Rapid Synthesis

Empowering Caregivers to Deliver Home-based Restorative Care

27 May 2019

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Rapid Synthesis:
Empowering Caregivers to Deliver Home-based Restorative Care
30-day response

27 May 2019

McMaster Health Forum
> The McMaster Health Forum's goal is to generate action on the pressing health-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health systems – locally, nationally, and internationally – and get the right programs, services and drugs to the people who need them.

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Timeline
> Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. This synthesis was prepared over a 30-business-day timeframe. An overview of what can be provided and what cannot be provided in each of the different timelines is provided on McMaster Health Forum's Rapid Response program webpage (www.mcmasterforum.org/find-evidence/rapid-response).

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KEY MESSAGES

Questions
- What knowledge, attitudes and behaviours do caregivers need support in building from regulated and unregulated health professionals in order to build their confidence and engage them in restorative-care processes?
- What are the most effective ways to teach regulated and unregulated healthcare providers to engage, educate and build the confidence of caregivers in restorative-care processes?

Why the issue is important
- Canada, like most high-income countries, is experiencing an aging population, with those over 65 being on track to represent 25% of the Canadian population by 2050.
- This shift in population demographics is requiring significant changes in the delivery of health and social services including an increased focus on helping individuals to age well at home, and with the significant majority of older adults (93%) living at home, it is estimated that unpaid caregiving accounts for up to 75% of the care older adults receive, roughly equal to $24-$31 billion in unpaid work annually.
- Supporting such transitions is challenging, which is evident from the large number of people classified as an alternative-level-of-care (ALC) patient, which refers to anyone who occupies an acute-care bed in a hospital and who is not acutely ill or does not require hospital-based care.
- To support transitions from hospital to home or other community settings, Canadians have been called on to provide a significant amount of caregiving to their friends and families (e.g., often by choice, 28% of Canadians provide care to a family member, friend or neighbour and roughly half will do so in their lifetime) with the most extended forms of caregiving being for older adults.
- However, caregivers often feel unprepared to provide intensive care and receive little guidance from healthcare providers, and healthcare providers need tools and strategies to enable them to educate, coach and communicate with caregivers.
- Given this, the Canadian Home Care Association requested this rapid synthesis to support the development of a training program for regulated and unregulated healthcare providers within home-based transitional restorative-care (i.e., a focus on supporting optimal functioning over time by enabling clients to regain independence after an illness or injury) teams to engage, educate and empower caregivers in the post-acute care of frail seniors.

What we found
- We found three overviews of systematic reviews which addressed the second question, 29 systematic reviews (seven of high methodological quality and 22 of medium quality) of which 27 address the first question and four address the second question (two included information relevant to both questions), and 17 primary studies of which 15 address the first question and two address the second question.
- We also conducted five key informant interviews to gather additional insights from those with experience and expertise with the questions.
- We identified 27 systematic reviews and 15 primary studies that addressed part of the first question, however, of the literature included, only seven primary studies reported actively engaging with caregivers to determine the knowledge, skills, attitudes, behaviours and resources they believe they need.
- The studies highlight that caregivers emphasized the need for validation of their role, information about the condition and how to provide care, information about the roles of different health professionals and the health system, and informal information from friends and family who have also been caregivers.
- The systematic reviews and other primary studies tended to report on the results of single or multiple interventions which often included skill building or behaviour changes as one element, but was not the primary focus of the study or review.
- Key informants highlighted the need to increase caregivers' technical knowledge (e.g., about the condition, treatment and management of the condition, available resources to support their role, and features of and resources available from the health system to improve navigation), as well as skills in negotiation, communication (both with the recipient of care and with care providers) and using technology.
- The three overviews of systematic reviews, four systematic reviews and two primary studies that were relevant to the second question focused on four broad areas of training/approaches to training: 1) promoting professional behaviour change; 2) using technology to provide training; 3) providing interprofessional training; and 4) providing training as part of dementia care.
- Across these approaches, several common themes about how to develop training programs for healthcare providers include the need to: adopt an iterative and flexible approach that adjusts the training based on needs assessments conducted prior to training and on evaluations of previous offerings of training; derive content based on multiple sources, including from engagement of caregivers, literature (e.g., research evidence and guidelines that provide best practices in a particular care domain); use small-group approaches; combine digital/online and in-person training; provide opportunities for interactive and experiential learning (e.g., in the settings where providers are interacting with caregivers and clients); and use multifaceted approaches that support changing practices, behaviours and peer-group norms.
- Each of the key informants emphasized that training to do this requires a multifaceted, interprofessional approach that is tailored to the unique needs of unregulated and regulated health professionals. This should include didactic, experiential, 'just-in-time' support and ongoing mentorship in order to build reinforcement over time.

QUESTIONS

- What knowledge, attitudes and behaviours do caregivers need support in building from regulated and unregulated health professionals in order to build their confidence and engage them in restorative-care processes?
- What are the most effective ways to teach regulated and unregulated healthcare providers to engage, educate and build the confidence of caregivers in restorative-care processes?

WHY THE ISSUE IS IMPORTANT

Canada, like most high-income countries, is experiencing an aging population, with those over 65 being on track to represent 25% of the Canadian population by 2050. This shift in population demographics is requiring significant changes in the delivery of health and social services including an increased focus on helping individuals to age well at home.(1) However, despite provincial investments in home and community care, the transition away from acute care and towards the community has been relatively slow.

An important part of the problem related to supporting such transitions is the large number of people classified as an alternative-level-of-care (ALC) patient, which refers to anyone who occupies an acute-care bed in a hospital and who is not acutely ill or does not require hospital-based care. For example, estimates indicate that 13% of hospital beds are occupied by ALC patients of which 85% are seniors with complex care needs.(2) Many ALC patients still require care, which can be provided in the home or in other settings (e.g., long-term care homes). The implications of this are that patients are not in the most appropriate setting for receiving the care they need and that hospitals may face difficulty in finding beds for those who need them, thereby causing longer waits for services.(3; 4)

To support transitions from hospital to home or other community settings (e.g., retirement homes and supportive-living facilities), Canadians have been called on to provide a significant amount of caregiving to their friends and families. A pan-Canadian study from 2012 show that each day about 28% of Canadians provide care for a family member, friend or neighbour, and that approximately half of Canadians will do so over the course of their lifespan.(1) Further, statistics show that while many Canadians across the life span require support, the most extended forms of caregiving are provided to meet the needs of older adults.(1) With the significant majority of older adults (93%) living at home, it is estimated that unpaid caregiving accounts for up to 75% of the care older adults receive, roughly equal to $24-$31 billion in unpaid work annually.(5) The average Canadian caregiver provides an average of 19 hours a week of care, with one in 10 providing 30 hours or more.(5) This work comes at a cost beyond that of the valuation of work, as it is estimated that 60% of those providing care to a mother or father report regularly feeling worried or distressed because of their responsibilities, 21% reported feeling depressed, and 7% reported financial difficulties associated with caregiving.(5)

Therefore, while caregivers are essential for determining whether an ALC patient can return and remain at home and for providing care and supports once home, caregivers often feel unprepared to provide intensive care and receive little guidance from care providers for this role. Given this, there is a need to equip caregivers with the knowledge, skills and behaviours needed to be able to provide the care and supports that their family and friends need. In addition, the lack of training or support in providing care causes significant stress among caregivers,(5) and training and education programs for caregivers have been found to have the potential to alleviate some of this stress, and in turn to provide better care for those who need it.(6-8)

However, embedding these types of supports requires changes to the way in which healthcare providers deliver care. In particular, there is a need for increased acknowledgment of the caregiver as part of the care team, and providing frequent and meaningful opportunities for patient and family engagement. For example, communication in care processes can often focus

only on the patient's rehabilitation needs rather than also on the caregiver's needs or how the caregiver's knowledge and strength can be used to enable effective restorative care. In addition, better engaging caregivers requires resources (e.g., to move from predominantly short-term post-acute care to longer-term support for clients and their families dealing with ongoing health concerns), as well as specific tools and strategies to enable healthcare providers to educate, coach and communicate with caregivers. These types of initiatives are increasingly being emphasized as a policy priority in health systems across the country. For example, both the training and education of caregivers as well as patient partnership and community engagement feature prominently in the application for Ontario Health Teams as part of the recently announced health-system reforms.(9)

Given this, the Canadian Home Care Association requested this rapid synthesis to support the development of a training program for providers within home-based transitional restorative-care (i.e., care with a focus on supporting optimal functioning over time by enabling clients to regain independence after an illness or injury)teams to engage, educate and empower family caregivers in the post-acute care of frail seniors.

WHAT WE FOUND

We found:
- three overviews of systematic reviews which addressed the second question;
- 29 systematic reviews (22 of high methodological quality and seven of medium quality) of which 27 address the first question and four address the second question (two included information relevant to both questions); and
- 17 primary studies of which 15 address the first question and two address the second question.

In addition, to gather additional insights from those with experience and expertise with the question, we conducted interviews with five key informants. Two of the key informants were managers in provincial health authorities in two different provinces (Alberta and Ontario). Another key informant was a manager of a hospital-based program supporting transitions to independence at home following hospital care. The remaining two key informants were researchers who have provided training sessions to unregulated and regulated health professionals as part of their research focused on developing and evaluating approaches to empowering caregivers that support older adults with complex conditions. We summarize the key findings from the evidence and insights from interviews with key informants about each of the questions in turn below.

Question 1 - What knowledge, attitudes and behaviours do caregivers need support in building from regulated and unregulated health professionals in order to build their confidence and engage them in restorative-care processes?

Summary of key findings from systematic reviews and primary studies

We identified 27 systematic reviews and 15 primary studies that addressed part of the first question. However, of the literature included in this synthesis, only seven primary studies reported actively engaging with caregivers to determine the knowledge, skills, attitudes, behaviours and resources they believe they need. The systematic reviews and other primary studies tended to report on the results of single or multiple interventions which often included skill building or behaviour changes as one element, but was not the primary focus of the study or review. Given that this information is still relevant to the question and the design of any interventions, we have included it in Table 1 and our summary of key findings below.

Box 2: Identification, selection and synthesis of research evidence

We identified research evidence (systematic reviews and primary studies) by searching (in April 2019) Health Systems Evidence (www.healthsystemsevidence.org), the McMaster Optimal Aging Portal and PubMed. In Health Systems Evidence we conducted two searches for overviews of systematic reviews and systematic reviews using the caregiver category under type of provider combined with: 1) the optimal aging category under themes; and 2) engag* entered in the open search. We also conducted searches for overviews of reviews and systematic reviews in the Staff – Training category (under delivery arrangements) combined with: 1) the optimal aging category under themes; and 2) educational materials, educational meetings and educational outreach under provider-targeted implementation strategies. In the McMaster Optimal Aging Portal we conducted two searches for: 1) caregiver engagement; and 2) caregiver education. In PubMed we searched using the following combination of terms: caregiv* AND (frail* OR older adults OR seniors) AND (engag* OR educat* OR train OR capacity) AND Canada.

The results from the searches were assessed by one reviewer for inclusion. A document was included if it fit within the scope of the questions posed for the rapid synthesis.

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool (see the Appendix for more detail), and the proportion of the included studies that were conducted in Canada. For primary research (if included), we documented the focus of the study, methods used, a description of the sample, the jurisdiction(s) studied, key features of the intervention, and key findings. We then used this extracted information to develop a synthesis of the key findings from the included reviews and primary studies.

All seven of the primary studies that actively engaged caregivers to determine the knowledge, skills, attitudes, behaviours and resources they believe they need used semi-structured interview methods. The studies highlight that caregivers emphasized the need for validation of their role, information about the condition and how to provide care, information about the roles of different health professionals and the health system, and informal information from friends and family who have also been caregivers. In addition, the need for information about other needed non-healthcare resources were emphasized including the importance of financial resources and housing.(10-16) In two of the primary studies, caregivers described the challenges of working in an unrecognized role without adequate financial, informational or educational resources to support them. In particular, caregivers described grappling with constantly changing roles, grasping medical knowledge, emotional stress, financial strains, and changing family dynamics.(10; 13)

For the knowledge required, three reviews and three primary studies placed a significant focus on the need for caregivers to understand the unique conditions being cared for as well as condition-specific management and treatment.(13; 14; 17-20) In particular, one recent medium-quality review and one primary study noted that health providers had a key role in supporting caregivers with this type of information and ensuring it is delivered in plain-language.(13; 17) One review and four primary studies focused on caregivers' need for information during transitions from hospital to home, whether through formal (e.g., health professional about the management of the individual or set up of their home) or informal channels (e.g., experience of friends or family members with similar transitions).(11; 15-17; 21) One of the primary studies also suggested that health professionals use both verbal and written communication to help caregivers to remember instructions moving forward.(15)

With regards to skills, one recent medium-quality review emphasized the importance of providing education on caregiving skills such as personal care, rehabilitation and helping the individual to maintain function, improved patient outcomes related to confusion, incontinence and depression.(17) However, one of the studies included in the review showed no measureable effects from the involvement of carers during the recipient's hospital stay.(17) In addition, seven reviews and one primary study focused broadly on interventions to improve coping and problem-solving skills, finding generally that these interventions helped to support caregiver well-being and reduce the number of problems experienced,(18; 19; 22-27) with one review in particular suggesting the inclusion of both caregivers and patients in training for problem-solving.(24) Two reviews focused on communications training provided to both health professionals and caregivers, finding mixed effects between the two reviews with one reporting improved knowledge and competency while the other found no significant post-training improvement on behavioural challenges, but some reduction in caregiving anxiety and depression.(28; 29) Finally, one study included in a recent medium-quality review examined the impact of calendars and note-taking among caregivers of those with mild-cognitive impairments, and found this practice improved mood and decreased depressive symptoms of caregivers, while another recent medium-quality review found that teaching mindfulness to informal palliative caregivers reduced depression, anxiety and caregiver burden, as well as increased quality of life, hope and overall mental health of the caregiver.(24) The outcomes associated with specific educational and training strategies could not be determined given the multi-component nature of the interventions, and in many instances, no supplementary analyses to tease out the different effects.(23)

Less evidence was found about what is needed to support building the attitudes and behaviours needed by caregivers to engage in restorative-care processes, but this may be a result of the way in which these traits were included in the literature as either part of the intervention or as the outcome of interest. With regards to attitudes, one older medium-quality review included education on attitudes towards people with dementia as part of its training curriculum, but no specific outcomes of the effects of cultivating a positive attitude were reported.(28) In addition, one primary study found that providing caregivers with affirmation and validation of their role from peer helpers was a particularly accessible form of support that allowed caregivers to feel more confident in their roles.(20)

With regards to behaviours, we found three relevant systematic reviews. One recent medium-quality review found social participation to be critical in reducing caregiver isolation, suggesting purposeful activities such as daily tasks and chores and personal development by adopting new hobbies and recreational activities.(30) One older medium-quality review found that half of the studies focused on helping caregivers to support care recipients to conduct activities of daily living, which showed positive effects for activities such as encouraging their participation in daily activity training, choosing meaningful activities, and making environmental adaptations.(31) Another older medium-quality review found that modifications to physical and emotional factors or to lifestyle adaptations can be supported through the use of family-based education that includes the caregiver and care recipient.(32)

Apart from the findings related to knowledge, skills, attitudes and behaviours, a significant portion of the evidence found in the systematic reviews examined the effectiveness of different modes of interventions (e.g., web-based, group-based, etc.) rather than examining whether the content met caregivers' needs.(19; 25; 26; 33-39) In general, these reviews focused on the use of technology, including web- and computer-mediated programs to deliver information, education, training, and psychosocial and behavioural supports to improve the quality of life of caregivers and those they are caring for.(19; 25; 26; 33-37; 39) These reviews found that the use of technology as a mode of delivery is on average as effective as face-to-face interventions, and help to support positive caregiver outcomes, including improved mental well-being, improved caregiving

skills, higher quality of life and improved coping skills.(19; 25; 26; 33-37) Further, one recent medium-quality review found a number of facilitators and barriers for the use of technology to deliver supports for caregivers.(38) Facilitators include: greater independence of the individual receiving care; improved understanding of the condition and visibility of results from treatment and management; improved communication with health professionals; positive outcomes from the inclusion of technology; and improved quality of life for both caregivers and those receiving care.(38) Barriers included: the complexity of the technology; a lack of organizational readiness for implementation; exclusivity of some technology (e.g., requirements to have a smartphone); and concerns about privacy, security and technologies being invasive.(38)

In addition to the use of technology, one primary study found that select tools being used for health professionals can also be used by caregivers, such as observational pain-assessment tools which can help to identify pain levels in individuals with dementia.(40) Two primary studies noted that designing effective supports for caregivers involves assessing the needs of the caregiver, the relationship to the care recipient, unique care situations, and cultural influences, with one finding that this approach led to improved well-being, quality of life, and independence of the caregiver and care recipient.(41; 42) Further, efforts should focus on stimulating caregiver involvement and interest by fostering networking among each other, connecting caregivers to community services, and offering online interactive programs to teach the application of knowledge and skills.(42) Finally, one recent high-quality review found models to support caregivers were most effective on reducing caregiver burden and increasing quality of care when they: included a long-term intervention; face-to-face contact; individualized education and support based on needs; multidisciplinary teams; collaborative input; health and clinical background of support workers; ongoing follow-up; and interprofessional and inter-sectoral collaboration.(43)

Additional information on the systematic reviews and primary studies is available in Table 1 below.

Table 1. Findings from systematic reviews and primary studies on knowledge, skills, attitudes, behaviours, and other resources required

Area to empower caregivers	Examples from the included literature	Modes of delivery and key findings

Knowledge	• Understanding of the individual's condition and medical history
	• Management and treatment of conditions
	• Knowledge of care transitions
	• Community services
	• Health system and roles of health professionals
		• One recent medium-quality review found that structured information tools and sharing life stories can help to improve the sharing of information between recipients, caregivers and staff.(17)
		  ○ The review also found that health professionals have a significant role to play in providing information to support caregivers, in particular about disease-specific information and management and treatment of the condition.(17)
		• One older medium-quality review and three primary studies identified the need for caregivers to be empowered with disease-specific knowledge for them to understand the condition and management symptoms, plan for future decision-making, make timely decisions about preferences, maintain community connection, and access peer support.(13; 14; 19; 20)
		  ○ One of the studies suggested that this information could be provided through education from health professionals delivered in plain language, while the review also identified the need for carers to be involved in and understand the hospital discharge process for better outcomes.
		• Similarly, another recent medium-quality review found that challenges for carers often take place at transitions including a lack of knowledge about medicines and how best to prepare the home following hospital discharge.(17)
		• Four primary studies examined the importance of providing caregivers with information about the transition from hospitals, with the studies emphasizing the importance of acquiring both formal and informal information.(11; 15; 16; 21)
		  ○ One of the studies found that a telephone support program helped caregivers to feel supported and secure in their caregiver role, but also noted that the calls could have been more time-effective.(21)
		  ○ One of the studies suggested that instead of relying on verbal communication, which can be easily forgotten, healthcare providers write down a care outline that details caregivers' responsibilities.(15)
		• One older high-quality review found that teaching procedural knowledge to individuals caring for those who have had a stroke prior to their discharge from hospital was found to have positive effects on stress, strain, distress, depression, anxiety and health-related quality of life.(44)

		• One older medium-quality review found that providing easily accessible information on management and treatment of conditions and the availability of local community services (whether through an online encyclopedia, personalized text and video messages, or a telephone network) reduced caregivers' anxiety and enhanced their self-efficacy.(18) o The same review found that information and advice had no significant reduction in caregiver burden, though resulted in other positive improvements for care recipients including better quality of life. However, given this element was often embedded within larger interventions, delineating specific effects of each program element was difficult. • One primary study found that a significant challenge in understanding health professionals, which exacerbated already fragmented care.(16) • One primary study evaluated the use of an online toolkit to deliver information and education about Alzheimer's and found mixed results among caregivers, with some finding it helpful while others found it was time consuming and not provided at the right time in their caregiving journey.(25)

Skills	• Caregiving (e.g., personal care; helping individual to cope and feel in control; maintaining function; helping with rehabilitation; providing dementia support)
	• Organizational (e.g., note-taking)
	• Coping
	• Advocacy
	• Problem-solving
	• Mindfulness
	• Communication and verbal skills
	• Non-verbal and emotional skills
	• Behavioural management skills
		• One recent medium-quality review found positive effects from educating caregivers on skills for caregiving (e.g., personal care, rehabilitation, helping the individual to cope and feel in control, and maintaining function) improved patient outcomes related to confusion, incontinence and depression, however one included study showed no measureable effects from the involvement of carers during the recipient's hospital stay.(17)
		• One older medium-quality review found evidence to support the adoption of coping strategies, given dysfunctional coping has been associated with depression.
		  o The same review and an older medium-quality review found that training or education for carers of people with dementia to equip them with problem-solving skills can reduce the number of problems carers experience and improve caregivers' ability to manage problem behaviours.(18; 19)
		• One recent and one older medium-quality review found mixed evidence of effectiveness for the use of web-based education for training, coping and advocacy skills, with the most promising outcomes in caregivers' mental health, including reductions in depression, stress and anxiety.(25; 26)
		  o The second review found that the most effective modes of delivery were combined interactive online and person delivered.
		• One study included in a recent medium-quality review examined the impact of calendars and note-taking among caregivers of those with mild-cognitive impairments and found this practice improved mood and decreased depressive symptoms of caregivers.(23)
		• One recent high-quality review found that education interventions to improve coping, knowledge and social support (included as a behaviour below) reduced caregiver burden of those with dementia.
		  o However, the specifics of what was included in each of the interventions was not provided in the review.(45)
		• Similarly, one older medium-quality review found that education alone was insufficient to improve overall attitudes and feelings of distress, guilt and strain, but provided some evidence that education on coping strategies could help to improve interactions between caregivers and care recipients.(46)
		• One recent high-quality review and one older-medium quality review found some evidence to support the use of psycho-education to teach problem-solving, coping and communication skills, however the review cautioned the use of this finding given the heterogeneity of interventions.(47; 48)
		  o Similarly, one primary study found psycho-education can be used to help learn problem-solving and coping skills, but to be effective must involve care recipients as well as caregivers and involve individual behavioural management.(22)
		• One older medium-quality review found involvement of caregivers and care recipients in skill building including problem solving, goal setting, stress management and communication, as well as psycho-education to support stroke

		survivors to cope with changes in lifestyle, resulted in improvements in survivors' physical functioning, knowledge and satisfaction as well as caregiver preparedness, but found mixed effects on burden, anxiety and stress.(27) • One recent medium-quality review found that teaching mindfulness to informal palliative caregivers reduced depression, anxiety and caregiver burden, and increased quality of life, hope and overall mental health of the caregiver.(24) • One older medium-quality review and one recent medium-quality review examined communication-skills training for health professionals and family caregivers and found mixed effects between the two reviews, with one reporting that family caregivers demonstrated improved knowledge and competency, in particular with regards to awareness of communication problems and strategies, while the other found no significant post-training improvements on behavioural challenges, but some reduction in caregiver anxiety and depression.(28; 29)
Attitudes	• Self-efficacy • Self-esteem • Attitudes towards people with dementia • Resiliency • Affirmation	• One older medium-quality review included education on attitudes towards people with dementia as part of its training curriculum, however no specific outcomes towards attitudes were reported.(28) • One primary study found that providing caregivers with affirmation and validation of their role from peer helpers was a particularly accessible form of support that allowed caregivers to feel more confident in their roles.(20)
Behaviours	• Social participation • Activities of daily life • Environmental adaptations • Lifestyle adaptations	• One recent medium-quality review examined ways to reduce isolation through social participation including engaging in purposeful activities such as regular daily tasks and animal contact, or personal development, as well as through structured social participation by joining clubs, engaging in volunteer work, or pursuing recreational activities.(30) • One older medium-quality review found half of the studies focused on helping caregivers to support care recipients to conduct activities of daily living had positive effects and included encouraging their participation in daily activity training, choosing meaningful activities, and making environmental adaptations.(31) • One medium-quality systematic review found that family-based education for heart failure patients and their caregivers that focus on modifying physical and emotional factors or lifestyle adaptions such as reducing sodium intake, can result in improved knowledge in both the caregiver and the patient.(32)
Physical assets	• Housing • Financial resources	• One primary study found that caregivers of stroke survivors identified housing as a critical asset, in particular highlighting the need for it to be in a central location, accessible to stores and readily available support (e.g., close by family or friends or a building manager in an apartment complex).(12) • One primary study documenting focus groups with caregivers acknowledged the financial toll that caregiving can take and emphasized that expanded tax credits could help to lessen the financial burden.(13)

Summary of insights from key informants

Five key informants provided several insights about the types of knowledge, skills, attitudes, behaviours and assets caregivers need to empower them through the restorative-care process. Key informants highlighted the need for role-based and technical knowledge (e.g., about the condition, treatment and management of the condition, available resources to support their role, and features of and resources available from the health system to improve navigation), as well as skills in negotiation, communication (both with the recipient of care and with care providers) and using technology. One of the key informants indicated that the foundation of these types of activities needs to be ensuring that it is done in a way that is culturally appropriate and that overcomes language barriers. It was noted that whenever possible, efforts need to be made to pair caregivers and clients with unregulated or regulated healthcare professionals who speak their language.

For role-based knowledge, one key informant emphasized the need to prepare caregivers for what is going to be involved in their new role in order to ensure that they are prepared to take it on. The key informant highlighted that many new caregivers do not immediately realize the extent of the role until they get home, and then become overwhelmed, but with little access to information as well as professional expertise and support. As a result, the need for enhanced collaboration with families and caregivers prior to discharge was emphasized as a way to equip them with the knowledge, skills and tools related to playing

the role of a caregiver during the restorative-care process. The same key informant also emphasized that the approach and attitude of the entire team needs to be focused on changing the mindset that their role as caregiver is an opportunity to build function for their loved one over time.

With regards to technical knowledge, key informants emphasized the need for caregivers to have a basic understanding of the care recipient's condition and any unique treatment and management approaches that need to be put in place. Key informants described similar areas of focus as in the literature, noting that this practical information is critical for transitions in patient care, such as between the hospital and home. Key informants described the need for caregivers to be informed on how the care recipient's home should be reconfigured to encourage safety, function and independence, how to support the individual in and out of vehicles, and how to encourage activities of daily living. Other technical knowledge that key informants thought caregivers would need is an understanding of what resources are at their disposal, including any community-based supports in place for caregivers as well as any financial or employment supports (e.g., extended time off for caregiving) that may be available. Key informants also noted the importance of caregivers having a working knowledge of the health system to be in a position where they are able to effectively coordinate care, as well as skills to effectively communicate with providers and advocate for the care recipient. This was also highlighted in the literature included above.

Closely tied to understanding available resources and the set-up of the health system, key informants described the need for negotiation skills when acting as a care coordinator and to gain access to available resources. They also stressed that caregivers should be good communicators to effectively pass information between providers and to provide support and motivation for the care recipient. In addition, key informants described having good technology skills as being an asset to home-based restorative care. The additional supports that can be provided through technology, whether monitoring blood pressure or using an assistive device, can relieve the caregiver of significant work, and the use of this technology is easier when the caregiver is familiar and comfortable with it.

Question 2 - How should education and information-provision interventions be provided to health professionals to best empower caregivers throughout restorative-care processes?

Summary of key findings from systematic reviews and primary studies

We identified three overviews of systematic reviews (two conducted recently and one older),(49-51) four medium-quality systematic reviews (three were conducted recently and one was older)(28; 29; 52; 53) and two primary studies (54; 55) related to this question. None of the reviews or studies focused specifically on restorative care, but we included them given the potential to provide insights for empowering caregivers for older adults. The three overviews of systematic reviews, four systematic reviews and two primary studies focused on four broad areas of training/approaches to training:
1) promoting professional behaviour change;
2) using technology to provide training;
3) providing interprofessional training; and
4) providing training for those engaged in dementia care.

We provide key findings about these four areas in Table 2 below.

Several common themes about how to develop training programs are noteworthy from the summary of key findings in Table 2, which include the need to:
- adopt an iterative and flexible approach that adjusts the training based on needs assessments conducted prior to training and on evaluations of previous offerings of training;
- derive content based on multiple sources, including from engagement of caregivers and literature (e.g., research evidence and guidelines that provide best practices in a particular care domain);
- use small-group approaches;
- combine digital/online and in-person training;
- provide opportunities for interactive and experiential learning (e.g., in the settings where providers are interacting with caregivers and clients); and
- use multifaceted approaches that support changing practices, behaviours and peer-group norms.

Table 2: Overview of key findings related to question 2

Type of training	Key findings
Use of strategies that promote professional behaviour change	• A recent overview of systematic reviews that evaluated three domains of interventions to promote professional behaviour change (persuasive, educational and informational, and those that involved action and monitoring) found that the most positive outcomes were for interventions that focused on action or education such as audit and feedback, reminders and educational outreach, as well as for those that used collective action and reflexive monitoring.(50) • The overview concluded that multifaceted interventions that focus on normative restructuring of practices, modifying peer-group norms and expectations (e.g., through educational outreach interventions), and reinforcing any modified norms in peer groups from the interventions provide the most promising chances of successfully changing provider behaviours.(50)
Using technology to provide training	• A recent overview of systematic reviews evaluated the effects of digital education on several outcomes, including knowledge or learning, student satisfaction, student enrolment, attendance rates, course completion rates, clinical practice, patient health outcomes and cost-effectiveness, and found (based on 16 systematic reviews) that other teaching methods were not superior to digital learning approaches, but that when digital education was used in addition to traditional methods knowledge acquisition was enhanced.(51) • Most of the systematic reviews included in the overview reported high satisfaction with digital education, with highest satisfaction and increases in time spent on learning, when it is used in combination with in-person educational sessions and when interactive components are included in the approach when in-person training is not available. • The overview of systematic reviews also found that design preferences include using goal-directed curriculum, including regular evaluations of student progress, dividing training/courses into small units of material, incorporating short video clips, providing the ability to return to materials (e.g., replaying videos in different modules), using a variety of activities that include both visual or auditory stimulation (materials that only include text are of limited value), and using motivating exercises and real-world examples. • A second but older overview of systematic reviews evaluated computer-mediated continuing education for healthcare professionals and found that professionals were satisfied with computer-mediated continuing programs, and that comparisons between computer-mediated and traditional approaches resulted in comparable learning outcomes.(49) • A qualitative study conducted in Hamilton, Ontario with health and social-service practitioners, educators, researchers, and representatives of relevant advocacy groups and professional agencies who had expertise in interprofessional education (IPE) and older adults, found that most participants recommended the use of information technology that revolves around the learner, practitioner, and patient-related processes.(55)
Providing interprofessional training	• One recent medium-quality review examined interprofessional education for professionals who specialize in the care of people diagnosed with dementia and their caregivers.(46) Positive outcomes regarding the acquisition of collaborative knowledge and skills in dementia care were reported, and the interventions included in the review were delivered using a variety of approaches, such as providing: o an internet-based learning management system to participants with an online case study, which was explored over the course of four weeks; o many offerings (n=39) of half-day training sessions across three health systems; o training sessions lasting four hours accompanied by five clinical observership experiences; o a two-day course that was offered three times over 18 months; and o a case study, a didactic lecture about dementia care, interprofessional team meetings, and a large-group feedback session for undergraduate students.(46)

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	• A qualitative study conducted in Ontario, Canada (in Hamilton) with health and social-service practitioners, educators, researchers, and representatives of relevant advocacy groups and professional agencies who had expertise in interprofessional education (IPE) and older adults found that:
	   o one of the most frequently cited themes in participant interviews was the importance of engaging clients and their family members in the education of care providers in order to gain a better understanding of patients' values and needs; and
	   o current training is almost exclusively provided in acute-care settings, but that most participants recommended that training should also take place in home and community settings in order to better simulate the environment in which care will take place, and facilitate the development of relationships between care providers and caregivers and clients.(55)
	• A key recommendation from a qualitative analysis of a one-day symposium in Alberta, Canada was that health professionals receive education on involving family caregivers of older adults on care teams and in care settings, and that doing so will require improved communication between health professionals, caregivers and patients.(54)

Providing training for those engaged in dementia care (see row above for an additional review that was also focused on dementia)	• Two medium-quality reviews focused on communication-skills training for health professional and family caregivers as part of dementia care.(28; 29)
	   o The recent review included 38 studies and found that most training was grounded in person-centred care approaches, and that the most effective training approaches generally involved active participation by caregivers and included opportunities to practise skills and for discussion/interaction.(29)
	   o The older review included 12 studies that examined communication-skills training for health professionals and family caregivers in dementia care.(28)
	      ■ Interventions took place through either in-service training sessions in small groups or face-to-face training sessions in the homes of patients and family caregivers.
	      ■ In community-dwelling care settings, individualized training was used most frequently as a means of education.
	      ■ For in-service training, almost all interventions included a brief lecture by a facilitator.
	      ■ Most of the interventions varied from two sessions lasting approximately two hours, to 13 one-hour sessions.
	      ■ Training also often involved small-group discussions on frustration and self-experience, brainstorming sessions on successful and failed communication, and role-play.
	      ■ Materials used for training included workbooks, booklets, memory books, flashcards, caregivers' guides, training videos, handouts, presentations, and recommendations for further reading.
	      ■ Some of the interventions were delivered by members of the research team, but other professionals acted as facilitators, including speech-and-language therapists, health and nursing scientists, licensed clinical psychologists, psychiatrists, consultants, and social workers.
	      ■ Skills taught in training included verbal skills, non-verbal and emotional skills, attitudes towards people with dementia, behavioural-management skills, usage of tools, individual experiences, and theoretical knowledge.
	      ■ Almost all programs for health professionals had a positive influence on professional caregivers' knowledge, skills and attitudes.
	      ■ Three studies that were conducted in home-care settings demonstrated a significant effect of such training on family caregivers' knowledge and competencies, especially with regards to awareness of communication problems and strategies.
	      ■ Overall, family caregivers' reports of communication problems significantly decreased and two studies showed an increase in quality of life for people with dementia who were cared for at home.
	• A recent medium-quality systematic review evaluated dementia-training programs for staff working in general hospital settings and found much variability in how

	training programs are developed and provided, but interdisciplinary training that is based in the hospital ward where patients are, tailored and using short experiential session with active learning, were the most common features.(53)

	• The same review found that the most common strategies for developing training programs included:
	  ○ reviewing the literature;
	  ○ adopting previously developed training packages or resources; and
	  ○ conducting a needs assessment with participants before providing training.

	• Needs assessments were conducted by convening focus groups with staff in the hospital, having discussions with hospital managers to identify their priorities for training, conducting surveys and engaging other stakeholders (e.g., mental health specialists, patients and family carers) to identify important information to include in training.
	• The review also identified one study as having conducting the most comprehensive approach through the development of an interactive training program that could have content and delivery mechanisms modified over time based on participant feedback, which was built by identifying training outcomes from administrative staff, conducting an assessment of perceived staff attitudes, engaging daily caregivers in discussions, reviewing literature and expert opinions, and identifying ways to refine/improve the approach based on evaluations of the program.

Summary of insights from key informants

The five key informants that we interviewed provided insights about how to educate and provide information to unregulated and regulated health professionals to empower caregivers throughout restorative-care processes. Many of these insights support what we identified from literature. During the interviews, key informants provided insights into what needs to be considered in preparation for training and approaches to providing training in ways that are best suited to unregulated and regulated healthcare professionals.

Key informants identified several important considerations in the preparation phase of training. As a general suggestion, one of the key informants emphasized the importance of clearly articulating the principles and focus/goals of the educational initiative at the outset. It was suggested that emphasizing principles of restorative care and re-ablement early was important for developing materials or approaches that focus on processes of empowering caregivers to support those who they care for to re-establish independence over time. In addition, the same key informant emphasized the need for a client-centred approach to developing and implementing education for unregulated and regulated healthcare professionals. This could include co-creation approaches with caregivers and patients in order to ensure that what is being developed reflects their needs (this in turn also contributes to question 1 above for identifying the knowledge, skills, attitudes and behaviours that caregivers need to empower them in restorative-care processes). Lastly, the other two key informants identified the need to conduct a learning needs assessment before providing any training in order to tailor training to the specific needs of the group that it is being delivered to (e.g., to better understand the context within which providers are working and the barriers and facilitators to providing training). This can include identifying the optimal mix of mechanisms for providing training (e.g., a mix of didactic, case-based and experiential learning) and specific skills that are needed from a broader menu of what could be focused on.

Building on the general approaches to preparation for providing training to unregulated and regulated health professionals, each of the key informants provided several suggestions on how best to provide training. Across the approaches suggested, several key informants emphasized the need for training to continuously highlight how to adjust workflows and approaches to interactions with caregivers and clients to emphasize principles of restorative care. In particular, this should involve empowering caregivers with knowledge and skills to enable them to provide the care and support needed by the person they are caring for, as well as how to enable the client to increasingly self-manage their care needs over time. Moving beyond the traditional role of providing a discrete list of services identified in a client's care plan (e.g., wound cleaning, applying bandages, bathing, etc.) to one that also emphasizes self-management and behaviour-change strategies (e.g., motivational interviewing or strengths-based practice) allows caregivers and clients to learn and be empowered and increasingly independent over time.

Each of the key informants emphasized that training to do this requires a multifaceted, interprofessional approach that is tailored to the unique needs of unregulated and regulated health professionals. One key informant indicated that they have had success with using a 'train-the-trainer' model to continually build a cadre of social workers who can provide training.

Suggestions for types of training that could be provided included didactic, experiential, 'just-in-time' support and ongoing mentorship in order to build reinforcement over time. Suggestions for each of these are provided in the list below.

- Didactic approaches
  - Focus on conveying the key principles of restorative care and the knowledge, skills, attitudes and behaviours that caregivers need to be empowered as part of restorative-care processes (as outlined in question 1);
- Interactive and experiential training approaches
  - Use case-based scenarios (e.g., at time of discharge from hospital and when at home) presented to trainees followed by discussion and interactive and collective problem-solving for how to identify caregiver and client needs and empower them throughout each phase of restorative care
  - Provide the opportunity for trainees to walk through the process and do it together, which could involve using role playing (as one key informant pointed out – "it's all well and good to show and teach, but it only becomes real when you walk through it and do it")
- 'Just-in-time' support
  - Using information technology (e.g., through smartphones) to enable interactive learning between healthcare professionals, caregivers and clients at the point of care, which over time can enable the shift from healthcare professionals 'doing' to 'enabling'
- Mentorship
  - Having the opportunity to connect with a mentor or supervisor who can provide guidance and support over time to build needed skills

Each of the key informants raised specific considerations for providing training to unregulated health professionals. These included:

- the need to help unregulated healthcare professionals reorient from typically being task focused to also being focused on self-management to help build the skills of caregivers and clients;
- whenever possible using small-group training sessions;
- engaging regulated health professionals in training to enable interprofessional collaboration and learning (e.g., training unregulated health professionals in the process of creating and/or monitoring care plans and working in collaboration with regulated health professionals in doing so);
- not engaging managers in training sessions given the potential to create a power imbalance within the group;
- using a strengths-based approach (e.g., personal-support workers are typically in the home with caregivers and clients and can use this to act as a source of motivation in supporting restorative care); and
- using a person- and family-centred approach.

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APPENDICES

The following tables provide detailed information about the systematic reviews and primary studies identified in the rapid synthesis. The ensuing information was extracted from the following sources:

- systematic reviews - the focus of the review, key findings, last year the literature was searched, and the proportion of studies conducted in Canada; and
- primary studies - the focus of the study, methods used, study sample, jurisdiction studied, key features of the intervention and the study findings (based on the outcomes reported in the study).

For the appendix table providing details about the systematic reviews, the fourth column presents a rating of the overall quality of each review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered "high scores." A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8).

All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

Appendix 1: Summary of findings from systematic reviews

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
What knowledge, attitudes and behaviours do caregivers need support in building from regulated and unregulated health professionals in order to build their confidence and engage them in restorative-care processes?	Examining the impact of web-based technologies on mental health, general caregiving outcomes, and general health for caregivers of adults with chronic conditions living in the community (25)	Web-based technologies have the potential to provide education and support to caregivers. However, limited evidence is available regarding the impact of these interventions for caregivers of adults with chronic conditions living in the community. This rapid evidence review included 17 randomized controlled trials. The randomized controlled trials included education-only interventions, education and peer-support interventions, education and professional-support interventions, and a combination of education, peer-support and professional-support interventions. The most common outcome assessed was mental health, and approximately half of the included studies demonstrated positive outcomes. Other significant results were found in the outcomes of caregiver gain, knowledge and bonding. This review was limited by the high heterogeneity within the included studies that prohibited the comparison of findings across studies. As a result, within this review, it is not possible to determine which interventions can provide the most effective outcomes for caregivers. Thus, web-based technologies may result in improvements in mental health symptoms, but further research is needed to determine which type of interventions are the most effective.	2016	5/10 (AMSTAR rating from McMaster Health Forum)	2/17
	Examining interventions and strategies that affect social connectedness for older adults (30)	This scoping review included 44 studies that examined interventions and strategies that affect social connectedness for older adults. The authors' description and rationale for why the interventions may be effective were described in this review. Nine interventions were identified within the 44 included studies. The interventions included personal contact, activity and discussion groups, animal contact, skills course, multi-faceted programs, implementation of a new philosophy, reminiscence, support groups, and public broadcasts. This review found that the key features of the interventions included contact, social participation, feeling cared for, personal development and social support. Limitations to this study included that only studies in English and French were reviewed. Overall, this review described key features of interventions and strategies that affect social connectedness for older adults. This review provides a foundation for future research to evaluate the effectiveness of the interventions.	2015	5/10 (AMSTAR rating from McMaster Health Forum)	3/44
	Examine the efficacy of non-pharmacological	This review included four studies that examined the effect of non-pharmacological interventions on the reduction of burden, psychological symptoms, and improving the quality of life of caregivers with mild	2018	5/9 (AMSTAR rating	Not reported

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	interventions reducing burden, psychological symptoms, and improving quality of life of caregivers (23)	cognitive impairment. The included studies examined cognitive interventions and multifaceted interventions. One study evaluated the impact of a cognitive intervention, which was a calendar and note-taking rehabilitation intervention. This study found that this intervention resulted in improved mood and decreased depressive symptoms of caregivers. Three studies examined the impact of multidimensional interventions. One study examined the effect of cognitive behaviour therapy and cognitive rehabilitation and found no significant effects on subjective burden or mental health outcomes. One study examined the Daily Engagement of Meaningful Activities tool combined with psycho-education. This study demonstrated moderate improvements in depressive symptoms. One study examined the effect of cognitive rehabilitation and psycho-education and found no significant impact on depressive symptoms. This review was limited by the small number of included studies with small sample sizes and the methodological differences in the designs of the studies. Overall, the included studies did not have an impact on caregiver burden, and two of the included studies showed an effect in reducing depressive symptoms of caregivers. Future research should involve studies with larger sample sizes and focussing on single-component interventions instead of combination interventions to better determine the most beneficial interventions for caregivers.		from McMaster Health Forum)	
	Examining the impact of internet-based interventions on caregiver mental health outcomes (34)	Internet-based interventions have the potential to improve the negative mental health outcomes associated with caregiving. This review examined the impact of internet-based interventions on caregiver mental health outcomes and the impact of different types of internet-based intervention programs. This review included 13 studies. Eleven of the studies were randomized controlled trials, one study was a controlled clinical trial, and one study included both designs. Compared to no internet-based intervention, any type of internet-based intervention resulted in a decrease in stress, distress and anxiety among caregivers. Compared to no internet-based interventions, information or education-only interventions resulted in a decrease in depression, stress, distress and anxiety among caregivers. No differences were found between no internet-based intervention and information or education plus peer psychological support. Compared to no internet-based interventions, information or education interventions plus professional psychological support resulted in a decrease in depression and anxiety. Compared to no internet-based intervention, information and education plus combined peer and professional psychological support resulted in increased overall health among caregivers. Limitations of this review include methodological weakness of the included studies and considerable heterogeneity across the interventions.	2018	8/10 (AMSTAR rating from McMaster Health Forum)	1/13

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		Thus, this review provides evidence for the benefit of internet-based interventions on mental health of caregivers. However, further research of higher quality is needed to better support the findings of this review.			
	Examining the effectiveness of internet-based interventions for caregivers of older adults (26)	Internet-based interventions have the potential to support caregivers. However, there is limited knowledge regarding the components and effectiveness of internet-based interventions. This review included 12 studies that described 10 internet-based interventions. Three intervention categories were found: web-based interventions, self-help web-based therapeutic interventions and human-supported web-based therapeutic interventions. Self-help web-based therapeutic interventions and human-supported web-based therapeutic interventions that included behaviour change techniques were found to be efficacious. Improvements in depressive symptoms, anxiety and self-efficacy were found within these interventions. This review was limited by the heterogeneity of the outcomes which prohibited the use of a meta-analysis. Overall, this review suggests that internet-based interventions that include behaviour change techniques can have beneficial effects on caregivers.	2015	8/10 (AMSTAR rating from McMaster Health Forum)	0/12
	Examining the effectiveness of educational and support programs for caregivers on reducing their burden (45)	This systematic review included seven randomized controlled trials that examined the effectiveness of educational and support programs for caregivers on reducing their burden. The included studies examined interdisciplinary education and support for caregivers of patients with dementia. Four of the included studies were evaluated in a meta-analysis. A positive impact was found on caregiver burden when compared to standard care. This review is limited by the small number of studies with small sample sizes, and the heterogeneity in the included studies. Overall, the findings of the review suggest that interdisciplinary education and support for caregivers of patients with dementia can provide beneficial effects to caregivers.	2011	5/11 (AMSTAR rating from McMaster Health Forum)	2/7
	Examining the effectiveness of information and support-provision interventions for informal caregivers (47)	Providing informal care for individuals with health conditions, such as dementia, can be extremely difficult for those involved. This review examined the effectiveness of information and support-provision interventions for informal caregivers of people with dementia in community settings. Forty-four randomized controlled trials were included in this review. Four studies involved technology-based interventions, 13 studies involved group-based interventions, and 27 studies involved individual-based interventions.	2005	6/11 (AMSTAR rating from McMaster Health Forum)	5/44

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		Of the included studies, only group-based interventions were found to have a positive impact on depression in caregivers. No significant results were found within the other intervention types. Limitations of this review include the heterogeneity in the outcomes used in each trial, the short follow-up periods used within each study, and the low methodological qualities of the included studies. Thus, group-based interventions may have a positive impact on informal caregivers of people with dementia in community settings. However, further high-quality research is needed to better support the findings of this review.			
	Examining the impact of supportive interventions for carers provided in general practice (48)	Due to the challenging nature of the role, caregivers of individuals with dementia and stroke may require support themselves. This review examined the impact of supportive interventions for caregivers provided in general practice. Four studies were included in this review. All of the included studies focused on caregivers of individuals with dementia and investigated psychosocial interventions. The interventions were targeted to improve the mental health of caregivers and reduce caregiver burden. The interventions involved primarily information and educational materials. The findings of this review demonstrate that supportive interventions for caregivers provided in general practice result in improved psychological well-being and reduced burden and depressive symptoms. However, there was limited evidence to support the impact of supportive interventions on physical health and social variables. Limitations of this review include the variable quality of the included studies and the small number of included studies. Overall, this review suggests that supportive interventions for caregivers provided in general practice may improve caregiver well-being and emotional health. Further research is needed to better support these findings.	2015	8/10 (AMSTAR rating from McMaster Health Forum)	0/4
	Examining the components of the key worker-type model of support for people living with dementia and their caregivers (43)	Thirty-six studies were included in this review to examine the components of the key worker-type model of support for people living with dementia and their caregivers. This review also investigated how the role can be best utilized to assist community-dwelling people with dementia and their caregivers. This review included 24 randomized controlled trials, eight qualitative studies, two mixed method studies, one case-report and one cohort study. Most of the studies evaluated counselling support roles and the other studies evaluated support worker, case manager, team-based and case-manager roles.	2014	8/10 (AMSTAR rating from McMaster Health Forum)	1/36

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		The findings of the review suggest that that essential components shared across support-worker models included long-term intervention, face-to-face contact, individualized education and support based on needs, multidisciplinary teams, collaborative input, health/clinical background of support workers and ongoing follow-up. This review was limited by the high heterogeneity of the included studies which prohibited the use of a meta-analysis. Thus, this review identified the essential components of worker-type support models. These findings could be used to enhance current support models and to assist community-dwelling people with dementia and their caregivers.			
	Examining telehealth interventions which deliver home-based support via group videoconferencing (37)	A systematic review of 17 studies examined the feasibility, acceptability, effectiveness, and implementation of health professional-led group videoconferencing interventions which provide education and social support to patients and caregivers at home. Although some participants reported preferring face-to-face groups, the overall acceptability of the home-based videoconferences was high, with its ease of access from home highly valued by participants. The intervention was found to be feasible even for those with limited digital literacy when good IT support and training was provided for facilitators and participants. Privacy was seldom expressed as a concern. The review demonstrated that communication can be adapted for the web environment and enhanced by clear communication strategies and protocols. Benefits of videoconferencing groups included engaging with others with similar problems, improved accessibility to groups, and development of health knowledge, insights and skills. These outcomes replicate those of face-to-face interventions. Overall, videoconference groups were found to be a promising way of providing education and social support, particularly for those who live in rural areas, have limited mobility, are socially isolated, or fear meeting new people. However, it must be noted that included studies in this review generally had small sample sizes and the comparability of study findings was limited by the heterogeneity of the interventions and study designs.	2016	9/10 (AMSTAR rating from McMaster Health Forum)	6/17
	Examining caregiver-focused, web-based interventions (35)	A systematic review of 14 studies examined the effect of caregiver-focused, web-based interventions on caregiver outcomes. In addition, the efficacy of different types of web-based interventions (e.g. education, peer and professional psychosocial support, and electronic monitoring of the care recipient) was compared. Web-based intervention programs were found to have a positive effect on self-efficacy, self-esteem, and strain of caregivers of adults living with a chronic condition. There were no statistically significant effects found for caregiver burden, life satisfaction, reaction to problem behaviour, and social support.	2017	8/11 (AMSTAR rating from McMaster Health Forum)	Not reported.

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		For interventions based only on information or education, results showed a significant but small reduction in caregiver strain and self-efficacy or mastery. Statistically significant effects were not found for life satisfaction or reaction to problem behaviour.			
		Studies that examined information or education plus peer psychosocial support found no differences between intervention and control groups for any of the examined outcomes. For studies of information or education plus professional psychosocial support, positive outcomes were found for self-efficacy or mastery compared to no or minimal web-based interventions.			
		Studies that examined information or education plus combined peer and professional psychosocial support showed positive effects on self-esteem and self-efficacy mastery. However, the single study that examined information or education plus professional psychosocial support and electronic monitoring found no statistically significant difference between groups.			
		One of the main limitations of this review involved the overall low quality of included studies. The strength of the results on different types of web-based interventions was also limited by the small number of studies in each group.			
	Examining methods to support and sustain care at home for people with dementia (19)	A review of 131 studies examined the effectiveness of services intended to support home-dwelling people with dementia and their caregivers. The review found limited research on the needs or experiences of paid caregivers who support people with dementia to live at home. The small body of literature focuses mainly on biomedical supports. One study on Norwegian doctors, pharmacists and nurses found that healthcare professionals do not receive much training in drug treatments for older people. In the U.K., one study found that community psychiatric nurses reported limited knowledge of memory strategies and aids to support people with dementia under their care. One meta-analysis presents strong evidence supporting the efficacy of support groups to support informal caregivers at home. Coping-strategy-based support was found to be especially helpful, as 'dysfunctional coping' is a strong predictor of depression and anxiety in carers. Another promising area of support is training or education for caregivers. These types of interventions can support caregivers in maintaining engagement and activity of people with dementia by providing ideas about how to do so. Many studies recommend a user-centred approach on the basis that information can increase as well as reduce problems for carers. The review highlights the fact that very little research has been conducted on the needs of black and minority ethnic caregivers; it was also found that service providers have made little attempt to engage with minority communities.	2012	6/9 (AMSTAR rating from McMaster Health Forum)	12/131

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		Of the 131 publications evaluated, 56 were assessed to be of 'high' quality, 62 of 'medium' quality and 13 of 'low' quality. The strength of the review's results are limited by the lack of methodological detail presented in many of the included studies.			
	Examining dyadic interventions for community-dwelling people with dementia and their family caregivers (31)	A systematic review of 23 studies examined the effects of dyadic psychosocial interventions focused on community-dwelling people with dementia and their family caregivers. Dyadic psychosocial interventions focus on both the person with dementia and the informal caregiver. A dyadic approach has been found to be effective because of the mutual influence between the person with dementia and the informal caregiver. Nineteen of the 20 dyadic programs included in the review demonstrated significant effects on the patient with dementia, the caregiver, or both. Programs with intervention components that actively trained one or more specific functional domains for the person with dementia or the caregiver were found to have a beneficial impact on that domain. Most programs provided caregiver support in terms of informational training, psycho-education, skills training, and training on coping strategies. Targeted functional domains for caregivers included mood, burden, competence, and quality of life. Statistically significant positive effects for all four domains were found after caregiver participation in different programs. All 20 programs tailored their interventions to the dyad's needs. Eight out of 20 programs began with a needs assessment for the caregiver, and some programs also assessed the needs of the person with dementia. Overall, 10 programs showed statistically significant positive effects for both members of the dyad, four programs showed statistically significant effects for the person with dementia only, and six programs found statistically significant effects for the caregiver only. Only two programs did not show any statistically significant effects. Limitations for this review can be found primarily in the heterogeneity of program lengths (from five weeks to two years) and measurement instruments, which made study results difficult to compare. Findings from the review should be interpreted in the context of these limitations.	2012	6/11 (AMSTAR rating from McMaster Health Forum)	2/23
	Examining non-pharmacological interventions for caregivers of stroke survivors (44)	A systematic review of eight studies examined the effect of interventions targeted towards informal caregivers of stroke survivors. Review authors determined that there is currently insufficient data to support or refute the use of either "information and support" interventions or "psycho-educational" interventions to reduce or prevent stress, strain, distress, depression, anxiety, or health-related quality of life in informal caregivers of stroke survivors. An intervention involving "teaching procedural knowledge" to caregivers prior to stroke patients' discharge from hospital was found to have positive effects in reducing caregiver stress, strain, distress, depression, anxiety, and health-related quality of life when compared to usual care. This was only one small, single-centre study, however, so results should be interpreted with caution.	2010	10/10 (AMSTAR rating from McMaster Health Forum)	0/8

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	Examining the effects of mindfulness-based interventions for informal palliative caregivers (24)	A systematic review of 10 studies examined the effects of mindfulness-based interventions for informal palliative caregivers. A mindfulness-based intervention (MBI) is a multicomponent program that aims to teach participants, through meditation practices, how to cultivate attention, feelings, and sensations in the present moment with non-judgmental openness. 28 different measures were employed across the included studies, with the most common being depression, anxiety, perceived stress, caregiver burden, and mindfulness. The type of MBI delivered included mindfulness-based stress reduction (MBSR), mindfulness-based cognitive therapy (MBCT), an acceptance and commitment therapy-based model, and an existential behaviour therapy (EBT) approach with mindfulness as its core driver. Nine of the 10 studies used a face-to-face group-based format. Mindfulness protocols varied from four to 10 weekly sessions of variable length (1-2.5 hours). Five of seven studies found a significant effect for depression, two out of three studies found a significant effect for quality of life post-intervention, a significant reduction in caregiver burden was found in four out of five studies, two out of five studies found a significant effect for anxiety reduction, and one out of five studies identified a significant effect when measuring mindfulness. Significant effects, both post-intervention and at follow-up, were also found for hope, overall mental health, and psychological distress. Results of this study may suffer from publication bias as it did not include grey literature. Findings should be interpreted in the context of this limitation.	2014	5/9 (AMSTAR rating from McMaster Health Forum)	0/10
	Examining services that provide information and/or advice to people with dementia and/or their caregivers (18)	A review of 13 randomized controlled trials were examined to determine whether information services were beneficial to the quality of life of people with dementia, their neuropsychiatric symptoms, and carer burden. The information services included elements such as skills training, telephone support, and direct help. Two out of three studies indicated benefits to quality of life, while significant benefits were found in regard to lessening their symptoms. Carer burden, however, was not found to be significantly affected. While the review of the data analyses suggested that dementia advisory and information services did provide some benefit, the review reported that the interpretation of these effects was not straightforward as many studies involved additional services beyond information services.	2009	7/10 (AM STAR rating from McMaster Health Forum)	0/13
	Examining technology-driven interventions for caregivers of persons with dementia (56)	A systematic review of eight studies examined the efficacy of technology-driven interventions for caregivers of people with dementia. All eight studies demonstrated positive findings on the caregivers' psychosocial outcomes (e.g., burden, depression, anxiety, stress or strain - common psychosocial outcomes). One of the interventions explored was ComputerLink, a computer network that acted as an electronic encyclopedia for information (e.g., management and treatment, community services, and caregiver's self-care), and a public and private	2012	4/10 (AM STAR rating from McMaster Health Forum)	0/8

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		forum for communication between caregivers. While the technology did not reduce overall strain, it reduced spouse strain and improved the confidence of caregivers' decisions. A web-based multimedia intervention that delivered positive caregiving strategies through text and video messages had the additional function of personalization. Caregivers were able to alter the program based on their specific concerns and the degree of dementia of their family member. The intervention significantly increased the caregiver's self-efficacy, intention to get social support, and perception of the positive aspects of caregiving for caregivers. They also reported a significant reduction in stress, strain, anxiety and depressive symptoms. Another study consisted of a telephone network that was able to provide an interactive voice response, which improved carer anxiety and bother. Also, the provision of home-based family therapy had a significant impact on depression.			
	Examining the effectiveness of computer-mediated interventions for informal carers of people with dementia (33)	A systematic review of 14 studies examined the effectiveness of computer-mediated interventions for informal carers of people with dementia. The studies used a variety of interventions including a computer-mediated automated interactive voice response system, a computer-telephone integration system, and a DVD program. Eight used education as the main intervention. Three combined professional therapy or support with education while two combined it with general support. Seven of the eight studies measured depression. Three found no effect while three found mixed results. One study suggested that carers with greater baseline depression showed greater improvements. In terms of anxiety, two studies reported a reduction in carer anxiety while most studies reported an increase in positive aspects of caring and carer self-efficacy. Mixed results were found in regard to social support while no studies reported effects on the physical aspects of caring. In terms of clinical implications, the generally positive results of computer-mediated interventions suggest that it would be beneficial to further expand upon this medium. There are potential cost-saving implications for services as well as an increase in the number of carers who would benefit from the interventions. With the widespread use of technology, the viability of computer-mediated interventions also increases.	2012	4/9 (AMSTAR rating from McMaster Health Forum)	3/14
	Examining information and communication technology-based support interventions for carers of home-dwelling older people (39)	An integrative review of 123 studies examined the support for information and communication technologies for carers of older people. The interventions were broadly categorized into support, information or education, or a combination of the three. The most common type of intervention, however, was emotional or psychosocial support, which was comprised of counselling, support groups and follow-up programs. Education and information supports were another carer-support intervention and carried out via formats such as websites, didactic instruction, role playing, problem solving, skills training, interactive exercises, and psycho-educational programs. It was found that the interventions were effective in decreasing healthcare costs and healthcare utilization while reducing caregiver burden. These interventions were most effective when built on the carers'	2016	4/9 (AMSTAR rating from McMaster Health Forum)	13/123

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		specific needs and provided skills training and support. In fact, carers reported their want for individualized information and communication technology solutions that could target stress levels and increase personal motivation and self-confidence. As a result, vulnerable groups of carers or dyads should receive prioritized identification of their needs and preferences. On the micro level, carer variables were found to play an influential role on carer outcomes. Certain characteristics of the carer, such as the relationship with the care recipient, extent of employment, and race and ethnicity, had an impact on the degree of the outcomes.			
	Examining communication skills training for healthcare professionals and family carers in dementia care (28)	A systematic review of 12 studies examined communication skills training for healthcare professionals and family caregivers in dementia care. Interventions took place at either in-service training sessions in small groups or face-to-face training sessions in the homes of patients and family caregivers. In community-dwelling care settings, individualized training was used most frequently as a means of education. In in-service training, almost all interventions included a mini-lecture by the facilitator. Interventions varied from two 2-hour sessions to 13 1-hour sessions. Learning also often involved small group discussions on frustration and self-experience, brainstorming sessions on successful and failed communication, and role-play. Materials used for training included workbooks, booklets, memory books, flashcards, caregivers' guides, training videos, handouts, PowerPoint presentations, and recommendations for further reading. While some interventions were delivered by members of the research team, other professionals acting as facilitators included speech-and-language therapists, health and nursing scientists, licensed clinical psychologists, psychiatrists, consultants, and social workers. Skills taught in training included verbal skills, non-verbal and emotional skills, attitudes towards people with dementia, behavioural management skills, usage of tools, individual experiences, and theoretical knowledge. Almost all programs for healthcare professionals had a positive influence on professional caregivers' knowledge, skills and attitudes. Three studies in home-care settings demonstrated significant effects on family caregivers' knowledge and competencies, especially with regards to awareness of communication problems and strategies. Overall, family caregivers' reports of communication problems significantly decreased, but problem behaviours remained stable. Two studies showed an increase in quality of life for people with dementia who were cared for at home.	2009	5/10 (AMSTAR rating from McMaster Health Forum)	0/12
	Examining communication training interventions for family and professional caregivers of people living with dementia (29)	A systematic review of 38 studies examined communication training interventions for family and professional caregivers of people living with dementia. Overall, training interventions for both family and professional caregivers were found to improve knowledge and communication skills. Although family caregiver interventions were generally found to be effective post-treatment, mixed results were found across follow-up time points. More research must be done to establish whether training interventions are able to maintain their effects on communication over	2016	7/9 (AMSTAR rating from McMaster Health Forum)	0/38

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Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		time. No significant post-training improvements were found for caregiver stress and burden, with only one out of five studies reporting positive effects on quality of life post-intervention. Four out of eight studies found that training interventions reduced caregiver anxiety and/or depression. Studies that examined effects of training on behavioural challenges did not find statistically significant results. Although acceptability levels were generally high, satisfaction ratings were found to be higher for family caregivers than professional caregivers. Person-centred care was found to be the most common framework described. Effective interventions generally involved active participation by caregivers and were skills based (e.g., including practising skills and discussion). Both individual and group interventions were found to be effective. Interventions that had a significant impact on family caregiver burden tended to be intensive and include regular home visits. Results of this study may suffer from publication bias as study authors did not search the grey literature. Findings should be interpreted in the context of this limitation.			
	Examining interventions for caregivers of people living with dementia (46)	A systematic review of 36 studies examined interventions for caregivers of people living with dementia. Four of the included studies utilized education as an intervention to improve the skillset of caregivers in a variety of domains. These included distress, guilt, assertiveness and strain. Unfortunately, all studies but one indicated that education alone was insufficient to improve overall caregiver psychological well-being or reduce disruptive behaviours by the care recipient. One study demonstrated, however, that the death of the care recipient was delayed with a caregiver training program. Another study showed that interventions which taught caregiver coping methods improved the quality of interactions between caregivers and care recipients. The primary limitation of this review lies in the poor quality of included studies. The review is also subject to publication bias as grey literature was not included for analysis.	2003	4/9 (AMSTAR rating from McMaster Health Forum)	Not reported
	Examining telehealth tools and interventions to support family caregivers (36)	A systematic review of 65 studies examined telehealth tools and interventions designed to support family caregivers. The telehealth technologies analyzed in the review included videoconferencing, telephone, web resources, and telemetry monitoring. These tools were used to deliver various interventions, including education, consultation, cognitive behavioural therapy, social support, data collection and monitoring, and clinical care delivery. Videoconferencing was the most commonly used technology. 95% of included studies reported positive caregiver outcomes, including enhanced psychological health (less anxiety, depression, stress, burden, irritation and isolation) (44%), greater comfort with the usage of telehealth (38%), improved caregiving skills (20%), higher quality of life (12%), more social support (14%), improved coping skills (8%), and enhanced communication skills (5%).	2014	4/9 (AMSTAR rating from McMaster Health Forum)	8/65

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		Although preliminary findings are promising, more research must be done to examine cost-effectiveness and identify the most effective telehealth technology for caregivers.			
	Examining caregiver engagement in the hospital care of older people (17)	A systematic review of 103 studies examined caregiver engagement in the hospital care of older people. From the review, six distinct components of caregiver engagement were identified: patient caregiving, information sharing, shared decision-making, caregiver support and education, caregiver feedback, and patient care transitions. Specifically related to caregiver support and education, the research focused on informational and psychological supports given to caregivers of older people. Many interventions in this domain involve elements to reduce caregiver stress, address caregiver needs, provide education about applicable conditions, and give training for caregiver skills. Of note, the research indicated that caregivers of older people tend to be older themselves, with their own health problems and support needs. For example, a study involving 41 caregivers of frail older people found 85% had health problems of their own, which affected their caregiving. This suggests that differential planning based on individual caregivers' needs can maximize the care they provide. The overall quality of evidence included in this review is moderate according to the GRADE criteria. The primary limitations of this review lie in the poor quality of included studies. The review is also subject to publication bias as grey literature was not included for analysis.	2015	5/9 (AMSTAR rating from McMaster Health Forum)	4/103
	Examining interventions done with caregivers of stroke survivors improve some caregiver and patient outcomes (27)	A systematic review of 26 randomized controlled trials and six nonrandomized studies examined interventions that could be done with caregivers to improve caregiver and patient outcomes. The studies focused specifically on people caring for a family member or friend who had survived a stroke. The interventions explored included: skill building (e.g., problem-solving or goal setting, stress management, communication), providing psycho-educational information (e.g., teaching how to manage emotions and health needs of caregivers and stroke survivors, coping with changes in lifestyle), and support (e.g., peer-support groups, online discussion groups). All the interventions provided psycho-educational information. Five combined it with skill building, while three combined it with support, and one combined it with both skill building and support. The study found that both the interventions conducted solely with caregivers and those conducted with caregivers and stroke survivors all resulted in improvements. In interventions conducted with caregivers, 16 studies (94%) demonstrated improvements in caregivers while one study showed a decrease in social functioning. Interventions done with caregivers and stroke survivors demonstrated improvement in eight studies (53%), no effect in five studies (27%), and decrease in social functioning/satisfaction in one study.	2012	4/10 (AMSTAR rating from Program in Policy Decision-making)	0/32

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	Assessing the effectiveness of family-based education for heart failure patients and caregivers (32)	Family-based education may promote improved well-being in heart failure patients and their caregivers. However, little evidence exists to assess the effectiveness of these interventions. This review aimed to determine the effectiveness of family-based education for heart failure patients and their caregivers. Six randomized controlled trials were included in this review. The education programs included in the studies were heterogenous. One study focussed on assisting patients and caregivers in recognizing and modifying physical and emotional factors. One study used self-determination theory and social cognitive theory to help patients and caregivers improve dietary sodium. One study utilized the European Society of Cardiology clinical practice guidelines for heart failure to create education sessions. One study used a preliminary qualitative study to inform the design of an education program. The overall findings of the review suggest that family-based education improved knowledge in both the caregivers and the patients. The findings also suggested that these interventions may lead to improvements in other health outcomes, such as quality of life and mental health outcomes in both the caregivers and the patients. However, firm conclusions cannot be drawn based on the heterogeneity that existed within the education strategies, duration of the intervention and the sample sizes. This review is limited by the heterogeneity in the included studies which precluded a meta-analysis. This review is also limited by the small number of included studies and the absence of blinding allocation. Thus, the findings of this review demonstrate improvements with family-based education for both the caregivers and patients, and highlight the need for further research of more robust methodological quality to better support these findings.	2015	7/10 (AMSTAR rating from McMaster Health Forum)	0/6
	Facilitators and barriers to equipping older adults with mHealth technology (38)	The review included 36 studies focused on barriers and facilitators to the use of mobile health technologies. Significantly more facilitators of the use of mobile technologies were found in the included literature than barriers. Reasons for the adoption of mobile technology were varied but included its widespread adoption among baby boomers, its better enable home care, it is highly customizable, and it provides early detection of symptoms. Themes that were found across included primary studies included: enables improved understanding about their condition and increases their engagement in their own care; inclusion of technology increases communication channels, positive outcomes including early diagnosis and increased medication and therapy adherence as well as ability to detect a fall; improved quality of life; and convenience. Barriers included: the complexity of mobile technologies and a lack of readiness for implementation with organizations; limitations by users (e.g., lack of technological literacy) and the cost of technology; beliefs that the technology is ineffective or exclusive (e.g., to people with a smartphone); and privacy/security/invasiveness.	2015	4/9 (AMSTAR rating from McMaster Health Forum)	5/36

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
How should education and information-provision interventions be provided to health professionals to best empower caregivers throughout restorative-care processes?	Characteristics and efficacy of digital health education (51)	The overview evaluated the effects of digital education on several outcomes, including knowledge or learning, student satisfaction, student enrolment, attendance rates, course completion rates, clinical practice, patient health outcomes and cost-effectiveness. The overview included 16 systematic reviews, which included data from 31,730 participants. Digital education was used in the included systematic reviews to refer to "the use of technology to communicate information for the purposes of knowledge or skill transfer." All of the interventions included the use of a computer and a multimedia component, four systematic reviews included virtual patients and case-based scenarios, and five systematic reviews included computer-assisted learning where digital education approaches (e.g., using web-based material, videos and other online resources) were used in combination with traditional in-person methods. The included systematic reviews did not find that other teaching methods were superior to digital learning approaches, but that when digital education was used in addition to traditional methods knowledge acquisition was enhanced. Most of the systematic reviews reported high satisfaction with digital education, with highest satisfaction and increases in time spent on learning when it is used in combination with in-person educational sessions, and when interactive components are included in the approach when in-person training is not available. Design preferences include using goal-directed curriculum, including regular evaluations of student progress, dividing training/courses into small units of material, incorporating short video clips, providing the ability to return to materials (e.g., replaying videos in different modules), using a variety of activities that include both visual or auditory stimulation (materials that only include text are of limited value), and using motivating exercises and real-world examples.	2017	No rating tool available for this type of document	Not applicable (included systematic reviews, not single studies as the unit of analysis)
	Promoting professional behaviour change in healthcare (50)	The review included 67 systematic reviews that related to any of the professional interventions from the Cochrane Effective Practice and Organisation of Care Review Group. The interventions included in the reviews were grouped into categories related to those that were persuasive in nature, educational and informational, and that involved action and monitoring. The most positive outcomes were found for interventions focusing on action or education such as audit and feedback, reminders and educational outreach, and that used collective action and reflexive monitoring. The overview concluded that interventions that focus on normative restructuring of practices, modifying peer-group norms and expectations (e.g., through educational outreach interventions), and reinforcing any modified norms in peer groups from the interventions provide the most promising chances of successfully changing provider behaviours.	2015	No rating tool available for this type of document	Not applicable (included systematic reviews, not single studies as the unit of analysis)

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
	Computer-mediated continuing education for healthcare providers (49)	The overview of systematic reviews included 11 systematic reviews. Findings indicate that healthcare providers were satisfied with computer-mediated continuing education programs and that comparisons between computer-mediated and traditional approaches resulted in comparable learning outcomes.	2013	No rating tool available for this type of document	Not applicable (included systematic reviews, not single studies as the unit of analysis
	Examining communication training interventions for family and professional caregivers of people living with dementia (29)	A systematic review of 38 studies examined communication-training interventions for family and professional caregivers of people living with dementia. Overall, training interventions for both family and professional caregivers were found to improve knowledge and communication skills. Although family-caregiver interventions were generally found to be effective post-treatment, mixed results were found across follow-up time points. More research must be done to establish whether training interventions are able to maintain their effects on communication over time. No significant post-training improvements were found for caregiver stress and burden, with only one of five studies reporting positive effects on quality of life post-intervention. Four of eight studies found that training interventions reduced caregiver anxiety and/or depression. Studies that examined effects of training on behavioural challenges did not find statistically significant results. Although acceptability levels were generally high, satisfaction ratings were found to be higher for family caregivers than professional caregivers. Person-centred care was found to be the most common framework described. Effective interventions generally involved active participation by caregivers and were skills based (e.g., including practising skills and discussion). Both individual and group interventions were found to be effective. Interventions that had a significant impact on family caregiver burden tended to be intensive and include regular home visits. Results of this study may suffer from publication bias as study authors did not search the grey literature. Findings should be interpreted in the context of this limitation.	2016	7/9 (AMSTAR rating from McMaster Health Forum)	0/40
	Dementia training programs for staff working in general hospital settings (53)	Fourteen studies were included, which were of variable methodological quality. The review found much variability in how training programs are developed and provided, but interdisciplinary training that is based in the hospital ward where patients are, tailored and used short experiential session with active learning were the most common features. The most common strategies for developing training programs included reviewing the literature, adopting previously developed training packages or resources, and conducting a needs assessment with participants	2016	4/9 (AMSTAR rating from McMaster Health Forum)	0/14

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		before providing training. Needs assessments were conducted by convening focus groups with staff in the hospital, having discussions with hospital managers to identify their priorities for training, conducting surveys, and engaging other stakeholders (e.g., mental health specialists, patients and family carers) to identify important information to include in training. The review identified one study as having conducted the most comprehensive approach through the development of an interactive training program that could have content and delivery mechanisms modified over time based on participant feedback, which was built by identifying training outcomes from administrative staff, conducting an assessment of perceived staff attitudes, engaging daily caregivers in discussions, reviewing literature and expert opinions, and identifying ways to refine/improve the approach based on evaluations of the program.			
	Examining interprofessional education in the care of people diagnosed with dementia and their carers (52)	A systematic review of six studies examined interprofessional education of professionals who specialize in the care of people diagnosed with dementia and their carers. Interventions investigated in this study were delivered in various modalities. One internet-based learning management system provided the student participants with an online interprofessional dementia case study, which was explored over the course of four weeks. Another program involved 39 different half-day training sessions delivered in three healthcare systems. A program designed for students training in dementia care involved a four-hour session and five clinical observership experiences. Another program aimed to improve the practice of existing professionals through a two-day course, which was delivered three times over 18 months. Finally, an intervention for undergraduate students training in dementia care involved the review of a case study, a didactic lecture about dementia care, interprofessional team meetings, and a large group feedback session. While four of the studies reported positive outcomes regarding the acquisition of collaborative knowledge and skills in dementia care, none of the studies assessed outcomes related to patients or their carers. The primary limitation of this review lies in the poor quality of included studies. As the search was limited to studies published in English over the past 10 years, the study is also subject to both language bias and time-lag bias.	2014	7/10 (AMSTAR rating from McMaster Health Forum)	1/6
	Examining communication skills training for healthcare professionals and family carers in dementia care (28)	A systematic review of 12 studies examined communication-skills training for healthcare professionals and family caregivers in dementia care. Interventions took place at either in-service training sessions in small groups or face-to-face training sessions in the homes of patients and family caregivers. In community-dwelling care settings, individualized training was used most frequently as a means of education. In in-service training, almost all interventions included a mini-lecture by the facilitator. Interventions varied from two 2-hour sessions to 13 one-hour sessions. Learning also often involved small group discussions on frustration and self-experience, brainstorming sessions on successful and failed communication, and role-play.	2009	5/10 (AMSTAR rating from McMaster Health Forum)	0/12

Question addressed	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		Materials used for training included workbooks, booklets, memory books, flashcards, caregivers' guides, training videos, handouts, PowerPoint presentations, and recommendations for further reading. While some interventions were delivered by members of the research team, other professionals acting as facilitators included speech-and-language therapists, health and nursing scientists, licensed clinical psychologists, psychiatrists, consultants, and social workers. Skills taught in training included verbal skills, non-verbal and emotional skills, attitudes towards people with dementia, behavioural-management skills, usage of tools, individual experiences, and theoretical knowledge. Almost all programs for healthcare professionals had a positive influence on professional caregivers' knowledge, skills and attitudes. Three studies in home-care settings demonstrated significant effects on family caregivers' knowledge and competencies, especially with regards to awareness of communication problems and strategies. Overall, family caregivers' reports of communication problems significantly decreased, but problem behaviours remained stable. Two studies showed an increase in quality of life for people with dementia who were cared for at home.			

Appendix 2: Summary of findings from primary studies

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
What knowledge, attitudes and behaviours do caregivers need support in building from regulated and unregulated health professionals in order to build their confidence and engage them in restorative-care processes?	Examine the experiences of caregivers who participated in the FECH program (21)	*Publication date:* 2019 *Jurisdiction studied:* Australia *Methods used:* Semi-structured interviews and thematic analysis	Interviews were conducted with family caregivers who had participated in the Further Enabling Care at Home (FECH) program. A total of 21 caregivers completed the interview out of the 62 caregivers who participated in the program. The median age of the caregivers was 67 years and 81% were female. There were no statistically significant differences between the interviewed caregivers and the overall group.	The FECH program was a telephone-based intervention delivered to caregivers of older patients discharged from the hospital. The telephone calls were delivered by nurses and they aimed to assess the caregivers' understanding of the patient's discharge summary, to provide guidance to resources. A qualitative evaluation, in the form of semi-structured interviews, was conducted to explore the caregiver's experiences and perceptions of the FECH program.	Three main themes emerged from the thematic analysis. The first theme was 'The experience of caregiving'. Caregivers reported that their role was busy and complex as a result of the large amount of responsibility that comes with taking care of an older person. Some caregivers reported that caring for an older person comes with great demands and is burdensome, and other caregivers reported that caring for an older person is a fulfilling experience. The second theme was 'The experience of receiving FECH program support'. Caregivers reported that the FECH program over the telephone was convenient, allowed them to feel more connected to support, feel more prepared to care, and to feel more secure in the caregiving role. The third theme was 'Caregivers' suggestions for improvement'. The overall perception of the FECH program was positive, but some caregivers suggested that the calls could have been more condensed and time-effective. The authors noted that it is a possibility that caregivers who preferred to not be contacted by telephone declined the invitation to participate. As a result, the perspectives of caregivers who may not have accepted the FECH program were not represented in the findings.
	Identify the unmet needs of caregivers (10)	*Publication date:* 2018 *Jurisdiction studied:* Canada and New Zealand *Methods used:* Qualitative description	The participants in this study were adult caregivers providing unpaid support for an older adult who was linked to a community-based primary healthcare site. A total of 80 caregivers participated in this study. Most of the caregivers were over the age of 50, female and ethnically diverse. A majority of the caregivers cared for an older adult in the same residence that they lived in.	Qualitative interviews were conducted to identify the unmet needs of caregivers.	The qualitative findings from the interviews were organized into three main themes. The first theme was unrecognized role. The caregivers felt that they were unrecognized, and they wanted to be acknowledged for the care they provided. Moreover, the caregivers felt that they had special and important knowledge about the individuals that they cared for that was not identified by the care team. The second theme was that there are no breaks even when services are in place for caregivers. Caregivers identified that even when the individuals they care for are receiving services, they still are required to play an active role in providing and coordinating care. Similarly, caregivers reported that there are long waits for care, poor communication between providers, and high turnovers of home care staff – all of which compromise care.

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
					The third theme was lack of personal resources. Caregivers reported that there were few financial, informational, or educational resources available to support them. They also reported that, when these supports were available, they were difficult to access.
	Examining the caregiver journey in the transition from home care into residential care (11)	*Publication date:* 2017

Jurisdiction studied: Western Canada

Methods used: Qualitative thematic analysis | Family caregivers who self-identified as the primary person involved in the management of their family member's move from home care (HC) into residential care (RC) in the past five years were recruited to participate. Seven of the 15 participant interviews were completed with urban caregivers, three with suburban caregivers, and five with rural caregivers. | A total of 15 one-on-one, semi-structured interviews were undertaken between July 1st and November 30th, 2015. Interviews ranged from 45 to 150 minutes in length and each interview was taped and transcribed. | Caregivers interviewed for this study consistently emphasized the importance of acquiring information from both formal (e.g., social workers, case managers, and other health professionals) and informal (e.g., friends and family) sources during the transition from HC to RC. In this regard, social workers were highlighted as a particularly important resource. Those who experienced challenges largely attributed difficulties to problems related to communication between themselves and their healthcare professionals. Others expressed frustration with the perceived lack of empathy and compassion from healthcare providers. In terms of caregiver support, most participants expressed a reliance on a wide range of formal supports (e.g., caregiving groups run through the health region or RC facility) and informal supports (e.g., family members, friends, church congregation, choir, and bowling). |
| | Examining asset literacy following stroke and its implications for disaster resilience (12) | *Publication date:* 2018

Jurisdiction studied: Ontario, Canada

Methods used: Qualitative thematic analysis | Study participants included six women over the age of 55 who had survived a stroke as well as four of their male spouses, over the age of 55, who served as their primary caregivers. All participants resided in Ontario, Canada. | Semi-structured interviews were held with women who had survived a stroke as well as men over the age of 55 who were the primary caregivers for wives who had experienced a stroke. Each participant was interviewed once, with each lasting approximately one hour. | Most stroke survivors who were married identified their spouse as a critical social asset, providing company, care and encouragement, and managing the household. Additionally, many participants highlighted the importance of family, friends and neighbours for providing social stimulation for the stroke survivor.

Housing was identified as a critical physical asset for most participants, who highlighted several key attributes of their living environments critical to supporting their autonomy and independent living. Such attributes included a central location in the community, accessibility to stores and public transportation, and availability of support (such as a building manager in an apartment complex). Assistive devices (e.g., mobility assists, handrails, walk-in showers) and accessible transportation were also considered important for autonomy in daily living.

While not completely controllable, money, supplies, and time were identified as key energy assets that support household resilience in daily living and during a disaster. Health and well-being were also identified as important personal characteristics that were assets in this regard. |

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	Examining the use of observational pain assessment tools by people who are not health professionals (40)	*Publication date:* 2017 *Jurisdiction studied:* North America *Methods used:* Quasi-experimental design	Long-term care nurses and laypeople with no healthcare training	Quasi-experimental design: videos depicting patients with dementia (actors) displaying either pain or no pain to long-term care nurses and laypeople. Participants rated the pain behaviours in each video.	The study examined the ability of laypeople to assess pain using observational measures developed by health care professionals. Participants were presented with videos depicting patients with dementia either displaying pain or no pain (calm, relaxed state) followed by two standardized observational measuring tools to rate the pain behaviours in each video. Both groups of participants, nurses and laypeople, effectively were able to discriminate between painful and non-painful behaviours. No statistically significant differences were found between the nurses and laypeople. As a result, the study provides some evidence indicating that laypeople can effectively utilize observational pain assessment instruments designed for health professionals.
	Examining patient and provider perspectives on optimal decision-making among vulnerable patients referred for cardiac surgery (57)	*Publication date:* 2016 *Jurisdiction studied:* Nova Scotia, Canada *Methods used:* Qualitative Analysis	Healthcare providers (intermediate medical-care unit nurses, intensive-care unit nurses, surgeons, anesthesiologists, cardiac intensivists) and former cardiac patients (with coronary artery bypass graft, valve, or coronary artery bypass graft + valve).	Three focus groups were held with providers and three were held with former cardiac patients. An interview format was then used.	The study examined the optimal approach to decision-making in patients referred for cardiac interventions through the input from patients and caregivers. There were three focus groups each with either patients or providers. Several structural and conceptual barriers existed with the consent document itself that was used prior to the treatment, which included language complexity, small font, and other conceptual barriers. Both groups identified several key components necessary to promote a positive educational experience for the patient. When facilitators are educating patients, they should be mindful of allowing enough time for the discussion, reducing language complexity and form length, providing patient-specific risk information, and using multimedia aids. The focus group patients expressed that they often did not comprehend the information provided by their providers but were hesitant to ask for further clarification. They expressed that the use of larger fonts, increased graphics, and reduced language complexity can aid in their understanding. Additionally, family members and close friends who are able to act as the third party between the patient and physician to acquire information and ask questions would be a valuable aid in the decision-making process. Another factor that improves the confidence of patients during the decision-making process is ensuring early communication and the transfer of information through multiple meetings rather than a single, brief encounter. Learning is also more effective when simultaneous auditory and

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
					visual delivery is used, so decision aids or a decisional coach can be beneficial.
	Examining the voices of family caregivers of seniors with chronic conditions (13)	*Publication date:* 2016 *Jurisdiction studied:* Alberta and Northwest Territories, Canada *Methods used:* Ethnographic, qualitative analysis	Family caregivers with chronic conditions	Three two-hour focus groups.	The study examined the perspectives of family caregivers, including their challenges, joys, and motivation, and their recommendations for resources that can support them in the process. Caregivers identified that their main barriers involved time burden, constantly changing roles and responsibilities, grasping medical knowledge on health conditions, emotional stress, financial strains, changing family dynamics, and personal health. However, they also identified several facilitators that aid their work which include a sense of purpose and validation, spirituality, emotional experiences and coping strategies. It was identified that educational opportunities for both the caregiver and health professional are critical. Education for caregivers can improve their knowledge on the medical conditions of their care recipients, which allows them to better advocate for their recipients. Caregivers believe that education for healthcare professionals can garner more compassion and allow for better communication between providers and patients. The use of more accessible language by providers when conveying information was recommended. Services such as community resources, workshops, emergency management, placement options, and respite services were also recommended as they provide an opportunity for caregivers to learn how to best accommodate their care recipients. Emotional support and services are suggested to be beneficial for teaching coping abilities and decreasing distress in caregivers. Another recommendation was the implementation of public-service announcements that recognize the work of caregivers and clarifies the definition of one. Currently, many caregivers are often providing care without self-identifying themselves as such. Financial supports, such as expanded tax credits, were predicted to lessen the financial burden often associated with caregiving. A more responsive caregiver-centred system that allows for personalized care and easier system navigation (e.g., a specific help and health line) was also identified to be needed. Other

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
					recommendations include the expansion for healthcare providers to take on more health political advocacy.
	Examining patient perspectives to guide recovery for older adults after hip fracture (14)	*Publication date:* 2014 *Jurisdiction studied:* British Columbia, Canada *Methods used:* Qualitative study	Women and men aged 60 and older with previous hip fracture and their caregivers.	Conducted semi-structured interviews either in person or over the telephone.	The study examined the recovery experience of older adults with hip fractures and ways that health professionals could improve health communication. Three themes regarding the recovery experience emerged: seek support, move more, preserve perspective. The first theme of asking for help and clarifying information was a recurring theme from caregivers and patients. They expressed a need for information about community resources and acknowledged the difficulty of maintaining a balance between accepting help and preserving personal independence. Additionally, participants felt inadequate in terms of their medical knowledge and thus noted the importance of asking questions. They also expressed their desire for someone of their own age, who has undergone similar experiences, to provide peer support. The second theme of 'moving more' rather than remaining sedentary was another prevalent topic that arose. Exercise programs such as physiotherapy for home interventions were seen to be beneficial. The third theme consisted of preserving a positive perspective, including remaining patient and setting realistic expectations. These results indicate the importance of patient-centred care which can facilitate the decision-making and recovery process. A 'recovery map' that provides information and resources during the recovery stages is a type of resource that could be implemented. Further, opportunities for caregivers to ask questions and gain knowledge are other ways for more patient-centred care.
	Examining the transition from reactive to proactive supports for family caregivers across the healthcare system (42)	*Publication date:* 2014 *Jurisdiction studied:* Ontario, Canada *Methods used:* Participatory action research	Various caregivers in Ontario.	Participatory action research methods were used. There were five phases which consisted of a steering committee, a literature review, a collection of caregiver stories, engagement with caregivers, and an audit and review.	The study examined practices and indicators of effective caregiver education and resources that can meet caregiver needs. The first practice that effectively provides caregiver support is support programs that are able to adapt to the unique care situations of each caregiver. Five indicators should be considered, including assessing the needs of the caregiver, the relationship to the care recipient, and cultural influences. It should also provide strategies that address family dynamics.

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
					Secondly, such caregiver programs should stimulate caregiver involvement and interest by fostering networking among each other, connecting them to community services, offering online interactive programs, and teaching the application of those knowledge and skills. Thirdly, the emotional status of caregivers is an important aspect to consider. Education programs that validate the personal knowledge, experience and successes of caregivers are much more promising. Additionally, it is important to educate caregivers on how the system works, provide practical strategies for caring, and address informational needs over time. Enabling caregiver participation through arranging for transportation or making the program more convenient are other methods to encouraging caregivers and building their confidence.
	Examining the provision of care for caregivers of high-needs older persons (41)	*Publication date:* 2014 *Jurisdiction studied:* Ontario, Canada *Methods used:* Review	Various caregivers of high-needs older persons in Toronto.	The Caregiver Framework for Seniors Project (CFSP) is an initiative that supports 'at-risk' caregivers of high-needs older persons in Toronto.	The paper details the Caregiver Framework for Seniors Project (CFSP), an initiative that aims to increase caregiver resiliency and capacity. The program provides intensive case management and ongoing counselling with a budget of approximately \$1.500 per caregiver per year. It specifically targets caregivers who provide at least 10 hours of direct care per week and are 'at risk' of burnout. Some of the risk factors could include physical, emotional, social or financial pressures which are assessed using the Resident Assessment Instrument – Home Care (RAI-HC). In the latter half of 2011, 406 caregivers participated in the program. The care recipient cohort consisted of more than half speaking a language other than English and those who were fully dependent on others to perform activities of daily living. To decrease the stress that caregivers often experience, the program provides funds for a respite. The program is highly flexible and personalized with a selection of direct assistance (e.g., cash) or in-kind services which include solution-focused counselling and case management. It also provides training in problem-solving and resource sheets to improve caregiver education. Caregivers are followed up at regular intervals throughout the program to ensure that the care plans are effective.

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	Examining family caregiver experiences during care transitions of older adults (15)	*Publication date:* 2014 *Jurisdiction studied:* Ontario, Canada *Methods used:* Qualitative interviews	Study participants included six case managers from Community Care Access Centres in Ontario and 12 family caregivers who were providing support to older adults with hip fracture and stroke.	One-on-one, semi-structured interviews lasting an average of 38 and 44 minutes were conducted with each of the case managers and family caregivers, respectively.	The research findings indicated a critical need for healthcare providers to work closely with family members to identify and address their support needs during transitions between hospital and home. It was also noted that a caregiver's capacity to care is not a static concept, but rather one that has the potential to dynamically change and improve over time. Discharge was described by many participants as a critical time-point for all members of the care team and the older adult to be in mutual understanding regarding the care plan and next steps. Unfortunately, this is also a time when the most miscommunication and information-sharing errors take place. Instead of relying solely on verbal communication, caregivers suggested that healthcare providers work with them to fill out a written care outline, detailing their responsibilities for care in the home. Any support services the older adult would be eligible to receive could also be conveyed at this time. During interviews, many caregivers shared that the biggest challenge they faced was isolation and doubt in their abilities to provide care. To mitigate this, caregivers expressed a desire to have their emotions validated by others and to have someone they could contact to ask questions of or to talk with.
	Examining the transitional care experience of a hip fracture patient (16)	*Publication date:* 2013 *Jurisdiction studied:* Southern Ontario, Canada *Methods used:* Literature review, semi-structured interviews, and participant observation	The single participant in this study was a hip fracture patient from Southern Ontario who was expected to undergo multiple transitions in care. She had involved family caregivers, had multiple care providers, and was over 65 years old.	Face-to-face semi-structured interviews (30 to 60 minutes) were conducted to achieve an in-depth, rich description of each of the participant's experience of transitional care. The participant, her family caregivers and healthcare providers were asked to openly describe their experiences at each point of transition.	Four themes emerged from the multi-perspective data to describe the transitional care experience of the participant across her entire care trajectory. The overarching trend across all themes was that care transitions present multiple challenges not only for patients, but also for family caregivers and health care providers. One theme evident in the data was that the patient and her family caregivers felt unimportant and left out of the decision-making process surrounding the patient's care plan. The patient felt like she had little input in terms of her next steps in care, with family members sharing similar sentiments. Family caregivers also described challenges managing communications outside of the immediate circle of care due to the issues with effective communication within the circle of care. Another theme that arose was lack of clarity in healthcare provider roles. This lack of clarity exacerbated already fragmented care responsibilities during transitions between settings and providers. Within disciplines, role confusion was

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
					discussed as an issue largely due to the constant and quick turnover of staff across a variety of care settings. The third theme that emerged was that the patient and her family caregivers did not feel equipped or prepared for the care transitions as they occurred. All those who were interviewed and involved in the care transition process expressed feeling unprepared and overwhelmed with their individual role in care. The final theme that emerged was that health-system policies and procedures restricted healthcare providers' ability to deliver individualized care. According to healthcare providers, the healthcare system's focus on discharge-centred care planning put pressure on them to initiate transitions with the patient before they felt comfortable doing so. Other constraints of this nature were found to inhibit optimal care throughout the transition process.
	Examining caregiver and patient-focused interventions for dementia (22)	*Publication date:* 2008 *Jurisdiction studied:* Ontario, Canada *Methods used:* Evidence-based review	N/A	The two main categories of caregiver-directed interventions examined in this review are respite care and psychosocial interventions.	Respite care, defined as a break or relief for the caregiver, is identified by caregivers as one of the key formal supports to alleviate the stress of caring. Psychosocial interventions encompass many different types of interventions. They may include educational, behavioural, dementia-specific, supportive, and coping interventions. Effective psychosocial interventions had four key characteristics in common: they sought to improve caregivers' problem solving and coping strategies; they involved patients in addition to caregivers; they involved individual behavioural management therapy; and they were multi-component. Ineffective interventions were typically one-dimensional, involving only education about dementia by itself, supportive therapy by itself, or group behavioural therapy by itself.
	Examining accessible support for caregivers of seniors with chronic conditions (20)	*Publication date:* 2006 *Jurisdiction studied:* Alberta, Canada *Methods used:* Analysis of qualitative findings pertaining to intervention processes	A total of 128 participants were recruited across three sites in Alberta. This paper focuses on the 66 family caregivers in the intervention, who were caring for 47 relatives with Alzheimer's disease and 19 with stroke.	Over the course of six months, 27 experienced family caregivers provided weekly support to 66 new family caregivers over the telephone. Qualitative data was used to assess the perceived impact of the intervention, including increased	Overall, the evidence indicates that caregivers received various forms of support from the intervention agents via telephone. Notably, information and affirmation supports, which were virtually non-existent within the usual support networks, were the major forms of support provided by peer helpers during the intervention. Family caregivers also received significant emotional support from their peers. Informational support was the form of support most frequently noted by family caregivers. From their peer mentors, participants gained a better understanding of the chronic

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
				satisfaction with support, coping skills, caregiving competence and confidence, and decreased caregiver burden and loneliness.	disease they were helping manage and the resources available to them (e.g., long-term care centres, support groups, respite homes). Information was also offered to help solve specific care challenges (e.g., managing behaviour, environmental adaptations, setting boundaries). Affirmation support, involving the provision of constructive feedback and validation of caregivers' feelings, were also found to be particularly powerful. Emotional support focused on caregivers' feelings about their new, stressful caregiving responsibilities. Peer helpers' understanding was very helpful due to their experience with similar situations. Overall, family caregivers had many immediate support needs met through the course of the intervention. Caregivers reported increased satisfaction with the various forms of support available through the intervention. Approximately 50% of caregivers revealed that the intervention increased their feelings of competence and confidence in caregiving; 37% of caregivers disclosed that the intervention helped reduce their feelings of loneliness and isolation; and 16% of caregivers reported that their caregiving burden had decreased following the intervention.
	Assessing the impact of a web-based transition toolkit for caregivers of older adults with Alzheimer's disease (25)	*Publication date:* 2018 *Jurisdiction studied:* Alberta and Ontario, Canada *Methods used:* Mixed-methods randomized controlled trial	Caregivers who were providing physical, emotional or financial support to older adults living at home who had Alzheimer's disease and related dementias. Participants included 56 caregivers. The median age of the caregivers was 64 and 77% of the caregivers were female.	The originally developed Transition Toolkit was converted to a web-based toolkit known as My Tools 4 Care. This web-based toolkit consisted of six sections: about me; common changes to expect; frequently asked questions; resources; important health information; and a calendar. This toolkit was self-administered by the caregivers and was used at their own schedule and at their own convenience.	The caregivers participated in at least one semi-structured telephone interview. The caregivers expressed that using the My Tools 4 Care toolkit encouraged reflection, encouraged sharing of caregiving experiences, provided a source of information and education, and provided affirmation. Some participants reported that using this toolkit did not help them because they had already met their caregiving needs in other ways, they felt it was not the right time to engage in using the toolkit or they did not have time to use the toolkit. Caregivers reported that this toolkit was both easy to navigate and easy to use. The caregivers found that it was helpful to be able to reflect on their experiences through the toolkit, access resources and obtain validation of their caregiving experiences. Some caregivers also reported that there were challenged with the technology, they had concerns with safety and the toolkit was too time-consuming for practical use.

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Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
					Limitations to this toolkit include that it was only available in English and that it has little ethnic or cultural diversity at present.
How should education and information-provision interventions be provided to health professionals to best empower caregivers throughout restorative-care processes?	Identify the needs of caregivers and provide recommendations to address these issues (54)	*Publication date:* 2018

Jurisdiction studied: Alberta, Canada

Methods used: Qualitative analysis of conservation circles and written notes | A one-day symposium on supporting family caregivers was conducted and 106 participants attended. Of these participants, 38 were frontline healthcare providers (physician, nursing, allied health, administrative support staff), 36 were healthcare manager, 16 were senior service organizers, eight were family caregivers, five were academics, and three were policymakers. | Participants engaged in conversation circles which were audio-recorded and transcribed. Participants also recorded their thoughts on index cards. | From the conversations at the symposium, six main themes were highlighted. The first theme was orientation and education of healthcare providers. It was recommended that healthcare providers receive education on involving family caregivers of older adults on care teams and in care settings. It was also recommended that communication is improved between healthcare providers and patients and caregivers to promote more meaningful engagement and improve information sharing.

The second theme was facilitation of culture change toward respect and honour of family caregivers. It was recommended that the communication with family caregivers is a normal part of care, and family is recognized as an important part of the care team.

The third theme was enhancement of resilience among caregivers. It was recommended that healthcare providers be proactive in their support of family caregivers and have an accessible list of resources that support caregivers.

The forth theme was identification of caregiver stress and burden. It was recommended that healthcare providers receive training on how to assess caregiver burden, and how to ensure the necessary supports are in place to help caregivers.

The fifth theme was provision of palliative care and end-of-life supports. It was recommended that healthcare providers be educated on the available options for palliative and end-of-life care, and how to connect caregivers to the available services.

The sixth theme was facilitation of policy and practice change. It was recommended that policies need to be developed that are more comprehensive to the needs of caregivers. It was also suggested that caregivers be involved in the development of these policies. |
| | Examining experts' perceptions on the use of interprofessional education to | *Publication date:* 2017

Jurisdiction studied: Hamilton, Canada | The 32 participants of this study included health and social-service practitioners, educators, researchers, and representatives of relevant | A qualitative interview was conducted with each participant by two members of the research team who had expertise | One of the most frequently cited themes in participant interviews was the importance of engaging clients and their family members in the education of care providers. By working closely with older adults and their families, care providers can gain a better understanding of patients' values and needs. |

Question addressed	Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
	support collaborative practice in the care of community-living older adults (55)	*Methods used:* Qualitative descriptive study	advocacy groups and professional agencies who had expertise in interprofessional education (IPE) and older adults.	in qualitative and aging research. All interviews were audio-recorded and ranged from one to 1.5 hours in length.	Another critical component of effective care-provider education is the setting in which it takes place. Although current interprofessional education occurs almost exclusively in acute-care settings, training in home and community settings throughout the training process was recommended by most participants. Doing so better simulates the environment in which care will take place, facilitates the development of relationships between care providers and recipients, and incentivizes care providers to stay and work in their training environments upon graduation. Participants also highlighted current gaps in interprofessional education related to aging, pointing to a need for a curriculum that includes aging in both content and core competencies. They also emphasized a need for dedicated resources to support faculty development in order to achieve more efficacious training outcomes. The use of innovative information technology that revolves around the learner, practitioner, and patient-related processes was also recommended by participants.