



# Interventions for Caregivers of Older Adults with Dementia Living in the Community: A Rapid Review of Reviews

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## Article

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## Résumé

Cette brève revue de revues systématiques examine les interventions non professionnelles qui ont été mises en œuvre pour soutenir les proches aidants de personnes âgées atteintes de démence qui vivent dans la communauté. Un corpus important de littérature empirique examine de telles interventions, mais cette brève revue ne porte que sur les revues systématiques. Des recherches ont été menées dans les bases de données MEDLINE, CINAHL et EMBASE de septembre à décembre 2020 et 19 revues systématiques ont été sélectionnées pour une revue complète. Des résultats positifs sur divers paramètres ont été constatés avec des interventions psychosociales, psychoéducatives et de soutien social et des interventions multicomposantes. Les données probantes indiquent que les interventions multicomposantes, qui sont conçues en fonction des besoins individuels des aidants, sont les plus fructueuses et devraient être appliquées dans l'élaboration de futurs programmes. La combinaison d'interventions la plus efficace demeure inconnue et doit faire l'objet de recherches plus approfondies. Cependant, le succès répété des interventions psychoéducatives, psychosociales et de soutien social montre que lorsqu'elles sont mises en œuvre ensemble, elles peuvent constituer une combinaison efficace qui contribue à des effets positifs pour les aidants. Ce type d'intervention multicomposantes doit être flexible, car les interventions sont plus efficaces lorsqu'elles sont adaptées aux besoins individuels des aidants et modifiées au fil du temps, à mesure que la maladie progresse et que les besoins de l'aidant et du bénéficiaire de soins évoluent.

## Abstract

This rapid review of systematic reviews examines non-professional interventions that have been implemented to support family caregivers of older adults with dementia who are living in the community. There is a robust body of empirical literature examining such interventions for family caregivers; therefore, this rapid review includes only systematic reviews. MEDLINE, CINAHL, and EMBASE databases were searched from September 2020 to December 2020, and 19 systematic reviews were selected for a full review. Psychosocial, psychoeducational, social support, and multicomponent interventions consistently show positive impacts on a variety of outcomes. The evidence suggests that multicomponent interventions that are tailored to the needs of individual caregivers are the most impactful interventions and should be utilized in future program development. The most effective combination of interventions is unknown and warrants further investigation. However, the repeated success of psychoeducational, psychosocial, and social support interventions suggests that when used together, they may be a successful combination that contributes to positive impacts on caregivers. This multicomponent intervention should be flexible, as interventions are most effective when they are tailored to the individual needs of caregivers and adapted over time as the needs of the caregiver and person living with dementia change with disease progression.

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## Introduction

The Canadian health care system is facing one of its greatest challenges as its population is aging so rapidly that predictions suggest that, in 2036, 24.5% of the population will be above the age of 65 (Marier, 2013). Older adults often struggle with several serious health conditions, including dementia. Dementia is a neurodegenerative disorder for which there is no current cure. It impacts an individual's memory and reasoning capabilities, is associated with functional decline, contributes to personality changes, and exacerbates an older adult's vulnerability to adverse health outcomes (McGregor et al., 2017). Worldwide, 46 million people are living with dementia with a projected increase to 131.5 million by 2050 (Petersen, Houston, Qin, Tague, & Studley,

2017). By 2031, it is expected that approximately 1.6 million individuals in Canada will be living with dementia (Petersen et al., 2017). The multitude of costs associated with this complex disease is only increasing, fueling concerns that by 2030 dementia will be the most expensive disease of our society (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014).

Dementia has a profound impact on family and friend caregivers. These informal caregivers have always been an integral part of the care community; however, research into the demographics and needs of this population is relatively recent (Cooke, McNally, Mulligan, Harrison, & Newnam, 2001). In Canada, there are 7.8 million family and friend caregivers who provide essential unpaid care to persons living with dementia, while juggling the demands of work, families, and their own health needs (Family Caregivers of British Columbia, 2020). In high- and middle-income countries, such as Canada, approximately 60% of caregivers are female spouses or middle-aged daughters of the care recipients (Bunn, Goodman, Pinkney, & Drennan, 2016). These caregivers provide support to those who are diagnosed with dementia with varying severities and who require diverse levels of support with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Caregivers often struggle with depression, hopelessness, anxiety, feelings of being overwhelmed and burdened, a lower quality of life, and cardiovascular diseases (Bressan, Visintini, & Palese, 2020; Cheng et al., 2020). Further, an alarming 39% of caregivers experience depression (Abrahams et al., 2018) and do not prioritize mental health support for themselves (Bressan et al., 2020). This has earned caregivers the insightful label of the invisible second patient (Boots et al., 2014; Bressan et al., 2020). The importance of meeting caregivers' needs is reflected in the World Health Organization (WHO) Dementia Action Plan and the National Dementia Strategy in Canada in which they explicitly identify support for dementia carers as a priority action area (Public Health Agency of Canada, 2019; World Health Organization, 2017). Although there are services in place to support caregivers of older adults with dementia, they have a higher level of unmet needs and lower utilization rates of available services in comparison to caregivers of individuals with other chronic diseases (Bressan et al., 2020). If caregivers lack support, their ability to provide adequate care to those with dementia may be compromised. This could diminish the amount and quality of care that is provided to older adults with dementia, subsequently contributing to increased demands on the health care system.

The purpose of this rapid review was to identify and report the evidence from systematic reviews examining interventions that could be implemented by non-professionals to support the needs of caregivers of persons living with dementia. It is essential to understand the efficacy of interventions in meeting the needs of family and friend caregivers to ensure that the development of new interventions is evidence-based, and will contribute to positive impacts on caregivers.

## Methods

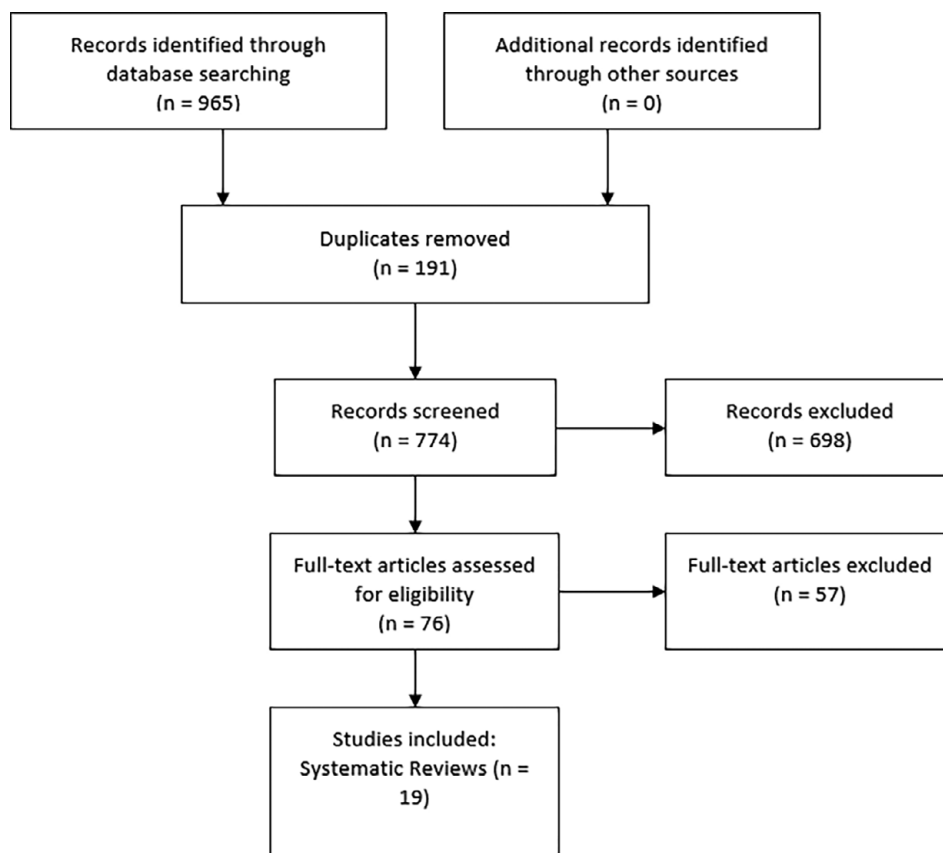
This overview followed the Joanna Briggs methodology (The Joanna Briggs Institute, 2015). To ensure all requirements of a rapid review were met, the Brief Review Checklist (BRC) by Abrami et al. (2010) was also used (see [Supplementary Material](#)). The BRC ensures that key components of a brief review are adequately focused on through a methodical process (Abrami et al., 2010). A brief review is an examination of the literature with limits, which

may include the time period in which the review was conducted, the breadth of the research question, and the depth of the analysis (Abrami et al., 2010). These reviews are useful for developing a broad understanding of evidence to inform precise questions for future research (The Joanna Briggs Institute, 2015). Brief reviews that follow the BRC can be useful as they consolidate evidence that can support research and be useful to policy-makers (Abrami et al., 2010).

This rapid review was conducted using MEDLINE, CINAHL, and EMBASE databases over a four-month period from September 2020 to December 2020. The review question was, "What is the empirical evidence on non-professional interventions to meet the needs of family caregivers of persons living with dementia?" As there is a robust body of literature examining interventions for caregivers, only systematic reviews were examined in this review. A review of systematic reviews can make sense of a large amount of data by providing a succinct summary of findings from a variety of studies. The search strategy included conceptual terms related to dementia AND caregiving AND systematic review (see [Table 1](#)). Terms were identified in consultation with a library scientist and from a review of key terms of studies that had been identified as applicable to the review. The search strategy was designed to identify systematic reviews of qualitative and quantitative studies that examined interventions to support family and friend caregivers of older adults with dementia. The limits applied to this search included systematic reviews published in the English language, those with abstracts, and those published during or after the year 2000. The search yielded 965 systematic reviews (see [Figure 1](#)). After duplicates were removed, these systematic reviews were screened using the inclusion and exclusion criteria outlined in [Table 2](#). It is important to note that this overview was conducted to inform the development of a community-based, peer-led intervention. Therefore, reviews that focused only on interventions that could be provided by a professional (e.g., mental health services) were excluded to ensure that the interventions could potentially be provided by trained volunteers and findings could support the development of a volunteer navigation program. Some systematic reviews discussed interventions that also included a service provided by a professional. However, the program was coordinated by a non-professional and/or provided additional services that did not require a professional. Therefore, the findings were still relevant to

**Table 1.** Search strategy

Database	Search String
MEDLINE	"caregivers" MH, "dementia" MH, "Alzheimer's disease" MH, "cognitive dysfunction" MH, (1)"dementia" OR "Alzheimer's disease" OR "cognitive dysfunction", (2)"caregivers" AND "dementia" OR "Alzheimer's disease" OR "cognitive dysfunction", (3)"systematic review" MH, combined search (1), (2) and (3)
CINAHL	"caregivers" MH, "dementia" MH, "Alzheimer's disease" MH, "cognitive dysfunction" MH, (1)"dementia" OR "Alzheimer's disease" OR "cognitive dysfunction", (2)"caregivers" AND "dementia" OR "Alzheimer's disease" OR "cognitive dysfunction", (3)"systematic review" MH, combined search (1), (2) and (3)
EMBASE	"caregivers" MH, "dementia" MH, "Alzheimer's disease" MH, "cognitive dysfunction" MH, (1)"dementia" OR "Alzheimer's disease" OR "Cognitive Dysfunction", (2)"caregivers" AND "dementia" OR "Alzheimer's disease" OR "cognitive dysfunction", (3) "systematic review", combined search (1), (2) and (3)



**Figure 1.** Prisma flow diagram. The search was conducted over a four-month period from September 2020 to December 2020.

**Table 2.** Inclusion and exclusion criteria

Inclusion	Exclusion
English language	Reviews addressing needs of caregivers when the care recipient is being transferred to long-term care.
Systematic review	Reviews that targeted person living with dementia.
Reported outcomes for an intervention for caregivers of older persons living with dementia	Reviews focused specifically on grief and bereavement of caregivers.
Articles available during the search period from September 2020 to December 2020	Reviews specific to early onset dementia.
	Reviews focused on a specific subset of the caregiver population (e.g., ethnicity specific, veterans, community specific).
	Reviews that focused only on professionally delivered interventions (e.g., mental health interventions).
	Reviews published during or after the year 2000

the purposes of this review. A screening of abstract and titles was conducted by a single reviewer (MH) in consultation with a second reviewer (BP). No reliability indices were calculated. The full texts of seventy-six systematic reviews were retrieved and reviewed for potential inclusion. This resulted in a final sample size of 19 systematic reviews. Reference searching of these systematic reviews yielded no further results.

Data from these systematic reviews were described using a data extraction table to help facilitate an analysis of the interventions, identify common outcomes measured, the kind of interventions implemented, and the strengths and limitations of the studies, while also enable comparisons across studies. That table is provided in the [supplementary material](#). There was a diverse set of interventions and outcomes reported on in the final sample of reviews. To facilitate analysis across these reviews, a thematic analysis was constructed of the interventions (see [Table 3](#)) and outcomes (see [Table 4](#)). This was necessary as there were a number of interventions and outcomes that were conceptually similar but named differently across systematic reviews. Placing these into thematic groupings allowed a more robust comparison across reviews. The significance and impact of interventions reported were collected from the reporting in the systematic reviews, and additional analyses were not conducted for this review.

### Findings

There is a large body of research that examines a variety of interventions intended to support caregivers of people living with dementia. Interventions were thematically organized as psychosocial, key workers, technology based, multicomponent, case management/care coordination, psychoeducational, and exercise and health promotion (see [Table 3](#)). Outcomes were thematically organized as burden, depression and anxiety, social outcomes, knowledge and skills, quality of life, health and well-being, and health care services utilization (see [Table 4](#)). The most frequently examined outcomes included burden, depression and anxiety, and health and

**Table 3.** Intervention categories

Intervention Category	Interventions Mentioned in Systematic Reviews
Psychosocial interventions	Support groups, role play, counselling, stress and mood management, CBT, general social support, befriending, peer support, respite
Key workers	Admiral nurses, guidance by a coach, professionals, volunteers
Technology-based interventions	Any type of intervention administered electronically, telephone-based supports, e-health, computer-based
Multicomponent interventions	Interventions that utilize more than one form of intervention together
Case management/care coordination	Case management, care coordination
Psychoeducational interventions	Interventions providing people with information (about their personal needs, and the care recipient's needs), social skills training
Exercise and health promotion	Complementary and alternative medicine (CAM) therapy, healing touch (e.g., registered massage therapist), yoga, meditation, aerobics, strength, balance, occupational therapy

**Table 4.** Outcome categories

Outcome Categories	Outcomes Mentioned in Systematic Reviews
Burden depression and anxiety	Burden, stress Depressive symptoms, depression, anxiety, depressive symptoms and anxiety, psychological morbidity
Social outcomes	Social support, support needs, being supported, reduced isolation, loneliness
Knowledge and skills	Sense of competence, mastery, educational needs, knowledge, ability/knowledge, receiving accessible and personalized information, being trained and educated to care for beloved with dementia, sense of competence, decision-making confidence, self-efficacy, self-esteem, ability to continue with caring role, self-efficacy
Health and well-being	Physical well-being, mental well-being, general health or well-being, subjective well-being, psychosocial well-being, neuropsychiatric symptoms, mood
Quality of life	Balance between caregiver and people living with dementia's needs, positive aspects of caregiving
Health care services utilization (caregivers and person living with dementias)	Time for the care recipient to be institutionalized, move into long-term care, hospitalizations, number of volunteer visits

well-being. Fewer studies examined the efficacy of interventions on social outcomes, knowledge and skills, quality of life, and health care services utilization. While there is variation in the efficacy of interventions across outcomes, psychoeducational, psychosocial, social support, and multicomponent interventions that utilize a combination of these approaches consistently result in positive impacts on several outcomes.

### Burden

Burden, which encompasses the experience of both burden and stress, was the most frequently investigated outcome. Seventeen of the 19 systematic reviews that were extracted examined the impact of various interventions on caregiver burden (Abrahams *et al.*, 2018; Boots *et al.*, 2014; Bunn *et al.*, 2016; Cheng *et al.*, 2020; Cooke *et al.*, 2001; Corbett *et al.*, 2012; Dam, de Vugt, Klinkenberg, Verhey, & Van Boxtel, 2016; Deeken, Rezo, Hinz, Discher, & Rapp, 2019; Goeman, Renahan, & Koch, 2016; Hopwood *et al.*, 2018; Kishita, Hammond, Dietrich, & Mioshi, 2018; Leven *et al.*, 2013; McKechnie, Barker, & Stott, 2014; Smith & Greenwood, 2014; Smits *et al.*, 2007; Thompson *et al.*, 2007; Vandepitte *et al.*, 2016). The interventions used to address burden included psychosocial, key workers, case management and/or care coordination, education and skills training, exercise and/or health promotion, and multicomponent (Abrahams *et al.*, 2018; Boots *et al.*, 2014; Bunn *et al.*, 2016; Cheng *et al.*, 2020; Cooke *et al.*, 2001; Corbett *et al.*,

2012; Dam *et al.*, 2016; Deeken *et al.*, 2019; Goeman *et al.*, 2016; Hopwood *et al.*, 2018; Kishita *et al.*, 2018; Leven *et al.*, 2013; McKechnie *et al.*, 2014; Smith & Greenwood, 2014; Smits *et al.*, 2007; Thompson *et al.*, 2007; Vandepitte *et al.*, 2016). Fifteen of the 17 systematic reviews reported that the caregiver intervention under investigation significantly decreased caregiver burden (Abrahams *et al.*, 2018; Boots *et al.*, 2014; Bunn *et al.*, 2016; Cheng *et al.*, 2020; Cooke *et al.*, 2001; Dam *et al.*, 2016; Deeken *et al.*, 2019; Goeman *et al.*, 2016; Hopwood *et al.*, 2018; Kishita *et al.*, 2018; Leven *et al.*, 2013; McKechnie *et al.*, 2014; Smith & Greenwood, 2014; Smits *et al.*, 2007; Vandepitte *et al.*, 2016). Specific components of interventions that contributed to positive outcomes included psychoeducational skill-building, interventions that were delivered individually rather than in groups, and multicomponent interventions (Kishita *et al.*, 2018; Vandepitte *et al.*, 2016). Eight of the 17 systematic reviews reported null associations (Bunn *et al.*, 2016; Cooke *et al.*, 2001; Corbett *et al.*, 2012; Dam *et al.*, 2016; Deeken *et al.*, 2019; Leven *et al.*, 2013; Smits *et al.*, 2007; Vandepitte *et al.*, 2016). Non-significant results, or no impacts, were noted as attributed to volunteer led interventions, group-based single component interventions, and low-quality studies (Boots *et al.*, 2014; Bunn *et al.*, 2016; McKechnie *et al.*, 2014; Vandepitte *et al.*, 2016). Specific measurements contributed to mixed findings. Quantitative measures often identified conflicting findings from those found through qualitative measurements, which contributed to the mixed results (Corbett *et al.*, 2012; Smith & Greenwood, 2014).

In addition, assessments conducted at longer follow-up time points demonstrated non-significant results or no impacts (Leven et al., 2013). Two studies recognized that, in some cases, peer telephone network and telephone lectures, as well as case management interventions, further exacerbated burden (Cooke et al., 2001; Smits et al., 2007).

### *Depression and Anxiety*

Depression and anxiety were grouped as one outcome as they were often targeted together in interventions and assessed together in the presentation of findings. Fourteen studies investigated this outcome and identified positive effects (Abrahams et al., 2018; Boots et al., 2014; Bunn et al., 2016; Cheng et al., 2020; Dam et al., 2016; Deeken et al., 2019; Hopwood et al., 2018; Kishita et al., 2018; McKechnie et al., 2014; Parra-Vidales, Soto-Pérez, Perea-Bartolomé, Franco-Martín, & Muñoz-Sánchez, 2017; Smith & Greenwood, 2014; Smits et al., 2007; Thompson et al., 2007; Vandepitte et al., 2016). The specific components of interventions that contributed to positive impacts included befriending, peer support, cognitive behavioural therapy, psychoeducational interventions, group-based interventions, telephone support groups for caregivers over the age of 65, and multicomponent interventions (Dam et al., 2016; Kishita et al., 2018; Parra-Vidales et al., 2017; Smith & Greenwood, 2014; Smits et al., 2007; Vandepitte et al., 2016). Ten systematic reviews reported non-significant results or no impact, which were noted as being attributed to assessments that were conducted during long follow-up periods, low quality studies, individual and group-based, single-component interventions, telephone support groups, and psychoeducational skill building (Abrahams et al., 2018; Boots et al., 2014; Bunn et al., 2016; Dam et al., 2016; Deeken et al., 2019; Kishita et al., 2018; McKechnie et al., 2014; Smits et al., 2007; Thompson et al., 2007; Vandepitte et al., 2016). One study identified a negative outcome when correlated with case management interventions (Smits et al., 2007).

### *Health and Well-Being*

Health and well-being are outcomes that encompass several aspects of health, including physical well-being, mental well-being, general health, subjective well-being, and mood. These outcomes were discussed in 13 systematic reviews (Abrahams et al., 2018; Bunn et al., 2016; Cheng et al., 2020; Cooke et al., 2001; Goeman et al., 2016; Hopwood et al., 2018; Kishita et al., 2018; Leven et al., 2013; McKechnie et al., 2014; Parra-Vidales et al., 2017; Smith & Greenwood, 2014; Smits et al., 2007; Vandepitte et al., 2016). Positive impacts from interventions were highlighted in 11 systematic reviews (Abrahams et al., 2018; Bunn et al., 2016; Cheng et al., 2020; Cooke et al., 2001; Hopwood et al., 2018; Kishita et al., 2018; Leven et al., 2013; McKechnie et al., 2014; Parra-Vidales et al., 2017; Smits et al., 2007; Vandepitte et al., 2016). The types of interventions associated with positive outcomes included multicomponent interventions, specialist nursing and community support, psychosocial interventions, Internet-based support interventions, psychoeducational and psychotherapeutic programs, dyadic psychosocial interventions between the caregiver and person living with dementia, computer-based, and supportive strategies (Abrahams et al., 2018; Bunn et al., 2016; Cheng et al., 2020; Cooke et al., 2001; Hopwood et al., 2018; Kishita et al., 2018; Leven et al., 2013; McKechnie et al., 2014; Parra-Vidales et al., 2017; Smits et al.,

2007; Vandepitte et al., 2016). Non-significant results or no impacts were identified in 10 systematic reviews (Abrahams et al., 2018; Bunn et al., 2016; Cooke et al., 2001; Goeman et al., 2016; Kishita et al., 2018; Leven et al., 2013; McKechnie et al., 2014; Smith & Greenwood, 2014; Smits et al., 2007; Vandepitte et al., 2016). These results were noted as being attributed to low-quality studies, one-to-one befriending, programs that lacked communication skills training components, psychoeducational interventions, psychosocial interventions, support worker roles, and long follow-up periods (Abrahams et al., 2018; Bunn et al., 2016; Cooke et al., 2001; Goeman et al., 2016; Kishita et al., 2018; Leven et al., 2013; McKechnie et al., 2014; Smith & Greenwood, 2014; Smits et al., 2007; Vandepitte et al., 2016). Negative impacts on health and well-being were not noted.

### *Social Outcomes*

The category of social outcomes includes aspects of social support, support needs, and reductions in isolation and loneliness. Social outcomes were examined in seven systematic reviews (Abrahams et al., 2018; Cheng et al., 2020; Cooke et al., 2001; Dam et al., 2016; Goeman et al., 2016; McKechnie et al., 2014; Smith & Greenwood, 2014). Positive impacts were identified in six systematic reviews and were noted as being attributed to the use of multicomponent interventions, psychosocial interventions, computer-mediated interventions, and telephone peer support interventions (Abrahams et al., 2018; Cheng et al., 2020; Cooke et al., 2001; Dam et al., 2016; McKechnie et al., 2014; Smith & Greenwood, 2014). In five systematic reviews, non-significant impacts or no reporting of results was provided (Cooke et al., 2001; Dam et al., 2016; Goeman et al., 2016; McKechnie et al., 2014; Smith & Greenwood, 2014). It was highlighted that these results were attributed to poor quality studies, non-standardized measurements among studies, which made it challenging to determine the collective impacts of interventions, and quantitative assessments that failed to recognize the positive results identified through qualitative assessments (Cooke et al., 2001; Dam et al., 2016; McKechnie et al., 2014; Smith & Greenwood, 2014). Negative impacts on social outcomes were not identified in any of the systematic reviews.

### *Knowledge and Skills*

Knowledge and skills are outcomes that encompass feelings of competency, knowledge about dementia, the acquisition of accessible and personalized information, self-efficacy, and self-esteem. These outcomes were evaluated in six systematic reviews (Boots et al., 2014; Cheng et al., 2020; Dam et al., 2016; McKechnie et al., 2014; Parra-Vidales et al., 2017; Vandepitte et al., 2016). Positive results were found in five of these systematic reviews, and authors attributed these to the success of Internet-based supportive interventions to meet educational and support needs, computer-mediated interventions, psychoeducational interventions through web-based and non-web-based platforms, and supportive strategy interventions (Boots et al., 2014; Cheng et al., 2020; McKechnie et al., 2014; Parra-Vidales et al., 2017; Vandepitte et al., 2016). Two systematic reviews found non-significant results or no impacts and attributed these results to the use of quantitative measures that may have been unable to detect the full impact of interventions (Boots et al., 2014; Dam et al., 2016). Negative impacts were not reported in any systematic reviews.

### Quality of Life

Quality of life was examined in seven systematic reviews, and positive impacts were identified in all of them (Corbett *et al.*, 2012; Dam *et al.*, 2016; Goeman *et al.*, 2016; Lee, Ryoo, Crowder, Byon, & Williams, 2020; Leven *et al.*, 2013; McKechnie *et al.*, 2014; Smits *et al.*, 2007). It was highlighted that these results were attributed to the use of information and advice services, social support using video-conferencing, support groups, support workers, supportive strategies, psychosocial interventions, dyadic psychosocial interventions between the caregiver and person living with dementia, and computer-mediated interventions (Corbett *et al.*, 2012; Dam *et al.*, 2016; Goeman *et al.*, 2016; Lee *et al.*, 2020; Leven *et al.*, 2013; McKechnie *et al.*, 2014; Smits *et al.*, 2007). Non-significant results or no impacts were identified in five systematic reviews (Dam *et al.*, 2016; Lee *et al.*, 2020; Leven *et al.*, 2013; McKechnie *et al.*, 2014; Smits *et al.*, 2007). It was highlighted that specific interventions attributed to these results included befriending and peer support, family support, network interventions, and case management (Dam *et al.*, 2016; Lee *et al.*, 2020; Leven *et al.*, 2013; McKechnie *et al.*, 2014; Smits *et al.*, 2007). In some cases, positive impacts that were identified in the first measurement were non-significant at follow-up (Corbett *et al.*, 2012). Negative impacts were not reported in any systematic reviews.

### Health Care Services Utilization

The outcome of health care services utilization includes the time for the person living with dementia to move into long-term care or includes when the care recipient moved into long-term care, the number of times the person living with dementia is hospitalized, person living with dementia hospitalizations, and the number of volunteer visits made to the caregiver. This outcome was examined in three systematic reviews, and positive impacts were identified in all (Bunn *et al.*, 2016; Goeman *et al.*, 2016; Vandepitte *et al.*, 2016). Interventions that had positive impacts included psychosocial support provided by specialist nursing and community support, support worker roles, support group meetings, at-home training, and information sessions (Bunn *et al.*, 2016; Goeman *et al.*, 2016; Vandepitte *et al.*, 2016). The efficacy of information sessions was assessed again at a two-year follow-up time point, and non-significant results were detected (Vandepitte *et al.*, 2016). Inconclusive results were determined in one intervention that utilized case management (Bunn *et al.*, 2016). Negative impacts were not identified in any of the systematic reviews.

### Discussion

The aim of this review was to identify and report the evidence from systematic reviews examining interventions that could be implemented by non-professionals to support the needs of caregivers of persons living with dementia. This review demonstrates that while there is variation in their efficacy, psychosocial, psychoeducational, social support, and multicomponent interventions consistently contributed to positive impacts on a multitude of outcomes for caregivers of people with dementia. Psychosocial interventions were positively related to increased health and well-being, social outcomes, quality of life, and health care utilization (when provided by specialist nursing and community support). Psychoeducational interventions positively impacted burden, depression and anxiety, health and well-being, knowledge and skills, and health care utilization. Social support interventions contributed to positive impacts

on depression and anxiety, health and well-being, knowledge and skills, quality of life, and health care utilization. Evidently, psychosocial, psychoeducational, and social support interventions can have broad impacts and may be important to incorporate into multicomponent interventions that are developed in the future.

Multicomponent interventions that are tailored to the individual needs of caregivers appeared to be the most frequently cited effective intervention, demonstrating positive impacts on burden, depression and anxiety, health and well-being, and social outcomes and should be utilized more frequently. The Resources for Enhancing Alzheimer's Caregivers (REACH II) project and the New York University Caregiver Intervention Program are successful multicomponent interventions that may provide insight into what features of interventions are impactful and the role of different care providers in administering interventions (Bunn *et al.*, 2016; Cheng *et al.*, 2020). REACH II incorporates nine one-hour home visits, three telephone follow-up sessions, and phone-based or center-based support group sessions with training that focuses on safety, social support, self-care, emotional well-being, managing difficult behaviours, communication, and community support (Cheng *et al.*, 2020). The New York University Caregiver Intervention Program consists of individual and family counselling sessions and a weekly support group (Cheng *et al.*, 2020). Both of these programs use a mix of individual sessions and group meetings through face-to-face or telephone-assisted mediums. Each program focuses on the specific and tailored needs of the caregiver, which was highlighted as an effective component of interventions (Cheng *et al.*, 2020; Fauth *et al.*, 2019). Further, each program incorporates psychosocial, psychoeducational, and social support interventions. These programs may provide guidance as components of interventions in both programs demonstrate positive impacts on burden, depression and anxiety, health and well-being, and social outcomes.

Mixed results, non-significant findings or no impacts were frequently found and were noted as being attributed to several factors, including measurements to assess effects, specific components of interventions, and methods of delivery of interventions. These factors included low-quality studies, the use of quantitative measurements that were unable to capture the nuances of the impacts, and follow-up assessments in which the impacts were no longer identifiable. Single-component interventions were associated with non-significant results on burden, depression and anxiety, and health and well-being. Specifically, interventions that did not incorporate communication skills training, psychoeducation, psychosocial support, and support workers contributed to non-significant results on health and well-being. The interventions' method of delivery also impacted efficacy. Interventions provided through various forms of technology positively affected depression and anxiety, social outcomes, health care utilization, quality of life, knowledge and skills, and health and well-being. Interventions conducted over the phone, such as telephone support groups, decreased experiences of depression and anxiety and had positive impacts on social outcomes. Social supports that were provided through video conferencing also had positive impacts on quality of life. Computer-based interventions had positive impacts on health and well-being, social outcomes, knowledge and skills, and health care utilization. Finally, whether interventions were conducted individually or in groups contributed to different impacts on various outcomes. For example, the experience of burden was reduced when interventions were delivered individually. In contrast, depression and anxiety were reduced when interventions were provided in groups. Specifically, support groups were

impactful on depression and anxiety as well as the utilization of health care services, and quality of life. These findings demonstrate that there is insufficient evidence to suggest that one measurement type, specific component of an intervention, and mode of delivery are more effective as findings were case-specific, contextual, and inconsistent.

### Limitations

This is a rapid review of systematic reviews. Therefore, some of the nuanced findings may have been unintentionally excluded as a review of primary research was not conducted. Often, the systematic reviews did not provide detail on the specific components of interventions, or additional factors that may have contributed to findings. This made it challenging to understand the root cause of the efficacy of interventions and how best to implement them in future programs. Systematic reviews that were examined presented findings that did not differentiate between qualitative and quantitative data, as well as those that differentiated between qualitative and quantitative data. This resulted in the inability for qualitative and quantitative findings to be presented and discussed separately in this review. It was difficult to compare findings across studies as there was much heterogeneity among intervention and outcome labels and definitions, which was a problem also noted in many of the systematic reviews. Systematic reviews that focused on understanding the impact of interventions on a very specific population such as veterans or non-English speaking caregivers were excluded as this level of specificity limited the generalizability of findings. However, this is a limitation of the review. A further limitation was the lack of inter-rater reliability and systematic review quality assessment. Finally, this review was conducted over a four-month period with a limited number of databases and can be considered as brief (Abrami et al., 2010). Articles published after the search period ended in 2020 are not included in this review. Therefore, the findings may not be as comprehensive as other reviews.

### Implications for Program Development and Clinical Relevance

There are several key findings that could be used to guide the development of new programs to support caregivers more effectively. Psychosocial, psychoeducational, social support, and multi-component interventions consistently show positive impacts across a multitude of outcomes. While many interventions had positive impacts on one variable, only these had positive impacts on several outcomes. This is important as it provides an understanding of effective interventions that can be used in future programs. Multicomponent interventions that are tailored to the needs of individual caregivers should be the focal point in future programs as they consistently contributed to positive impacts. Increased clarity regarding which interventions should be used in conjunction with one another within multicomponent interventions is required and can be realized through the development of additional programs and evaluations of their impacts. Future programs should implement a combination of psychosocial, psychoeducational, and social support interventions as they were successful interventions when implemented individually, and in the multi-component REACH II and New York University programs. The use of technology in administering interventions can impact several outcomes. This is important as it is a cost-effective approach that can increase access for a variety of caregiver populations, such as those living in rural communities (Newman, He Wang, Ze Yu Wang, & Hanna, 2019). It is essential that future programs identify

and target the outcomes they intend to impact through interventions in the development stages as the efficacy of interventions are often outcome-specific. Further, adaptations to some interventions are required, as several interventions, such as case management, were consistently unable to achieve positive impacts. Careful consideration of these key findings and efforts to incorporate their lessons into the development of new programs may increase the efficacy of interventions and the positive impacts on caregivers.

It is crucial to the health and well-being of caregivers, the person living with dementia, and the health care system that caregivers receive adequate support to remain capable of providing care to older adults with dementia as they are essential providers in the care community. The hours of informal care that they provide are approximately 82 billion worldwide, which is equivalent to more than 40 million full-time workers (Cheng et al., 2020). As the population of older adults continues to increase, this number is projected to rise to 65 million full-time workers by 2030, representing a potentially detrimental economic and workforce strain on our health care system (Cheng et al., 2020). The diminished mental and physical health of caregivers will increase the likelihood that care recipients are moved to long-term care facilities, which is an extremely costly form of care for both individual families and the health care system (Abrahams et al., 2018). Further, the preference of many persons living with dementia is to age in place. Currently, dementia has no known cure and pharmacological approaches to mitigate symptoms are limited; therefore, the need for caregivers will only continue to increase. Evidently, a deep understanding of the most effective interventions that can be used to inform the development of future support programs is essential to adequately care for caregivers, and subsequently the person living with dementia hospitalizations for the person living with dementias hospitalizations for the person living with dementias.

### Recommendations for Future Research

Several adaptations to future research can contribute to a reduction in inconsistent findings and improve the quality of evidence to support the use of specific interventions. First, it was frequently noted that quantitative assessments did not detect changes that were identified through qualitative research (Boots et al., 2014; Cheng et al., 2020; Dam et al., 2016; Smith and Greenwood, 2014). This may highlight the ability for qualitative assessments to more accurately capture the nuances of the impacts of interventions. Therefore, increased use of qualitative research methods may provide a deeper understanding of the impacts. Second, studies with long follow-up periods were often unable to detect significant impacts of interventions. Therefore, when possible, future studies should incorporate longitudinal research methods to increase the volume of studies and therefore the understanding of the longitudinal impacts of interventions. This will increase our understanding of the long-term impacts of interventions and caregivers' changing needs throughout the disease progression. Other factors that contributed to low-quality studies, such as small sample sizes, psychometrically weak measures, and study designs, contribute to the need of increasing methodological rigor in future research. Third, there is much heterogeneity among outcome and intervention labels throughout studies, which makes it challenging to compare findings. Therefore, standardized labels and definitions of interventions and outcomes should be established and used as a reference point for future research. Fourth, much of the research focused on assessing the impacts of interventions on burden,

depression and anxiety, and health and well-being. As such, future research should focus on understanding the impacts of interventions on other outcomes such as social connections, quality of life, and health care utilization, as they are equally important. Finally, it is essential that efforts are made to determine the most impactful combination of interventions that should be incorporated into multicomponent interventions as this knowledge is required to develop the most effective programs. Therefore, studies comparing multicomponent interventions that utilize different combinations of interventions are important.

## Conclusion

While there is variation in the efficacy of interventions across outcomes, there is sufficient evidence to guide the development of future programs to address the needs of caregivers. Psychoeducational, psychosocial, social support, and multicomponent interventions consistently result in positive impacts on a variety of outcomes. However, the most impactful combination of specific interventions that should be utilized in multicomponent interventions is unclear. Despite this uncertainty, the repeated success of psychoeducational, psychosocial, and social support interventions suggests that these components should be utilized in conjunction with one another in multicomponent interventions that are tailored to the needs of individuals. In order to accomplish this, future programs need to provide adequate time for caregivers and intervention administrators to develop meaningful relationships in which the caregivers feel comfortable to share their individual needs, and the administrator can truly understand them. Improved programs that meet the needs of caregivers must be developed in order to ensure that this vulnerable population is adequately supported, the person living with dementia is cared for, and the financial costs to our health care system and society are reduced.

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