (16.7)
50-59	3 (50)
60-69	1 (16.7)
70 and older	1 (16.7)
Sex	
Male	3 (50)
Female	3 (50)
Ethnicity or cultural group	
White/Caucasian	5 (83.3)
Chinese	1 (16.7)
Highest level of education completed	
College diploma	1 (16.7)
Bachelor’s degree	3 (50)
Graduate or professional degree	2 (33.3)
Current employment status	
Retired from paid work	2 (33.3)
Working part-time	3 (50)
Working full-time	1 (16.7)
Number of chronic conditions	
None	1 (16.7)
1-2	4 (66.7)
3-4	1 (16.7)
Relationship to person with dementia	
Spouse	2 (33.3)
Son/daughter	4 (66.7)
Number of years as a caregiver (Mean [SD])	4.9 [3.2]
1-3	3 (50)
4-6	2 (33.3)
6 and up	1 (16.7)
Person with dementia demographics	
Age in years (M [SD])	78.3 [7.6]
65-69	1 (14.3)
70-79	2 (28.6)
80-89	3 (42.9)
90 and older	1 (14.3)
Sex	
Male	3 (42.9)
Female	4 (57.1)
Number of years diagnosed with dementia (Mean [SD])	4.9 [3.3]
1-3	2 (28.6)

4-6	2 (28.6)
7-9	2 (28.6)
10 and up	1 (14.3)
Number of chronic conditions	
1-2	1 (14.3)
3-4	3 (42.9)
5	3 (42.9)

Note. The total percentages for some categories do not equal 100% due to rounding of values. One caregiver was a former caregiver as both parents passed away within the last five years. The age and number of years diagnosed with dementia at the time of their passing were included. The total number of persons with dementia was seven.

Table 3. Overview of themes

Category	Theme
Rationale for Adapting Namaste Care	
Perceived need for adapting Namaste Care for home use	-Help to relieve frustration during interactions -Enhance daily activities with creative ideas -Increase connections between caregivers and persons with dementia
Namaste Care Intervention Adaptation	
Modifications for the implementation of Namaste Care sessions	- Gradually increasing Namaste Care sessions - Using shorter and less frequent sessions to fit the realities of caregiving
Contextual modifications for delivering Namaste Care	- Caregivers are highly involved in supporting persons with dementia daily - Persons with moderate dementia can also benefit from Namaste Care by tailoring activities - Namaste Care is delivered wherever it is convenient
Nature of Namaste Care content modifications	- Asking persons with dementia to reciprocate an activity - Integrating Namaste Care into daily care routines
Namaste Care Training Adaptation	
Modifications for training in Namaste Care	-Wanting to know how persons with dementia may respond to Namaste Care activities -Identifying videos for demonstrating hands-on activities -Using Zoom as a good alternative to in-person training - Limiting repetition through a shorter training session

	-Maximizing uptake of Namaste Care by exploring caregivers’ understanding of dementia

Note. The Stirman et al. (2013) framework was used to guide theme development.

Table 4. Comparison of Namaste Care in LTC versus a home setting

Original Namaste Care in LTC	Adapted version of Namaste Care for a Home Setting
Original target population • Persons with advanced dementia	Target population • Persons with moderate to advanced dementia living at home
Main principles • Comfortable environment • Loving touch	Main principles continue to be reflected in the approach
Frequency of delivery • Delivered twice a day and two-hours at a time	Frequency of delivery • Delivered at least twice a week for a minimum of 20-30 minutes at a time
Time of delivery • Delivered at scheduled times as negotiated by LTC settings • Delivered in the morning and afternoon	Time of delivery • Approach to be integrated into daily activities and routines • Flexibility in when the approach is used (morning, afternoon, or evening)
Area for delivery • Private and quiet room (e.g., common room, activity room, bedroom) • Typically, a designated area is selected for group sessions	Area for delivery • Private and quiet room within the home • Approach is used wherever the person with dementia and caregiver chooses to be (e.g., bedroom, living room, backyard)
Mode of delivery • In a group setting or individually • Typically delivered by designated care providers	Mode of delivery • Individually • Other family members, friends, and personal support workers can also join
Core activities • Using a person-centred approach • Incorporating comfort and pain management • Scenting a room • Playing relaxing/upbeat music • Providing touch activities • Offering beverages and snacks • Encouraging range of motion activities • Providing reminiscence activities	Core activities • All of these activities continue to be incorporated in the approach • If unable to fit all activities in one session, at least three of the core activities need to be integrated to count as a full approach
Training • Typically, a full day of training is provided in-person, preferably	Training • A one-hour virtual training session is provided with bi-weekly follow-up over the 3-month intervention period

	to address questions and provide additional education

Note. Information on Namaste Care was referenced from books by Simard (2013) and Kendall (2019).

CHAPTER 5

TITLE: Experiences of Caregivers of Community-Dwelling Older Persons with Moderate to Advanced Dementia in Adapting the Namaste Care Program: A Qualitative Descriptive Study[3]

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Plain language summary

As older persons with dementia transition from early to moderate or advanced stages of dementia they require more support from family and friend caregivers to accomplish their daily activities. Caregivers, however, often report a lack of preparation for their caregiving role. There are few programs focusing on skill-building and positive interactions that can be delivered by caregivers of older persons with moderate to advanced dementia at home. Namaste Care is a program originally created for long-term care that provides multisensory stimulation for persons with dementia through activities such as music, massage, aromatherapy, and nutrition. It has not yet been adapted for use by caregivers in the community. There is a need to involve caregivers in adapting programs and understanding their experiences in research involvement. The purpose of this study is to explore the experiences of caregivers who participated in workshops to adapt Namaste Care for older persons with moderate to advanced dementia at home. A qualitative descriptive design was used. Six caregivers from Ontario, Canada attended virtual workshop sessions (i.e., by phone or videoconference) and completed individual post-workshop interviews. Interviews and notes were analyzed for themes. Key findings were that caregivers had a positive experience by learning how to improve their caregiving skills and being supported to engage in research through numerous strategies such as flexible scheduling and an inclusive environment. Findings support the need to improve caregiver research engagement by ensuring that caregivers experience benefits of their involvement and empowering them to value their contributions in adapting interventions.

Abstract

Background: Globally many older persons with dementia are living at home to maintain independence within the community. As older persons with dementia transition from early to moderate or advanced stages of dementia they require more support from family members and friends to complete their daily activities. Family and friend caregivers, however, often report a lack of preparation for their caregiving role. There are few psychosocial programs that can be delivered by caregivers of community-dwelling older persons with moderate to advanced dementia. Namaste Care is a psychosocial intervention, predominantly used in long-term care, to improve the quality of life of persons with advanced dementia. Namaste Care provides multisensory stimulation for persons with dementia through meaningful activities such as music, massage, aromatherapy, and nutrition. It has not yet been adapted for use by caregivers in the community. There is a need to involve caregivers in adapting programs and understanding their experiences in research involvement so that strategies can be put in place for a positive experience. The purpose of this study is to explore the experiences of caregivers who participated in workshop sessions to adapt Namaste Care for community-dwelling older persons with moderate to advanced dementia.

Methods: A qualitative descriptive design was used. Six caregivers residing in Ontario, Canada attended virtual workshop sessions (i.e., by phone or videoconference) that were guided by the Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework. Caregivers completed individual post-workshop interviews. Experiential thematic analysis was used to analyze interviews and post-interview researcher notes.

Results: Key findings were that caregivers had a positive experience in adapting Namaste Care by learning how to improve their caregiving skills and being supported to engage in research through multiple facilitators such as flexible scheduling and an inclusive and respectful environment. Having designated time for discussions between caregivers was perceived as important to forming partnerships within the group to support co-creation of knowledge.

Conclusion: Findings support the need to improve caregiver research engagement processes by ensuring that caregivers can benefit through learning opportunities and discussions and empowering caregivers to value their contributions in adapting interventions.

Keywords: Dementia, Caregivers, Family, Older Persons, Workshop, Namaste Care, Community, Qualitative

Background

More than 50 million individuals worldwide are affected by dementia (1). In Canada approximately 60-70% of persons with dementia are living at home to maintain independence and engagement with their community (2, 3). Close to 50% of Canadians with moderate dementia and 14% of those with advanced dementia live at home rather than a retirement or long-term care home (4). Family and friend caregivers (hereafter referred to as caregivers) are highly involved in supporting persons with dementia; however, many caregivers report an unmet need related to caregiver education and few persons with dementia are provided with meaningful activities (5). Meaningful activities for persons with dementia are key to ensure their well-being and enable their participation in daily activities and social relationships (6).

Providing education for caregivers on psychosocial interventions (e.g., sensory activities, cognitive stimulation, exercise, art-based therapy) can provide them with greater confidence to deliver meaningful activities for persons with dementia (7). Psychosocial interventions can improve the quality of life of both caregivers and persons with dementia by slowing or preventing a decline in mental and physical health of caregivers and/or persons receiving care by targeting caregiver skills, knowledge, activities and/or relationships (8). These interventions have been found to improve the quality of life of caregivers, their knowledge of dementia, and their competencies in delivering care (9-12).

To date there are few psychosocial approaches suitable for caregivers supporting older persons with moderate to advanced dementia (13). Most interventions are designed to support caregivers of older persons with early to moderate dementia (9). Caregivers are often not invited to participate in designing or adapting psychosocial interventions, including those for individuals with moderate to advanced dementia (14-17). The absence of caregiver voices in intervention development can limit the fit of interventions with their realities of caregiving. Namaste Care is a psychosocial intervention that can potentially be used by caregivers of persons with advanced dementia at home (18), however it has not yet been adapted for home use by caregivers.

Namaste Care offers multisensory stimulation for persons with advanced dementia (18). Its principles are: (a) providing a comfortable Namaste Care environment and (b) using an unhurried, loving touch approach (18). In long-term care, Namaste Care is usually delivered in a group setting and begins by welcoming persons with dementia to a quiet room with soft lighting, relaxing music, and soothing scents. They receive person-centred activities including music, massage, socialization, aromatherapy, and nutrition. Namaste Care has gained worldwide recognition and has been used in long-term care, hospice, and acute care settings, and in one study by volunteers in home settings for people at different stages of dementia (18). The impacts of Namaste Care include the decreased use of antianxiety medications and psychotropic medications and reduced pain while improving quality of life for persons with advanced dementia and relationships with others such as staff and family members (19-24). Only one study implemented Namaste Care in a home setting (25) and family caregivers were not involved in determining how the program should be implemented in a home setting.

Higher quality research is created by involving persons with lived experience to share unique insights regarding their needs that can ultimately lead to the development of solutions to address complex problems (26, 27). There is more efficient use of research funding when involving persons with lived experience as researchers can ensure that they are asking relevant questions and considering outcomes that are important to service users (28). People with lived experience include caregivers supporting persons with dementia. Caregivers are valuable partners in collaborating with researchers to develop and refine programs, especially when older persons with more advanced forms of dementia may be unable to collaborate in research (29). Caregivers have a wealth of knowledge and experience to share with researchers and this valuable information may be missed when they are not provided with opportunities to collaborate on intervention development (30). Involving caregivers ensures that research is meaningful, results in higher quality research, and eases the way for knowledge transfer (31, 32). Caregivers may also experience benefits in the process of research collaboration by learning how to engage persons living with dementia in different ways.

Some of the commonly used methods for engaging persons with lived experience (e.g., focus groups, interviews) consist of those often used in qualitative research (33, 34). Workshop sessions are another type of qualitative method that can be used to involve caregivers in co-producing solutions or generating new ideas to common problems by ensuring that caregivers are provided with opportunities for open discussion (35). This can help support their comfort in sharing within a new group and promote dialogue. Engagement of persons with lived experience and building trust between researchers and persons with lived experience can be achieved using strategies found within qualitative methods including active listening, reflection, and co-creation of knowledge (36).

Despite the growing trend to involve persons with lived experience in research, few studies explicitly evaluated or explored the benefits or disadvantages for caregivers collaborating in research (37). There is a need to explore the perceptions of individuals with lived experience in participating in research engagement opportunities. Seeking this feedback can provide insight into how best to support them in research and ensure that they benefit from the experience.

In light of these considerations, the purpose of this study is to explore the experiences of caregivers of community-dwelling older persons with moderate to advanced dementia in adapting the Namaste Care program for home use through workshop sessions. The research questions were: (a) What were the perceived contributions and impacts of caregivers in adapting Namaste Care? and (b) What were caregivers' perceptions of the factors influencing their experiences in adapting Namaste Care? The current study is part of a multiphase mixed methods study which aims to adapt (38), implement, and evaluate Namaste Care for use by caregivers of community-dwelling older persons with moderate to advanced dementia. The study protocol is published elsewhere (39).

Methods

Study Design

Qualitative description design. The research design for this study consists of qualitative description (40). This design was chosen because it allows for straight descriptions of phenomena with some flexibility for interpretation (40, 41). It is important to ensure that the description of caregivers' experiences in collaborating to adapt Namaste Care reflects their own words. In the next section we provide an overview of the adaptation workshop sessions to shed light on the process of engaging caregivers in adapting Namaste Care.

Adaptation workshop sessions. Adaptation of Namaste Care occurred by conducting a total of four small group workshop sessions with caregivers of community-dwelling older persons with moderate to advanced dementia. Each caregiver attended two workshop sessions, an initial workshop session and a follow-up session. Workshops were facilitated by the first author, a Registered Nurse with experience in caring for persons with dementia and their caregivers and conducting caregiver education sessions for the Alzheimer Society. The workshop sessions lasted about 60-90 minutes. Most caregivers participated by videoconference (i.e., Zoom) except for one who participated by telephone. At the first workshop session, caregivers were provided with a 20-minute educational presentation of Namaste Care followed by a detailed discussion on their thoughts and suggestions for adapting the Namaste Care program for use in their homes. Prior to the second workshop session a draft of the Namaste Care training guide based on the first workshop discussion was shared with caregivers by email. The training guide included a full description of the adapted program as well as tips and strategies for caregivers who planned to implement the program. Key topics included a description of the program, steps for delivering the program, examples of sessions, and description of sensorial activities (e.g., music, aromatherapy, range of motion and touch activities). At the follow-up workshop session, the training guide was presented to caregivers followed by a discussion on further revisions required.

The workshop sessions were guided by the Strategy for Patient-Oriented Research (SPOR) Patient Engagement Framework (42). The term ‘patient’ is a generic term used in this framework and in the context of this study to refer to people with lived experience. Caregivers have lived experience of caring for persons with dementia. The overarching vision of the Patient Engagement framework is to include people with lived experience as active participants in health research to improve health outcomes and lead to a better health system. The SPOR Patient Engagement Framework consists of guiding principles (i.e., inclusiveness, mutual respect, co-building, and support) and targeted outcomes of research engagement (42). These guiding principles were incorporated before, during, and following the workshop discussions. Inclusiveness was upheld by including diverse caregivers based on sex and relationship with persons with dementia at the workshops and unique caregiving contexts. Mutual respect was achieved by acknowledging the experiences of caregivers in caring for older persons with advanced dementia and using these to draft the training guide. Co-building occurred through collaboration with caregivers in adapting Namaste Care and encouraging caregivers to build on each other's ideas. Ongoing support was delivered during the adaptation phase by creating a safe and welcoming environment where caregivers felt comfortable in sharing, eliminating the use of technical or medical jargon, and providing education to meet their learning needs. Applying these principles throughout the adaptation process increased the potential for successful engagement of caregivers.

We recognize that our study does not truly reflect co-design as we started with an existing program, so we limited the use of the framework by only incorporating its guiding principles and outcomes. Some of the targeted outcomes of engaging people with lived experience include: (a) inclusive mechanisms and processes created; (b) respectful collaboration between researchers and people with lived experience; and (c) experiential knowledge of people with lived experience being valued as evidence for research (42). In this study these outcomes were targeted by ensuring that the voices of caregivers were reflected in the adapted Namaste Care program and that the process of developing the approach was a positive experience for caregivers. These perceived outcomes were explored by conducting qualitative interviews with caregivers at the end of the workshop sessions to understand their experiences in adapting Namaste Care. See Additional File 1 for the GRIPP2 reporting checklist (43).

Setting

Following the adaptation workshop sessions, caregivers met individually with the lead author using a method (i.e., by telephone or Zoom) that was most convenient for them and adhered to the local public health guidelines at the time of the COVID-19 pandemic.

Sample

A total of six family and friend caregivers of older persons with moderate to advanced dementia, living in urban areas of Ontario, Canada, were included. Caregivers were selected based on purposive sampling, specifically criterion and snowball sampling (44). Criterion sampling was used to locate participants who were: (a) 18 years and older with experience providing physical, emotional, and/or psychological support at home for a family member or friend aged 65 years or older with moderate to advanced dementia for at least four hours a week within the previous five years; (b) able to speak, write, and understand English; (c) living in Ontario; and (d) capable of providing informed consent. Snowball sampling (44) was used by asking caregivers to share study and researcher contact information with other caregivers who might be interested in participating in the study.

Recruitment

Caregivers were recruited from the Alzheimer Society of Canada, local Alzheimer Societies, and Dementia Advocacy Canada. The lead author presented the study at virtual Alzheimer Society dementia education series for caregivers (e.g., Care in the Later Stages Series). The study was also presented to clients and staff (e.g., public education coordinators, counsellors, recreational therapists) of the Alzheimer Society. Information about the study was shared through websites, social media and in electronic newsletters of the listed organizations.

Data Collection

Data were collected from October 2020 to January 2021. Demographic data were collected including age, sex, education, relationship to the person with dementia, number of years in the caregiver role, and type of support provided. Individual semi-structured interviews lasting approximately 30-60 minutes were conducted with caregivers following the completion of the second workshop session. See Table 1 for the interview guide. The interviews explored research engagement experiences of caregivers. Reflective notes were made immediately after interviews. Interviews were audio-recorded and transcribed by an experienced transcriptionist. The interview guide was developed based on a review of the literature, research team expertise, the SPOR patient engagement framework (42), and the Patient and Public Engagement Evaluation Tool (45). The Patient and Public Engagement Evaluation Tool was developed to assess four principles for effective engagement (i.e., integrity of design and process, influence and impact, participatory culture, and collaboration and common purpose) from different perspectives (e.g., persons with lived experience, members of an organization) (46).

Data Analysis

Interviews and notes were analyzed using thematic analysis to identify themes and patterns within the data (47). Experiential thematic analysis was selected as it allows one to focus on the experiences of participants and their perceptions of their world (48). Braun and Clarke’s (47, 48) method for thematic analysis has been used in other qualitative descriptive studies (49, 50). Inductive coding helped to identify unique codes that arose from the post-workshop interviews. Deductive coding was also used by analyzing data to fit within a coding framework developed from a review of the literature and the expertise of the research team. We followed the six phases of thematic analysis as outlined by Braun and Clarke (47): (a) gaining familiarity with the data; (b) conducting coding; (c) locating themes; (d) reviewing themes; (e) developing a definition for themes and naming them; and (f) developing a report.

In gaining familiarity with the data the lead author reviewed the transcripts twice before commencing coding. The lead author analyzed data concurrently as interviews were being completed and sought feedback from the research team regarding the coding process. Constant comparative analysis was used to determine similarities and differences across participants. This approach is consistent with the use of a qualitative description design (40). Themes were identified from the codes to highlight meaningful patterns within the data. Once themes were identified they were reviewed by all members of the research team for completeness and relevance to the data. We reflected on names for themes and named them by considering fit with the data and appropriateness (47). We ensured that the story we told reflected the voices of the participants and the data and provided direct quotes of participants to support claims (47). NVivo version 12 software (51) was used for data management.

Rigour and Trustworthiness

To uphold rigour and trustworthiness in qualitative research, the lead author made notes in a reflexive journal to document personal reactions and former experiences with possible impact on the research process (52). We implemented strategies to address Lincoln and Guba's (53) trustworthiness criteria consisting of credibility, transferability, dependability, and confirmability. Credibility was met through investigator triangulation and seeking feedback from members of the research team as they hold expertise in researching and working with caregivers and people with dementia in the community. This process also met the criterion of complementarity and supported the validation of data (53). Rich thick descriptions were used to describe the setting and sample of the study to ensure transferability of findings (53). We ensured that the study followed clear logic by conducting a comprehensive review of the current literature to determine gaps in the literature.

Ethical Considerations

Ethics approval was granted from the local Research Ethics Board (#10526). All caregivers received a written introduction to the study and an informed consent form written in lay language. Caregivers provided oral informed consent to participate in the study. Study IDs were provided for each participant and were used to label data collection forms to maintain anonymity. The three core principles of the Tri-Council Policy Statement, respect for persons, concerns for welfare, and justice, were maintained throughout the conduct of the study (54). A $25 gift card was offered to caregivers as an incentive.

Findings

Demographic Characteristics

Characteristics of caregivers involved in adapting Namaste Care were varied in terms of sex, age, highest level of education attained, and number of years in the caregiver role. See Table 2 for the demographic characteristics of caregivers and persons with dementia. Caregivers who identified as being male or female were equally represented (50%). The mean age of caregivers was 56.5 years, with a standard deviation (SD) of 12.1. Most reported caring for a parent (66.7%). All caregivers were actively caring for a family member except for one participant whose parents had died within the previous two years. Most caregivers had completed post-secondary education and half of them had a bachelor's degree (50%). More than half were working (66.7%). Caregivers reported few chronic conditions (e.g., chronic musculoskeletal pain, osteopenia, gastrointestinal issues) with most reporting 0 or 2 conditions (83.4%). The mean number of years in the caregiver role was 4.9 years (SD=3.2). All caregivers reported providing support for their family member in the form of advice or emotional support and assistance with daily activities such as maintaining the home, transportation, and managing bills. All except one caregiver reported assisting in personal care activities such as assistance with mobility, meals, and bathing. Older persons with dementia had a mean age of 78.3 years

(SD=7.6). Most had 3 to 5 chronic conditions (85.8%) (e.g., depression/anxiety, hypertension, cardiovascular disease, stroke, osteoporosis, chronic musculoskeletal pain).

Themes of Adaptation Experience

Overall, main themes were categorized under: (a) perceived contributions in adapting Namaste Care; (b) factors influencing caregivers' experiences in adapting Namaste Care; and (c) perceived impacts of learning about Namaste Care. Quotes of caregivers are embedded within the description of themes and identified by a study ID (i.e., CG-X).

Perceived contributions in adapting Namaste Care. Caregivers perceived that they made contributions in adapting Namaste Care and in developing the training guide. The themes were: (a) caregivers felt involved in redesigning Namaste Care and (b) the training guide reflected caregivers' ideas and experiences.

Caregivers felt involved in redesigning Namaste Care. Caregivers perceived that they contributed to revising the Namaste Care program so that it could be used in a home setting. They recognized that the purpose of their research engagement was to be actively involved in providing recommendations for adapting Namaste Care. Caregivers felt that not only were their direct suggestions being incorporated in adapting the intervention, but their experiences and situations were being reflected in the recommendations. For example, caregivers felt that it was important to acknowledge that not all activities would work for each person living with dementia.

> *I appreciate what you are trying to do...hopefully this can help. It's just hard because every case is different...and that's when you have to tailor to each individual, but overall you outlined and thought through that as well and these are the different things that can be done, but they won't all work for everybody.* (CG-4)

It was also suggested that caregivers use the adapted program at least twice a week rather than daily as stated in the original Namaste Care program to avoid creating additional burden for caregivers.

The training guide reflected caregivers' ideas and experiences. The training guide that was developed based on workshop discussions with caregivers was perceived as reflecting their ideas and experiences. Caregivers provided various insights in adapting Namaste Care for home use, and this ensured that recommended changes to the program were relevant to their situations. Caregivers were asked to review and comment on the training guide. There was good collaboration between caregivers and the researcher in the process of developing the training guide. Caregivers perceived that the researcher already had knowledge about the program so caregivers felt they had a smaller role in developing the training guide.

> *I think you knew a lot too to begin with in developing this [training guide]. You weren't coming out cold turkey. So, you knew a lot already there so I felt that I did part of it. And it was nice to see the stuff that you had.* (CG-1)

Some caregivers were therefore not aware that sharing their lived experiences in being a caregiver can also be valuable in informing the development of programs.

Factors influencing caregivers' experiences in adapting Namaste Care. Overall, caregivers reported positive experiences in collaborating to adapt Namaste Care at the workshops. They perceived many factors as supporting their involvement. The themes were: (a) caregivers felt comfortable sharing ideas for adapting Namaste Care; (b) research strategies enabled meaningful engagement of caregivers; (c) caregivers appreciated the opportunity to discuss and learn from other caregivers; and (d) virtual workshops were convenient but limited interactions.

Caregivers felt comfortable sharing ideas for adapting Namaste Care. Caregivers reported being comfortable in sharing personal experiences with other caregivers and the lead author. One caregiver stated that she was *"very comfortable"* (CG-4) in sharing. Caregivers perceived that they had enough knowledge of Namaste Care to confidently contribute to adapting the program. They felt included in discussions and that their ideas were respected and valued by all members present at the workshop. Having a small group of people attend each workshop made it easier for all caregivers to share how they envisioned Namaste Care for home use. Caregivers mentioned the diversity of the group as being a strength with the presence of both seasoned and 'new' caregivers and dynamic personalities. *"Because [CG-5] was so forthcoming with his experiences, it made me feel that I need to be more forthcoming of mine too, which wasn't a problem at all"* (CG-6).

Research strategies enabled meaningful engagement of caregivers. Caregivers described a number of research strategies that enabled meaningful engagement such as the creation of a welcoming, respectful safe space to share, flexible scheduling of the workshops, and timely sharing of materials. They reported working on the project to be "*easy*" (CG-3). In terms of resources and scheduling, caregivers reported appreciation for scheduling workshops around their availability. This was especially important for caregivers who were working or required a personal support worker to be present with their family member. *"I think the scheduling and the coordination was done very well"* (CG-5). Caregivers also appreciated receiving materials ahead of time so that they could be prepared for the workshops.

Caregivers appreciated the opportunity to discuss and learn from other caregivers. One component of the workshop sessions that was perceived as valuable for caregivers was the opportunity to meet and learn from other caregivers. Caregivers reported learning from the care strategies of others and gained new ideas for activities to try with their own family member. "*Sometimes you live in your own little bubble and you are on your own trying to think of things. So that knowledge and experience from other people has helped"* (CG-4). The workshops took place during the COVID-19 pandemic and many organizations paused in-person caregiver support activities. Caregivers felt that taking part in the workshops allowed them to talk to others about their experiences and challenges.

> *I think part of it was just a chance to talk to people in different stages of being caregivers and hearing how they are managing it. I think that was a good opportunity. Like any opportunity for caregivers to talk about their experiences and hear other people is always good. I really value that aspect that there's a little bit of time for debriefing or chatting about what each of us were going through.* (CG-2)

Some caregivers reported making new connections with those attending the workshops and wanted to keep in contact.

Virtual workshops were convenient but limited interactions. Caregivers perceived that attending workshops by Zoom was convenient as it eliminated the need to travel, arrange for respite care, and the need to book time off work. Caregivers who were working from home felt that it was easy for them to attend the workshops and schedule these around their work hours. Caregivers felt at ease participating as they did not feel rushed and still had time to attend to other activities. The quality of interactions by Zoom was perceived by most as similar to in-person interactions.

> *I think Zoom actually works very well. It didn't feel totally different than sitting in a room. When you are in a room, you would notice a little more body language, but I mean you pick up on the facial involvement. And I think that everybody felt comfortable so I actually enjoyed the interaction and the environment, doing it this way.* (CG-3)

Although Zoom had its strengths in terms of convenience and simulating face-to-face interactions, it was still perceived by a few caregivers as not as effective as in-person meetings.

Some caregivers felt that barriers to meeting virtually were not being able to read the body language of others and being concerned about interrupting others.

> *At least the way we had Zoom set-up is more of one person goes then the next person goes, the next person goes like that way. What I perceive by losing that is the spontaneity as far as you have an idea that comes to your mind. If I had to hold it for a second that is okay. But if I had to hold it for five minutes, I might forget what I was trying to say.* (CG-5)

Caregivers may also not have been aware of how to change Zoom settings to see all attendees at once. One caregiver recommended having a training session on Zoom prior to workshops.

Perceived impacts of learning about Namaste Care. Caregivers were learning about Namaste Care for the first time. They had not heard of such a program even though some were caring for a family member for several years. In addition to having the opportunity to contribute to the adaptation of Namaste Care, caregivers benefitted from the experience as they learned about Namaste Care and how they could use this program. The themes related to the impacts of learning about Namaste Care include: (a) increased awareness of the need for meaningful activities and (b) eagerness to start using Namaste Care.

Increased awareness of the need for meaningful activities. Although caregivers had implemented some activities in the past, learning about Namaste Care at the workshops made them even more aware of the importance of meaningful activities for older persons with dementia. Caregivers discussed the need to be present and the need for an unhurried approach when interacting with their family member. Namaste Care validated what caregivers were already doing and made them more aware of the need for multisensory stimulation.

> *Until Namaste Care, I hadn't really thought a lot about that side of it. I mean there were things we are doing just because, okay it would be nice to do. But, I haven't really given a lot of thought as to the senses, the five senses that are affected. So yes, it had made me more aware and made me aware that maybe this is something that I have to do.* (CG-1)

The workshop sessions provided caregivers with a learning opportunity about how to provide meaningful activities: "*To learn about it [Namaste Care] it's like taking a very intensive course for two days. Finding out different things that I can do for my mom and going back to my caregiving process. All that was good"* (CG-6).

Caregivers perceived that Namaste Care could help to ensure that their day is filled with activities to keep both caregivers and persons with dementia occupied. Caregivers mentioned how taking part in the workshop sessions had changed their way of thinking regarding how they deliver activities and provided them with more ideas to engage persons with dementia. "*It's just given me some more ideas. I have been getting limited on what we can do and so it has at least opened my eyes to a few little things that we can do"* (CG-3). Some caregivers mentioned that they would like to share Namaste Care with personal support workers involved in supporting their family member at home.

Eagerness to start using Namaste Care. After learning about Namaste Care caregivers wanted to start using it after the workshop sessions. Many caregivers expressed interest in taking part in the next phase of the study which focuses on delivering and evaluating the adapted version of Namaste Care. Some planned to use a chart with dates and times for when to use Namaste Care.

> *Like with this program...I want to do it three times a week, 20 minutes a time. I want to put a chart up on my wall and figure out which days I am going to this and what is the timeframe when I'm going to do it and not when I feel like doing it.* (CG-1)

They perceived that the approach was aligned with their usual routines and could be used even after the study is completed.

Discussion

This is the first study to explore the experiences of caregivers of older persons with moderate to advanced dementia in participating in workshop sessions to adapt Namaste Care for home use. Although one study explored the process of co-designing the Namaste Care intervention for long-term care use with multiple stakeholders (55), the authors did not seek feedback from family members about their experience in co-design workshops. The present study also fills a gap in the current literature related to the involvement of caregivers in adapting or designing interventions to support persons living with moderate to advanced dementia at home. Key findings of the present study included: (a) there were multiple benefits to caregivers in terms of adapting Namaste Care; (b) there is a need to ensure that caregivers recognize their valuable role in research; and (c) numerous strategies contribute to meaningful engagement of caregivers.

While the research team was learning from caregivers in adapting Namaste Care through the workshop sessions, caregivers also benefitted by gaining new knowledge in how to deliver care for family members and the importance of meaningful activities. This finding reveals the extent to which caregivers continue to seek education and support in caring for older persons with dementia at home and how this area remains an important research priority (5, 56). When caregivers are presented with relevant and timely information in a way that can be easily understood this can positively transform their daily activities of caregiving and improve their confidence in supporting persons with dementia (57).

Despite inviting caregivers to collaborate on adapting a pre-selected intervention in the present study, there were multiple impacts on the project and caregivers themselves. Caregivers perceived that they made valuable contributions in adapting Namaste Care and learned about how they could use Namaste Care to implement meaningful activities at home. Findings from the study reveal the need to empower caregivers in their role in research so that they recognize the value of their research involvement. There are many roles that people with lived experience can play in research. As seen in the present study some roles involve adapting certain parts of research such as interventions through co-development or sharing experiences, ideas, and preferences to help inform the decisions of the research team (58). Adaptations made to Namaste Care enabled the program to reflect the realities of caring for persons with moderate to advanced dementia living at home. There is a need for more interventions that can be used by caregivers supporting this population (13). Future studies may want to engage caregivers even more by involving them early on in deciding about research questions and selecting interventions (59).

The present study revealed the importance of using several strategies to support the engagement of caregivers in adapting Namaste Care. These strategies can be used to mitigate barriers in research engagement such as lack of perceived direct benefit and distrust of researchers (60). Recognizing that most caregivers who attended workshops were actively caring for older persons with moderate to advanced dementia, strategies were put in place to support their engagement including flexible scheduling, offering respite care, and creating a welcoming and inclusive environment for sharing. These strategies were aligned with the guiding principles (i.e., inclusiveness, mutual respect, co-building, and support) of the SPOR Patient Engagement Framework and targeted outcomes of research engagement (42). Opportunities for research engagement should be scheduled conveniently for caregivers and web-based videoconferencing platforms (e.g., Zoom) can be used as an alternative to in-person meetings (60). As a result of these strategies caregivers perceived that they contributed to the development of the adapted Namaste Care program and training guide and were well supported to participate in research.

Caregivers perceived participating in research to be a positive experience and they benefitted from learning about Namaste Care. This indicates the potential for caregivers to participate in similar research in the future.

A key factor in engaging in research mentioned by most caregivers was having time to discuss and share experiences with other caregivers at the workshops. Using an authentic partnership approach when collaborating with people with lived experience in finding solutions to improve and better understand dementia care provides opportunities for shared learning, dialogue, and critical reflection (61). In the present study caregivers appreciated learning from each other’s experiences to inform their own caregiving processes. In another study family members perceived that having more time for discussion was considered essential in being able to form partnerships (59). Spending time to get to know each other was important in helping caregivers feel comfortable in sharing personal stories.

In the present study we involved caregivers in adapting Namaste Care and this strategy has multiple advantages when implementing the intervention in the real-word context. Adaptations made to interventions through engagement of people with lived experience have been found to lead to less burden for those delivering the intervention, greater fit between interventions and preferences, and increased intervention adherence (58). Caregivers appreciated participating virtually in adapting Namaste Care as this eliminated the need for travelling, taking time off work, and minimized disruptions when caregiving at home. To date few studies included virtual workshops to adapt programs for persons living with dementia. One project conducted during COVID-19 that involved the engagement of a stakeholder advisory council for research in dementia care similarly found that virtual meetings using Zoom technology had benefits for clinicians, caregivers, and persons with dementia such as eliminating the need for travel and creating an enjoyable experience (62).

Strengths and Limitations

This study provided a comprehensive description of the perceived contributions, impacts, and factors influencing the experiences of caregivers in adapting Namaste Care. All except one caregiver who participated in the study were active caregivers. The former caregiver was last caring for a family member two years previously and still strongly identified with the caregiver role (63). Former caregivers may feel a need to seek opportunities to help other caregivers of people with dementia by sharing their experiences and solutions (64, 65). Although a small sample size was included in the study, caregiver characteristics varied in terms of sex, relationship to the person with dementia, and length of time as a caregiver. A lack of cultural diversity among caregivers was a limitation as all but one caregiver identified as being White/Caucasian. There is a need to target culturally diverse caregivers as Black, Hispanic, Asian and Indigenous Peoples have been found to face discrimination in seeking dementia care and participating in research (66). We also did not include older persons with dementia in adapting Namaste Care. Engaging both persons with dementia and caregivers at the same time may however impact their comfort level for full expression (67).

Conclusion

Overall, caregivers perceived that they had a positive experience in collaborating through workshop sessions to adapt the Namaste Care approach to be used by caregivers of older persons with moderate to advanced dementia in their homes. They enjoyed opportunities for rich learning and to be able to contribute their experiences and ideas in adapting Namaste Care. Findings reveal the need to recognize that caregivers can benefit from education in participating in research and the need to empower caregivers to value their contributions in developing interventions. Implications of the findings are to better integrate caregiver engagement in research by seeking feedback from these individuals regarding their experiences. Caregivers need to be supported to engage in research through multiple strategies. The next step for this study is to support caregivers in using the adapted Namaste Care program and evaluate its implementation and preliminary effects.

List of Abbreviations

SPOR: Strategy for Patient-Oriented Research

Declarations

Ethics Approval and Consent to Participate

Institutional ethics approval was obtained from the local Research Ethics Board (#10526). All caregivers received a written introduction to the study and an informed consent form written in lay language. Caregivers provided oral informed consent to participate in the study

Consent for Publication

Not applicable.

Availability of Data and Materials

The data for this research consists of questionnaires, interviews and transcriptions and notes. Raw data cannot be publicly released due to the risk of compromising participant confidentiality

Competing Interests

The authors declare that they have no competing interests.

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Authors' Contributions

MY, JP, SK, and CM designed the study. MY performed recruitment and data collection. MY wrote the initial draft of the manuscript. MY, JP, SK, and CM participated in data analysis, creating tables, and making critical revisions to the manuscript.

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Table 1. Interview Guide

Post-Workshop Interview Guide
1. What did you think about the workshop sessions?
2. How did you feel included in discussions? Please explain.
3. How comfortable were you in sharing your ideas in adapting the program?
4. How did you feel that your ideas and experiences were being respected during the workshops? Explain?
5. How did you feel that your ideas were reflected in the training guide? Please explain.
6. What were the strengths of the workshops?
7. What could have been done differently to make this experience better for you?
8. What would you like us to know about how your participation in the workshops were supported?
9. What would you like us to know about the influence you think the workshops will have?
10. Are there other effects your work in this project had on you?

Note. The interview guide was inspired by the targeted outcomes of the SPOR Patient Engagement framework (42) and the Patient and Public Engagement Evaluation Tool (45).

Table 2. Demographic Characteristics

Category	n (%)
Caregiver demographics (n=6)	
Age in years (Mean [SD])	56.5 [12.1]
30-49	1 (16.7)
50-59	3 (50)
60 and older	2 (33.3)
Sex	
Female	3 (50)
Male	3 (50)
Ethnicity	
White/Caucasian	5 (83.3)
Chinese	1 (16.7)
Highest level of education attainment	
College diploma	1 (16.7)
Bachelor’s degree	3 (50)
Graduate or professional degree	2 (33.3)
Employment status	
Retired from paid work	2 (33.3)
Working part-time	3 (50)
Working full-time	1 (16.7)
Relationship to person with dementia	
Son/daughter	4 (66.7)
Spouse	2 (33.3)
Number of years as a caregiver (Mean [SD])	4.9 [3.2]
1-3	3 (50)
4-6	2 (33.3)
7 and up	1 (16.7)
Number of chronic conditions	
None	1 (16.7)
1-2	4 (66.7)
3-4	1 (16.7)
Person with dementia demographics (n=7)	
Age in years (M [SD])	78.3 [7.6]
65-69	1 (14.3)
70-79	2 (28.6)
80 and older	4 (57.1)
Sex	
Female	4 (57.1)
Male	3 (42.9)
Number of years diagnosed with dementia (Mean [SD])	4.9 [3.3]
1-3	2 (28.6)
4-6	2 (28.6)
7 and up	3 (42.9)

Number of chronic conditions	
1-2	1 (14.3)
3-4	3 (42.9)
5	3 (42.9)

Note. The total percentages for some categories do not equal 100% due to rounding of values. One caregiver was a former caregiver for both parents who were living with dementia and died in the last five years. The age and number of years diagnosed with dementia at the year of their passing were included.

Table 3. Overview of Namaste Care Adaptation Experience Themes

Categories	Themes
Perceived contributions in adapting Namaste Care	(a) Caregivers felt involved in redesigning Namaste Care (b) The training guide reflected caregivers’ ideas and experiences
Factors influencing caregivers’ experiences in adapting Namaste Care	(a) Caregivers felt comfortable sharing ideas for adapting Namaste Care (b) Research strategies enabled meaningful engagement of caregivers (c) Caregivers appreciated the opportunity to discuss and learn from other caregivers (d) Virtual workshops were convenient but limited interactions
Perceived impacts of learning about Namaste Care	(a) Increased awareness of the need for meaningful activities (b) Eagerness to start using Namaste Care

CHAPTER 6

TITLE: Feasibility, Acceptability, and Preliminary Effectiveness of the Adapted Namaste Care Program Delivered by Caregivers of Community-Dwelling Older Persons with Moderate to Advanced Dementia: A Mixed Methods Feasibility Study[4]

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Abstract

Background: Caregivers have considerable caregiving responsibilities in supporting persons in advanced stages of dementia, however they receive little education. Namaste Care is a multisensory program originally designed to be delivered by healthcare providers in long-term care homes for persons with advanced dementia. The program has not yet been adapted or evaluated for use by caregivers of persons with moderate to advanced dementia living at home. The purpose of this feasibility study is to determine the feasibility, acceptability and preliminary effectiveness of the adapted Namaste Care program for use by caregivers of community-dwelling older persons with moderate to advanced dementia.

Methods: This feasibility study, with a one-group before-after design and interviews, was part of a larger study using a multiphase mixed methods design. A total of 12 caregivers delivered the program over three months. Caregivers completed questionnaires on caregiver quality of life, perceptions of caregiving, self-efficacy, and burden at baseline and 3-month follow-up. Caregivers participated in interviews at the 3-month follow-up to explore acceptability and perceived benefit. Descriptive statistics and paired t-tests were used to analyze quantitative data. A secondary analysis used multiple imputation to explore the impact of missing data. Experiential thematic analysis was used in analyzing qualitative data.

Results: The adapted Namaste Care program was judged to be feasible, given that all caregivers used it at least twice a week over the 3-month period. The retention rate of caregivers was 83%. Caregivers perceived that the program was practical, enhanced the wellbeing of persons with dementia, and brought them closer in their relationships with persons with dementia. There were no statistically significant changes for outcomes of quality of life, perceptions of caregiving, self-efficacy, or burden. Multiple imputation results reveal promising findings for an improvement in caregiver wellbeing related to quality of life.

Conclusions: The adapted Namaste Care program for use by caregivers of community-dwelling older persons with moderate to advanced dementia was feasible and acceptable. The program has the potential to enhance the quality of life and other outcomes of caregivers, however there is a need to conduct a larger trial that is adequately powered to detect these effects.

Keywords: Dementia, Caregivers, Family, Older Persons, Namaste Care, Community, Psychosocial Intervention, Mixed Methods, Quantitative, Qualitative

Background

Over 50 million individuals worldwide are living with dementia (1). The number of people impacted by dementia is expected to double every two decades due to a growing global aging population with a projected increase to 78 million people by 2030 (2). In Canada, 60-70% of persons with dementia are living at home to remain independent and engaged in their community (3, 4). Approximately 50% of Canadians with moderate dementia and 14% of persons with advanced dementia live at home versus a retirement or long-term care (LTC) home (5). As individuals progress towards moderate to advanced stages of dementia they will experience significant changes such as profound memory loss, minimal speech, loss of independent ambulation, and inability to complete activities of daily living (6). At this stage, persons with dementia living at home will require greater supports from family and friend caregivers.

Despite the growing numbers of caregivers supporting older persons with dementia at home, most caregivers receive very little education and support in their role. In a sample of 246 caregivers of community-dwelling persons with dementia from the United States more than 85% of dementia caregivers reported that they had unmet needs related to caregiver education (7). Most of these caregivers were caring for a person with moderate (38%) or advanced (18%) dementia at home (7). A lack of education and support contributes to caregiver stress, burden, depression, poor physical health and wellbeing, and low confidence levels in caring for older persons with dementia (8). A solution to meeting the educational needs of caregivers is the implementation of a psychosocial intervention. A psychosocial intervention is intended to slow or prevent a decline in mental and physical health of caregivers as well as persons receiving care by targeting caregiver competencies, knowledge, activities and/or relationships (9). Many psychosocial interventions are intended for both caregivers and persons with dementia.

Psychosocial interventions (e.g., leisure activities and exercise programs, counselling, and support programs) (10) can help caregivers build their confidence in providing meaningful activities that uphold personhood and promote social engagement of persons with dementia (11). Some psychosocial interventions are intended to be delivered as shared activities between caregivers and persons with dementia. For example, some interventions require that caregivers deliver leisure activities for persons with dementia at home which can lead to decreased caregiver burden (12). Leisure and physical activity interventions are perceived by caregivers as being enjoyable through co-participation and offering temporary relief of daily tasks which results in improvements in physical and mental health (10). These interventions have been found to increase the QOL of caregivers, their knowledge of dementia, and skills in delivering care (13-16). Psychosocial interventions delivered by caregivers are a safe alternative to pharmacological interventions to support the quality of life (QOL) of persons with dementia (17-19). When persons with dementia are provided with meaningful activities that enhance their QOL this will likely improve the QOL of caregivers.

To date there are few psychosocial approaches intended for older persons with moderate to advanced dementia and suitable to be delivered by caregivers at home (20). Most interventions are intended for those with early to moderate dementia (14). Among the studies evaluating psychosocial programs, few report outcomes based on the severity of dementia (21-24). In addition to the lack of interventions for people with moderate to advanced dementia, caregivers have had little to no involvement in designing psychosocial interventions (22, 25-27). Their lack of involvement in program design can limit the fit of interventions with their realities of caregiving. Namaste Care is a promising psychosocial intervention that can be used by caregivers of persons with moderate to advanced dementia at home (28). It has not yet been adapted nor evaluated for use by caregivers in a home setting. To date, caregivers have had no involvement in designing Namaste Care so that they could deliver it at home. In order to address this gap, in the present study caregivers were involved in designing Namaste Care for home use.

Namaste Care

Namaste Care is a psychosocial, multisensory program that was originally developed for use in LTC in the United States to fill a gap related to a lack of programs suitable for persons with advanced dementia (28). The core principles of Namaste Care consist of creating a comfortable environment and using an unhurried, loving touch approach during interactions with persons with dementia (28). Namaste Care combines different modalities including music, massage, reminiscing, socialization, aromatherapy, and snacks. The program provides practical skills for families and healthcare providers to meaningfully engage people with dementia in activities.

Namaste Care sessions are delivered in a quiet room with low lighting and no distractions. In LTC settings, the sessions are expected to last 2 hours and are delivered daily in the morning and afternoon. People with dementia are welcomed into a designated room where relaxing music is being played in the background and scents (e.g., lavender, seasonal scents) are being diffused. Namaste Care incorporates principles of touch to provide stimulation for persons with dementia. Healthcare providers provide tactile activities throughout the session such as hand/foot massages, applying lotions, and hair brushing. Healthcare providers speak to the person with dementia throughout the session. Persons with dementia are provided with a Namaste Care Toolbox that has unique items based on preferences such as lotions, life-like dolls, photos, plush animals, and balls to provide sensory stimulation. Throughout the Namaste Care program persons with dementia are being monitored by healthcare providers for signs of pain and discomfort (28). Caregivers may participate in the sessions.

The core principles of the Namaste Care program that should remain intact when being adapted include creating a comfortable environment and using an unhurried, loving touch approach. The frequency and duration of the program is tailorable based on the setting of delivery and who is delivering the program. The program can be delivered by more than one individual including more than one family member. Activities that are part of Namaste Care such as scenting a room, playing music, providing touch activities, offering beverages and snacks, encouraging range of motion activities, and providing reminiscence activities (e.g., photo albums, conversations about life stories) are expected to be tailored to individuals with dementia, their abilities, and interests (28).

Namaste Care has now been used internationally in various settings including LTC, hospice, acute care, and home settings (where it was delivered by hospice volunteers) (28). Namaste Care has resulted in positive changes such as reduced use of antianxiety medications and other psychotropic medications, lower risk of delirium, lessened pain symptoms, and reduced responsive behaviours while improving QOL for persons with advanced dementia and relationships with staff (29-34). In LTC settings, family members feel more comfortable and relaxed when interacting with persons with dementia when engaging in Namaste Care (32).

Tasseron-Dries et al. (2021) evaluated Namaste Care in LTC homes in the Netherlands by implementing an adapted version of the original program that placed a greater emphasis on involving families in the program, however only nursing staff and volunteers received formal training (34, 35). Active family caregiver involvement was hindered in the study as family caregivers were unsure about the purpose of their involvement in the program and its potential benefits (34). There is only one study that explores the use of Namaste Care in a home setting (36). In this study, Namaste Care was delivered by volunteers of a hospice in England who went into the homes of persons with dementia. The program was found to increase socialization for persons with dementia (36). Although the program was implemented in a home setting, the focus was on training volunteers, not caregivers, to deliver the program.

It is essential to assess feasibility of interventions when considering their delivery in a new setting and when in-depth knowledge of the target population's environmental and social context was not considered in previous studies (37). Feasibility studies are used to determine whether an intervention can be implemented and how it should be implemented (38). Feasibility studies are designed to determine the feasibility of methods so that they can be repeated in a larger scale study or reveal potential effects that warrant further investigation in a follow-up larger scale study (39). In terms of program evaluation for caregivers, some researchers have conducted trials to evaluate interventions without first conducting feasibility studies (26, 40). Assessing feasibility is of particular significance in the current study because Namaste Care has not yet been implemented in a home setting by caregivers and it is unknown whether it will be accepted by caregivers or feasible for them to deliver the program. Findings of the feasibility study can inform whether a larger study such as a randomized controlled trial is warranted and feasible to evaluate effects of the program.

The Adapted Namaste Care Program

The Namaste Care program was adapted in terms of content, care activities and implementation process. The adaptation process and findings are presented elsewhere (41). Adaptation was informed by conducting small group virtual (i.e., videoconference or phone) workshop sessions with caregivers who had experience in supporting persons living with moderate to advanced dementia at home. A training guide was created, and caregiver feedback was sought. The training guide included links to reputable video clips and websites exploring how to deliver specific activities such as hand massages and range of motion exercises based on the suggestions of caregivers. The System for Classifying Modifications to Evidence-Based Programs or Interventions (42) was used to guide the adaptation process of Namaste Care, document changes made to the original Namaste Care program to assess fidelity, and as a coding framework for qualitative analysis. Key results of the adaptation process that informed the adapted Namaste Care program were that the program is expected to be integrated into daily care routines, tailored to individual preferences and abilities of persons with dementia, and delivered twice a week instead of twice a day as per the original program to fit the realities of caregiving. All of the activities included in the original Namaste Care program were left intact based on the recommendations of caregivers: (a) using a personalized approach; (b) integrating comfort and pain management; (c) scenting a room; (d) playing relaxing/energetic music; (e) providing touch activities; (f) offering beverages and snacks; (g) encouraging range of motion activities; and (h) providing reminiscence activities (e.g., photo albums, conversations about life stories (43). In the original Namaste Care program these activities can be further tailored based on preferences, cultural values, and life stories.

As part of this study, caregivers each received a Namaste Care Toolbox by mail at no cost. MY had conversations with caregivers about items to include prior to sending the Namaste Care Toolbox. Items were tailored to the preferences and abilities of each person with dementia. Standard items included a training guide, Namaste Care activities checklist forms, a plastic storage container, an aromatherapy diffuser with lavender essential oil, hand and/or body lotion, a squeeze ball, a lip balm, and a microwavable magic bean hot and cold compress. In addition to standard items caregivers received items based on the personal interests of each person with dementia such as dolls, face cream, hairbrushes, fleece blankets, manicure sets, jigsaw puzzles, wordsearch puzzles, light-up balls, blankets, arts and crafts kits, painting supplies, granola bars, and/or pudding. Some caregivers also used items that they already had in their possession to deliver the adapted Namaste Care program sessions such as trivia games or gardening supplies. Participants received a 30 to 60-minute virtual training session by phone or by Zoom on implementing the adapted Namaste Care program at home. MY provided bi-weekly check-ins over 3 months of program implementation with caregivers to assess their needs regarding additional training or material resources, address their questions, and provide information such as links to reputable video clips and websites. Caregivers also communicated by email if they had any questions or concerns in between check-ins.

Aim and Research Questions

The aim of this mixed methods feasibility study was to determine the feasibility, acceptability and preliminary effectiveness of the adapted Namaste Care program in supporting caregivers. The primary aim of the study was to explore feasibility and acceptability of the adapted Namaste Care program. The secondary aim was to determine preliminary effectiveness of the adapted program. The primary research question was: What are caregivers’ views regarding the feasibility and acceptability of the adapted Namaste Care program? The secondary research question was: What are the preliminary effects of the program on QOL, perceptions of caregiving, self-efficacy and burden for caregivers? The overarching mixed methods research question was: To what extent and in what ways do the findings from the qualitative interviews with caregivers contribute to a more comprehensive and nuanced understanding of the feasibility, acceptability and potential effectiveness of the adapted Namaste Care program delivered by caregivers in a home setting?

Methods

Multiphase Mixed Methods Design

This feasibility study was part of a larger study using a multiphase mixed methods design which incorporated quantitative and qualitative approaches as well as sequential and concurrent strands over time to address an overall program objective (44). The overall program objective was to support caregivers of community-dwelling older adults with moderate to advanced dementia by adapting, implementing, and evaluating Namaste Care. The notation of the study design was QUAL —> [quan + QUAL] as we began the program of research using a qualitative strand to adapt Namaste Care, which is discussed elsewhere (41), and then evaluated the adapted program using quantitative and qualitative methods. The focus of this paper is on the [quan + QUAL] components. See Figure 1 for study flow diagram of strands. The qualitative strands were given greater priority because this was a feasibility study of a newly adapted program with preliminary effects of the program as a secondary outcome. In this study feasibility is defined as whether the adapted Namaste Care program can be used in a home setting and how should this be done. The main focus of this study was to understand explore feasibility and acceptability of the adapted Namaste Care program by allowing them to share their experiences. The study protocol is published elsewhere (45).

Quantitative study design. A single group, before-after design was used to assess feasibility of the adapted Namaste Care program and assess preliminary effects for QOL, perceptions of caregiving, self-efficacy, and burden of caregivers. A before-after design, also called non-randomized design, was selected as it is often used in feasibility studies where the focus is on understanding the delivery process relating to the intervention arm, thus randomization is not essential (46). The design is also cost-effective in assessing preliminary outcomes to determine whether further research is needed and eliminates the ethical challenge of assigning caregivers to a control group where they may not benefit from the intervention immediately (39, 47, 48). The feasibility study is reported as per the guidelines of the Consolidated Standards of Reporting Trials (CONSORT) for pilot and feasibility studies (49). Since the current study consists of a one-group, pre-post feasibility study certain criteria of the CONSORT guidelines related to a randomized controlled trial do not apply.

Qualitative study design. Qualitative description was used to explore the acceptability of the program among caregivers, the experiences of caregivers in using the adapted Namaste care program, and to help explain preliminary effects of the program (50). This design was selected to remain close to the words of the participants while giving room for some interpretation of data (50).

Setting, participants and recruitment

Setting. Individual interviews took place virtually due to the COVID-19 public health restrictions at the time of the study. Individual training sessions for the adapted Namaste Care program occurred virtually using videoconferencing or by phone.

Participants. Types of purposive sampling used to select caregivers were criterion and snowball sampling (51). Criterion sampling was used to seek participants who met the following study inclusion criteria: (a) aged 18 years or older currently providing physical, emotional, and/or psychological support for at least four hours a week for a family member or friend aged 60 years or older with moderate to advanced dementia living at home; (b) able to speak, write, and understand English; (c) currently living in Canada; and (d) able to provide informed consent.

In this study caregivers were defined as unpaid caregivers who provide support or physical care for a family member or friend.

Snowball sampling was also used by asking caregivers to share study and researcher contact information with other caregivers who may be interested in participating in the study (51). A total of 10-20 caregivers was sought and 12 were recruited. In feasibility studies, a primary outcome and power calculation for sample sizes may not be necessary (52). The sample size for caregivers was determined based on previous Namaste Care studies which included anywhere from 8 to 15 caregivers (31, 36, 53-56). Some of the previous Namaste Care studies reporting the inclusion of a small number of caregivers consisted of a feasibility study and a feasibility study using a mixed methods design (53, 54). Computer tablets and access to the internet were offered to caregivers who did not have access to these and who were interested in participating by videoconferencing.

Recruitment. Caregivers were recruited from the Alzheimer Society of Canada, local and provincial Alzheimer Societies, Dementia Advocacy Canada, provincial and local caregiver organizations, and community-based geriatric services. MY presented the study virtually for caregivers and Alzheimer Society staff (e.g., public education coordinators, counsellors, recreational therapists). MY presented the study at virtual Alzheimer Society dementia education series for caregivers (e.g., Care in the Later Stages Series). Information about the study was shared through websites, social media, and in electronic newsletters of the listed organizations.

Data Collection

Data were collected from October 2020 to September 2021. Demographic data, such as age, sex, education level, relationship to care recipient, ethnicity, and chronic conditions, were collected using questionnaires. Baseline data including demographic and preliminary effectiveness data (i.e., QOL, perceptions of caregiving, self-efficacy, and burden) were collected immediately after informed consent was obtained. A research activity log was completed bi-weekly to document the number of days the adapted Namaste Care program was used per week and the number and type of adverse events reported. At the end of the 3-month intervention period, outcome assessments were collected again along with qualitative data (e.g., acceptability, perceive benefits, barriers and facilitators to implementation). Post-intervention data were collected within a timeframe of two-weeks following study completion. Details about the data collected are described below.

Feasibility. Data on feasibility were collected by completing the research activity log. MY updated the log based on information obtained from caregivers (e.g., Namaste Care Activities Checklist and notes) during the bi-weekly telephone or videoconference check-ins. Caregivers were provided with a Namaste Care Activities Checklist that listed common activities that can be delivered during a session. Caregivers were asked to complete a brief Namaste Care Activities Checklist on the days they delivered the program to indicate the type of activity delivered during a session such as massage, aromatherapy, snacks, beverages, and music [See Additional file 1 for the checklist]. The Namaste Care Activities checklist was also used to assess fidelity by ensuring that caregivers deliver the Namaste Care activities listed on the checklist. Fidelity of the intervention was established by implementing standardized training protocols and analyzing the Namaste Care Activities checklist to measure adherence to the intervention (57). Feasibility was evaluated by comparing the research activity log to pre-set target criteria: (a) number of days the adapted Namaste Care program was used (target: at least 2 out of 7 days per week for at least 8 out of 12 weeks for participants who delivered the program over 3 months); (b) retention rate (target: 75% of participants have completed the 3-month outcome data questionnaires and interviews); and (c) percentage of adverse events for persons with dementia (e.g., falls, injuries, skin breakdown) reported (target: 0%). If a caregiver combined two or more activities in a session, the adapted Namaste Care program was considered as being implemented on that day. The target for the number of days the Namaste Care program used was based on the feedback provided by caregivers when adapting the program and used in another study evaluating Namaste Care in LTC (53).

Acceptability. The acceptability of the adapted Namaste Care program was explored through individual interviews with caregivers by phone or by videoconference at the end of the study period (i.e., at 3-month follow-up). These interviews explored caregiver perceptions of the following: (a) benefits of the program; (b) satisfaction with the process of implementation; (c) barriers and facilitators to implementation; and (d) recommendations to improve the program. Qualitative data were collected bi-weekly through notes and at the 3-month follow-up which consisted of a 30- to 60-minute individual virtual (i.e., telephone or videoconference) semi-structured interview with caregivers to explore their experiences in implementing the adapted program. The interview guide was used to explore experiences with the program and acceptability. See Table 1 for the interview guide. The aims of the qualitative strand and the interview guide were developed based on the Bowen et al. (2009) Feasibility Framework (37), semi-structured qualitative research methods (58), recommendations by research team members and dementia literature. Reflective field notes made immediately after the interviews were completed to capture actions and to highlight personal reactions by bringing important elements to light such as emotions experienced by participants (59). Interviews were audio-recorded and transcribed by an experienced transcriptionist.

Preliminary effectiveness. Preliminary effectiveness data were collected at baseline and at the 3-month follow-up. Preliminary effectiveness was assessed using four caregiver outcomes – QOL, perceptions of caregiving, self-efficacy, and burden. QOL was measured using two subdomains from the Carers-DEMentia Quality of Life (C-DEMQOL) scale for obtaining the QOL of caregivers of people with dementia (60). To alleviate the burden for caregivers in completing a 30-item questionnaire, relevant subdomains of the scale were used in the study (i.e., carer wellbeing and carer role). These subdomains were selected as they closely resembled goals of the Namaste Care program such as enhancing the relationships between persons with dementia and caregivers (28). The other subdomains were excluded because they focus on meeting the personal needs of caregivers, perceptions of the future, and social and professional support, which were not a focus of the Namaste Care program. Other effectiveness measures included caregivers': (a) perceptions of caregiving measured using the 9-item Positive Aspects of Caregiving (PAC) scale (61); (b) self-efficacy measured using the Relational, Instrumental, Self-soothing (RIS) Eldercare Self-Efficacy scale (62); and (c) caregiver burden measured using the short form Zarit Burden Interview scale (ZBI-12) (63). Caregivers were provided with the option to complete questionnaires independently or with MY by phone or videoconference.

The instruments were carefully selected based on validity and reliability and whether they were specific for caregivers of people with dementia and fit the home setting context. For the two C-DEMQOL subdomains that were used in the study, each composed of six items, carer wellbeing had a Cronbach alpha of 0.91 and care-patient relationship/carer role had a Cronbach alpha 0.82; scores range from 6-30 for each of these two subdomains, and higher scores reflect better QOL (60). For the PAC nine-item measure the Cronbach alpha for the scale was 0.89;

scores range from 9-45, and higher scores reflect greater positive feelings towards caregiving (61).

The RIS Eldercare Self-Efficacy scale is a 10-item tool that measures different forms of self-efficacy or perceived belief in being able to complete an activity (62). Instrumental self-efficacy consists of one’s belief in being able to complete personal care tasks for the care recipient; relational self-efficacy consists of one’s belief in maintaining a positive relationship with the care recipient; and self-soothing efficacy is one’s belief in being able to maintain one’s own wellbeing amidst all the demands of caregiving (62). Scores range from 10-50 with higher scores reflecting greater self-efficacy. Internal consistency was established for relational self-efficacy with a Cronbach alpha of 0.73, 0.78 for instrumental self-efficacy and 0.72 for self-soothing self-efficacy (62). The validity of the instrument was established with the ability to explain 61.2% of total variance using a principal component factor analysis (62).

The ZBI-12 (63) measures caregiver burden and is a short (12-item) version adapted from the 22-item and the original 29-item scales created by Zarit et al. (1980) (64). Scores range from 0 to 48 with higher values representing greater burden. Internal consistency was established with a Cronbach alpha value of 0.88 found for the ZBI-12 scale (63).

Data Analysis

Demographic characteristics of participants were analyzed using descriptive statistics. Means and standard deviations were reported for continuous variables and frequency counts and percentages were reported for categorical variables. Quantitative data analyses were conducted using SPSS version 28. The statistical software used for multiple imputation was the MICE package in R. Pooling was done using mi.t.test routine in MKmisc package, base R Version

4.0.2. All tests were completed using 95% confidence intervals (CI) and a two-sided alpha level set at 0.05.

Feasibility. Feasibility data obtained through the research activity log and Namaste Care Activities Checklists completed by each caregiver were analyzed. Descriptive statistics were used to summarize results to provide an overview of different types of Namaste Care activities delivered by caregivers and the frequency of activities delivered. Results were also reported in relation to whether pre-set target criteria of the study were met.

Acceptability. Qualitative data obtained from the interviews were analyzed using experiential thematic analysis, which is suitable for the study as it focuses on the experiences of participants and how they make sense of their world (65, 66). Analysis was both inductive and deductive in nature. Categories for qualitative themes were developed based on selected areas of focus of the Bowen et al. (2009) Feasibility Framework (37) including acceptability, demand, implementation, practicality, efficacy, and adaptation. We followed the six phases of Braun and Clarke's (2006) thematic analysis (65): (a) gaining familiarity with the data; (b) conducting coding; (c) locating themes; (d) reviewing themes, (e) developing a definition for themes and naming them; and (f) developing a report. MY analyzed data concurrently as interviews were being completed and then shared findings with the research team for feedback. Qualitative description allows researchers to begin analysis with the use of pre-existing coding systems and adapting these systems during the analysis to ensure they fit the data (50). Consistent with qualitative description (50), constant comparative analysis was used to identify similarities and differences across participants. NVivo version 12 software (67) was used for data management.

Preliminary effectiveness. Normalcy was assessed using Shapiro-Wilk tests to determine whether the data were normally distributed before deciding to conduct parametric or non-parametric tests to assess the statistical significance of the change in scores from baseline to 3 months for the measures of effectiveness. Based on the findings paired t-tests were used. A secondary analysis explored the impact of missing data (18% missing for the 3-month outcomes), with multiple imputation employed using chained equations, predictive mean matching and 5 imputed data sets (68). All variables (e.g., demographic, health status, caregiver outcomes) were included in the imputation model. The 5 imputations were pooled to estimate the treatment effect for each caregiver outcome.

Mixed methods analysis. Once data analysis for both the quantitative and qualitative strands were completed, the findings of both analyses were compared to develop the mixed methods interpretation (44). Meta-inferences were made at the end of the study by combining the inferences from quantitative and qualitative strands to provide a broader interpretation (44, 69). A joint display was used to show the connection between quantitative results and qualitative findings that either supported or diverged from one another (44). The Bowen et al. (2009) Feasibility Framework was used to develop the mixed methods interpretation and inform the joint display structure that included feasibility, acceptability, and preliminary effectiveness data (37).

Ethical Considerations

Ethics approval was received from the local Research Ethics Board (#10526). The three core principles, respect for persons, concerns for welfare and justice, of the Tri-Council Policy Statement were applied throughout the study (70). All caregivers received a written introduction to the study and an informed consent form written in lay language. Caregivers provided oral consent, and this was audio-recorded. A token of appreciation in the form of a $25 gift card was offered to all caregivers for participating in the study.

Validity, Rigour, and Trustworthiness

Quantitative validity. When selecting the quantitative instruments, we considered content validity to ensure that the instruments measured relevant aspects of caregiver outcomes and face validity to ensure that the measurement and number of items included appeared reasonable (71). The instruments selected were relevant to the target population of the study and were used in previous studies that evaluated effectiveness of caregiver interventions (26, 72-77). They were also selected based on the outcomes anticipated to be impacted by the adapted Namaste Care program.

Qualitative validity. MY maintained a reflexive journal to document reactions and experiences potentially having an impact on the study process (78). We implemented strategies to meet Lincoln and Guba's (1985) trustworthiness criteria consisting of credibility, transferability, dependability and confirmability (79). Credibility was upheld through investigator triangulation by seeking feedback from research team members as they hold research expertise in the areas of caregiver support, dementia care, psychosocial interventions and/or community support programs. This process promoted credibility and complementarity as well as validated data (79). To increase the transferability of the study findings, rich thick descriptions were used to describe the study setting and sample (79). MY conducted a study audit to meet the criteria of dependability and confirmability to ensure that the process for collecting and analyzing data was systematic and findings were supported by data.

Mixed methods study validity. We implemented strategies to minimize threats related to data collection, data analysis and interpretation of both quantitative and qualitative findings. We used data collection methods that were appropriate for quantitative and qualitative methods (44). We upheld validity by integrating quantitative and qualitative strands to answer the mixed methods research question and revealing convergences and divergencies between the findings of both strands in a joint display. The Mixed Methods Appraisal Tool (MMAT) was used to ensure that methodological quality criteria unique to mixed methods studies were considered in the current study such as adequate justifications for selecting a mixed methods design, effective integration of qualitative and quantitative strands, and clear reporting of divergences and consistencies (80).

Results

In this section we present quantitative and qualitive findings and mixed methods interpretations. We begin by providing demographic information of participants followed by feasibility, acceptability, and preliminary effectiveness findings. We summarize the overall findings in the section on mixed methods interpretations.

Demographics Characteristics

A total of 12 caregivers participated in the study and implemented the adapted Namaste Care program at home, however only 10 caregivers completed the study. The demographic data of the 12 participants who enrolled in the study are discussed here. The mean age of caregivers was 62.3 years [SD (standard deviation=11.8)]. Most of the caregivers were female (83.3%). Caregivers were from four Canadian provinces with most living in Ontario (66.7%) and in urban areas (83.3%). All except one caregiver identified as being White/Caucasian (91.7%). A little over half of caregivers were retired from paid work (58.3%) and most had completed post-secondary education (91.6%). There was an equal number of caregivers who were children versus spouses of persons with dementia (50%). The mean number of years since caregivers took on the caregiving role was 5.1 years [SD=3.6]. In terms of number of chronic conditions most caregivers reported anywhere from 1 to 4 conditions (83.3%) such as thyroid disorders, chronic musculoskeletal conditions causing pain or limitations, hypertension, and gastroesophageal reflux disease. Most caregivers (75%) were responsible for providing all types of support such as emotional support, assistance with household activities, and assistance with personal care for persons with dementia. See Table 2 for the demographic characteristics of caregivers.

In terms of the demographic characteristics of persons living with dementia, the mean age was 76.9 years [SD=9.5]. A little over half of persons with dementia were male (58.3%). The mean number of years that an individual was diagnosed with dementia was 4.8 [SD=4]. Most persons with dementia were in the moderate stages of dementia (66.7%) versus the advanced stage (33.3%). Stages were determined using the Reisberg/Global deterioration scale based on what was reported by caregivers (81). Persons with dementia at stages 5 (moderate) or 6 (moderately severe) were considered as having moderate dementia and those at stage 7 (severe) consisting of the last stage of the scale were considered as having advanced dementia (81). Persons with dementia had many chronic conditions with most having 3 to 6 conditions (91.7%), such as depression or anxiety, cardiovascular disease, hypertension, hyperlipidemia, and chronic musculoskeletal conditions causing pain or limitations. See Table 3 for the demographic characteristics of persons living with dementia.

Feasibility Results

We present results that provide evidence for the feasibility in implementing the adapted Namaste Care program and the types of activities that were feasible to deliver by caregivers. All 10 caregivers who completed the study met the pre-set target criterion of using the adapted Namaste Care program for a minimum of twice per week for at least 8 out of the 12 weeks of the study. Eighty-three percent of the caregivers (10 of 12) completed the study, which exceeded the target retention rate of 75% or more. The reasons for study withdrawal were due to the death of the spouse with dementia and a parent with dementia experiencing a decline in health status. No adverse events related to program delivery were reported by caregivers.

Type and frequency of activities delivered. Caregivers were asked to document activities delivered during sessions using the Namaste Activities checklist [See Additional file 1]. Caregivers combined 2 or more activities in a session. Providing snacks and beverages outside of mealtimes was the most frequently completed activity with 83.3% of caregivers taking part in this activity and doing so at least 5 times a week on average. In terms of reminiscing activities (e.g., storytelling, looking at photo albums or family videos), 75% of caregivers delivered this activity weekly for 4 days a week on average. Physical touch activities (e.g., washing and/or moisturizing hands, face and/or feet, massaging) were provided by 66.7% of caregivers and delivered 3 times a week on average. Range of motion/exercise-based activities (e.g., walking, exercise routines, playing with a ball) were delivered by 66.7% of caregivers and offered 3 times a week on average. Audio/visual activities (e.g., reading, listening to music, watching video clips) were provided by 66.7% of caregivers twice a week on average.

Comforting activities (e.g., providing a hot/cold pad, implementing aromatherapy, offering a soft blanket) were delivered by 58.3% of caregivers for 3 times a week on average. Despite COVID-19 public health restrictions, caregivers still found alternative ways to provide opportunities for socialization for persons with dementia. Family/friend visits (e.g., phone or Zoom calls, in-person visits when safe to do so) and outings were provided by 58.3% of caregivers at least twice a week on average. Games (25%) and arts and crafts (0.8%) were the least frequently delivered activity with both being delivered once a week on average. See Table 4 for the type and frequency of activities delivered during program sessions.

Acceptability Findings

Qualitative themes were categorized under the following: (a) program implementation experiences of caregivers; (b) facilitators supporting program delivery; (c) barriers to program delivery; (d) perceived benefits for caregivers; (e) perceived benefits for persons living with dementia; and (f) recommendations for further adaptations. See Table 5 for an overview of categories and themes.

Program implementation experiences of caregivers. Caregivers reported positive experiences in implementing the adapted Namaste Care program at home. Themes were: (a) caregivers were highly satisfied with the program resources and training; (b) delivering the program was manageable and fit into caregivers' routines; and (c) bi-weekly check-ins helped caregivers deliver the program confidently and consistently.

Caregivers were highly satisfied with the program resources and training. All caregivers reported high levels of satisfaction in delivering the adapted Namaste Care program and stated that they would continue using the program after the study was completed. "*There are tools in my toolbox as the result of Namaste Care that I will take forward*" (CG-211). They found value in using the program as it gave them various ideas for activities to engage older persons with dementia. Some caregivers planned to try different activities with their family members (e.g., outdoor activities, painting sessions) and one caregiver planned to complete a chart to track activities. Caregivers perceived that this program would be helpful for other caregivers, and many shared the program with other caregivers and family members. "*Extremely satisfied [with the program]. I think it would be great for everybody to have that opportunity, to have that help, that program, that support, all of it. I think it's fantastic"* (CG-204). Caregivers were also satisfied with the training session, resources, and items included in the Namaste Care

Toolbox. "*[When asked about training] Excellent. The whole idea of how to incorporate things. It was all so helpful. Like any input is like gathering information and then using what you can of it in your situation"* (CG-212).

Delivering the program was manageable and fit into caregivers' routines. Caregivers perceived that delivering the program at least twice a week was manageable in terms of meeting other priorities such as work and daily household tasks. Some caregivers were even able to deliver the program daily. The program did not create additional burden for caregivers and provided them with a different approach to care. "*It didn't feel like I was doing any extra work, it just sort of changed the pace of things that I would do for the caregiving"* (CG-205). The program was perceived as complementing the routines of caregivers. They reported providing some activities that were on the checklist before, but the program helped them in *"making it [activities] a little bit more special"* (CG-212). They also felt comfortable in delivering the program sessions because some activities were familiar to them.

Bi-weekly check-ins helped caregivers deliver the program confidently and consistently. Caregivers reported that having regular bi-weekly meetings with MY were helpful to provide them with feedback regarding program delivery, answer questions, and support them to try different ideas for activities. The consistent support provided confidence and encouragement for caregivers to continue with the delivery of the program. *"It's good just to have that social feedback and... every two-weeks is about right. And it enabled me to sort of stay focused as well"* (CG-203). Caregivers appreciated receiving validation for their efforts in delivering the program and appreciated receiving website links to help address their needs.

> *You reassuring me that I am actually doing quite a lot when sometimes I feel like I am not, you know or where I intended to spend longer, I think it helped me feel better, so that was very valuable. And sometimes I tell you the struggles that we had, just as it comes. Not, thinking that you had any suggestions, but then you would send me some resources, or you*

> *will send me some links. That was useful for sure.* (CG-206)

Facilitators supporting program delivery. Caregivers perceived that they were well supported to deliver the adapted Namaste Care program in terms of training and education, material resources, and regular communications. They were also comfortable in ensuring the program was tailored to the preferences, needs, and abilities of persons with dementia. Themes for program delivery facilitators were: (a) being provided with a Namaste Care Toolbox; (b) having written resources at hand; and (c) delivering activities in a language familiar to persons living with dementia.

Being provided with a Namaste Care Toolbox. Caregivers perceived that being provided with a Namaste Care Toolbox at no cost made it easy to implement the program because caregivers may not have the time or expertise to purchase items on their own. *"If you had to go out and purchase them yourself, the uncertainty, 'did I get the right thing?' It was super easy, I opened the box and utilized it. So, there wasn't any guess work"* (CG-211). When caregivers wanted to deliver a session, they did not need to search for items as all items were located in one container.

> *Well, it was nice to have all the stuff there all in the box. I kept them in the box and container...I appreciated you bringing them and having them all there. And you know, when I was done, I just put it back so that everything is all there. So, that helped. (CG-204)*

Having written resources at hand. Caregivers were provided with a training manual and additional resources (e.g., links to videos or websites, research articles) that were tailored to their learning needs. Having written resources available supported program delivery so that caregivers could refer to information about the program as needed. They were given a checklist to record the activities provided and many referred to the checklist for ideas for activities.

> *It is great to have everything, you made it very easy because everything [resources] was all there...if you didn't give me the checklist, I have to record everything in my diary and think*

> *of things to write probably, but not too much information or detail.* (CG-205)

Delivering activities in a language familiar to persons living with dementia. The adapted Namaste Care program is intended to be further tailored based on individual preferences, cultural values, and life stories. Caregivers perceived that this aspect of the program was important to consider when delivering the program for older persons with dementia to ensure they can relate and meaningfully engage in activities. All caregivers were expected to take part in the study in English, however some caregivers were supporting family members who no longer communicated in English and used their primary language when engaging in daily activities. Being able to play music or provide reading materials in one's primary language made it easier for caregivers to engage with their family members.

> *Because for the music and the video I had to do things...that meant something to her. So, if I had to play something that I relate to, she may not relate to. She may not relate to it at all and not the language part. She can't understand it.* (CG-205)

Barriers to program delivery. Caregivers perceived that they experienced some challenges in delivering the adapted Namaste Care program. These were: (a) persons living with dementia did not want to engage in activities at times; (b) persons living with dementia did not respond to all items provided in the Namaste Care Toolbox; and (c) meeting the numerous daily demands (e.g., work, housework, appointments).

Persons living with dementia did not want to engage in activities at times. At times it was frustrating and/or disappointing for caregivers when they wanted to engage their family members in activities and felt they were not successful in doing so. Persons living with dementia were perceived as not being alert enough, not liking specific activities, and being too restless at times to participate in activities. Some persons with dementia did not want to engage in activities because they wanted to spend time alone.

> *The only thing is, if he wants alone time, more. Even...was it a couple nights ago? I went to go in to just chat with him or something. What did he say to me? You know, 'what are you doing in here? Or 'what do you want'... So, you know I find the fluctuation as time is going on.* (CG-212)

Persons living with dementia did not respond to all items provided in the Namaste Care Toolbox. Despite tailoring items provided in the Toolbox as best as possible to the stages and individual preferences of persons with dementia, some did not respond to all items in the Toolbox such as baby dolls. Caregivers were expecting that a response would be seen for most of the items such as items capturing the attention of persons with dementia or being held in their hands for longer periods. Caregivers perceived that when persons with dementia were in advanced stages there were greater limitations in activities that could promote a response such as a smile, eye contact, or attempts at verbal communication.

> *As in regards to any of the equipment and stuff because you provided a box of things, again unfortunately, [wife] appears to be beyond most of those. She wasn't interested in sitting with a doll. Really, the squeeze ball and the one that lights up, she pays attention to that, if you bounce it around. The squeeze ball would be the one she spent the most time with and got the most attention.* (CG-203)

Meeting the numerous daily demands (e.g., work, housework, appointments). Most of the caregivers were primary caregivers who were living with their family member with dementia. They had numerous responsibilities in terms of work, household tasks, and managing appointments. Caregivers perceived that some activities proposed in the program conflicted with the time reserved to meet other responsibilities.

> *So, some of the things were specific, if you had time to say, 'well, I wonder what I'll do this morning. Oh, let's get out the photo albums', but in our household, there is so much that I need to be doing that I really don't have the time. [husband] sleeps 'till late, so I try to use that time to have a bit of time for myself, walk the dog, plan the day and you know, so it's a bit complicated.* (CG-208)

Some caregivers initially viewed the program as adding on to an already busy routine, but soon realized that the program could be integrated in everyday routines. *"It did become kind of common place after the first little while"* (CG-210).

Perceived benefits for caregivers. The adapted Namaste Care program was perceived by caregivers as having positive benefits for them. Themes were the following: (a) the program encouraged a more structured approach and use of creativity in delivering activities; (b) caregivers gained a better understanding of how to address the various needs (e.g., physical, emotional, social) of persons living with dementia; and (c) the program brought caregivers and persons living with dementia closer in their relationships through mutual enjoyment of activities.

The program encouraged a more structured approach and use of creativity in delivering activities. Caregivers perceived that the program provided them with a structured approach to deliver activities consistently and increased their efforts in forming connections with persons with dementia. *"More conscious in trying to take a structured approach... There is an effort to do something with her on daily basis which she can and hopefully responds too. And it's worth it because, you get the great big smile..."* (CG-203). The program helped them to use creativity in delivering activities and awaken the different senses of persons with dementia.

> *I draw her attention to the different flavors that she is drinking. We often have like carbonated water, but it's got a flavor in it. ...the Play-Doh and that also felt really good for her...the Namaste got me expanded to think beyond just what sort of colouring can we do.* (CG-206)

Caregivers gained a better understanding of how to address the various needs (e.g., physical, emotional, social) of persons living with dementia. Implementing the adapted Namaste Care program helped caregivers better understand the various types of needs persons living with dementia have and different strategies that they could use to address these. Caregivers perceived that prior to the program they were providing basic care needs for persons with dementia such as nutrition and now felt more confident in meeting other needs such as social and emotional needs. Some caregivers reported that they now recognized the needs of their family members amidst the overwhelming daily tasks.

> *It's very easy and it's really hard not to get caught up with the mental load with everything that has to get done in a day. And I think sometimes those tasks and chores are overloading. They are things that just have to get done, but this way you more see it as the person that you are looking after more of a person with needs, like we all have.* (CG-202)

The Program brought caregivers and persons living with dementia closer in their relationships through mutual enjoyment of activities. Caregivers perceived that the program changed their relationship with their family members by bringing them closer and created more opportunities for interactions. They felt that the program helped them be patient and present when interacting with persons with dementia. Caregivers enjoyed taking part in activities and felt that these benefitted them as well. Some caregivers reported that persons with dementia would do activities for them such as applying lotion or providing a massage, and this provided opportunities for persons with dementia to lead activities. "*I found that [spouse applying lotion to my feet] would help to bring us together again, to have that touch.* (CG-209).

Perceived benefits for persons living with dementia. Caregivers identified many benefits of the program for persons living with dementia. Perceived benefits for persons with dementia were: (a) persons with dementia were more engaged in meaningful activities consistently; (b) enhanced wellbeing of persons living with dementia; and (c) the program instilled confidence in persons living with moderate dementia to participate in different activities.

Persons with dementia were more engaged in meaningful activities consistently. Caregivers perceived that the program ensured that persons living with dementia were provided with more frequent and regular opportunities to be engaged in meaningful activities. Persons with dementia were receiving much needed attention from caregivers and enjoyed pleasant conversations that did not require recall of events. Without this engagement caregivers perceived that family members would sleep or watch television.

> *I think she feels when we have a session like that she is being paid attention to and that she is doing something worthwhile because when I am not doing a session with her she is either sleeping or watching TV. So, doing something a bit more constructive, feels good for her because she has something to do and she feels more engaged.* (CG-202)

Enhanced wellbeing of persons living with dementia. The program was perceived by caregivers as improving the wellbeing of persons with dementia through better mood following the delivery of pleasant activities and decreasing agitation. Aromatherapy and physical touch activities such as massages helped persons with dementia to relax. *"He is a little bit more relaxed and more engaged. And...it almost soothes him"* (CG-204). Caregivers reported positive responses such as smiling and increased verbal communication. One caregiver noted that his mother looked forward to the program every day and disruptions to its delivery had an impact on her.

> *It's sort of a routine that she knew everyday and if that's in the morning, the snacks, the beverage and the lotioning. So, I think the routine actually helped her get more settled. She knows she can look forward to that every day. And there was a time when I had to go out for meetings or had to go out for groceries, the timing of those activities were disrupted. She became disoriented by that. So that's when I knew that Namaste Care had an impact on how she is.* (CG-205)

The program instilled confidence in persons living with moderate dementia to participate in different activities. Caregivers perceived that the program provided opportunities to support persons with moderate dementia in completing as many activities as they could. Caregivers of persons with moderate dementia felt it was important for their family members to retain their abilities as much as possible and encourage them to participate in different activities.

> *Well, I think it also gives her a little bit of confidence too, she is doing different things because when she is with my dad...he doesn't let her do anything, so it takes her away from*

> *the boredom of just sitting there at the TV...I think she had some fun. So, she's been enjoying music and she's been exercising, so we get her a little bit in shape. And she is trying different food that my dad would have never have eaten...* (CG-206)

Caregivers were present to assist persons with dementia even if activities were challenging at first such as completing a puzzle or baking.

Recommendations for further adaptations. Although caregivers were highly satisfied with the overall program, some had recommendations to improve the program. Themes were: (a) offering more caregiver training and information on how to involve others (e.g., other family members, personal support workers) in delivering the program; (b) further tailoring of items provided in the Namaste Care Toolbox to increase the likelihood of engagement; and (c) reformatting the Namaste Care activities checklist.

Offering more caregiver training and information on how to involve others (e.g., other family members, personal support workers) in delivering the program. Despite being provided with a training session and manual, there was still some uncertainty for caregivers in how they should be presenting items to persons with dementia and using them effectively. One caregiver recommended role playing during the training session to simulate how an activity may be delivered during a session to maximize the use of an item such as a doll.

> *...because I am new to this, I think even having examples of how to do it [activities]...I guess, it could build confidence if we almost role played...Because sometimes, I have something and my mom would say 'what am I supposed to do with this?' And I'll be like 'I am not entirely sure, but I think we could do with it...' You know in a way, it could be good, because maybe we explore ways and ways that were not intended. But maybe they could be used better than what I had used them for.* (CG-206)

On a few occasions, some caregivers engaged other family members to take part in learning and delivering the program together. Some family members joined caregivers in delivering the program and others were hesitant to do so. Some caregivers saw the value that this program could bring for personal support workers in the delivery of their care and interactions for persons with dementia. This finding reveals the need for greater support and information on how to involve others such as family members and personal support workers to use the program.

Further tailoring of items provided in the Namaste Care Toolbox to increase the likelihood of engagement. Given that one of the barriers to delivering the program consisted of persons with dementia not responding to all items included in the Toolbox, caregivers recommended further tailoring prior to sending the Toolbox. Although MY had a conversation with caregivers about the items to be included and whether they would be things that the person they were caring for may like to try, there could have been different options provided in case caregivers were unsure if activities were too hard or easy for individuals such as puzzles. *"Have a bigger piece of puzzle to begin with and maybe have a little piece puzzle like you did. But...depending on the person, maybe putting in a different kind of puzzle"* (CG-210). Some caregivers were hoping to deliver various types of activities such as arts and crafts and building small cars, however some caregivers felt that their family members had progressed beyond such activities throughout the 3-month study period. *"As he got worse, its just made it harder to do the other things that I was hoping to do. That were in the box"* (CG-204).

Reformatting the Namaste Care activities checklist. Although caregivers appreciated receiving a checklist to record activities completed during program sessions, some caregivers perceived that it was challenging to complete because it was organized by month and caregivers did not always start the program the first day of the month.

> *I don't know how you can do it. But it's sometimes confusing to have the first, first day of the week and all of sudden it skips to the middle of the week. You know, because I would kinda fill it in and start doing and realize, "Oh, today is not the 6th".* (CG-209)

They recommended having a space for them to record the day of the week or having the whole month on a single sheet. One caregiver recommended a fillable online checklist that could be completed on a hand-held device such as a phone.

Preliminary Effectiveness Results

This section describes the preliminary effects of the adapted Namaste Care program in terms of selected QOL, perceptions of caregiving, self-efficacy, and caregiver burden. See Figures 2 and 3 for the baseline and 3-month scores for QOL in terms of caregiver wellbeing and caregiver role, Figures 4 and 5 for perceptions of caregiving and self-efficacy, and Figure 6 for caregiver burden. Despite favorable changes in some outcomes, none of the changes were statistically significant. For QOL of caregivers measured by two sub-domains of C-DEMQOL, a mean difference of -1.10 (95% CI: -2.47, 0.27; p=0.102) was found for C-DEMQOL Carer Wellbeing and -0.20 (95% CI: -1.14, 0.74; p=0.642) for C-DEMQOL Carer Role. A mean difference of 1.20 (95% CI: -3.36, 5.76; p=0.566) for perceptions of caregiving and a mean difference of 0.70 (95% CI: -1.98, 3.38; p=0.569) for self efficacy were found. A mean decrease of -0.50 (95% CI: -4.26, 3.26; p=0.770) was found for caregiver burden. See Table 6 for the baseline and post-adapted Namaste Care program preliminary effectiveness results.

Multiple imputation results did not reveal any statistically significant changes from baseline to the 3-month follow-up outcome scores. A promising finding was however found when examining the individual imputations as 2 out of 5 imputations showed statistically significant increases for caregiver QOL in terms of caregiver wellbeing. For the 2nd imputation for QOL in terms of caregiver wellbeing the mean difference was 1.08 (95% CI: 0.13, 2.04; p=0.03). For the 3rd imputation for QOL in terms of caregiver wellbeing the mean difference was 1.42 (95% CI: 0.19, 2.64; p=0.03). See Table 7 for the multiple imputation results.

Mixed Methods Interpretations

In this section we provide a summary of overall findings from Phase 2. We selected and adapted areas of focus and outcomes of interest from the Bowen et al. (2009) Feasibility Framework (37). The categories were: (a) feasibility with regards to demand, implementation and practicality; (b) acceptability of the program; (c) limited preliminary effectiveness testing; and (d) further adaptations. See additional file 2 for the joint display of quantitative and qualitative findings.

Feasibility with regards to demand, implementation, and practicality. The adapted Namaste Care program was in demand as supported by its actual use and the positive perceptions of caregivers towards the program. With regards to degree of implementation, caregivers felt supported and confident in implementing a variety of different activities during a session due to the bi-weekly check-ins, information received, and receiving a Namaste Care Toolbox. More than half of the caregivers provided 7 out of 9 activities from the checklist. The ability of caregivers to provide the program at least twice a week was supported by the perceived perceptions of caregivers regarding the program being manageable and having many perceived benefits for persons with dementia and caregivers. Caregivers perceived that barriers to program implementation included meeting other demands such as work and household tasks and persons with dementia not wanting to engage in activities at times. These barriers may be reflective as to why snacks and beverages and reminiscing activities were provided more often as these may require less time to implement and persons in moderate to advanced stages of dementia may be more willing to accept these activities. Based on the feasibility results, caregivers were able to consistently deliver the same number of activities throughout the 3-month study period indicating the likelihood that a routine for implementing activities had developed for caregivers.

Acceptability of the program. Caregivers were highly satisfied with using the program and the supports provided. Caregivers perceived that the virtual training session, written resources, bi-weekly check-ins, and the Namaste Care Toolbox were helpful in delivering the adapted Namaste Care program. Being satisfied with the program led to its frequent use. The program was perceived as appropriate for persons with dementia and caregivers felt comfortable in delivering it as well as trying different activities to engage their family members. All of the caregivers shared their interest in continuing to use the program after the study was completed.

Limited preliminary effectiveness testing. Quantitative results for caregiver QOL revealed that the program did not statistically significantly improve caregivers' QOL. This finding aligns with qualitative notes recorded during the bi-weekly check-ins where caregivers discussed the stress of caregiving and trying to adapt to deteriorating conditions of persons with dementia. Despite non statistically significant changes found for all outcomes, positive trends were found for some outcomes such as perceptions of caregiving, self-efficacy, and caregiver burden. These positive trends converge with data obtained from qualitative interviews and check-ins as caregivers reported a greater awareness of the need for meaningful activities, perceived that the program brought them closer in their relationships with persons with dementia, and benefited them and persons with dementia. Caregivers did not perceive the program as creating additional burden as it was practical and manageable to deliver consistently.

Further adaptations. Although 66.7% of persons with dementia were in the moderate stages of dementia, activities such as arts and crafts and games were not delivered on a weekly basis and were delivered by few caregivers. This finding aligns with the suggestions received to increase supports for training and to provide more demonstrations for activities to increase the confidence of caregivers in delivering these. Further tailoring of items included in the Namaste

Care Toolbox may also be required to ensure that the level of difficulty associated with specific arts and crafts and games are appropriate for each person with dementia. Persons with dementia may also benefit from multiple options for activities with varying levels of difficulty.

Discussion

To our knowledge this study is the first to implement and evaluate the adapted Namaste Care program for caregivers of older persons with moderate to advanced dementia at home in the community. The key findings of this present study were: (a) the adapted Namaste Care program and its proposed activities were feasible and acceptable and (b) caregivers perceived that the adapted Namaste Care program had many benefits for them and older persons with moderate to advanced dementia, however no statistically significant differences in outcome measures were found.

Caregivers were able to deliver the adapted Namaste Care program at least twice a week for 3 months and the activities proposed were provided regularly on a weekly basis. The ability of caregivers to deliver the program and their interest in continuing to use the program after 3 months is also reflective of the support that they received consisting of regular contact with MY who is a Registered Nurse with experience in supporting dementia care. Providing caregiver support can greatly alleviate caregiver burden related to changes in the cognitive function and mood of persons with dementia (82).

In terms of the activities delivered by caregivers, we conducted an analysis of the types of activities provided during the program sessions. Despite the growing research on Namaste Care, none of the studies to date described the frequency of use of various activities and none explored the activities delivered by family caregivers (29-34). Roland and Chappell (2015) explored the types of meaningful activities that persons with dementia engaged in based on the perspectives of family caregivers, however close to 60% had mild dementia and most of the activities were done outside the home such as social outings and playing sports (83). The findings of the present study revealed that persons with moderate to advanced dementia can engage in simple, meaningful activities without leaving the home and without creating additional burden on caregivers.

Arts and crafts were less often offered for persons with dementia in the present study and this may be due to older persons with dementia being in advanced stages that limit their ability to engage in these types of activities. The activities included in Namaste Care such as aromatherapy, offering snacks and beverages, music, reminiscence, and touch/massage also have proven efficacy for persons with advanced dementia (29). Hui et al. (2021) conducted a systematic review of psychosocial interventions for persons with moderate to severe dementia. These interventions however were not limited to home settings (23). For persons with moderate to advanced dementia, aromatherapy and reminiscence had the strongest evidence in improving QOL and there was some evidence of improved cognitive function for a multicomponent program implemented in hospital involving music, exercise, and games (22, 84).

With regards to qualitative findings, caregivers perceived that the adapted Namaste Care program had many benefits for them and older persons with moderate to advanced dementia. Caregivers in the present study perceived that the program helped them to incorporate structure and creativity in engaging in activities with persons with dementia, improved their understanding of meeting the needs of their family members, and brought them closer in their relationships through mutual enjoyment of activities. Other studies exploring the experiences of family caregivers in participating in delivering Namaste Care in LTC similarly found that they formed greater connections with persons with dementia through the program and preferred delivering activities in which they shared personal interests such as games (34, 85).

Despite the positive perceptions caregivers had of the program in the current study and some promising trends in improvement in scores, there were no statistically significant changes in caregiver QOL, perceptions of caregiving, self-efficacy, and burden, most likely due to the small sample size and somewhat high baseline scores of caregivers. Multiple imputation results did reveal a promising finding in examining the individual imputations as 2 out of 5 imputations showed statistically significant increases for caregiver QOL in terms of caregiver wellbeing. This finding helps to shed light on the potential for a treatment effect by considering the variation inherent in the dataset. Mixed results have been seen for these outcomes in other studies of psychosocial interventions, which may reflect small samples, differences in program components or delivery mechanisms, choice of measures/outcomes, or the complexity of caring for persons with moderate to advanced dementia. To date only Lee (2021) used C-DEMQOL to evaluate caregiver QOL for a community singing program involving both persons with dementia and their caregivers delivered over six weeks (76). Only four caregivers completed the study due to COVID-19 restrictions and no statistically significant results were found (76).

Another study including caregivers of persons with dementia that used the same perceptions of caregiving measure (61) used in our study found an improvement in perceptions of caregiving in the experimental (n=13) versus control (n=16) group following a memory and community program for family and persons with dementia dyads (p=0.039) (26). Czaja et al. (2013) similarly found a significant improvement in perceptions of caregiving following the implementation of a multicomponent psychosocial intervention for dementia caregivers delivered in-home and by videophone technology in the intervention (n=26) versus control (n=50) group (p=0.006) (73). The authors found that 46.2% of caregivers in the intervention group had improved perceptions of caregiving scores while in the control group only 16% had improved scores (73).

In terms of self-efficacy and caregiver burden, there is evidence of results similar to those found in this study for other studies of psychosocial interventions employing the same measures we used. For example, two studies showed no statistically significant changes in self-efficacy scores (72, 75) and three studies showed no statistically significant changes in caregiver burden scores (26, 72, 74). These findings suggest that self-efficacy and caregiver burden are complex and may require a more targeted approach when implementing psychosocial interventions. They may also reflect challenges in managing the progressive nature of dementia and/or persons with moderate to advanced dementia.

Caregivers perceived that the adapted Namaste Care program had many benefits for persons with moderate to advanced dementia. These included ensuring that persons with dementia are engaged in meaningful activities consistently, enhancing the wellbeing of persons with dementia, and building the confidence of persons with moderate dementia to participate in different activities. There is growing evidence for the effectiveness of psychosocial interventions tailored to the specific needs of persons with dementia in increasing their wellbeing through decreased agitation and depression (23, 86). Improved wellbeing of older persons with moderate to advanced dementia may in turn increase the QOL of caregivers (87). Ensuring that caregivers have the skills to deliver meaningful activities is also important to support their engagement in daily activities and social relationships (83).

The practice implication of this study is to work with community partners such as the Alzheimer Society to determine how best to offer the adapted Namaste Care program for caregivers. Possible options are to: (a) create an online toolkit made available through the

Alzheimer Society website for caregivers to deliver the program on their own or (b) have a health or social care provider such as a nurse, social worker, or recreational therapist offer training and bi-weekly check-ins for caregivers to support them in delivering the program. As seen in the present study, caregivers valued the regular contact with a nurse in delivering the adapted Namaste Care program and caregivers may require this level of support to successfully deliver the program at home. There is also a need to ensure that programs have room for flexibility so that they can be tailored to better meet the individual needs, abilities, and preferences of persons with dementia and caregivers.

The policy implication of this study is to offer education and support for psychosocial programs such as the adapted Namaste Care program within the community to build positive perceptions of caregiving and caregiver self-efficacy. Creating a peer support program can also be helpful in connecting caregivers with experience in delivering the adapted Namaste Care program with caregivers who are new to the program. There is a need to support organizations in offering evidenced-based interventions for their clientele to better meet their learning needs and support their caregiving practices. By supporting caregivers who care for persons with moderate to advanced dementia, persons with dementia can have their care needs met at home which can reduce the use of LTC and hospital services. Supporting caregivers to care for persons with dementia at home should be an important priority for the healthcare system due to long wait-times for LTC and the rising costs of LTC (18).

Despite the multitude of organizations that exist, caregivers continue to seek education and support for caring for older persons with dementia at home making this area an important priority for research (7, 88). Future research is needed to evaluate the adapted Namaste Care program through a more rigorous research design such as a randomized controlled trial.

Although caregivers were asked about benefits of the program for persons living with dementia during interviews and at the bi-weekly check-ins we did not use formal measures to assess preliminary effectiveness for persons with dementia. Some common outcomes that have been included in other studies evaluating Namaste Care, and that could be used in future studies include pain, QOL, depression, agitation, or medication use (e.g., antipsychotic or antidepressant medications) (53). A next step could be to collect data on outcomes for persons with dementia receiving the adapted Namaste Care program at home such as QOL, pain, anxiety, and depression. A longitudinal study could be conducted. Caregivers could be asked about and receive training to complete questionnaires that measure these outcomes.

Strength and Limitations

The strengths of the study included the use of quantitative and qualitative methods to evaluate the implementation and preliminary effectiveness of the adapted Namaste Care program and the inclusion of caregivers from across Canada. Study limitations include weaknesses inherent in the before-after design, the absence of outcomes for older adults with moderate to advanced dementia, the small sample size, and the lack of ethnic or cultural diversity among caregivers. Strategies targeted at increasing the representation of Black, Hispanic, and Asian individuals in research are necessary as these populations experience high levels of discrimination in seeking dementia care and participating in research (89).

Conclusions

Overall findings of the present study revealed that the adapted Namaste Care program for use by caregivers of community-dwelling older persons with moderate to advanced dementia was feasible and acceptable. This is an important finding as caregivers supporting persons with dementia are highly involved in their day-to-day care, yet they were able to deliver the program without perceptions of increased burden. They found the program to be valuable and important to integrate into their caregiving routines. Despite the lack of statistically significant results supporting the preliminary effects of the program in terms of caregiver QOL, self-efficacy, positive perceptions of caregiving, and burden, caregivers perceived that the program had many benefits to support them in their caregiving role and enhance the wellbeing of older persons with dementia. These positive findings warrant further investigation in future studies with a stronger design and larger sample size.

List of Abbreviations

C-DEMQOL: Carers-DEMentia Quality of Life scale

LTC: Long-term care

PAC: Positive Aspects of Caregiving Scale

QOL: Quality of life

RIS-SE: Relational, Instrumental, Self-soothing Eldercare Self-Efficacy scale

ZBI-12: Short form Zarit Burden Interview scale

Declarations

Ethics Approval and Consent to Participate

Institutional ethics approval was obtained from the local Research Ethics Board (#10526). All caregivers received a written introduction to the study and an informed consent form written in lay language. Caregivers provided oral informed consent to participate in the study

Consent for Publication

Not applicable.

Availability of Data and Materials

The data for this research consists of questionnaires, interviews and transcriptions and notes. Raw data cannot be publicly released due to the risk of compromising participant confidentiality

Competing Interests

The authors declare that they have no competing interests.

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Authors' Contributions

MY, JP, SK, and CM designed the study. MY performed recruitment and data collection. MY wrote the initial draft of the manuscript. MY, JP, SK, CM, and KF participated in data analysis and making critical revisions to the manuscript.

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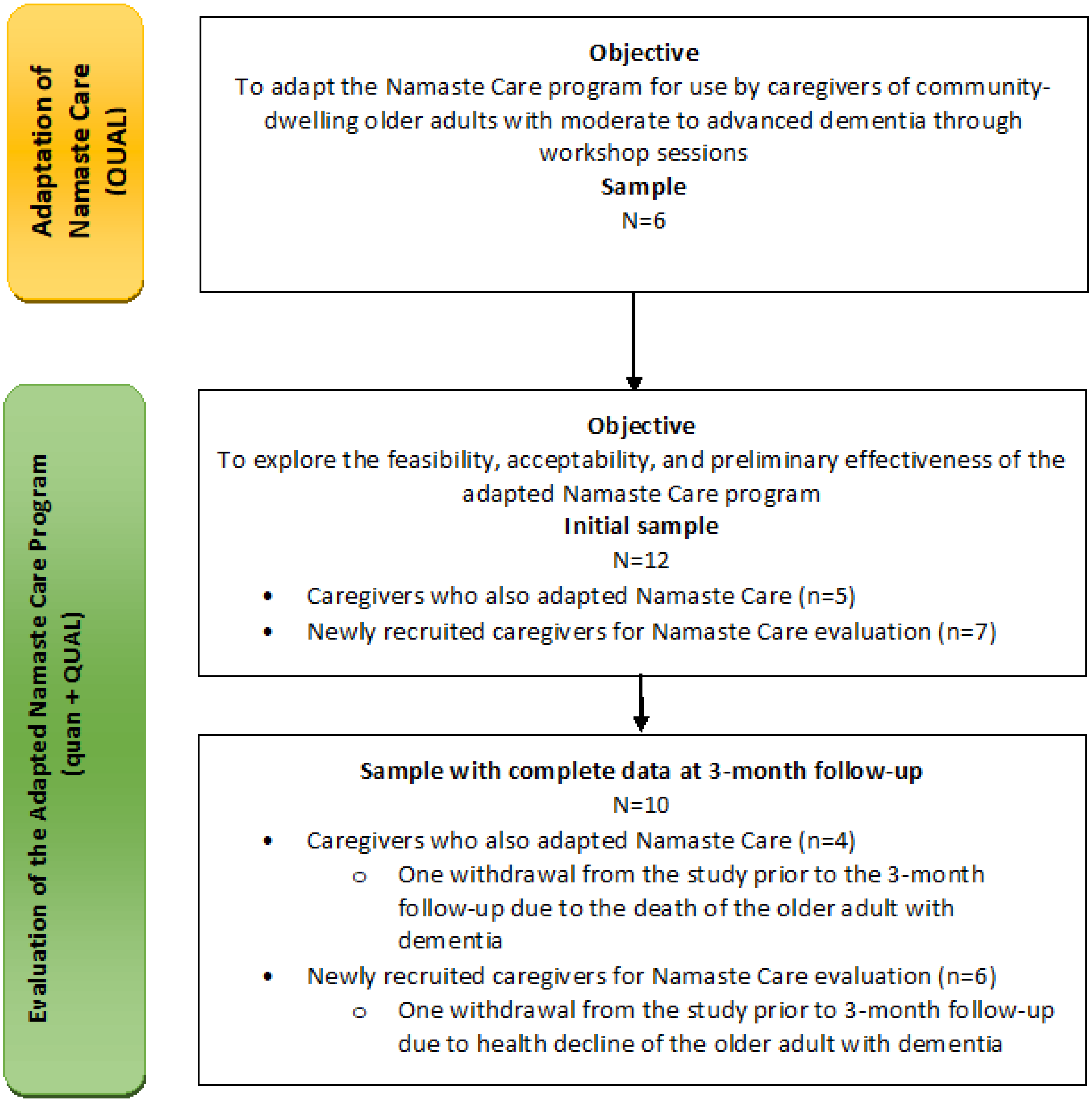
Figure 1. Mulitphase mixed methods study flow diagram



Objective

To adapt the Namaste Care program for use by caregivers of community-dwelling older adults with moderate to advanced dementia through workshop sessions

Sample

N=6

Objective

To explore the feasibility, acceptability, and preliminary effectiveness of the adapted Namaste Care program

Initial sample

N=12

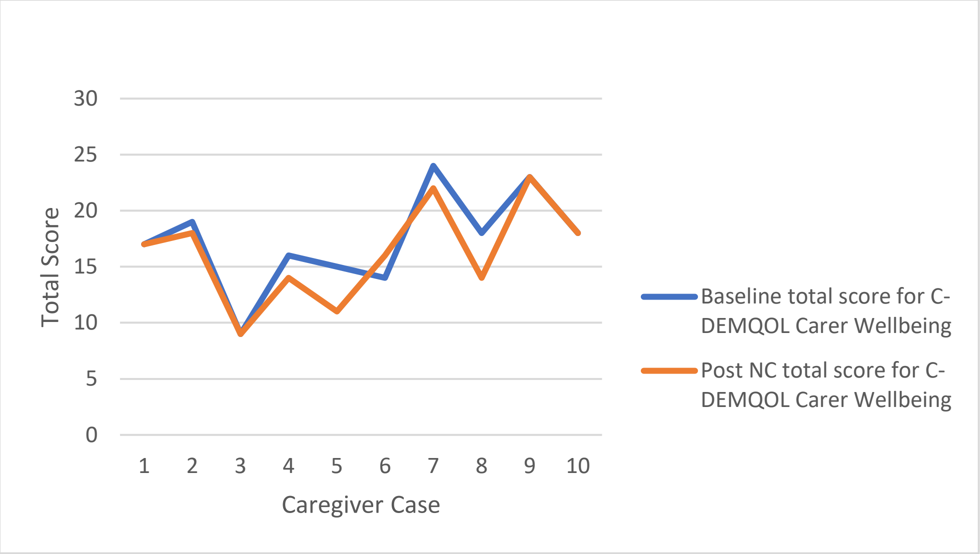
- Caregivers who also adapted Namaste Care (n=5)
- Newly recruited caregivers for Namaste Care evaluation (n=7)

Sample with complete data at 3-month follow-up

N=10

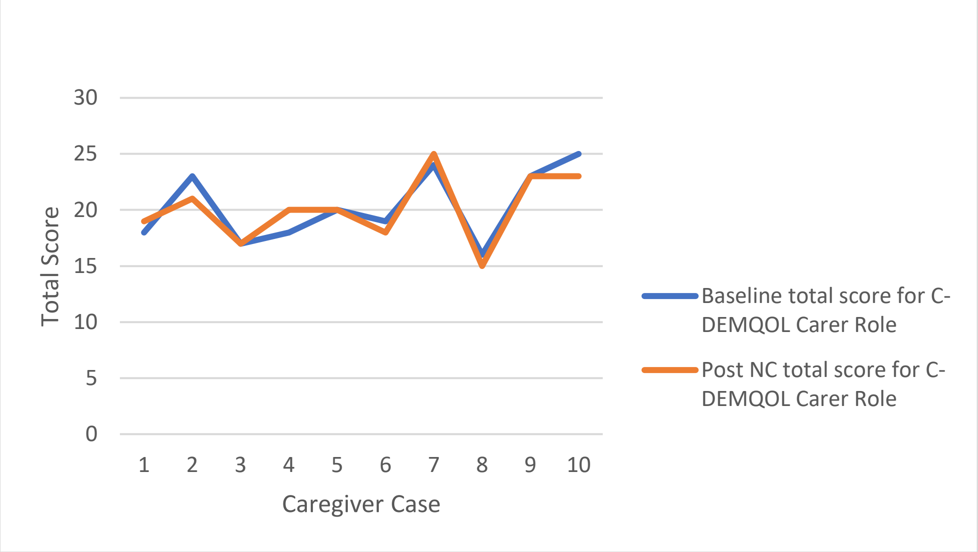
- Caregivers who also adapted Namaste Care (n=4)
    - One withdrawal from the study prior to the 3-month follow-up due to the death of the older adult with dementia
- Newly recruited caregivers for Namaste Care evaluation (n=6)
    - One withdrawal from the study prior to 3-month follow-up due to health decline of the older adult with dementia

Figure 2. QOL of caregiver wellbeing scores at baseline and 3-month by caregivers



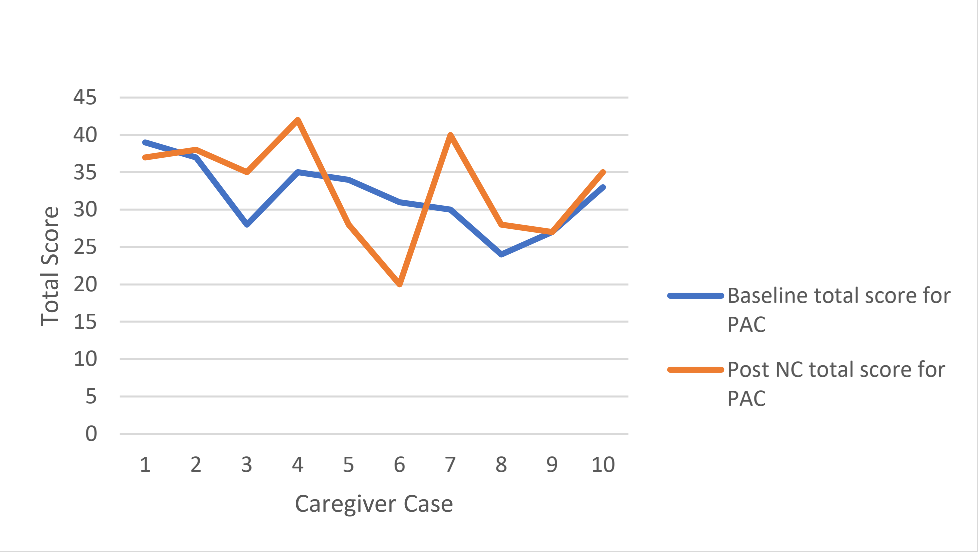
Legend. QOL = quality of life; C-DEMQOL = Carers-DEMentia Quality of Life scale; NC = Namaste Care

Figure 3. QOL in the caregiver role scores at baseline and 3-month by caregivers



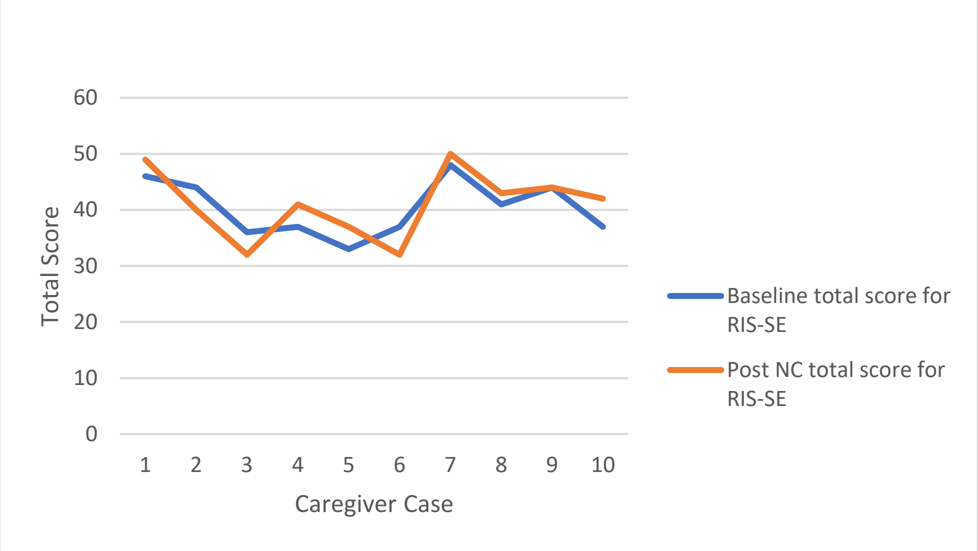
Legend. QOL = quality of life; C-DEMQOL = Carers-DEMentia Quality of Life scale; NC = Namaste Care

Figure 4. Perceptions of caregiving scores at baseline and 3-month by caregivers



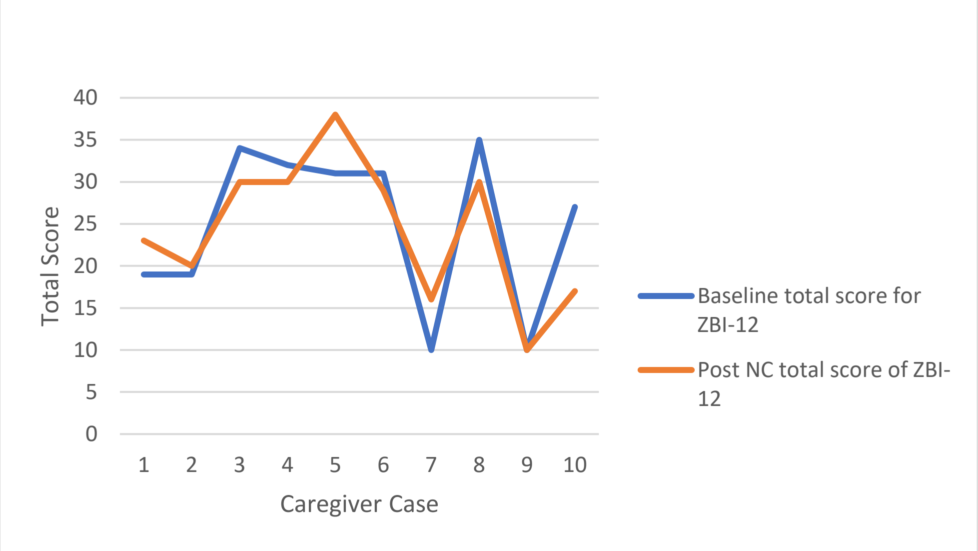
Legend. PAC = Positive Aspects of Caregiving scale; NC = Namaste Care

Figure 5. Self-efficacy scores at baseline and 3-month by caregivers



Legend. RIS-SE = Relational, Instrumental, Self-soothing Eldercare Self-Efficacy scale; NC = Namaste Care

Figure 6. Caregiver burden scores at baseline and 3-month by caregivers



Legend. ZBI-12 = Short form Zarit Burden Interview scale; NC = Namaste Care

Table 1. Caregiver post-intervention interview guide

Delivering the Adapted Namaste Care Program:

1. What were your experiences in delivering the program at home?
2. How did you feel about the resources provided to you to use the program at home?
3. How confident and comfortable did you feel in using the program at home?
4. How supported did you feel in implementing the program at home?
5. How often and over what length of time were you able to deliver the program?
6. What kind of activities did you provide for the person you are caring for?
7. How has the program changed the way you deliver activities?
8. What made it difficult to use the program?
9. What made it easy to use the program?
10. How did you personalize care activities for your family member or friend?

Satisfaction with the Adapted Namaste Care Program:

11. Would you continue to use the program at home after this study is done? Why or why not?
12. How satisfied were you in using the program?
13. What changes would you recommend to improve the program?

Effects of the Adapted Namaste Care Program:

14. What impact did Namaste Care have for you?
15. What impact did Namaste Care have for your family member or friend?
16. Has Namaste Care created any changes in how you see your role as a caregiver? If so, what kind of changes?
17. What impact did Namaste Care have on your connection and relationship with your family member or friend?
18. Did you feel like delivering Namaste Care made a difference for you and/or your family member or friend? In what ways?

Note. Some of the questions included in the guide were inspired by the Bowen Feasibility Framework (Bowen et al., 2009).

Table 2. Demographic characteristics of caregivers (N=12)

Category	n (%)
Age in years (Mean [SD])	62.3 [11.8]
30-49	1 (8.3)
50-59	4 (33.3)
60-69	4 (33.3)
70 and older	3 (25)
Sex	
Female	10 (83.3)
Male	2 (16.7)
Province of residency	
Ontario	8 (66.7)
Manitoba	2 (16.7)
Alberta	1 (8.3)
British Columbia	1 (8.3)
Geographical area of residency	
Rural	2 (16.7)
Urban	10 (83.3)
Ethnicity	
White/Caucasian	11 (91.7)
Chinese	1 (8.3)
Highest level of education completed	
High school diploma	1 (8.3)
College diploma	3 (25)
Bachelor’s degree	3 (25)
Graduate or professional degree	4 (33.3)
Other: Post secondary course	1 (8.3)
Employment status	
Working full-time	3 (25)
Working part-time	2 (16.7)
Retired from paid work	7 (58.3)
Relationship to person with dementia	
Son/daughter	6 (50)
Spouse	6 (50)
Number of years as a caregiver (Mean [SD])	5.1 [3.6]
2-4	6 (50)
5-7	5 (41.7)
8 and up	1 (8.3)
Number of chronic conditions	
None	2 (16.7)
1-2	7 (58.3)
3-4	3 (25)
Type of support provided	
Advice or emotional support and assistance with household tasks	3 (25)

Advice or emotional support, assistance with household tasks, and assistance with personal care	9 (75)

Note. The total value of some categories does not equal 100% due to rounding.

Table 3. Demographic characteristics of persons living with dementia (N=12)

Category	**n (%)**
Age in years (M [SD])	76.9 [9.5]
60-69	3 (25)
70-79	3 (25)
80 and older	6 (50)
Sex	
Female	5 (41.7)
Male	7 (58.3)
Number of years diagnosed with dementia (Mean [SD])	4.8 [4]
1-3	4 (33.3)
4-6	5 (41.7)
7 and up	3 (25)
Stage of dementia	
Moderate	8 (66.7)
Advanced	4 (33.3)
Number of chronic conditions	
1-2	1 (8.3)
3-4	6 (50)
5-6	5 (41.7)

Note. The total value for some categories does not equal 100% due to rounding.

Table 4. Type and frequency of activities delivered by caregivers during the adapted Namaste Care program sessions

Type of Activity	Average number and percentage of caregivers that delivered the activity weekly	Average number of days the activity was delivered per week
Snacks and Beverages -Flavored soda water -Coffee or tea -Milkshakes or smoothies -Dessert -Fruits -Pudding -Yogurt -Jell-O -Granola bars	10 (83.3%)	5
Reminiscing -Telling stories -Talking about family letters -Looking at photo albums or family videos	9 (75%)	4
Physical Touch -Face, hands, and/or feet washed and/or moisturized -Applied lip balm -Fingernails cleaned and/or clipped -Hair brushed or combed -Massage (Head/face, feet/legs, hand/arms, back)	8 (66.7%)	3
Audio/visual -Reading newspapers or magazines -Watching movies or shows -Listening to music -Watching video clips -Watching live virtual concerts	8 (66.7%)	2
Range of Motion/Exercise -Exercise videos -Walking outdoors -Walking up and down the stairs -Dancing -Yoga -Playing with a ball -Water workouts -Golf -Bike	8 (66.7%)	3

-Household chores (Dishes, yard work)		
Family/friend visit and/or outing -Phone or Zoom Calls -In-person visit -Outing to farmer's markets, greenhouses, beach, park, etc.	7 (58.3%)	2
Comforting -Aromatherapy (Electronic diffuser (lavender), flowers) -Hot/cold Pad -Fleece blanket -Meditation -Holding hands	7 (58.3%)	3
Games -Jigsaw puzzles -Wordsearch -Trivia -Checkers -Card games (Go Fish, Old maid)	3 (25%)	1
Arts and Crafts -Baking -Collages -Gardening -Play-Doh	1 (0.8%)	1

Table 5. Overview of qualitative themes

Category	Theme
Program Implementation Experiences of Caregivers	Caregivers were highly satisfied with the program resources and training
	Delivering the program was manageable and fit into caregivers' routines
	Bi-weekly check-ins helped caregivers deliver the program confidently and consistently
Facilitators Supporting Program Delivery	Being provided with a Namaste Care Toolbox
	Having written resources at hand
	Delivering activities in a language familiar to persons living with dementia
Barriers to Program Delivery	Persons living with dementia did not want to engage in activities at times
	Persons living with dementia did not respond to all items provided in the Namaste Care Toolbox
	Meeting the numerous daily demands (e.g., work, housework, appointments)
Perceived Benefits for Caregivers	The program encouraged a more structured approach and use of creativity in delivering activities
	Caregivers gained a better understanding of how to address the various needs (e.g., physical, emotional, social) of persons living with dementia
	The program brought caregivers and persons living with dementia closer in their relationships through mutual enjoyment of activities
Perceived Benefits for Persons Living with Dementia	Persons with dementia were more engaged in meaningful activities consistently
	Enhanced wellbeing of persons living with dementia
	The program instilled confidence in persons living with moderate dementia to participate in different activities
Recommendations for Further Adaptations	Offering more caregiver training and information on how to involve others (e.g., other family members, personal support workers) in delivering the program
	Further tailoring of items provided in the Namaste Care Toolbox to increase the likelihood of engagement
	Reformatting the Namaste Care activities checklist

Table 6. Baseline and post-adapted Namaste Care program preliminary effectiveness results (N=10)

Outcome	**Measure**	**Baseline Mean [SD]**	**Post-adapted Namaste Care program (3-months) Mean [SD]**	**Mean difference [95% CI]**	**P-value**
Caregiver wellbeing QOL	**C-DEMQOL Carer Wellbeing**	17.30 [4.32]	16.20 [4.42]	-1.10 [-2.47, 0.27]	0.102
Caregiver role QOL	**C-DEMQOL Carer Role**	20.30 [3.20]	20.10 [3.04]	-0.20 [-1.14, 0.74]	0.642
Perceptions of caregiving	**PAC**	31.80 [4.69]	33.00 [6.94]	1.20 [-3.36, 5.76]	0.566
Self-efficacy	**RIS-SE**	40.30 [4.99]	41.00 [6.13]	0.70 [-1.98, 3.38]	0.569
Caregiver burden	**ZBI-12**	24.80 [9.59]	24.30 [8.53]	-0.50 [-4.26, 3.26]	0.770

Legend. C-DEMQOL = Carers-DEMentia Quality of Life scale; PAC = Positive Aspects of Caregiving scale; RIS-SE = Relational, Instrumental, Self-soothing Eldercare Self-Efficacy scale; ZBI-12 = Short form Zarit Burden Interview scale; CI=Confidence Interval.

Table 7. Multiple imputation results

Outcome[a]	**Imputation #**	**Mean Diff**	**95% CI for Mean Diff**	**T test stat (p-value)**	**Pooled Results – Mean Diff [T test stat, p-value, 95% CI]**
Caregiver wellbeing QOL	1	0.50	[-0.57, 1.57]	1.03 (0.32)	0.80 [1.16, 0.31, -1.13 – 2.73]
	2	1.08	[0.13, 2.04]	2.49 (0.03)*	
	3	1.42	[0.19, 2.64]	2.54 (0.03)*	
	4	0.42	[-0.74, 1.58]	0.79 (0.45)	
	5	0.58	[-0.52, 1.68]	1.17 (0.27)	
Caregiver role QOL	1	0.42	[-0.42, 1.25]	1.10 (0.29)	0.37 [0.96, 0.36, -0.50-1.23]
	2	0.25	[-0.52, 1.02]	0.71 (0.49)	
	3	0.33	[-0.49, 1.16]	0.88 (0.39)	
	4	0.42	[-0.42, 1.25]	-1.10 (0.29)	
	5	0.42	[-0.42, 1.25]	-1.10 (0.29)	
Perceptions of caregiving	1	-2.08	[-4.87, 0.70]	-1.65 (0.13)	-2.17 [-1.46, 0.18, -5.60 – 1.26]
	2	-2.33	[-5.82, 1.15]	-1.47 (0.17)	
	3	-2.92	[-6.00, 0.17]	-2.08 (0.06)	
	4	-1.75	[-4.68, 1.18]	-1.31 (0.22)	
	5	-1.75	[-4.68, 1.18]	-1.31 (0.22)	
Self-efficacy	1	-1.25	[-3.45, 0.95]	-1.25 (0.24)	-1.25 [-1.26, 0.24, -3.51 -1.01]
	2	-1.58	[-3.43, 0.26)	-1.89 (0.09)	
	3	-1.33	[-3.56, 0.89]	-1.32 (0.21)	
	4	-1.17	[-3.31, 0.98]	-1.20 (0.26)	
	5	-0.92	[-3.02, 1.19]	-0.96 (0.36)	
Caregiver burden	1	0.92	[-2.18, 4.01]	0.65 (0.53)	0.78 [0.52, 0.61. -2.60, 4.17]
	2	0.58	[-2.45, 3.62]	0.42 (0.68)	
	3	0.67	[-3.14, 4.47]	0.39 (0.71)	
	4	1.17	[-2.10, 4.34]	0.81 (0.44)	
	5	0.58	[-2.45, 3.62]	0.42 (0.68)	

Note. [a] Outcomes expressed as differences between baseline and 3-months; * denotes a p-value of less than 0.05.

Additional Table 1.

Namaste Care Activities Checklist

Study ID: CG - ☐☐☐

Study Title: Feasibility, Acceptability and Preliminary Effectiveness of the Adapted Namaste Care Program Delivered by Caregivers of Community-Dwelling Older Adults with Moderate to Advanced Dementia: A Mixed Methods Study
Please place a checkmark or a cross in the boxes when you have completed an activity for each day that you used the Namaste Care approach.
D = Day

Activity	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	D11	D12	D13	D14	D15	D16
Face washed/moisturized																
Hands washed/moisturized																
Feet washed/moisturized																
Fingernails cleaned and clipped																
Hair brushed																
Offered a snack																
Offered a beverage																
Performed Range of Motion/Exercise																
Reading																
Aromatherapy/Scents																
Family/friend visit																
Played music																
Telling stories/having conversations																
Looking at photo albums or family videos																
Providing a massage																
Other: ______________																
Other: _________________																

Activity	**D1**	**D2**	**D3**	**D4**	**D5**	**D6**	**D7**	**D8**	**D9**	**D10**	**D11**	**D12**	**D13**	**D14**	**D15**	**D16**
Other: _________________																
Activity	**D17**	**D18**	**D19**	**D20**	**D21**	**D22**	**D23**	**D24**	**D25**	**D26**	**D27**	**D28**	**D29**	**D30**	**D31**	
Face washed and moisturized																
Hands washed and moisturized																
Feet washed and moisturized																
Fingernails cleaned and clipped																
Hair brushed																
Offered a snack																
Offered a beverage																
Performed Range of Motion/Exercise																
Reading																
Aromatherapy/Scents																
Family/friend visit																
Played music																
Telling stories/having conversations																
Looking at photo albums or family videos																
Providing a massage																
Other: ______________																
Other: _______________																
Other: _________________																

Note. The Namaste Care weekly log sheet was modified from the following source: Simard, J. (2013). *The end-of-life Namaste Care program for people with dementia* (2nd ed). Baltimore, MD: Health Professions Press.

Additional Table 2. Joint display of quantitative and qualitative findings

Adapted area of focus and outcome of interest of the Bowen et al. (2009) Feasibility Framework	**Quantitative**		**Qualitative**	**Mixed Methods Interpretation**	
	Feasibility	**Preliminary effectiveness**	**Acceptability, experiences, perceived benefits, and adaptation**	**Convergent**	**Divergent**
Feasibility with regards to demand, implementation, and practicality • Actual use • Intent to use • Degree of implementation • Ability of caregivers to deliver program activities	-100% of caregivers delivered the program at least 2 out of 7 days per week for at least 8 out of 12 weeks. -83.3% of caregivers had 3 months of data collection completed (1 caregiver withdrew due to the death of the person living with dementia and 1 caregiver withdrew due to the persons' living with dementia declining health) - No safety or adverse effects reported related to program use. -On average 10 (83.3%) of the caregivers offered **snacks and beverages** weekly for about 5 times a week. -On average 9 (75%) of the caregivers delivered **reminiscing activities** weekly for about 4 times a week. -On average 8 (66.7%) of the caregivers took part in **physical touch activities** weekly for about 3 times a week. -On average 8 (66.7%) of the caregivers provided **audio/visual**			**Convergent with acceptability and experiences findings:** -Some activities were provided more frequently by caregivers such as snacks and beverages and reminiscing activities. A perceived barrier to delivering the program was having to meet numerous demands while caregiving. This may be reflective of caregivers choosing to provide activities that take less time to implement. -Perceived barriers to program delivery such as persons with dementia not wanting to engage may have limited the ability of caregivers to provide a variety	

Adapted area of focus and outcome of interest of the Bowen et al. (2009) Feasibility Framework	**Quantitative**		**Qualitative**	**Mixed Methods Interpretation**	
	Feasibility	**Preliminary effectiveness**	**Acceptability, experiences, perceived benefits, and adaptation**	**Convergent**	**Divergent**
	activities weekly for about twice a week. -On average 8 (66.7%) of the caregivers delivered **ROM/Exercise** weekly for about 3 times a week. -On average 7 (58.3%) of the caregivers had **family/friend visits and/or outings** weekly for about twice a week. -On average 7 (58.3%) of the caregivers delivered **comforting activities** weekly for about 3 times per week. -On average 3 (25%) of the caregivers played **games** weekly for about once a week. -On average 1 (0.8%) of the caregivers delivered **arts and crafts activities** weekly for about once a week.			of different activities more frequently. -More than half of caregivers regularly provided at least 7 out of 9 activities included in the Namaste Care checklist. Caregivers also perceived that the program fits well with their routines and was manageable. -Caregivers perceived that being provided with information, bi-weekly-check-ins, and a toolbox of activities made it easy to deliver the program. This finding was supported by the feasibility results as caregivers were able to implement the program consistently and provided a variety of activities.	

Adapted area of focus and outcome of interest of the Bowen et al. (2009) Feasibility Framework	**Quantitative**		**Qualitative**	**Mixed Methods Interpretation**	
	Feasibility	**Preliminary effectiveness**	**Acceptability, experiences, perceived benefits, and adaptation**	**Convergent**	**Divergent**
Acceptability of the program • Satisfaction and experiences • Intent to continue use • Perceived appropriateness			- Caregivers were highly satisfied with the program as they felt supported in delivering activities through the bi-weekly check-ins, training resources, and Namaste Care Toolbox. -All caregivers stated that they would continue to use the program as it was manageable and had many perceived benefits. -Facilitators to program delivery were being provided with a Namaste Care Toolbox, having written resources readily available and delivering activities in a language familiar to persons living with dementia. -Barriers to program delivery were that persons living with	**Convergent with feasibility results:** -Caregivers expressed high satisfaction with all facets of the program including training, bi-weekly check-ins, and the Namaste Care Toolbox. Their satisfaction with the program was reflected in the feasibility results in terms of actual use. -All caregivers expressed their intent to continue to use the program after the study was completed which would likely occur based on the feasibility results that revealed a variety of activities were delivery regularly per week.	

Adapted area of focus and outcome of interest of the Bowen et al. (2009) Feasibility Framework	**Quantitative**		**Qualitative**	**Mixed Methods Interpretation**	
	Feasibility	**Preliminary effectiveness**	**Acceptability, experiences, perceived benefits, and adaptation**	**Convergent**	**Divergent**
			dementia did not want to engage in activities at times, did not respond to all items provided in the Namaste Care Toolbox, and caregivers had to meet the numerous daily demands (e.g., work, housework, appointments). - Delivering the program was perceived by caregivers as fitting into their routines. -Bi-weekly check-ins provided opportunities for caregivers to receive validation, ask questions, and stay focused with the program.		
Limited preliminary effectiveness testing • Effects of the program for caregivers and persons living with dementia • Evidence of trends in changes for		**-C-DEMQOL-Carer Wellbeing:** Baseline mean of 17.30 [SD=4.32] and median of 17.50; 3-month post-program mean of 16.20 [SD=4.42] and	-The program encouraged caregivers to take on a more structured approach and use creativity in delivering meaningful activities.	**Convergent with acceptability, experiences, and perceived benefits:** -Caregivers did not perceive that their QOL improved through the program. Scores for caregivers	**Divergent with acceptability and perceived benefits:** -No statistically significant results were found for changes to perceptions of caregiving, self-

Adapted area of focus and outcome of interest of the Bowen et al. (2009) Feasibility Framework	Quantitative		Qualitative	Mixed Methods Interpretation	
	Feasibility	Preliminary effectiveness	Acceptability, experiences, perceived benefits, and adaptation	Convergent	Divergent
caregivers' QOL, perceptions on positive aspects of caregiving, self-efficacy, and burden		median of 16.50; mean difference of -1.10 (95% CI: -2.47, 0.27; p=0.102). **-C-DEMQOL-Carer Role:** Baseline mean of 20.30 [SD=3.20] and median of 19.5; 3-month post-program mean of 20.10 [SD=3.04] and median of 20.00; mean difference of -0.20 (95% CI: -1.14, 0.74; p=0.642). -**PAC:** Baseline mean of 31.80 [SD=4.69] and median of 32.00; 3-month post-program mean of 33.00 [SD=6.94] and median of 35.00; mean difference of 1.20 (95% CI: -3.36, 5.76; p=0.566).	-Caregivers gained a better understanding of the various needs (e.g., physical, emotional, social) of persons living with dementia and how to address these. -The program brought caregivers and persons living with dementia closer in their relationships through mutual enjoyment of activities. -Persons living with dementia were more engaged in meaningful activities consistently through the program. -The program enhanced wellbeing of persons living with dementia by decreasing agitation, increasing verbal communication, and supporting their enjoyment of activities.	in terms of carer wellbeing and role mostly remained unchanged or worsened. -There was a positive, yet nonsignificant increase in positive aspects of caregiving scores. Caregivers perceived that the program brought them closer with persons living with dementia through mutual enjoyment of activities. -There was a positive, yet non significant increase in self-efficacy scores for caregivers. Caregivers perceived that the program increased their knowledge in providing a structured approach to activities and delivering these by being creative. They	efficacy, and burden for caregivers. Some of these findings conflict with qualitative data as caregivers perceived they had more confidence to deliver activities.

Adapted area of focus and outcome of interest of the Bowen et al. (2009) Feasibility Framework	Quantitative		Qualitative	Mixed Methods Interpretation	
	Feasibility	Preliminary effectiveness	Acceptability, experiences, perceived benefits, and adaptation	Convergent	Divergent
		-RIS-SE: Baseline mean of 40.30 [SD=4.99] and median of 39.00; 3-month post-program mean of 41.5 [SD=6.13] and median of 41.50; mean difference of 0.70 (95%CI: -1.98, 3.38; p=0.569). -**ZBI-12:** Baseline mean of 24.80 [SD=9.59]; 3-month post-program mean of 24.30 [SD=8.53]; mean difference of -0.50 (95% CI: -4.26, 3.26; p=0.770).	-For persons living with moderate dementia the program instilled confidence to participate in different activities.	also gained an increased awareness and skills in how to meet the various needs of persons living with dementia. -There was a non-significant decrease in caregiver burden scores indicating a positive improvement. Caregivers perceived the program to fit into their routines without being considered as extra work.	
Further adaptations - Need for further changes to the program			-Caregivers perceived the need to reformat the Namaste Care activities checklist to make it easier to complete. -Caregivers suggested further tailoring of items provided in the Namaste Care	**Convergent with feasibility results:** -Some activities such as arts and crafts and games were delivered by few caregivers on a weekly basis although 66.7% of persons with dementia were in the	

Adapted area of focus and outcome of interest of the Bowen et al. (2009) Feasibility Framework	Quantitative		Qualitative	Mixed Methods Interpretation	
	Feasibility	Preliminary effectiveness	Acceptability, experiences, perceived benefits, and adaptation	Convergent	Divergent
			Toolbox to increase the likelihood of engagement. -Caregivers perceived the need to offer more support and training for caregivers and information on how to involve others in the circle of care (e.g., other family members, personal support workers) in taking part in delivering the program.	moderate stages. This finding is aligned with the need for greater supports and training for caregivers in delivering these activities and further tailoring of items included in the Namaste Care Toolbox.	

Note. QOL = Quality of Life; ROM = Range of Motion; C-DEMQOL = Carers-DEMentia Quality of Life scale; PAC = Positive Aspects of Caregiving scale; RIS-SE = Relational, Instrumental, Self-soothing Eldercare Self-Efficacy scale; ZBI-12 = Short form Zarit Burden Interview scale; CI=Confidence Interval; p = p-value.

CHAPTER 7: DISCUSSION AND CONCLUSION

The current study is the first to adapt, implement, and assess the feasibility, acceptability, and preliminary effectiveness of Namaste Care delivered in a home setting by caregivers of older adults living with moderate to advanced dementia. In this section key findings are presented within the context of the existing literature. Novel contributions are highlighted as well as important considerations in light of study findings. Following the summary of findings, significant implications for nursing, policy and caregiver education, and research are discussed. Overall strengths and limitations of the thesis are presented prior to a concluding statement.

Summary of Key Findings

With regards to Chapters 4 (adaptation of Namaste Care) and 5 (adaptation experience), the main findings were as follows: (a) caregivers recognized the need for Namaste Care to support meaningful connections for older adults with dementia; (b) suggested adaptations to the original Namaste Care program were intended to make it manageable for caregivers to deliver the program at home; (c) flexibility for caregivers to tailor the program is important for its uptake; (d) multiple strategies are necessary to support research engagement among caregivers; and (e) virtual meetings were convenient to engage caregivers in research. The key findings of Chapter 6 (evaluation of the adapted Namaste Care program) consisted of: (a) the adapted Namaste Care program was feasible and acceptable to use by caregivers in a home setting; (b) caregivers perceived that the program increased their abilities to provide consistent, creative, and person-centred activities; (c) the program enhanced wellbeing of older adults with moderate to advanced dementia; and (d) the program supported closer relationships between caregivers and older adults with dementia. In terms of mixed methods findings, the involvement of caregivers in adapting the Namaste Care program for home use contributed to the findings related to the evaluation of the program as it was indeed acceptable and feasible to use. In the next section each of these findings are discussed and compared to the existing literature.

Caregivers who participated in the workshop sessions to adapt Namaste Care were interested in learning about Namaste Care because they saw the program as having the potential to reduce stress when interacting with and providing care for persons with dementia, offer ideas in delivering stimulating activities for persons with moderate to advanced dementia, and increase meaningful connections between caregivers and persons with dementia. Namaste Care can be a helpful approach in reducing care challenges at home as it leads to reduced refusal of personal care such as bathing and can increase the quality of interactions between family members and persons with dementia (Backhouse, Dudzinski, Killett, & Mioshi, 2020; Volicer, 2021). Caregivers in the current study perceived that Namaste Care incorporated gentle approaches to invite persons with dementia to participate in activities of daily living.

Caregivers supporting persons with dementia at home often report an unmet need related to social activities for persons with dementia (Mazurekm, Szcześniak, Urbańska, Dröes, & Rymaszewska, 2019). This was similarly reported in the current study as both new and experienced caregivers were seeking ways to enrich their caregiving routines by delivering activities that stimulate the senses of persons with dementia. Caregivers may find it difficult to come up with such activities on their own due to reduced verbal communication, responses, and mobility of persons with advanced dementia (Brown, Mitchell, Quinn, Boyd, & Tolson, 2020) and limited training for caregivers. Considering that the current study occurred during the COVID-19 pandemic, caregivers may have undertaken greater efforts to search for ways to continue to provide optimal care for persons with dementia in light of lockdown measures, social distancing, and pause of in-person programs such as day programs. Timely implementation of innovative virtual programs may be one solution to support social interactions and enhance the wellbeing of persons with dementia and caregivers in the community amid public health restrictions (Roach et al., 2021). In learning about Namaste Care through the workshop sessions, caregivers perceived the program as supporting meaningful connections between caregivers and persons with dementia. The caregiving experience has been found to be more meaningful when caregivers can appreciate connections that continue to be made with persons with dementia (Yu, Cheng, & Wang, 2018).

Caregivers in the current study recommended changes to the program that would ensure that it is manageable for caregivers (See Chapters 4 and 5). Some of the suggested changes for modifications were made to fit the realities of caregiving at home and included delivering the program twice a week, offering shorter sessions at a time, and integrating the program into daily care routines. Two aspects are novel in this study: (a) adapting the Namaste Care for caregivers to use at home and (b) engaging caregivers in collaborating in adapting the program. In previous studies involving caregiver participation in Namaste Care delivery, caregivers had little to no involvement in determining how the program should be delivered in long-term care (LTC) or home settings (Dalkin, Lhussier, Kendall, Atkinson, & Tolman, 2020; Smaling et al., 2018; Tasseron-Dries, Smaling, Doncker, Achterberg, & van der Steen, 2021; Walshe et al., 2019). Findings in the current study revealed the value of involving caregivers to promote uptake of the program and facilitate benefits for caregivers and persons with dementia.

Caregivers in the current study perceived that it was essential to have some flexibility for caregivers to tailor the Namaste Care program to the needs, abilities, cultures, and preferences of persons with dementia. Tailoring the program also meant ensuring that caregivers felt comfortable in completing activities such as massages and range of motion exercises. Such minor individualizations were not perceived as drastically changing the delivery of the adapted Namaste Care program, but rather potentially leading to better responses among persons with dementia and increasing its use among caregivers. For caregivers of persons with dementia living at home the effectiveness of psychosocial interventions is related to the delivery of tailored activities (Gitlin et al., 2016; Nakanishi et al., 2018). When programs are dyadic in nature, meaning that they involve both caregivers and persons with dementia, it is important to ensure that interventions can be personalized to reduce caregiver burden and maintain or improve the functional abilities of persons with dementia (Dawson & Menne, 2017). As seen in the current study, some caregivers were working and juggling many other priorities, so it is important to adapt programs to suit the caregiving context. In addition, interventions that are low-cost, tailored to persons with dementia and caregivers, and use virtual means such as videoconferencing and phone calls for regular communications can be helpful support for caregivers during the COVID-19 pandemic (Alves et al., 2020).

Overall, caregivers who participated in the workshop sessions to adapt Namaste Care perceived that they had a positive experience in adapting the program and felt that they played a part in its development. The positive experience of caregivers was influenced by the multiple strategies that were put in place to support their engagement in research guided by Strategy for Patient-Oriented Research (SPOR) patient engagement principles (Canadian Institutes of Health Research (CIHR), 2019) such as creating a welcoming, respectful safe space to share, flexible scheduling of the workshops, and recognizing the value of the experiences shared by caregivers. As COVID-19 led to a pause for many in-person support groups and educational programming to support caregivers, caregivers in the present study appreciated the opportunity to meet virtually with other caregivers, share stories, and learn about strategies in supporting persons with dementia at home that have worked well for others. In applying an authentic partnership approach among caregivers, this can help in the development of better solutions to enhance dementia care through dialogue, reflection, and communal learning (Dupuis et al., 2012).

Caregivers met as a group for the workshop sessions using Zoom videoconferencing software or by phone due to public health restrictions at the time of the study. Caregivers in the current study found that using a virtual approach was similarly effective in encouraging dialogue as in-person meetings. Virtual meetings were perceived to be even more advantageous compared to in-person meetings because these were convenient for caregivers as they could easily join from home, did not need to take time off work, were not asked to travel to a physical location, and did not need to arrange respite for their family member with dementia. In the current study there were few technological challenges experienced by caregivers. Although devices and access to the internet were offered by the research team, caregivers all had their own equipment. Despite few studies including virtual technology in the delivery of workshop sessions to adapt programs for persons with dementia, one study found similar benefits for Zoom meetings (i.e., no need for travelling and enjoyable experience) which involved caregiver participation in a stakeholder advisory council for research in dementia care conducted during COVID-19 (Masoud et al., 2021). Post-pandemic virtual approaches may therefore enable greater participation of caregivers in research. It is also important to ensure that caregivers have access to devices and the internet, support to develop digital literacy skills, and receive technological training in using videoconferencing software such as Zoom (Banbury, Parkinson, Gordon, & Wood, 2019).

After the Namaste Care program had been adapted, it was found to be feasible in a home setting with a caregiver retention rate of 83%. Caregivers implemented a variety of activities during the Namaste Care sessions and did so consistently from week to week. Feasibility findings align with previous findings with regards to the Namaste Care program implementation in LTC and hospital settings for older adults with dementia (Bray, Brooker, Latham, & Baines, 2021; Bray, Brooker, Latham, Wray, & Baines, 2019b; Froggatt et al., 2020; Kaasalainen et al., 2020; Rezapour-Nasrabad, 2020; St. John & Koffman, 2017). However, most previous studies focused on persons with advanced dementia exclusively. Only Dalkin et al. (2020) implemented Namaste Care in a home setting however this program was delivered by volunteers with little to no caregiver participation in the program and the authors did not directly explore feasibility of the program. The current study therefore makes a novel contribution by revealing that caregivers of older adults with moderate to advanced dementia are able to deliver the adapted Namaste Care program at home.

Although some studies have examined the evidence for different types of activities (e.g., aromatherapy, physical touch, music therapy) delivered during Namaste Care sessions (Bray, Brooker, & Garabedian, 2019a; Karacsony & Abela, 2021), the current study is the first to provide detailed information regarding the type and frequency of Namaste Care activities delivered by caregivers of community-dwelling older adults with moderate to advanced dementia. In the current study offering snacks and beverages outside of mealtimes was most often delivered by caregivers with 83% of them doing so at least five times a week. Other activities such as reminiscing activities (e.g., storytelling, looking at photo albums or family videos), physical touch activities (e.g., washing and/or moisturizing hands, face, and/or feet, massaging), range of motion/exercise-based activities (e.g., walking, exercise routines, playing with a ball), and audio/visual activities (e.g., reading, listening to music, watching video clips) were provided by greater than 65% of caregivers and delivered multiple times per week.

Activities were delivered in collaboration with persons with dementia and caregivers. These findings shed light on what activities caregivers are able to deliver at home and the areas in which they would require more training and support to implement such as games and arts and crafts.

As caregivers were involved in adapting the Namaste Care program prior to its implementation, caregivers in the current study perceived that the adapted Namaste Care program was acceptable to be used at home. They were highly satisfied with resources (e.g., articles, training guide, website links) provided through the program and virtual training in using the program. Caregivers found the program to fit well into their caregiving routines without creating additional burden. The bi-weekly check-ins were particularly helpful for caregivers so that they could deliver the program confidently and consistently. To date no other study of Namaste Care provides such frequent check-ins for caregivers to address their questions and provide support in using the program. Virtual interventions that include opportunities for discussions can therefore help meet a frequently reported unmet need of caregivers related to knowledge and skills to address responsive behaviours of dementia and how to connect with persons with dementia (Teles, Paúl, Sosa Napolskij, & Ferreira, 2020). With regards to who would be the most appropriate person to support caregivers through virtual interventions, in a study exploring the effects of a virtual support intervention for caregivers of persons with dementia at home, professionals (e.g., physicians, nurses, psychologists) were found to be suitable support persons for caregivers by providing specialized guidance and evidence-based information leading to significant improvements in caregiver helplessness (Han, Guo, & Hong, 2022). As a Registered Nurse (RN) with clinical expertise in dementia care, caregivers in the current study appreciated the one-on-one professional support that I provided to them through the adapted Namaste Care program over a period of three months.

Moreover, caregivers perceived that the adapted Namaste Care program increased their abilities to provide structured, creative, and person-centred activities. Through the program caregivers were made aware of the various needs (e.g., physical, emotional, social) that persons with dementia have and how to address these. The activities that caregivers implemented were not unfamiliar to them, however they gained a better understanding of the need to provide activities with greater awareness and purpose. Caregivers encouraged persons with dementia to participate in activities such as household chores to help them feel included and engaged in home routines. As considered in the current study, activities can be defined broadly and include household chores, social visits, and recreational activities (Vernooij-Dassen, 2007). Activities that appear to be mundane are made meaningful for persons with dementia if they provide a sense of purpose, promote pleasure, and enable connections, regardless of the level of autonomy or stage of dementia (Vernooij-Dassen, 2007). One of the most common reasons as to why an activity is meaningful is because it enables feelings of connections to others and can impact cognition, wellbeing, and joy among persons with dementia (Roland & Chappell, 2015).

Although no statistically significant effects of the adapted Namaste Care program were found in the current study in relation to caregiver outcomes consisting of quality of life, self-efficacy, positive perceptions of caregiving, and burden, caregivers perceived that the program led to multiple benefits for them and their family members. Multiple imputation results did not show statistically significant differences in terms of caregiver outcomes, however in examining the individual imputations 2 out of 5 imputations revealed statistically significant increases for

QOL for caregiver wellbeing. The lack of statistically significant effects found is most likely due to the small sample size of the study.

Caregivers perceived that the program improved the wellbeing of older adults with moderate to advanced dementia as evidenced by better mood of persons with dementia following sessions and decreased agitation. Outcome measures for older adults with dementia were not included in the current study as the focus was on caregivers, however findings related to perceptions of enhanced wellbeing and QOL of persons with dementia are aligned with outcomes of previous studies of Namaste Care in LTC (Bray et al., 2018; Bray et al., 2019a; Volicer, 2019; Kaasalainen et al., 2019; Kaasalainen et al., 2020; Manzar & Volicer, 2015). Caregivers in the present study also witnessed positive responses including smiling and increased verbal communication from attending Namaste Care sessions. When caregivers recognize that there is a link between their actions and the responses of persons with dementia to their actions that results in increased wellbeing, this can help caregivers feel a sense of personal accomplishment and satisfaction (Yu et al., 2018).

A final key finding of the current study was that caregivers perceived that the adapted Namaste Care program brought them closer in their relationships with their family members living with moderate to advanced dementia. In other studies, Namaste Care has been similarly found to lead to stronger and improved relationships between persons with advanced dementia and caregivers in LTC and hospital settings (McNiel & Westphal, 2018; Ali et al., 2020; Latham et al., 2020). Since the Namaste Care program is intended to be delivered as shared activities between persons with dementia and caregivers, this may also provide opportunities for caregivers to work on their relationships with their family members. Shared meaningful activities between caregivers and persons with dementia can lead to increased satisfaction with social relationships (Genoe & Dupuis, 2014; Roland & Chappell, 2015). The relationship between caregivers and persons with dementia is also an important component in upholding one's identity and personhood (Phinney, 2002; Roland & Chappell, 2015). In the next sections the implications of study findings are discussed.

IMPLICATIONS

Implications for Nursing

The findings of the current study have multiple implications for nursing practice and future directions for nursing education. The adapted Namaste Care program can be considered as a nurse-led intervention as I was responsible for training caregivers in using the program and supporting them over the 3-month study period. My involvement in supporting caregivers through the program may have been beneficial for caregivers especially during the COVID-19 pandemic when organizations such as the Alzheimer Society were not able to provide in-person programs and experienced delays in shifting programs to be offered virtually. Nurse-led interventions focused on dementia care including psychoeducational programs have been found to improve caregiver skills and performance, decrease caregiver burden, and reduce hospitalizations for persons with dementia (Chien & Lee, 2011; Ducharme et al., 2011; Wang, Chien, & Lee, 2012). In the current study caregivers also perceived that they had improved skills in delivering creative activities for persons with dementia at home. There is therefore a need for nurses with expertise in dementia care to develop and implement interventions such as Namaste Care to support caregivers at home. This is particularly important when community resources are lacking or there are long wait lists to obtain help from within the healthcare system and community organizations (Shepherd-Banigan et al., 2020).

Caregivers supporting persons with dementia at home perceive that educational programs should be led by community nurses to better prepare them for their caregiver roles and offer one-on-one consultations with nurses (Wang, Xiao, He, & De Bellis, 2014). In the current study, caregivers perceived that the information they were provided through the program was useful because it was evidence-informed and offered by a nurse. With regards to non-pharmacological interventions to address responsive behaviours of dementia, nurse-led education for caregivers is a key component to increasing the knowledge of caregivers in identifying and addressing responsive behaviours in collaboration with healthcare professionals (Huang et al., 2013; Johnson et al., 2013; Wolfs et al., 2012). Nurses are also well suited to provide training for caregivers in implementing psychosocial and educational interventions at home to improve physical and mental functional abilities of persons with dementia (Dahlrup, Nordell, Andrén, & Elmståhl, 2011). To ensure that community nurses have the expertise to support caregivers in dementia care there is a need to better prepare the current and future nursing workforce to be leaders in dementia care (Wang et al., 2014).

In the literature healthcare professionals, particularly nurses, have been found to be focused on meeting the medical or physical care needs of persons with dementia and stigmatize and hold negative perceptions about this population (Dewing & Dijk, 2016; Digby, Williams, & Lee, 2016). Both seasoned nurses and nursing students could benefit from dementia education so that they make greater efforts in supporting and involving caregivers in the care of persons with dementia (Matsuda et al., 2018). There is a need to prepare nurses early on in their education about the importance of caregiver support and building the skills of caregivers to care for older adults with dementia at home. With the risk of adverse effects associated with psychotropic medications, it is important for nurses to learn about non-pharmacological interventions such as

Namaste Care that can support their practice in caring for persons with dementia and caregivers. Due to a growing global aging population and increasing trends in terms of the number of people diagnosed with dementia (Alzheimer's Disease International, 2019), it is essential to ensure that nursing students recognize the importance of family involvement in the care of persons with dementia, role model person-centred care in all settings, and provide care to both caregivers and persons with dementia as a dyad (Kimzey & Mastel-Smith, 2021).

Implications for Policy and Caregiver Education

When caregivers are unable to meet the demands of caregiving and lack supports to effectively care for people with dementia at home, they are faced with having to place people with dementia in LTC or admit them to hospital. From 2015 to 2016, approximately 90,000 or one in five older adults with dementia were hospitalized in Canada (CIHI, 2022; Chambers et al., 2016), with many receiving care due to caregivers no longer being able to support their needs at home. Limited resources (e.g., healthcare personnel, equipment and supplies, and therapeutic/recreational activities) are available in hospitals and LTC to adequately support people with dementia leading to poor outcomes for this population such as delirium, dehydration, and falls (Béland & Marier, 2020; Dewing & Dijk, 2016; Yous, Ploeg, Kassalainen, & Schindel-Martin, 2019).

The policy implications of the study are to support optimal aging at home for older adults and caregivers so that people with dementia can continue to live comfortably and safely at home. Caregivers were supported to build on their knowledge and enhance self-efficacy using the Namaste Care approach when assisting people with dementia with activities of daily living and offering meaningful social activities. Through Namaste Care, care provision can be more effective and meaningful for caregivers while reducing the need for hospitalizations and LTC.

Caregivers in the current study perceived that they benefitted from implementing the adapted Namaste Care program. Other caregivers supporting persons with dementia at home may benefit from the program as well. It could be part of public policy to offer Namaste Care more broadly through dementia services and organizations. Models such as Namaste Care that are structured and offer individualized support for caregivers can inform public policy to make such models accessible to caregivers (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011). To be able to provide the adapted Namaste Care program to a larger number of caregivers across Canada there is a need to partner with existing organizations offering dementia services or caregiver support.

In the current study, organizations such as the Alzheimer Society provided support for recruitment and dissemination of preliminary results, however there is a need to form partnerships to offer evidence-based interventions such as Namaste Care as part of regular programming. Potential community partners would need to be consulted in developing a plan to offer the adapted Namaste Care program for caregivers. Possible alternatives in offering the program consist of: (a) creating a take-home or online toolkit for caregivers to deliver the program on their own through the support of local Alzheimer organizations or (b) involving a health or social care provider such as a nurse, social worker, or recreational therapist in offering training and bi-weekly check-ins for caregivers interested in delivering the adapted Namaste Care program. For example, caregiver education and support programs developed by dementia care experts at the Reitman Centre at Sinai Health are being offered by staff of local Alzheimer Societies throughout Ontario, Canada as regular programs in the Alzheimer Society education curriculum (Sadavoy, Sajedinejd, & Chiu, 2021; Sinai Health, 2020).

Organizations such as CIHR and the National Institute on Aging are recognizing that there is a pressing need to support older populations (Levine, Halper, Peist, & Gould, 2010; Nichols et al., 2011). Caregivers have been found to be increasingly involved in complex and demanding care to support family members at home (Levine, Halper, Peist, & Gould, 2010; Nichols et al., 2011). Caregivers deserve to know that governmental policy commitments will be followed through. Commitments need to be structured around what matters most to caregivers and what is most valuable in terms of support for them and persons with dementia (Larkin, Henwood, & Milne, 2020). Interventions such as Namaste Care can support the wellbeing of persons with dementia and help caregivers reduce agitation among persons with dementia. The program has the potential to reduce responsive behaviours of persons with dementia at home. As the presence of responsive behaviours have been found to be a common reason why persons with dementia are admitted to LTC, supporting caregivers to better address responsive behaviours at home can be beneficial in delaying the need for LTC (Afram et al., 2014; Yu et al., 2018).

In the current study some caregivers discussed how they had to tailor the adapted Namaste Care program to suit the culture and primary language of older adults with moderate to advanced dementia. For example, a few caregivers had to communicate during sessions or play music in a language other than English and provide snacks and beverages based on cultural traditions and preferences. This finding has implications for how caregiver education is offered as well as the need to further tailor the program including the training guide to suit the needs of diverse communities. The program and related resources should also be made available in multiple languages. Knowing that health disparities and caregiver burden are experienced differently between caregivers who are Caucasian and those who are part of racialized and minority groups, there is a need for culturally tailorable interventions (Pereira et al., 2021).

Moreover, only two male caregivers were included in the current study. This made it challenging to determine whether there were differences in terms of benefits or ease of program implementation for male and female caregivers. It is important to recognize that female caregivers have been found to experience higher levels of caregiver burden compared to male caregivers (Pillemer, Davis, & Tremont, 2018; Pöysti et al., 2012). This finding reveals the need for providing additional supports for female caregivers in using the adapted Namaste Care program due to pre-existing high levels of caregiver burden.

Implications for Research

Numerous implications for future research were identified that emerged from the current study. With regards to findings related to adapting the Namaste Care program, the involvement of persons with lived experiences (i.e., caregivers) was critical to the success of implementation of the adapted Namaste Care program. Caregivers who participated in the workshop sessions provided important insights regarding how Namaste Care should be delivered at home and what is feasible for caregivers of older adults with moderate to advanced dementia. The use of both quantitative and qualitative methods also contributed to rich findings related to the effects of the adapted Namaste Care program and its feasibility. From a research and policy standpoint, Larkin et al. (2020) similarly highlighted the need to embed the perspectives of caregivers in developing services, provide targeted support using a tailored approach, and incorporate both quantitative and qualitative approaches in evaluating interventions.

Future research on the adapted Namaste Care program should consist of a large trial to determine the extent of the effects of the program for caregivers and persons with dementia. A future study could examine differences in outcomes related to sex, spousal caregivers versus children, and ethnicity. A randomized controlled trial would be preferred as a rigorous design. It may also be beneficial to involve caregivers early on in the research planning phase and include a qualitative component to determine what kinds of outcomes are important to them and persons with dementia. Culturally relevant models, theoretical perspectives, and the inclusion of diverse samples, with a greater focus on minority groups, should be used when engaging caregivers in research and when implementing caregiver support interventions (Dilworth-Anderson, Moon, & Aranda, 2020). One of the key recommendations of a group of experts of the International Society to Advance Alzheimer's Research and Treatment is to use targeted recruitment and retention strategies to include ethnically diverse populations in research about Alzheimer's disease and related dementias (Babulal et al., 2019). A possible strategy to recruit and retain culturally diverse caregivers is to seek gatekeepers and leaders of community groups to help with recruitment of caregivers supporting persons with dementia at home.

Overall Study Strengths and Limitations

The strengths of the study include: (a) using an innovative co-design approach to adapt an intervention for caregivers of community-dwelling older adults with moderate to advanced dementia in collaboration with caregivers; (b) providing formal training for caregivers and regular support in using the adapted Namaste Care program; and (c) the inclusion of both quantitative and qualitative methods to provide comprehensive findings. This study focused on outcomes for caregivers which has often been absent in studies exploring Namaste Care. For example, positive aspects of caregiving can help to overcome stressors associated with the caregiving role.

In conducting the study multiple and reputable frameworks were used. The SPOR patient engagement framework (CIHR, 2019) and the Bowen et al. (2009) Feasibility framework were used to assist in the development of interview guides. The System for Classifying Modifications to Evidence-Based Programs or Interventions (Stirman, Miller, Toder, & Calloway, 2013) and the Bowen et al. (2009) Feasibility framework served as coding frameworks. The Bowen et al. (2009) Feasibility framework was also used to guide the mixed methods interpretation of findings. The use of these frameworks ensured that findings were theoretically driven, and components considered were consistent with previous research. A limitation in using the frameworks was not being able to collect data for all constructs of the framework as constructs did not always align with the objectives of the study.

The limitations of the study included the small sample size which limits our ability to generalize results and conduct further statistical analysis such as regression analyses. Another limitation was using a pre-test/post-test design with no control group comparison to evaluate feasibility and preliminary effectiveness of the adapted Namaste Care program. Given that this study assessed the feasibility of a version of Namaste Care to be delivered by caregivers, this study may later inform a more rigorous trial such as a randomized controlled trial with a larger sample size. There was also a lack of cultural diversity among caregivers and the inclusion of only two male caregivers. Given the importance of targeting diverse groups of caregivers as discussed above, there is a need to use more creative strategies for recruitment specifically targeted at male caregivers and ethnically and culturally diverse caregivers.

CONCLUSION

In this mixed methods study an adapted version of the multisensory, psychosocial intervention called Namaste Care was developed in collaboration with caregivers of persons with moderate to advanced dementia to be used in the community setting. The feasibility, acceptability, and preliminary effectiveness of the adapted Namaste Care program was assessed. The research involvement of caregivers in creating the adapted Namaste Care program ensured that the program met the realities of caregiving and still retained core components of the original program. Caregivers had an overall positive experience in adapting the program and perceived that they also benefitted from learning about the program to support their own caregiving practices.

With regards to the implementation of the adapted Namaste Care program it was found to be feasible and acceptable to be delivered by caregivers of community-dwelling older adults with moderate to advanced dementia. Despite non-statistically significant effects of the program on caregiver outcomes, qualitative data revealed that caregivers perceived that the program enhanced their abilities to provide structured and person-centred activities for persons with dementia and the program improved relationships between caregivers and persons with dementia. Caregiver support through interventions such as the adapted Namaste Care program remains a top 10 research priority for dementia care in Canada (Bethell et al., 2018). There is a need for further evaluation of the adapted Namaste Care program through a large randomized controlled trial. Nurses need to be provided with opportunities to lead interventions aimed at supporting caregivers of older adults with moderate to advanced dementia at home. Findings from a randomized controlled trial can provide greater support for the need to include caregiver support interventions such as Namaste Care on the agenda of policy makers.

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APPENDICES

Appendix A

Table 1. List of Terms and Definitions

Term	Definition
Stages of Dementia	Early Stage: People in the early stage of dementia may still function independently and require minimal assistance. They may be prone to forgetfulness and changes in mood and behaviour (Alzheimer Society of Canada, 2019).
	Middle Stage: People in the middle or moderate stage of dementia may experience a further decline in functional and cognitive abilities and require assistance with activities of daily living (Alzheimer Society of Canada, 2019).
	Late Stage: People in the late or advanced stage of dementia will require care 24 hours a day and may become unable to communicate verbally or care for themselves (Alzheimer Society of Canada, 2019).
Responsive behaviours	Older adults with dementia experience difficulties with language and speech and may not be able to verbally communicate their needs and concerns. As a result, they display responsive behaviours defined as words, sounds, behaviours, or actions in order to make their needs or concerns known to others. These behaviours occur in response to pain, hunger, thirst, and fear. The term was created by persons with dementia and is the preferred choice of term to represent dementia-related behaviours (Murray Alzheimer Research and Education Program, 2017). Researchers have adopted the socially acceptable term responsive behaviours to reflect the preferences of persons living with dementia. Examples of responsive behaviours are yelling, wandering, hitting, kicking, restlessness, repetitive sentences/questions, making sounds, and sexually inappropriate behaviours (Alzheimer Society of Canada, 2017; Draper, Finkel, & Tune, 2015).
Self-efficacy	Self-efficacy is defined as one’s perceived confidence in performing a behaviour (Ajzen, 2002).
Caregiver burden	Caregiver burden is defined as a multifaceted response to the physical, emotional, social, and financial stress associated with being a caregiver (Kasuya, Polgar-Bailey, & Takeuchi, 2000).

Appendix B

Table 1. Overview of the Namaste Care Program

Namaste Care	
Description of the program	Namaste Care is a person-centred, holistic program that provides multisensory stimulation for persons with advanced dementia. The program aims to honour the spirit that lives within each individual regardless of cognitive impairment. Activities of daily living are provided for persons with advanced dementia using a compassionate and meaningful approach. There is positive engagement between persons with advanced dementia and those delivering Namaste Care (i.e., trained providers and family members) by enhancing sensory input and comfort. There are two main principles for the program: (a) comfortable environment and (b) loving touch. Namaste Care is delivered in a calm and welcoming atmosphere that may include soothing scents of lavender and relaxing music. It typically takes place in a quiet space with low lighting and no distractions. It can be provided in a small group setting. Namaste care uses principles of touch to provide stimulation for persons with dementia through hand/foot massages, applying moisturizing cream, brushing the hair of persons with dementia, and comforting hugs. The program is delivered based on the preferences of persons with dementia and their unique life stories. Persons with dementia are provided with a Namaste Care sensory box that has unique items based on preferences such as lotions, life-like dolls, plush animals, balls, toy cars, and lollipops to provide sensory stimulation. Throughout the Namaste Care program persons with dementia are offered favorite snacks and beverages to maintain hydration. They are also monitored for signs of pain and discomfort.
Settings	The program has been used in LTC, acute care, hospice care homes, and in-home hospices.
Length of the program	In LTC, it is recommended that the program is implemented seven days a week for a minimum of four hours daily ideally separated into two sessions (e.g., two hours in the morning and two hours in the afternoon).

Note. The information source for the table consists of: Simard, J. (2013). *The end-of-life Namaste Care program for people with dementia* (2nd ed). Baltimore, MD: Health Professions Press.

Appendix C

Summary and Evaluation of Studies Included in the Literature Review

Table C1

Reviews of Skills-Based Training Interventions for Family Caregivers of Community-Dwelling Older Adults with Dementia

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
Brasure et al. (2016) (A total of 20 studies included were conducted in the United States, Hong Kong, Canada, France, Taiwan, Peru)	To evaluate the efficacy, effectiveness, and adverse effects of nonpharmacological interventions for people with dementia experiencing agitation and aggression	Systematic review of randomized controlled trials	Persons with dementia and informal caregivers	Moderate-strength evidence revealed that non-pharmacological interventions targeting caregiver skills and behaviour were more effective in managing caregiver distress and improving the confidence of caregivers in caring for community-dwelling persons with dementia compared to providing general information or education. Evidence found supporting an effect of caregiver interventions was insufficient to draw a conclusion and this was often due to moderate risk of bias, imprecise analysis or reporting of findings	2/3
Braun et al. (2019) (A total of 58 articles included were conducted in the United Kingdom, the United States, Australia, China, Canada, India, Tanzania, New Zealand, Spain, Norway, Sweden,	To explore perceptions and experiences of people living with dementia and caregivers about responsive behaviours and what helps to reduce their impact	Systematic review of qualitative studies	People living with dementia, family caregivers, and healthcare providers	Educational interventions aimed at enhancing the skills of family caregivers in addressing responsive behaviours can be helpful in providing care, dealing with sudden changes among persons with dementia, and prioritizing caregiving responsibilities. Joint reminiscence therapy was found to support family caregivers in providing them with opportunities to discuss their challenges within a	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
Ireland, Netherlands, Germany, and Denmark)				group setting and learn about the strategies that others use to support persons with dementia at home.	
Brodaty and Arasaratnam (2012) (A total of 23 studies included were conducted in Canada, the United States, Russia, the United Kingdom, the Netherlands, Italy, and Norway)	To review the effectiveness of nonpharmacological interventions delivered by caregivers in addressing behavioural and psychological symptoms among community-dwelling people with dementia	Meta-analysis of intervention studies consisting of randomized and pseudorandomized controlled trials	Persons with dementia and family caregivers	Nonpharmacological interventions were effective in reducing behavioural and psychological symptoms of dementia and improving the reactions of caregivers to behavioural and psychological symptoms. The effect sizes were small at 0.34 (95% CI: 0.20, 0.48; z=4.87; p=0.01) and 0.15 (95% CI: 0.04, 0.26; z=2.76; p=0.006), respectively.	2/3
Clarkson et al. (2018) (A total of 70 studies included were conducted in the United States, the United Kingdom, Russia, Peru, Taiwan, China, Canada, Spain, Greece, and the Netherlands)	To explicate the outcomes of home support interventions for older adults with dementia and/or their informal caregivers	Systematic review of quantitative and qualitative primary studies	Older adults with dementia and their informal caregivers	Interventions that employed environmental modification had low to moderate significant improvements in reducing responsive behaviours and improving daily functioning of care recipients. Multicomponent interventions combining education and behaviour management were most effective at reducing caregiver burden and behaviours and improving well-being. Most qualitative studies explored the quality of life of the caregiver and person with dementia, with an emphasis on caregiver burden.	3/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
Jensen et al. (2015) (A total of seven studies included were conducted in France, Russia, Peru, the United States, Germany, Austria, Switzerland, Spain, and Iran)	To evaluate the effects of educational programs for caregivers of community-dwelling people with dementia on caregiver burden, depression, quality of life, and transitions to LTC settings compared to usual care	Systematic review and meta-analysis of randomized controlled trials	Informal caregivers of community-dwelling people with dementia	Meta-analysis of five trials revealed that educational programs have a moderate effect on caregiver burden (Standardized Mean Difference (SMD) = -0.52; 95% CI = -0.79, - 0.26; $p<0.0001$). Meta-analysis of two trials revealed a small effect of educational programs on depression (SMD=-0.37; 95% CI = -0.65, -0.09; $p=0.01$). The overall effect of QOL was unknown as it was not possible to combine the results of studies due to heterogeneity of scales used to assess QOL and constructs considered.	2/3
Trivedi et al. (2019) (A total of 48 studies included were conducted in the United States, Canada, the United Kingdom, Japan, Hong Kong, Russia, Australia, Peru, the Netherlands, and Denmark)	To review the evidence from randomized controlled trials of effectiveness of interventions for addressing responsive behaviours among community-dwelling older people living with dementia	Systematic review of randomized controlled trials	Persons living with dementia and family caregivers	Educational programs and structured activity programs aimed at addressing responsive behaviours can reduce family caregiver burden. Findings from high quality studies suggest that psychoeducational programs aimed at supporting caregivers through problem-solving techniques and skills in addressing responsive behaviours can enhance their behaviour management skills while decreasing emotional distress related to presentation of agitation by persons with dementia. Caregivers who were part of multicomponent interventions	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
				combining behaviour management, stress-coping techniques, telephone support, and skills training were found to be less bothered by responsive behaviours.	
Vandepitte et al. (2016) (A total of 53 studies included were conducted in the United Kingdom, the Netherlands, the United States, Germany, Canada, Russia, Australia, Southern Europe, Sweden, France, Spain, Norway, Finland, Denmark, Italy)	To determine the effectiveness of different supportive strategies for informal caregivers of people with dementia and care recipients	Systematic review of randomized and non-randomized controlled trials	Persons with dementia and informal caregivers	Psychoeducational interventions improved self-efficacy of caregivers in caring for people with dementia and reduced depressive symptoms among caregivers. Occupational therapy interventions aimed at promoting function and participation in activities of daily living through meaningful activities led to a decrease in behavioural symptoms among persons with dementia and improve self-efficacy of caregivers.	2/3
Van't Leven et al. (2013) (A total of 23 studies included were conducted in the United States, the Netherlands, the United Kingdom, Hong Kong, Canada, Sweden, Finland,	To provide updated evidence related to dyadic psychosocial programs dyads that include both the community-dwelling patient with dementia and their family caregiver	Systematic review of randomized controlled trials	Persons with dementia and family caregivers	Moderate evidence showed that dyadic psychosocial programs reduced caregiver burden, improved the competency of caregivers, and improved their quality of life. These programs led to small improvements in reducing behavioural problems in people with dementia. There was moderate evidence showing an improvement in caregivers' abilities to support	1/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
India, Australia and Germany)				activities of daily living. There was moderate to strong evidence that revealed an improvement in the quality of life of people with dementia.	

Table C2

Primary Studies of Skill-Building Interventions for Family Caregivers of Community-Dwelling Older Adults with Dementia

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
Bass et al. (2019) (The United States)	To evaluate the impact of "Partners in Dementia Care (PDC)" on outcomes for persons with dementia and their family/friend caregivers	Translational study design	148 caregivers and 84 persons with dementia	Data collected before program implementation and at the 12-month follow-up	In terms of lack of caregiving confidence there was a statistically significant 0.32 decrease from baseline (mean=4.77; SD=2.24) to the 12-month follow-up (mean=4.45; SD=2.02) indicating greater confidence at follow-up (p = 0.01). There were no statistically significant differences in caregiver depression scores.	11-item Center for Epidemiological Studies Depression Scale (CES-D) (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993); Lack of caregiving confidence 4-point scale (Bass et al., 2019	2/3
Birkenhäger-Gillesse et al. (2020) (The Netherlands)	To determine the effectiveness of an Australian multicomponent community-based training program that was adapted and implemented in a	Randomized controlled trial with qualitative interviews of selected dyads	142 dyads of caregivers and persons living with dementia	Data collected at baseline, at the 3 and 6-month follow-up (due to high dropout rates 6- month follow-up data	There were no statistically significant differences found at the 3-month follow-up in terms of caregiver quality of life,	Care-Related Quality of Life-7 dimensions (CarerQol-7D) (Hoefman, van Exel, Foets, & Brouwer, 2011); CarerQol—visual	3/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	non-medical Dutch health care setting.			were not analyzed)	burden, and depression. With regards to qualitative findings from interviews with 38 dyads some caregivers perceived that they had better coping skills, improved skills to address responsive behaviours, and used the knowledge gained through the program.	analog scale (VAS) (Hoefman, van Exel, Rose, van de Wetering, & Brouwer, 2014); Self-Rated Burden Scale—VAS (van Exel et al., 2004)	
Burgio et al. (2009) (The United States)	To translate the Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) to be used in the community setting and assess possible moderating effects of participant characteristics on treatment outcomes	Quasi-experimental pre-post treatment design with no control group	272 dyads consisting of caregivers and care recipients living with dementia and 6 case managers	Data collected at baseline and at the four-month follow-up period	At four-month follow-up caregivers reported decreased caregiver burden (pre-mean= 2.40, [SD=0.74]; post-mean= 2.23 [SD=0.65]; p =0.0001), increased social support (pre-mean= 2.87	12-item modified Zarit Burden Inventory (Zarit, Orr, & Zarit, 1985); REACH OUT caregiver questionnaire (Burgio et al., 2009); REACH OUT risk appraisal (Burgio et al., 2009)	1/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					[SD=0.98]; post-mean= 3.16 [SD=0.82]; p=0.0001), decreased depression (pre-mean=2.10 [SD=0.86], post-mean=1.91 [SD=0.82]; p=0.001), and decreased caregiver frustration (pre-mean=1.39 [SD=0.46], post-mean= 1.26 [SD=0.38]; p= 0.0001).		
Drossel et al. (2011) (The United States)	To explore the effects of a dialectical behaviour therapy skills training program on caregivers' psychosocial adjustment and risk factors for elder abuse	Pre- and post-test design	16 family caregivers of persons with dementia	Data collected at baseline and at the end of the three-month intervention period	Family caregivers experienced an improvement in problem-focused coping (pre-mean=1.59 [SEM=0.09], post-mean=2.03 [SEM=0.12]; p=0.005) and emotional well-being (pre-	The Ways of Coping checklist - Revised (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985); Medical Outcome Studies Short-Form 36-Item Health Survey (Ware & Sherbourne, 1992)	1/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					mean=52.3 [SEM=5.34], post-mean=64.3 [SEM=4.94]; p=0.004) and were less fatigued (pre-mean=35.7 [SEM=6.01], post-mean=49.3 [SEM=6.78]; p=0.004) following the training program.		
Elliott et al. (2010) (The United States)	To explore the relationships between changes before and after implementing the Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention in caregiver's self-reported health, bother of memory and behaviour problems of care recipients, and burden	Multisite, randomized controlled trial	495 dyads consisting of caregivers (family members and close friends) and care recipients with dementia	Data collected at baseline and at the six-month follow-up period	Caregivers reported improved health, sleep quality, emotional health, and physical health. Findings were significant for the intervention group only and had small to medium effect sizes ($p < 0.01$). In the intervention group the post- and pre-intervention mean difference was 0.26 [standard	REACH II Measures (Elliott et al., 2010)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					error (SE) = 0.06] for self-rated health, -0.40 [SE=0.09] for caregiver sleep, -0.20 [SE=0.04] for mood improvement of caregivers, and -0.09 [SE=0.03] for physical improvement of caregivers (p< 0.01).		
Gitlin et al. (2021) (The United States)	To test whether the Tailored Activity Program (TAP) reduced clinical symptoms and health-related events, and improved caregiver wellbeing, and if TAP activities were well-tolerated	Single-blind randomized controlled trial	250 dyads composed of caregivers and persons with dementia with a clinical presentation of aggression or agitation	Data collection occurred at baseline, 3-month (program completion, and at 6-month follow-up	Caregivers in the intervention group compared to the control group had a statistically significant increase in caregiver wellbeing with a mean difference between groups of 3.50 (95% Confidence interval: 0.94, 6.06; p=0.01). This was measured using	13-item Perceived Change for Better Index (Gitlin et al., 2006); 5-items caregiver confidence scale (Gitlin et al., 2009)	3/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					the Perceived Change for Better Index (Gitlin, Winter, Dennis, & Hauck, 2006) with scores that ranges from 13 to 65 with higher scores indicating greater wellbeing. Caregivers in the intervention versus control group were found to have greater confidence in delivering activities at the 3-month period with a mean difference between groups of 3.46 (95% Confidence Interval: 0.42, 6.50) (p=0.03). This was measured using a 5-item scale with scores ranging from 0 to 50 with higher scores		

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					indicating greater confidence (Gitlin et al., 2009).		
Horvath et al. (2013) (The United States)	To evaluate the effects of a new self-directed educational intervention on caregiver competence in creating a safer home environment for persons with dementia	Randomized controlled trial	108 dyads composed of caregivers and persons with dementia	Data collected at baseline and at the 12-week follow-up	Caregivers in the intervention group had significant improvements compared to those in the control group in terms of self-efficacy ($p=0.002$), home safety ($p < 0.001$), and caregiver strain ($p < 0.001$).	The Revised Scale for Caregiving Self-Efficacy (Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002); the Home Safety Checklist (Horvath et al., 2013); The Margaret Blenkner Research Center Caregiver Strain Instrument (Bass, Noelker, & Rechlin, 1996)	2/3
Huang et al. (2013) (Taiwan)	To evaluate the effects of an individualized, caregiver training program implemented in a home setting for caregivers of elderly patients with dementia and	Single-blinded, randomized controlled trial	129 pairs of caregivers and people with dementia	Data collected at two weeks, three months, and six months post-intervention	At six months post-intervention the differences between groups were statistically significant. The intervention group had a mean self-efficacy score in addressing behavioural	The Agitation Management Self-Efficacy Scale (Huang, Shyu, Chen, Chen, & Lin, 2003); the 10-item Caregiver Preparedness Scale (Archbold, Stewart,	1/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	behavioural problems				problems of 177.33 (SD=30.85) and the control group had a mean of 151.83 (SD=37.43) (p< 0.001). At six months post-intervention the intervention group had a mean preparedness score of 36.02 (SD=5.31) and the control group had a mean of 32.13 (SD=8.43) (p< 0.001).	Greenlick, & Harvath, 1990)	
Hum et al. (2020) (Singapore)	To explore the symptoms of persons with advanced dementia and quality-of- life and their association with enteral feeding, evaluate the impact of the integrated palliative home care program on these parameters and	Prospective cohort study	254 dyads of caregivers and persons with advanced dementia	Data collection occurred at baseline and at the 5-month and 1-year follow-up	Caregivers had statistically significantly reduced caregiver distress scores with a mean of 3.6 (SD=4.9) at baseline and 1.8 (SD=3.6) at the 1-year follow-up (p<0.05). Caregiver burden	22-item Zarit Burden Interview (ZBI) (Zarit et al., 1980); Neuropsychiatric Inventory Questionnaire caregiver distress domain (Kaufer et al., 2000)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	examine family caregiver burden				was not measured pre- and post-intervention and was used to compare burden in different groups of caregivers.		
Kales et al. (2018) (The United States)	To evaluate the effects of using the WeCareAdvisor, a web-based tool created to enable family caregivers to assess, address, and track behavioural and psychological symptoms of dementia	Two-site, randomized controlled trial	57 primary caregivers caring and persons with a clinical diagnosis of dementia or a Mini-Mental State Examination score of less than 24	Data collected at baseline and at the one-month follow-up period	The intervention group had a significant reduction in caregiver distress with a mean change of 6.08 (SD=6.31); p<0.0001 and showed greater improvement in caregiver distress than the waitlisted group (p=0.02). The intervention group experienced decreased number of behaviours in persons with dementia with a mean change of -1.62 (SD=1.77); p<0.0001, decreased	Revised version of the Neuropsychiatric inventory questionnaire (Kaufer et al., 2000)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					behaviour frequency with a mean change of -3.60 (SD=5.05); p = 0.0002, and decreased behaviour severity with a mean change of -3.24 (SD=3.87); p=0.0003.		
Kwok et al. (2013) (Hong Kong)	To evaluate the effects of a telephone-delivered psychoeducational intervention for family caregivers of people with dementia on caregiver burden and caregiver self-efficacy	Single-blinded, randomized controlled trial	38 family caregivers of persons with dementia	Data collected at baseline and at the three-month post-intervention period	Caregivers in the intervention group had a decrease in caregiver burden with a mean change of -1.83 (SD=5.26) and those in the control group had an increase in burden from baseline to three-month follow-up with a mean change of 2.25 (SD=7.09; p=0.0002. There were no significant changes in self-	The Chinese version of the Zarit Burden Interview (Chan, Lam, & Chiu, 2005; Zarit, Reever, & Bach-Peterson, 1980); the Chinese version of the Revised Scale for Caregiving Self-efficacy Scale (Au et al., 2009; Steffen et al., 2002)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					efficacy in responding to disruptive behaviours or controlling upsetting thoughts post-intervention.		
Lee et al. (2010) (The United States)	To follow-up on the findings of the Resources for Enhancing Alzheimer's Caregiver Health II (REACH II) program (Belle et al., 2006) and determine the moderating influence of demographic characteristics, social support, and religious coping on the effectiveness of REACH II	Residual change scores and stepwise hierarchical regression analyses to extend on the results of a multisite, randomized controlled trial	642 dyads composed of caregivers and care recipients with dementia	Data collected at baseline and at the six-month follow-up period	Older Hispanic caregivers who received the intervention had a statically significant decrease in caregiver burden at follow-up, while those who were part of the control group had an increase in burden. ($p<0.05$). Older African American caregivers who received the intervention had a significant decrease in caregiver burden, while those in the control condition	The 10-item version of the Center for Epidemiological Studies-Depression scale (CES-D) (Irwin, Artin, & Oxman, 1999); The brief version (12 items) of the Zarit Caregiver Burden Interview (Zarit et al., 1985)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					had an increase in burden at follow-up ($p<0.01$).		
Liddle et al. (2012) (Australia)	To evaluate the effectiveness of a DVD-based training program using evidence-based strategies for memory and communication in dementia on the experience of caregivers and the well-being of persons with dementia	Pre-test/post-test-controlled trial	29 dyads consisting of informal caregivers (family or friend) and persons with dementia	Data collected at baseline and at three-months following the intervention	There was significant improvement in caregivers' knowledge of strategies in the training group (median=9.0) compared to the control group (median=5.75) ($p=0.0011$). The training group had a reduction in the frequency of disruptive behaviours among the care recipient ($p=0.028$) and increased beliefs associated with positive aspects of caregiving ($p=0.039$).	The Communication and Memory Support in Dementia Knowledge test (Broughton et al., 2011); the Revised Memory and Behavior Problems Checklist (Teri et al., 1992); the Positive Aspects of Caregiving questionnaire (Tarlow et al., 2004)	1/3
Llanque et al. (2015)	To evaluate the effects of a community-based psychoeducational	One-group, pre-test/post-test design	15 caregivers of persons with Alzheimer's	Data collected at baseline and post-intervention	Significant improvements in caregiving competence post-	The 4-item caregiving competence scale (Pearlin, Mullan,	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
(The United States)	intervention called the Family Series for care caregivers of community-dwelling persons with Alzheimer's Disease and Related dementias on caregiving competence, stress, and coping and determine the influence of this intervention on the relationship between stress, coping, and competence.		Disease or Related Dementias	following the six weekly sessions	intervention with a mean of 14.6 (SD=1.9) compared to the baseline mean of 11.6 (p=0.0358). There was no significant difference in caregiver stress from baseline to post-intervention. Coping as a caregiver using humour showed a marginal significant improvement from baseline with a mean of 2.6 (SD=1.0) to 4.1 (SD=2.2) post-intervention (p=0.493). Caregiving competence was also found to be predicted by stress (p=0.0062) and coping through	Semple, & Skaff, 1990); the Brief COPE scale (Carver, 1997); Caregiver Burden Inventory (Caserta, Lund, & Wright, 1996)	

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					humour (p=0.0015).		
Simpson and Carter (2010) (The United States)	To explore the feasibility of the Caregiver Sleep Intervention (CASI) among caregivers of community-dwelling and institutionalized persons with dementia	Quasi-experimental repeated measures design	10 caregivers of people with dementia	Data collected at baseline and at three-and five-week post-intervention	No significant difference in sleep quality and depressive symptoms among caregivers of community-dwelling persons with dementia and caregivers of institutionalized persons with dementia.	The Pittsburgh Sleep Quality Index (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989); the Quick Inventory of Depressive Symptoms Clinician Rating tool (Rush et al., 2003)	1/3
Teri et al. (2018) (The United States)	To evaluate the implementation of the Reducing Disability in Alzheimer's Disease-NorthWest (RDAD-NW) by case workers and the effectiveness of this program on mood, activity, and quality of life among community-dwelling older adults and their caregivers	Staggered multiple baseline design with randomization of study sites and a no-treatment baseline period where dyads serve as their own control	255 older adults with dementia and their family caregivers and 20 case managers	Data collected at baseline, the pre- to posttreatment intervention period (three months), the seven-month follow-up period, and the 13-month follow-up periods	Significant increase in mean from pre-to 3-months post-treatment (1.03 [95% CI: 0.50, 1.56], p < 0.001) in quality of life for people with dementia and decrease in mean caregiver depression scores from pre- to post-treatment (-1.15 [95% CI: -2.03,	The Quality of Life-Alzheimer's Disease Scale (Thorgrimsen et al., 2003); the Center for Epidemiological Studies Depression Scale (Lewinsohn, Seeley, Roberts, & Allen, 1997)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					-0.28], p=0.01). At 13 months follow-up both findings were no longer significant.		

Table C3
Reviews of Namaste Care for Older Adults with Advanced Dementia

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
Backhaus et al. (2020) (A total of 29 studies included were conducted in Australia, Belgium, Canada, the United Kingdom, the United States, Israel, Italy, and the Netherlands)	To review interventions to foster the inclusion of family members (e.g., partners, (grand) children, siblings) of people with dementia living in nursing homes within the nursing home setting	Systematic review	Family members, long-term care staff, and residents living with dementia	Two studies on Namaste Care (McNiel & Westphal, 2018; Stacpoole et al., 2017) were included. Namaste Care provided opportunities for family members to engage with their family members living with dementia and other families present in the Namaste Care room during the delivery of the intervention. Family members and friends were also involved in the Namaste Care intervention by participating in meetings to determine how best to tailor the program to the preferences and stories of residents.	2/3
Backman et al. (2021) (A total of 52 studies included were conducted in the United States, Australia, Turkey, Japan, Canada, the Netherlands, Belgium, Germany, the United Kingdom, Ireland, Denmark, Switzerland, Sweden, China, Korea, Portugal, Spain, and Iran)	To examine the available literature on the impact of sensory interventions on the quality of life of residents living in long-term care settings.	Scoping review	Resident living in long-term care homes (most studies report focusing on residents living with dementia)	Two studies on Namaste Care were included and categorized under interventions that stimulate multiple senses (Magee et al., 2017; Simard & Volicer, 2010). There were non-statistically significant findings found following the implementation of Namaste Care in terms of depression and agitation among residents.	2/3
Bray et al. (2019a)	To evaluate the quality of research evidence related to the different	Rapid assessment review	People with advanced dementia, family	Most of the research evidence supporting the use of smells and aromas, animal and doll therapy,	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
(A total of 127 studies included were conducted in the United Kingdom, China, Canada, the United States, New Zealand, Japan, Italy, Taiwan, Colombia, the Netherlands)	activity components of the Namaste Care program for care home residents with advanced dementia		members, and care home staff	music therapy, lighting, touch and massage, and sensory interventions was strong to medium. There was weak evidence supporting the benefits of food and drink for people with dementia. Some of the positive outcomes include social, emotional, and physical benefits for people with dementia (e.g., decreased agitation, improved quality of life, decreased depression).	
Bunn et al. (2018) (A total of 85 studies included were conducted in the United Kingdom, the United States, Australia, Japan, Taiwan, Canada, Portugal, Norway, Sweden, Spain, Italy, Netherlands, France, Belgium, and Ireland)	To explore how the Namaste Care intervention can lead to specific outcomes and under what circumstances	Realist review involving scoping of the literature and interviews with stakeholders	People with advanced dementia, family members, and care home staff	To support people with advanced dementia through Namaste Care there is a need to provide structured access to physical and social stimulation, equip care home staff with knowledge and skills to address complex behaviours and various responses to the intervention, and implement a person-centred care framework. Activities should promote meaningful connections for people with advanced dementia.	2/3
Camacho- Montaño et al. (2021) (A total of 12 studies were included from the United Kingdom, the Netherlands, Ireland, the United States, Finland,	To explore how healthcare providers of clients living with advanced dementia perceive the need for spirituality and interventions to provide spiritual care	Qualitative systematic review	Healthcare providers (e.g., nurses, physicians, occupational therapists, nursing aides, etc.) working in long-term care	Two studies on Namaste Care were included (Bray et al., 2018; Stacpoole et al., 2017). Namaste Care was perceived by healthcare providers as leading to positive responses among residents such as smiling, greater interaction between residents, increased communication,	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Relevant Findings (summary)	Quality Score
Germany, Belgium, Canada, and Israel)				better mood, and more relaxed appearance.	
Karacsony & Abela (2021) (A total of 11 studies included were conducted in Canada, the United Kingdom, Australia, and the United States)	To review qualitative findings of studies on Namaste Care to explore the potential for sense memories to be triggered by sensory stimulation	Literature review	Persons living with dementia, healthcare providers, volunteers, and family caregivers	Multiple expressions of touch used in Namaste Care were found to increase communication in people with dementia. Namaste Care helped persons with dementia be more engaged with their environment and aware of other people in the Namaste Care room. The program was found to have a positive effect on agitation for persons with dementia by providing familiar stimuli such as hymns. Persons with dementia appeared more comfortable due to a reduction in pain. Namaste Care promoted person-centred care by encouraging staff to get to know persons with dementia more intimately and support family members in focusing on what persons with dementia are still able to do.	3/3
Volicer (2019) (A total of 19 studies included were conducted in the United Kingdom, the United States, Spain, Portugal, and Japan)	To describe the needs of residents with dementia and programs intended to maintain quality of life of people with dementia near the end of life	Literature review	Persons with dementia, family members, and staff working in LTC facilities	Namaste Care reduced delirium indicators, decreased behavioural symptoms of dementia, decreased pain, decreased the use of antipsychotics and hypnotics, and increased social interaction between residents with advanced dementia, their families, and LTC staff.	1/3

Table C4

Primary Studies of Namaste Care for Older Adults with Advanced Dementia

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
Ali et al. (2020) (Singapore)	To explore the impact of Namaste Care on cognitive status and quality of life (QOL) of persons with advanced dementia, and perceptions and attitudes of family caregivers and nurses delivering Namaste Care toward dementia care	Mixed methods study	4 patients, 4 family caregivers, and 6 nurses from a step-down unit of a tertiary hospital	Survey data for patients and caregivers were collected at baseline and prior to the discharge of patients from the unit. Survey data for nurses were collected at baseline and 1 month after implementing Namaste Care. Individual interviews were conducted with caregivers and nurses 1 week after program completion.	Although a positive improvement in quality of life scores for persons with advanced dementia was found, the significance of this finding was unknown because p-values were not reported and only 4 patients were included in the study. With regards to qualitative findings nurses were found to use a more person-centred approach in caring for persons with dementia and had a better understanding of patients beyond dementia. Namaste Care provided opportunities for families to participate and deliver the program.	The Quality of Life in Late-Stage Dementia (QUALID) Scale (Weiner et al., 2000)	1/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					Caregivers had formed stronger relationships with persons with dementia through the use of touch.		
Bray et al. (2018) (The United Kingdom)	To learn from the experience of staff using Namaste Care and the perspective of staff regarding how Namaste Care can be implemented	Multiple methods design	100 staff members working in care homes, hospitals, hospices, and in the homes of clients completed a survey and 13 staff members who practice or had observed Namaste Care being implemented completed an interview	Survey data were collected over a period of four week and interview data were collected following surveys	Namaste Care was perceived to enhance the well-being and quality of life of people with dementia through physical, social, and emotional positive impacts. Staff perceived residents to be more relaxed, less agitated, and express a positive mood. Staff perceived that residents had improved skin condition, better hydration, weight gain, swallowing, and sleep. Residents also experienced less pain. The program increased social interaction	N/A	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					between residents and staff.		
Bray et al. (2021) (The United Kingdom)	To develop a theoretical cost model with real-world data, calculating staffing, resource and consumable costs of delivering Namaste Care sessions versus 'usual care' for long-term care residents with advanced dementia	Cost model design	Considered the costs of providing Namaste Care sessions to residents compared to usual care	Data on Namaste Care intervention costs were collected from 5 long-term care homes and data for usual care costs were based on expert opinion and observations	The average Namaste Care group session cost 220.53 euros, which was valued at 22% more than usual care. The average cost per session per resident was 38.01 euros, 7.24 euros more than usual care. Most of the equipment and supplies were already available in long-term care homes and this led to some offset of costs. The costs associated with delivering the program were still considered low-cost with positive impacts on the physical, emotional, and social well-being of residents.	N/A	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
Bray et al. (2019b) (The United Kingdom)	To create a full cost model for a UK version of Namaste Care for care home residents with advanced dementia	Cost model design	Considered the costs associated with providing the program to residents and staff costs	Data on costs in implementing the program were collected using various means such as internet searching for staff salaries, cost of a room in a care home and similar settings, and national prices of consumables	Namaste Care was found to cost about eight to 10 euros more per resident per session compared to usual care. Positive effects of the program for residents and staff may negate the additional costs of the program (e.g., reduced responsive behaviours, improved skin condition).	N/A	2/3
Dalkin et al. (2020) (The United Kingdom)	To create initial program theories to describe if, how, and under which circumstances Namaste Care works when implemented at home	Qualitative realist approach	27 volunteers implementing Namaste Care in the community and 8 family caregivers who had received Namaste Care	A total of 3 focus groups were held for volunteers and individual interviews were held for caregivers	Namaste Care was perceived to create personalized care for persons with dementia and engagement and emotional response among persons with advanced dementia. Family caregivers had little involvement in the Namaste Care program and did not feel confident in	N/A	3/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					applying the techniques. Caregivers perceived that the program increased socialization between volunteers and persons with dementia.		
El Alili et al. (2020) (The Netherlands)	To assess the societal cost-effectiveness of the Namaste Care Family program compared to usual care in long-term care home residents with advanced dementia	Cluster randomized controlled trial	231 dyads of caregivers and residents with advanced dementia	Data collection occurred at baseline and 1, 3, 6 and 12 months after baseline	The mean difference from baseline to 12-month follow-up in quality of life scores between the Namaste Care and usual care group improved, however this was not statistically significant at -0.06 (95% confidence interval: -0.42, 0.30). The mean difference for perceived gains in dementia caregiving scores for caregivers also improved but was not statistically significant between groups at 0.033	The Quality of Life in Late-Stage Dementia (QUALID) scale (Weiner et al., 2000); Gain in Alzheimer care Instrument (Yap et al., 2010)	3/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					(95% confidence interval: -0.24, 0.31). With regards to costs (e.g., secondary care, medication, family, Namaste Care program costs) results showed that the mean difference for the Namaste Care intervention group was 311 euros less than the usual care group, however this was not significant (95% confidence interval: -3397, 2097).		
Froggatt et al. (2020) (The United Kingdom)	To determine the feasibility of conducting a trial of Namaste Care	Cluster RCT with a process evaluation and economic analysis	32 residents with advanced dementia, 12 informal caregivers, and 67 nursing home staff	Data collection occurred at baseline, 2 weeks, 4 weeks, and 24 weeks after the first Namaste Care session. Methods for data collection included surveys,	The target of the attrition rate of no more than two residents per care home withdrawing for the intervention based on practical or preference reasons was met. The target of 80% completion of QOL questionnaires was	Primary outcomes and measures were: (a) quality of dying (dementia) using the Comfort Assessment in Dying – End of Life Care	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
				observations, interviews, completion of activity logs, and use of a sleep/activity monitoring device	met for residents with 94% being completed at 24 weeks. The indicators for number of sessions delivered per week (i.e., 7 out of 14 or 50%) and the length of the sessions (i.e., 1.5 hours) were not met. Only 30% of possible sessions were held and the average length of sessions ranged from 0.87 to 1.91 hours. Family caregivers found questionnaires to be easy to complete and their engagement in the study supported recruitment of residents.	in Dementia (CAD-EOLD) (Kiely et al., 2006) and (b) quality of life using the Quality of Life in Late Stage Dementia (QUALID) (Weiner et al., 2000)	
Hunter et al. (2017) (Canada)	To use the Ecological Framework to identify barriers and enablers to	Qualitative interpretive design	15 family members, 17 registered nurses, and 12 unlicensed providers (i.e., nursing assistants	Focus group interview data were collected prior to implementing Namaste Cares	Family members reported that they could also participate in implementing Namaste Care.	N/A	3/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	implementing Namaste Care		and recreation workers)		Facilitators for implementing Namaste Care were positive perceptions associated with a need for the Namaste Care program and benefits of the program.		
Kaasalainen et al. (2019) (Canada)	To explore the early experiences of LTC care staff and family and friends of persons with advanced dementia with the implementation of a new program, Namaste Care, in two LTC homes in Canada	Multiple methods design incorporating a cross-sectional survey and qualitative descriptive design	44 LTC staff and 44 family members and friends completed a survey. 18 LTC staff, five family members, and two volunteers participated in interviews.	Survey data collected immediately after participants attended the education program and semi-structured interview data were collected three-months after the launch of the program	Most of the LTC staff enjoyed learning how to reach residents with advanced dementia through Namaste Care (80%). Participants appreciated the benefits of Namaste Care including better mood, greater engagement of residents, individualized care, and staff and family becoming more empowered to participate in care. Some family members reported	Survey designed by Kaasalainen et al. (2019)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					that the program may help reduce the need for medications now that the residents were more content and engaged.		
Kaasalainen et al. (2020) (Canada)	To evaluate the feasibility, acceptability, and the effects of Namaste Care to enhance end-of-life care for people with advanced dementia	Mixed methods survey design	31 residents with advanced dementia, 10 family members, 28 LTC staff, and 6 volunteers	Measurement of outcomes for residents occurred at baseline and at three- and six-month post-intervention. Survey and semi-structured interview data were collected post-intervention	Significant decrease in antidepressant use with a mean difference of 0.4 (95% CI: 0.04, 0.83). Feasibility of the program was acceptable with a participation rate of 89%. Family members and staff perceived that the program led to positive changes in residents such as improved mood and engagement with staff and family.	Medication quantification index (Harden et al., 2005); the QUALID scale (Weiner et al., 2000)	3/3
Kohne et al. (2021) (Iran)	To investigate the effects of the Namaste care program on the quality of life of women with	Pilot study	25 women living with late-stage Alzheimer's disease in long-term care homes	Data were collected at baseline and after receiving Namaste Care	Namaste Care was found to improve quality of life scores from baseline (mean=25.64; SD=1.64) to 6-	Persian version of the Quality of Life in Late-Stage Dementia	1/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	late-stage Alzheimer's disease			program for 6 months	month Namaste Care program implementation (mean=18.72; SD=1.01). This finding was significant with a p-value of < 0.001. Even after controlling for demographic variables (e.g., age, marital status, education, occupation) and comorbidities, statistically significant improvement in scores were revealed.	(QUALID) scale (Weiner et al., 2000)	
Latham et al. (2020) (The United Kingdom)	To report on the impact of the Namaste Care program delivered consistently in 5 long-term care homes for 12–24 weeks.	Mixed methods process study	48 residents, 20 staff members, and 9 family members	Survey data were collected at baseline and at 12-week follow-up or 18-24 week follow-up for homes that implemented the program longer. Interviews with	Out of 31 residents with complete data, quality of life scores improved with a mean difference of -4.29 from baseline (mean=25.81; SD=10.03) to 12-week follow-up (mean=21.00;	The Quality of Life in Late-Stage Dementia (QUALID) scale (Weiner et al., 2000)	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
				family members were conducted at the end of the study period.	SD=6.99) (p=0.01). With regards to qualitative findings Namaste Care led to a reduction in anxiety and responsive behaviours among residents, including behaviours of a physical nature. Namaste Care helped residents to connect with others in the home and increased their verbal communication. The program was found to improve relationships between family members and residents through family engagement. Namaste Care was offered by long-term care homes as a practical way to involve family members in		

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					supporting the quality of life of residents.		
Magee et al. (2017) (The United Kingdom)	To describe the process of introducing Namaste Care in a Care Home and the impact of the program upon those who were involved (i.e., families/carers and care home staff)	Qualitative study design	Nine care home staff and nine family members	Focus group interview data were collected from family and staff at baseline and at the end of the program	Namaste Care improved relationships between family members and residents and family members and care home staff. Namaste Care was perceived as helping staff implement activities that recognize residents' abilities. Families who participated in Namaste Care enjoyed having the one-on-one time with residents and simple activities provided them with something to do when they visited loved ones.	N/A	1/3
Manzar and Volicer (2015)	To explore the effects that the Namaste Care intervention has	Multiple methods design including a	10 residents with advanced dementia and eight LTC staff members	Quantitative and qualitative data collected at baseline, at week	Significant improvement in quality of life at week three and	The QUALID scale (Weiner et al., 2000)	1/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
(The United Kingdom)	on quality of life of residents with advanced dementia	single group and using pre-post surveys and qualitative evaluations (i.e., questionnaires with open-ended questions)		three- and -seven of the intervention period, and three-months post-intervention	seven of the intervention. Lower scores on the QUALID scale signifies higher quality of life. The QUALID score decreased from a mean score of 23 (SD=7.9) to 15 (SD=6.4) at week 3 (p=0.008) and to 13 (SD=4.7) at week 7 (p=0.001). Staff reported that following the implementation of Namaste Care residents had improved verbal and non-verbal communication and decreased agitation.		
McNiel and Westphal (2018) (The United States)	To examine the experiences of residents with advanced dementia, family members, and staff in being involved in the	Qualitative study using a descriptive approach	14 LTC staff (e.g., certified nursing assistants, registered nurses, clergy, and therapists)	Interview data collected 12 months after the launch of Namaste Care	Residents were perceived by staff as being provided with a peaceful environment to experience moments of joy and engagement,	N/A	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	Namaste Care in a LTC facility				Namaste Care promoted meaningful connections between residents, staff, and families, care was more personalized for residents, and change was created for staff in engaging with residents within their unique capabilities.		
Nicholls et al. (2013) (Australia)	To improve delivery of end-of-life care to persons with advanced dementia and the knowledge and skills of LTC staff and enhance communication among residents, their families, and healthcare professionals	Three-phase mixed methods approach (this paper reports on qualitative findings)	12 registered nurses, eight assistants in nursing (i.e., personal support workers/healthcare aides), and 11 family members	Focus group data collected at six-month following the Namaste Care program	Staff reported that providing physical care to residents can also lead to opportunities for emotional engagement. When residents were provided with touch such as massaging, residents reciprocated such behaviours. Interconnectedness was enhanced through Namaste Care. Mental health was found to be part	N/A	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					of reciprocal connectedness with effects on both caregivers and those with advanced dementia.		
Rezapour-Nasrabad (2021) (Iran)	To explore the feasibility of delivering Namaste managed care for older adult patients with Alzheimer's disease in Iran	Feasibility study	20 staff members working in long-term care homes	Survey data collected at one point in time	On a Likert scale ranging from 1 to 5 staff perceived that they would have enough human resources to provide Namaste Care (mean=4.18) and the average feasibility score was 3.95 (SD=0.22). The significance of the findings was unknown as p values were not reported for feasibility.	N/A	1/3
Simard and Volicer (2010) (The United States)	To explore the effects of Namaste Care on residents with advanced dementia in LTC	Pre- and post-intervention design	86 residents with advanced dementia	Quantitative data collected at baseline and at least 30 days after the Namaste Care program	Residents who had baseline withdrawal or decreased social interaction experienced a significant decrease in responsive behaviours after enrolling in Namaste	Minimum Data Set (MDS) Cognitive Performance Scale (Morris et al., 1994); MDS Depression	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					Care with a mean of 3.27 (SD=0.30) at baseline and 2.00 (SD=0.47) post-intervention (p=0.046). There was a significant decrease in use of antianxiety medications post-intervention with a mean number of days when antianxiety medications were used of 0.80 (SD=2.18) at baseline and 0.49 (SD=1.79) post-intervention (p=0.035).	Rating Scale (Burrows, Morris, Simon, Hirdes, & Phillips, 2000); MDS Challenging Behavior Profile (Gerritsen et al., 2008)	
St. John and Koffman (2017) (The United Kingdom)	To understand staff perceptions of the care challenges for patients with advanced dementia and explore staff knowledge of Namaste care	Exploratory qualitative interview study design	Eight staff members including nursing staff, healthcare support workers, a student nurse, an occupational therapist, a dignity manager, and activity workers	Semi-structured interview data collected following the Namaste Care program completion	When Namaste Care was implemented, staff reported a reduction in agitated behaviour and improved connections and communications with patients with dementia through	N/A	2/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	and whether the program helped them provide better care for patients with dementia in an acute hospital setting				sensory stimulation. Staff felt that Namaste Care provided a means to demonstrate care and values towards people with dementia.		
Stacpoole et al. (2015) (The United Kingdom)	To evaluate the effects of Namaste Care on the behavioural symptoms of care home residents with advanced dementia and their pain management	Action research design (this paper reports the quantitative results)	37 residents with advanced dementia	Quantitative data collected at baseline and at three one to two monthly intervals	Severity of behavioural symptoms and occupational disruptiveness were significantly decreased following the launch of Namaste Care ($p<0.001$) and after the second interval ($p=0.003$). These measures were slightly increased in the third interval ($p=0.001$).	Neuro-psychiatric Inventory Nursing Home version (Cummings, 2009)	2/3
Stacpoole et al. (2017) (The United Kingdom)	To determine whether Namaste Care can be implemented in UK care homes and the effects	Organisational action research design (this paper reports on qualitative findings)	40 staff members participated in pre-implementation focus groups and 31 staff members participated in post-implementation	Focus group and interview data were collected at baseline and at three-month post-implementation	Namaste Care provided an alternative to structured care for older people with advanced dementia. After the first three	N/A	3/3

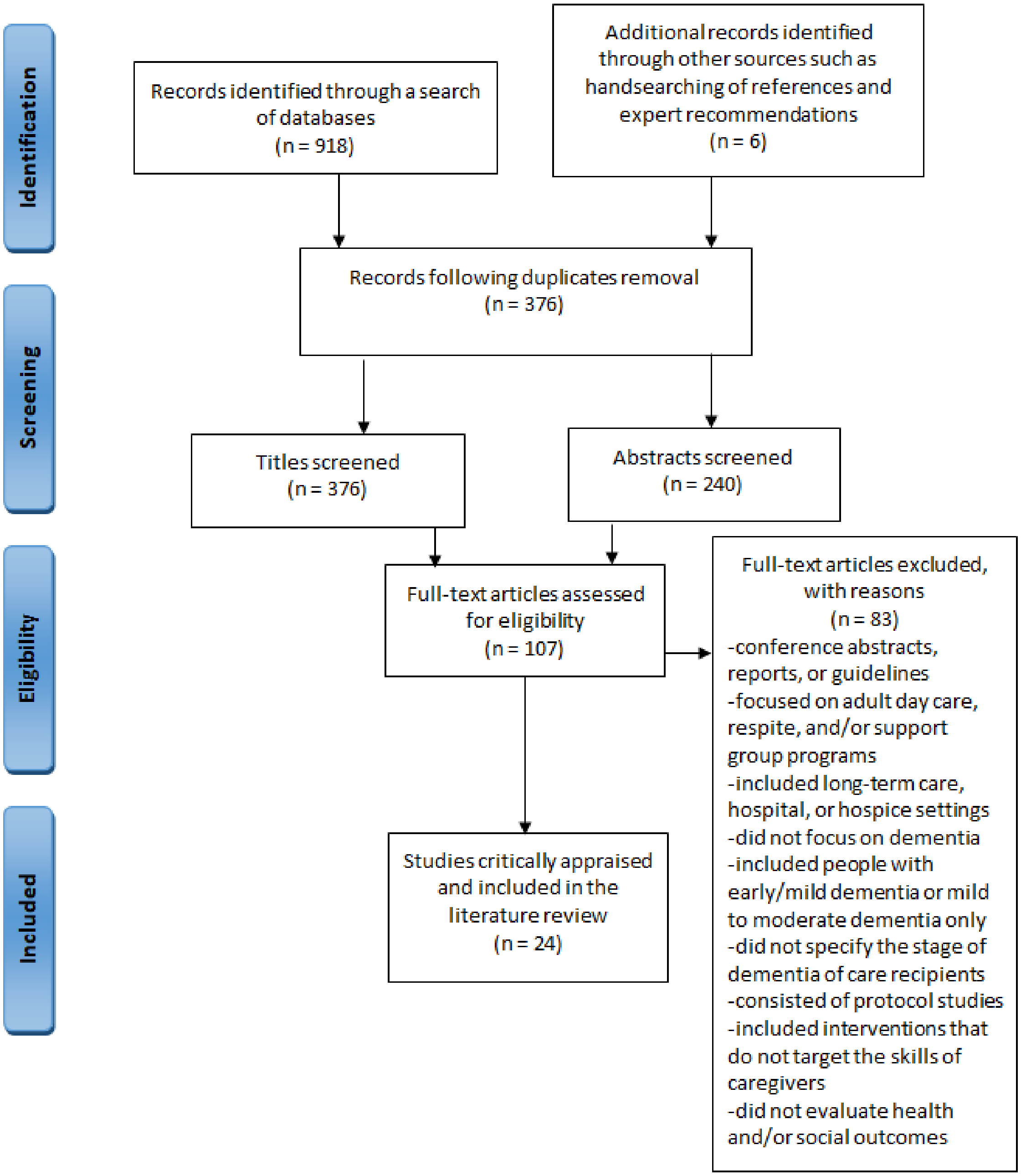
First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
	that the program has on the quality of life of residents with advanced dementia, families, and staff		focus groups. 11 family members participated in focus groups post-implementation. Five care home managers were interviewed either before or after the implementation of Namaste Care.		months that care homes started the Namaste Care program, participants reported a sense of calmness created in care homes and reduction in behavioural and psychological symptoms of dementia. Staff and families reported increased connections with residents with advanced dementia and touch brought them closer together. Namaste Care enhanced dignity for residents. Participants reported an enhanced feeling of well-being among residents, staff, and families.		
Tasseron-Dries et al. (2021)	To explore the experiences of family caregivers, staff	Descriptive exploratory qualitative design	10 family caregivers, 31 long-term care staff members and 2	Semi-structured interviews were conducted with caregivers, staff,	Providing Namaste Care activities was perceived as supporting	N/A	3/3

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
(The Netherlands)	and volunteers in the Namaste Care Family program and facilitators and barriers to family involvement		volunteers who participated in the Namaste Care Family Program.	and volunteers 12 months after Namaste Care was implemented	caregivers in connecting with their relatives which led to meaningful interactions. Caregivers perceived facilitators for their involvement in the Namaste Care Family program were witnessing and experiencing the benefits of the program for residents and matching activities to the preferences of both caregivers and residents. Some of the barriers for family caregivers to engage in Namaste Care were not knowing when to join sessions without feeling like they were disrupting a session, unclear communication about their role from		

First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
					staff, and feeling uncomfortable in delivering unfamiliar activities. For example, hand massages were perceived as too intimate to provide for their relatives. Caregivers perceived that they lacked knowledge and skills in delivering Namaste Care activities and were not certain how to address responsive behaviours occurring during group sessions for residents living with dementia. Not having enough time to participate in Namaste Care was a barrier as caregivers were working, had a family with children.		
Walshe et al. (2019)	To describe intervention	Four-phase study design	18 nursing care home staff, one	Data collected consisted of	Co-design with staff and family members	N/A	2/3

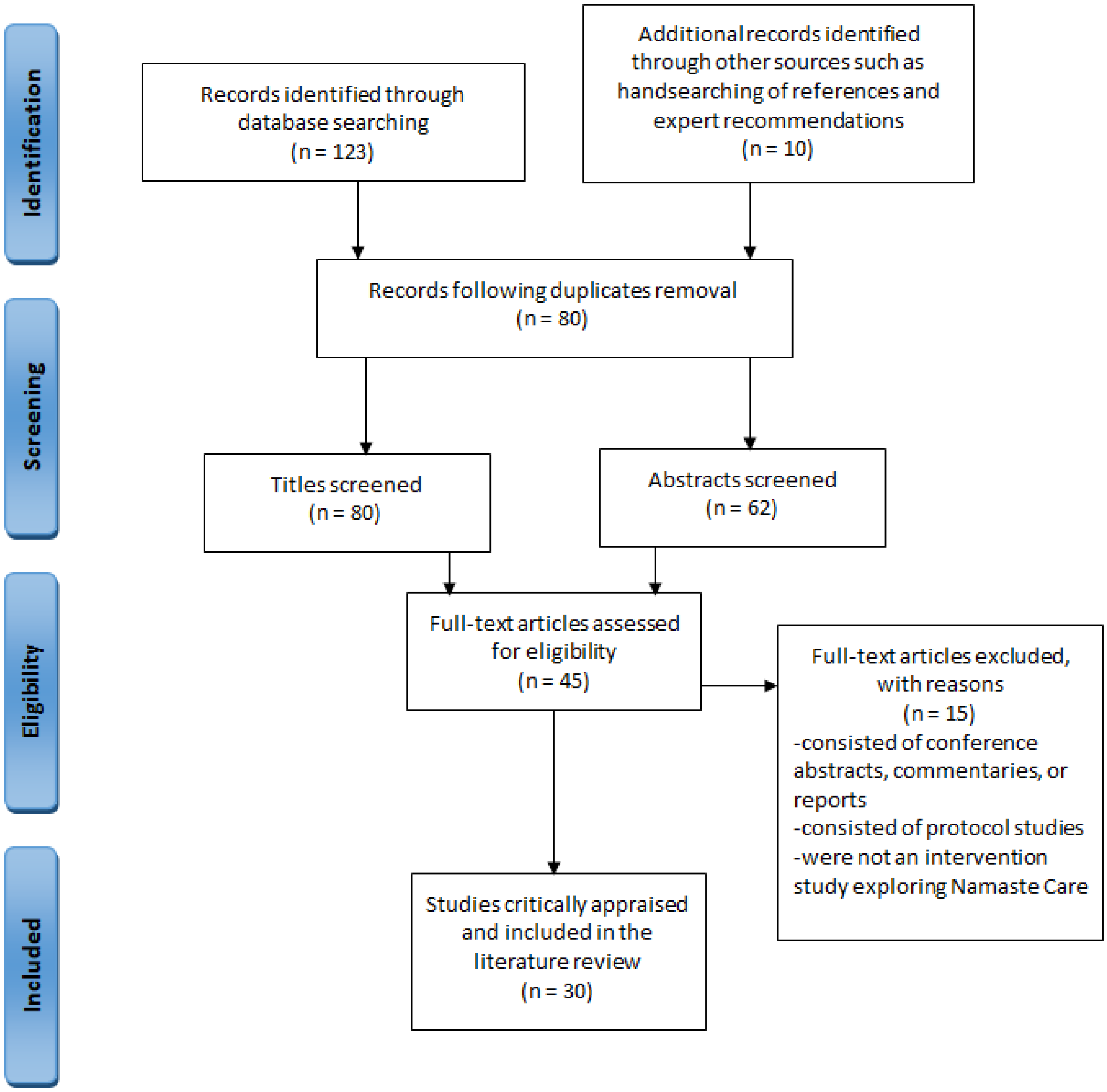
First Author, Publication Year, and Country	Aim(s) of the Study	Design	Sample	Data Collection	Relevant Findings (summary)	Relevant Tools	Quality Score
(The United Kingdom)	development to determine the feasibility of conducting a randomized controlled trial of Namaste Care in a nursing care home in the UK	incorporating workshops to co-design and refine the Namaste Care intervention	family caregiver, one volunteer, and five members of the public involvement panel were involved in all study phases	notes taken during the meetings and documents (e.g., post-it notes and flip-chart sheets)	is an effective approach to achieve consensus on program development. Creating a Namaste Care guide that is readable and accessible for all helps provide clear direction on how to implement it while still ensuring that there is room for flexibility with Namaste Care.		

Appendix D
PRISMA Flow Diagram of the Literature Search on Interventions for Caregivers



Note. The chart format was inspired by the PRISMA flow diagram (Moher et al., 2010).

Appendix E
PRISMA Flow Diagram of Literature Search on Namaste Care



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