Rapid Review

Peer Supports for Caregivers in Canada

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Executive Summary

Caregivers are increasingly recognized as the backbone of the healthcare system, providing much of community-based chronic disease and long-term care. Although many adults and children with complex health issues also require caregiver support, most caregiving in Canada is devoted to elder needs – a demand that will continue to rise as populations age. Peer-based caregiver support systems – where caregivers help each other through information sharing, skill development, emotional support, or by taking on caregiving duties – often emerge in response to the limitations of healthcare and social care institutions. The advent of online health and caregiving communities has further fueled these efforts in recent years. The goal of the present rapid review is to characterize the landscape of peer support initiatives and to identify features and approaches that may be effective in meeting caregiver needs.

In the literature, caregivers tend to be defined as family members, friends, and neighbours providing ongoing emotional, financial, and practical care to an individual with a long-term health condition on an informal and uncompensated basis, outside of the clinical setting. Peer caregivers are those with the lived experience of caring for a certain population. Interestingly, we found few Canadian studies in the academic literature, but a significant number of Canadian initiatives in the grey literature. This may reflect an interest in developing peer-based caregiver support programs in Canada, yet relatively limited empirical evaluation of these programs. The formats of the interventions within the academic and grey literature were largely congruent and could be classified into one-on-one peer supports (e.g., mentoring and befriending) or group-based supports (e.g., support groups/workshops, recreational activities, and online platforms). To optimize peer support programs, we present the following key findings for the consideration of program implementors:

1. Meeting caregivers' informational needs: Caregivers require ongoing informational support, though their informational needs may differ depending on the care recipient's type and stage of illness. General online information was typically sought early in the caregiving process, while individualized healthcare advice may be preferred at advanced stages.

2. Teaching skills relevant to caregiving tasks: Caregivers derived particular benefit from learning about disease care, coping strategies, family communication, and self-care skills. Understanding the perspective of the care recipient also helped caregivers adapt to challenges.

3. Peer-based emotional support: Caregivers valued both sharing their feelings and providing emotional support to others, and some caregivers may prefer peer support groups of similar age and gender. Ensuring that caregivers are able to do so in an open and private manner was deemed to be important. Caregivers should also be encouraged to establish healthy boundaries.

4. Instrumental support: When joining peer support programs, caregivers expected to receive tangible and concrete supports, including respite care, referrals to health and community resources, and transportation support. One-on-one peer mentoring interventions may be a well-suited vehicle for such approaches; however, the evidence base is limited, relative to the other types of peer support.

5. Flexible intervention delivery approaches: Remote/virtual peer support systems (including text-based, telephone-based, or live-streaming/telehealth media) were viewed positively by caregivers due to their flexibility. In-person support groups should also allow for flexibility in their curricula and scheduling to accommodate caregivers' dynamic circumstances and changing needs.

Introduction and Background

Caregivers are often described as the backbone of the health system, particularly as the responsibilities of complex chronic disease management and long-term care are increasingly shifting out of hospitals and institutions into home and community settings (1). In 2012, approximately 46% of the Canadian population reported performing caregiving duties at some point in their lives, with over a quarter having done so in the past year (2). Moreover, family caregivers have been estimated to provide over 75% of health care, amounting to nearly $25 billion per year in unpaid work in Canada (3). Further, over half of individuals whose paid work has been impacted by caregiving have reported reducing or modifying their hours to accommodate caregiving duties (3,4). Although caregiving can be rewarding (3,5), it also increases the risk of poor mental and physical health outcomes (6,7).

Given the complexity of the caregiving experience, a number of factors have been hypothesized to modify the relationship between caregiving burden and the occurrence of negative health outcomes (8). Social support may provide a protective role (9) and other caregivers may serve as a useful resource (10). Indeed, peer-based support programs appear to hold promise in improving caregiver wellbeing, though prior literature reviews have noted the evidence base to be sparse (11,12). Nonetheless, the value of "experiential similarity" in peer-based models has been highlighted as a factor meriting additional investigation (12).

Peer support initiatives may also emerge from caregiver and patient advocacy efforts in response to barriers within formal healthcare and social systems (13,14). As a result, peer support models may be situated within a broad range of organizational structures, including grassroots networks run by volunteers, independently funded peer initiatives, mainstream agencies with embedded peer support programs, and mainstream agencies that contract individuals to provide peer support (13). In addition, an increasing number of caregivers use the internet to gather health information, read other people's illness narratives, and search for individuals with similar health experiences (15,16). It is important to capture such grassroots initiatives, which may be underrepresented in the published academic literature, as socio-demographically marginalized populations often rely on non-formalized networks of support (17).

To address this need, we performed a rapid scoping review of recent academic and grey literature, including social media data, to characterize the wide landscape of peer support initiatives in Canada and abroad, and to identify features and approaches that may be effective in meeting caregiver needs.

Methods

Rapid Scoping Review

We undertook a rapid scoping review of the academic literature using systematic searching and data collation methods to characterize the current landscape of peer support interventions for informal caregivers.[1] Three bibliographic health research databases were searched for English-language studies published between 2017 and 2020 by using keywords related to the following search concepts: (1) informal caregivers and (2) peer support. We excluded study protocols and literature reviews to capture original studies with preliminary, pilot, or final results. We only included studies from countries in the Organization for Economic Co-operation and Development (OECD). The included studies were summarized according to the intervention format and the type of peer support provided.

Grey Literature Review

A rapid grey literature search was performed to describe the current landscape of peer caregiver support initiatives in Canada. The search consisted of targeted Google web searches, program and resource lists of key caregiving organizations, a review of a cross-section of Twitter data[2], and consultations with NAO network members with relevant expertise. We included current Canadian programs with publicly available information, involving peer-to-peer caregiver interaction. The initiatives were categorized based on shared key themes, including one-on-one supports, group supports, training opportunities to facilitate peer programming, social media platforms and discussion forums, and other support types.

Limitations

The academic literature search was limited by publication date (2017-2020) and language (English); however, language restrictions are unlikely to modify study conclusions (18). We may have excluded studies that served a peer support function or that took place within supportive environments but did not state so explicitly. While scoping reviews do not involve critical appraisal, study quality may still affect the strength and robustness of the review conclusions. Thematic analysis relied closely on author-reported inferences; as such, any biases in interpretation from the original works may have been carried over into our synthesis. The grey literature scan did not aim to provide an exhaustive listing of every peer caregiver support program in Canada; it may also be missing important program details due to our reliance on public information. Finally, the central focus of this report was on peer-to-peer caregiver supports and not the larger systemic structures or policies that may affect caregivers within and outside of Canada.

A detailed overview of the scoping and grey literature review methodologies (including search strategies, selection processes, and thematic analyses) and results are available in Appendices A-D.

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[1] Due to a significant variation in the terminology used to denote informal caregivers (e.g., unpaid or familial caregivers) and peers (i.e., those with lived experience of caregiving), we will use the terms "caregiver" and "peer" as umbrella terms throughout the report. Individuals receiving caregiver care will be referred to as "care recipients." Specific program descriptions or direct quotations may, however, contain the original terminology of their respective sources.

[2] Twitter data was collected and analyzed using Netlytic, an open-source software tool.

Analytic Overview

Following the selection procedures (**Appendix B**), we identified 36 studies of interventions related to peer-based caregiver support. All but two studies (19,20) were conducted outside of Canada, including in Australia, Austria, Italy, the Netherlands, New Zealand, Sweden, and the United Kingdom (UK). Over half (n = 20) of the studies were conducted in the United States (US). Studies overwhelmingly employed qualitative or mixed methods designs (n = 28) and nearly a third (n = 11) were described as pilot and feasibility studies. The largest category of care recipient health condition was dementia (n = 17); others included mental illness in children and youth (n = 4), mental illness in mixed-age populations (n = 2), advanced cancer in adults (n = 2), amyotrophic lateral sclerosis (ALS) (n = 2), developmental disabilities in children (n = 2), chronic illness in adults (n = 2), elder needs (n = 2), military veterans (n = 2), and genetic health conditions in children (n = 1). Although this scoping review only spanned three years, this distribution of care recipient conditions is likely to be consistent with the broader evidence base – for instance, 18 of the 29 systematic reviews (which encompassed wider time periods) excluded at the screening phase focused on caregivers of elderly individuals and/or those with dementia. Further, age-related needs comprise the most common issues requiring caregiving help (2).

Definitions

Informal caregivers

Among studies that provided an explicit definition of caregivers (n = 5), there was general agreement that caregivers are family members, friends, and neighbours providing ongoing emotional, financial, and practical care to an individual with a long-term health condition on an informal and uncompensated basis, outside of the clinical setting (22–26). While there is no consensus definition of informal caregiving, the description of informal caregiving in the included studies aligns with the broad definition developed by the Change Foundation (2015), where informal caregivers were defined as the "family, friends, [and] neighbours who provide critical and ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, disability, or end of life circumstances" (27).

Peer caregivers or peer support

Among studies that provided an explicit definition of peer caregivers (n = 9), all but two focused on caregivers of either children and youth (28–31) or family members (21,22,32) with severe mental health issues. All of these studies defined peer caregivers as those with the "lived experience" of caring for an identified population. Another study of dementia caregivers defined a peer caregiver as one who "has faced the same significant challenges as the [peer] support recipient and serves as a mentor to that individual" (12). Although there is no consensus definition of peer caregivers or peer support, our findings agree with the broad definition developed by the Mental Health Commission of Canada, where peer support is a "supportive relationship between people who have a lived experience in common" (33). **Appendix C** provides a more detailed overview of the implicit and explicit definitions of these terms.

In order to elucidate intervention delivery approaches and peer support features, we categorized interventions by (1) intervention format and (2) types of peer support provided (**Table 1**). A detailed overview of study characteristics and the analytic framework is provided in **Appendix C**.

Table 1. Overview of results by analytic framework

Intervention formats	Types of peer support			
	Informational (n = 25)	Instructional (n = 21)	Emotional (n = 20)	Instrumental (n = 4)
Peer mentoring and befriending (n=6)	3	5	3	2
Support groups and educational workshops (n=14)	12	10	7	1
Activity-based/recreational programs (n=5)	1	2	3	1
Social media platforms and discussion forums (n=11)	9	4	7	0

Intervention Formats

Peer mentoring and befriending

Six studies discussed one-on-one peer mentoring approaches. All but one intervention (34) were delivered through a partnership between a non-profit organization and a community-based health or social service, which paired caregiver clients with peer supporters, and had an oversight structure (e.g., case management team). One intervention was phone-based (34), while other programs involved in-person contact. Peer supporters provided education, modeled coping behaviours, and accompanied caregivers and care recipients to health appointments. One study reported that peer supporters (volunteers) were trained in safeguarding and protecting vulnerable adults (12), while another study employed individuals (part-time paid staff) with caregiving lived experience and a background in family therapy, carer consultancy, and clinical and community mental health services (22). The remaining programs recruited peer supporters based on self-assessed readiness and skill in providing caregiving mentoring (28–30).

Support groups and educational workshops

Fourteen studies described support groups and workshops. All but three studies (35–37) involved an educational component and a group discussion. Most interventions were primarily educational workshops with support group elements (21,23,25,31,38–40), while a few were support groups with educational elements (19,41–43). Groups were facilitated by peer caregivers only in two studies, with health professionals involved in designing one such program (21) and in co-facilitating the other (40). Three studies described programs for caregiver and care recipient dyads; however, the caregiver group discussions were held separate of and in parallel to the care recipient activities (36,41,42). Four studies described virtual support groups, facilitated via video-conferencing/live-streaming (19,23,39) or telehealth (25) technology. All virtual programs were adapted from an in-person version, with one virtual program offered as an alternative to the in-person program (23) and another offered only to caregivers who have reported barriers to attending the in-person program (25). Two studies on virtual programs described holding one initial in-

person session to give participants an opportunity to meet one another and to provide an orientation to the technology (25,39). Virtual support groups were regarded as beneficial because they eliminated travel time and the need to arrange respite care (25,39). Technological issues, such as audio feedback or difficulties in using intervention platforms, were highlighted among the main challenges (25). Caregivers did not find that the online environment interfered with their ability to connect emotionally: "To be honest with you, there was no difference [between online and live groups]…I did not perceive any difference in the ability to relate to each other" (39).

Activity-based/recreational programs

Five studies reported on recreational programs. Two studies described camps for young caregivers of family members with serious chronic conditions; one camp focused on caregiving skills (44), while the other focused on coping and emotional support (45). Both programs were facilitated by health professionals, including therapists, social workers, and clinical psychologists. Three studies discussed dyadic recreational programs for individuals with dementia and their caregivers. These included games of Boccia (indoor bowling) (46), a choir called "The Unforgettables", led by a conductor (47), and Dementia Cafés held at local libraries and community centers, where caregivers and care recipients could socialize with peers amid refreshments and crafts (48). Dementia Cafés also included occasional didactic education sessions about dementia and information about available external services. Recreational programs were deemed to be feasible (44), well-attended (47), and well-received among caregivers, as they provided a sense of routine (48) and involved enjoyable and "normalizing" activities (44,47,48).

Social media platforms and discussion forums

Eleven studies described social media platforms. Two studies described grassroots social media communities, such as blogs (49) and Facebook groups (50). Two studies described user testing of prototype websites, which involved educational modules, resources composed by other caregivers (e.g., instructional videos), and options to join discussion groups to chat with other caregivers (51,52). Another two studies evaluated the use of the Military and Veteran Caregiver Network (MVCN) in the US, which had a similar web-based multicomponent layout. Although MVCN engagement was found to be low overall, with users primarily using the site for informational purposes (26), the highest level of engagement was observed in caregivers that had the highest support needs (53). Two online platforms were developed and implemented with government support (32,54). Two studies described online discussion boards that were moderated by peers who took on an advisory role (24,32), while another discussion board intervention was moderated by a clinician (55). While online platforms offered a welcome degree of anonymity (49,55), some users expressed privacy concerns in relation to sharing their personal information online (54).

Types of Peer Support

Informational support

Information-sharing to empower one's self and others

Obtaining support related to information and resources was a common theme across studies (29,31,55). Caregivers sought out and provided support using online platforms, creating resource banks with links, books, articles, and strategies that have been useful for individuals during their "caregiving journey"; medical consultation and treatment options; local community support services; ongoing clinical trials and

completed studies with promising results; as well as calls to action to advocate for the needs of caregivers and those in their care (37,49,54,55). In moderated online discussion boards, the most knowledgeable caregivers were typically designated with oversight and information provision duties (24). In unmoderated online settings, similar roles emerged organically, with some individuals becoming information providers and others, information consumers (49,54). While informational websites were viewed as helpful for navigating the caregiving process (37,53), they offered limited opportunities for actively engaging with other caregivers to develop personal connections and receive emotional support (26,37). Another challenge of online resources reported by caregivers was difficulty in implementing the retrieved information into practice without professional or individualized guidance (54).

In-person programs involving more active caregiver engagement, such as peer mentoring, support groups, workshops, and recreational activities, often included an educational component about the care recipient's health condition. Focused educational workshops have generally been positively regarded among some caregivers (21,38,40); however, if such sessions were unclear in their purpose, incongruent with caregiver information needs, or were delivered in settings where the care recipients were present, they were viewed as overwhelming (23,48) and ineffective at improving caregiver knowledge (30).

Changing information needs during the course of illness

Caregiving was understood to be a "normal, stage-progression process," where the caregiver role "continues indefinitely" (25). As such, participants of caregiver support groups appreciated program curricula that discussed disease prognosis and provided flexibility to tailor the information to their changing circumstances (23,43). Caregivers also benefited from support groups, online groups, and one-on-one programs that involved peers caring for individuals at more advanced stages of the same health condition, as this allowed them to better "see what's coming" and feel prepared for the next steps (22–24,35,37). Feeling prepared manifested differently across different health conditions. In the context of mental illness, feeling prepared included feelings of hope that the care recipient will achieve recovery (22). Among parents of children with developmental disabilities, this involved feeling more positively about their child's development: "There is usually one mom there to give you the long view… When I first had [my daughter] I really didn't know what to expect and it was nice to see how other people's kids were doing (as a 3-, 7-year-old, etc.). Knowing she was doing the 90% normal thing was very reassuring" (37). In caregivers of individuals with advancing illness, this included feeling reassured that they will be able to cope with the care recipient's deteriorating health status: "The only way that you can take it is to accept it, but it is instinctive to fail at accepting this thing" (35).

It is important to note, however, that mixed stage-of-illness settings may not be suitable for all caregivers, as some noted that being reminded of the realities of the disease can be painful: "I have found it really, really difficult. [Care recipient] is one of the best here and one of the youngest, and it is hard seeing people further down the line than him" (35). Peer support, particularly that offered in online communities, was often sought out early on in the disease process, when caregiver information needs are broad (37). As caregiver information needs became increasingly specific with advancing care recipient illness, some caregivers preferred in-person services, such as support groups (37), while others saw less relevance in peer support services altogether and sought information from health and social care professionals instead (54). For example, despite the flexibility of the US Veterans Affairs dementia caregiver peer support groups, caregivers managing late-stage dementia reported seeking palliative care information from other sources (23).

Instructional support

Developing practical caregiving skills

Sharing practical advice regarding caregiving skills often emerged organically through caregiver discussions both online and in-person. For example, on a discussion board for caregivers of individuals with chronic illness, caregivers posed questions, sought input, and engaged in problem-solving on issues related to medical treatments, health system navigation, management of challenging behaviours, and enlisting support from other family members (55). In a dementia support group, caregivers reported receiving "a lot of practical help, like the whiteboard that can help cope with your life'' (42). Coaching of practical caregiving skills could also be a planned component of interventions. For instance, a camp for child caregivers of parents with ALS specifically focused on teaching children caregiving skills, including administering medications, assisting with supportive health equipment, and helping with hygiene and appearance. Teaching was performed by a multidisciplinary group of healthcare providers (e.g., physiotherapists, occupational therapists, speech-language pathologists, and social workers) and a "teach-back" method, involving skill demonstrations to peers, was employed to reinforce learning (44).

Increasing caregiving self-efficacy and coping skills

Instructional support also focused on cultivating caregiving self-efficacy by way of coping and regulation of negative feelings, such as stress (23,47). Participants of dementia caregiver support groups recalled that better regulation of their emotions in response to the care recipient's behaviours led to them seeing things "a little bit more objectively," feeling less overwhelmed, and feeling more equipped to face "the next day" (19,23). One dementia caregiver described regaining their confidence as follows:

> *"… this disease demolishes a lot of things in you that you have start building again. Like it demolished my self-esteem at the beginning… I didn't even know how to deal with it so I thought it was myself, so then… you have to start building it up again, so I think I'm doing much better than I was before" (19).*

Peer mentors or befrienders could be instrumental in helping to rebuild lost confidence, as mentioned by another caregiver: "… she shared some things that she admired me about, I never really saw them as strengths" (29). Among caregivers of individuals with mental health issues, better emotion regulation was noted to have a "ripple effect" on the care recipients: "I was calm, so I was better for her. I was not arguing as much, and arguing can make her illness worse" (22).

Gaining insight into the care recipient's perspective

Caregiving skills could also be improved by providing better insight into the care recipients' health conditions. Receiving possible explanations for the care recipients' challenging behaviours from peers also helped reduce caregivers' frustrations (24) and increase their comfort with their care recipient's health condition (31). One participant of a dyadic dementia support group noted "I am more careful because I didn't understand when I shift things, it always annoyed… So now I am more careful to leave things in the same place and I have labels on icing sugar" (42). A participant of another dementia support group stated: "I have much more peace and calm in dealing with my husband, much more accepting of what he can and can't do and what he's responsible for and not responsible for. And I'm happier and he's happier" (36). Such discussions also had a validating effect – for instance, parents of children with serious mental illness experienced relief in learning that they were "doing some things right" in supporting their children (31).

Improving family communication skills

Taking part in peer support programs allowed families to improve their communication skills, which, in turn, reduced family stress and conflict. This was perceived to have positive impacts on the care recipient – for example, as a result of improved family dynamics, caregivers of youth in the foster care system reported being able to present a "unified front" for the youth in their care (29). Dementia caregivers also noted that the dyadic support group gave their families a "topic of conversation" and opportunities to better engage the individual with dementia (36). Similarly, siblings of hospitalized children with mental illness mentioned that they felt that they could "talk with [their] parents more" following joint participation in support groups (31).

Developing self-care skills

Although the importance of taking time for oneself, away from caregiving, was recognized by caregivers across the reviewed studies (41,42), it was also identified to be an area in which caregivers required significant support and instruction. In a family-to-family peer support program for caregivers of children and youth with mental health issues, caregiver competency in items related to caring for oneself and communicating one's own needs were rated the lowest at baseline and were the slowest to improve at 3-6 months' follow-up (28). This may be due to feelings of guilt, which were noted to be attenuated in one study on ALS peer support groups (35).

In many interventions, peer caregivers explicitly urged others to prioritize self-care, rationalizing this as beneficial for the wellbeing of both the caregiver and the care recipient (23,24). For instance, peer moderators in a discussion forum for dementia caregivers provided the following response to an individual reporting caregiving fatigue: "Please try to find some relaxation, 'me time.' This will give you a way to stay healthy mentally, physically, and spiritually" (24). Peer moderators also encouraged some caregivers to seek external help, like obtaining counseling and medication (24). Among participants of a US Veterans Affairs dementia caregiver peer support group, caregiver focus on their own wellbeing during the course of the program was associated with sustained behaviour change post-intervention (e.g., sleep management) and motivation to seek external support, which was previously avoided (23). Similarly, in a telehealth-delivered elder care support group, which included educational modules on self-care techniques (e.g., action plans, deep breathing for relaxation, positive self-talk, resources, and taking personal time), participants showed improved self-management skills post-intervention (25).

Emotional support

Peer-based versus other sources of emotional support

Caregiving was regarded as a uniquely bonding experience (49). As such, peer caregivers were valued for their insider understanding of caregiving and an enhanced ability to empathize. This was consistent across most intervention modalities, caregiver types, caregiver-to-care recipient relationships, and jurisdictions examined (23,25,29,31,45,49,51). Mutual understanding led to a sense of community and reduced feelings of loneliness and isolation, as described by a caregiver in a support group for dementia patient-caregiver dyads: "It is helpful to know that other people have got similar problems. I take comfort from that. I think that nothing is more difficult to bear than a feeling of aloneness" (42). In addition to realizing that they are not alone, some caregivers suggested that meeting other caregivers was imperative for maintaining hope. A participant of a support group for parents and siblings of children hospitalized for mental health issues stated: "I learned how much the parents need each other" (31). Strong peer-to-peer bonds were particularly

important in light of difficult decisions, such as placing a family member with advanced dementia in a long-term care facility. In reference to this, one participant of a virtual dementia support group applauded the group for "being so open and going through this experience together" (39).

While receiving support and insights from health professional staff was welcomed by most caregivers, (23,35), others identified important contrasts between peer-based and other sources of support. For instance, in a support group for caregivers of individuals with ALS, some caregivers noted that sharing their feelings with other caregivers was preferable because they "understand without having to explain," while health professionals "understand but do not share the same suffering" (35). In a one-on-one peer mentoring service for caregivers of individuals with mental illness, peer support workers were viewed as independent from other staff, which was seen as important among caregivers who found health professionals intimidating or those who had negative experiences with mental health services (22). A similar observation was made by a parent of a child with a developmental disability about online caregiver communities: "When I had my son I received a lot of negativity from all of the doctors and I was worried that this support group will only perpetuate this attitude. I thought there will be a group of depressed people crying and complaining to each other. But it was just the opposite – uplifting and positive" (37).

Relevance of peer group composition

Although caregiving was regarded as a bonding experience, peer support dynamics varied within different caregiver subgroups. Cipolletta et al. (2018) conducted separate support groups for caregivers of individuals with ALS who were partners and those who were adult children. The experiences of the two groups were very different. The former group had difficulties integrating two individuals due to one's grief following the death of their partner and the other's caregiving demands. The latter group, however, had productive discussions, with participants whose parents were at more advanced stages of illness providing guidance to those whose parents were recently diagnosed. Similarly, in a mixed support group of partners and adult children of individuals with dementia, adult child caregivers expressed a desire to share their experiences with those they ''had more in common with'' (42). Individuals in another dementia caregiver support group expressed an appreciation for the group being composed of only women, noting that a mixed-gender environment would have made discussions more challenging (42). These findings suggest that common characteristics, such as the health condition of the care recipient, relationship to the care recipient, and caregiver demographics, may be important factors to consider when implementing support groups.

Private non-judgmental spaces

Across most intervention modalities, peer support programs were viewed as opportunities for caregivers to process their feelings around the care recipient's illness (31,46). In addition, caregivers often spoke of a need to share or "vent" authentically and free of judgment or negative impact on personal relationships (54). For example, in a personal blog, a caregiver of a family member with dementia stated: "I seriously feel a little better after lodging my complaint with the complaint department (a.k.a. my online caregiving friends). You guys understand and don't judge when bad days are had" (49). Such sharing was encouraged by others, as noted by an individual in another caregiver-only online discussion group: "Remember we are here to be your sounding board. We can offer unbiased opinions" (55). Online spaces in particular provided a sense of unique discreetness that facilitated open sharing, with one individual remarking "One of the nice things about this site is the ability to 'melt down' anonymously," (55) and another referring to a blog as "the church of online support" (49). One-on-one peer mentoring and befriending interventions offered a similar refuge, with peer support workers being described as "good listeners" (22,29).

Having private caregiver-only space in in-person group-based interventions that involved care recipients was also deemed to be important. For instance, caregiver participants of Dementia Cafés, which involve individuals with dementia and their caregivers joining their peers for social and recreational activities, described a need for a dedicated caregiver-only space, where they could discuss challenges they did not feel comfortable disclosing in front of their care recipients (48). Caregiver participants of another dementia support group for caregiver-patient dyads valued having caregiver discussions in a separate room, where they could talk about "how they really feel… with those that really understand," and do so "without upsetting anybody" (42). Relatedly, caregiver participants of ALS support groups reported high satisfaction post-intervention, highlighting their appreciation for having a personal space to share among those with similar experiences (35). This held true for young child caregivers as well, as they reported having "real" conversations about their experiences in "mostly unwatched" spaces (45).

Value of helping others

In addition to seeking emotional support from others, many caregivers found meaning in being a source of support for their peers (24). In a private blog, a dementia caregiver discussed their gratitude for the support they received from reading other blogs over the years, and saw "the idea that I may have helped someone else in the same situation [as] a very good one" (49). Another caregiver viewed sharing their struggles as a way of paying it forward: "I guess we all have no choice but to keep going day to day, keep writing our blogs and our books and hoping that the hardships we've experienced aren't for nothing – that maybe by telling them, someone else will be helped" (49).

In caregiver support groups, some individuals, particularly those who have been in the caregiver role for a longer period of time, took on a "lead" advisory role to coach others. These individuals found guiding others as helpful for reflecting on their own experiences (35). They also appreciated the opportunity to share the full extent of their experiences in the peer support setting, as normally they tended to "shield others" from the realities of caregiving (23). When providing one-on-one mentoring or respite care, peer supporters noted a "two-way flow of support," where seeing improvements in the caregivers' wellbeing and coping ability resulted in greater satisfaction for the peer supporter (37,56). Setting boundaries so as not to take on undue burden was identified to be a challenge when providing peer support: "I think one of the negatives is – I don't think it's a negative, but I think while one becomes very attached and engaged in someone's life, one has to remember where the boundaries are about how involved you are" (56).

Instrumental support

Providing respite for caregivers

Instrumental support occurred primarily in interventions delivered in a one-on-one format, such as peer mentoring and befriending. For example, at the outset of accepting peer support services, caregivers of youth in the foster care system expected to connect with resources related to finances, housing, transportation, and employment (29). Caregivers also anticipated help in finding activities outside the home for the youth in their care to participate in, including camps and recreation centers (29). In another peer support service for caregivers of individuals with mental illness, some caregivers were provided with financial assistance in the form of children's booklists and supermarket vouchers (22). Peer support workers also accompanied caregivers and care recipients to appointments with psychiatric treating teams (22). In both programs, caregivers were assisted with obtaining referrals to other services, accessing services, and navigating the health and social care systems (22,29).

Instrumental support also manifested as an extension of emotional comfort for the caregiver. One caregiver commented on receiving direct support from their peer during an acute moment of crisis: "I needed, you know, just a contact person if [youth] was in crisis. And if I needed to talk to someone that was like, a like parent, people, people like me" (29). An organizer of a Boccia group for individuals with dementia and their caregivers similarly stated that all the participating caregivers had the organizer's phone number so that "if they wake up in the middle of the night and need someone, they can always ring me, if they want. You know when you wake up and need to talk to someone, that's why I give my number out" (46).

Supporting care recipients

In some cases, peer supporters interacted with the care recipients directly to alleviate some of the caregiving burden from the primary caregivers. For instance, peer supporters of caregivers of youth in the foster system took the youth out for activities and connected them with community resources. This resulted in increased confidence, reduced emotional and behavioural difficulties, and improved academic performance in the youth (29). Group-based recreational interventions also offered moments of respite, as caregivers tended to one another's care recipients. This was noted by a participant of the Boccia group for individuals with dementia and their caregivers: "This group is a family, we care for and protect one another, and I've seen some carers out playing Boccia while others are looking after their partner [the care recipient]. It's that kind of relationship that's so good" (46). Similarly, parents of children with developmental disabilities organized babysitting groups, as stated by one mother: "I love watching the parents' faces. When they come at 5:30 they look stressed and tired and, when they come back a couple hours later, they have gone out to dinner together; they come in, they're smiling, they're holding hands, and you know it's just really nice so that's been wonderful for us to be a part of as well and I hope for the other families" (37).

Grey Literature Review: A Focus on Canada

One-on-one Support

A detailed overview of caregiver support programs in Canada identified in the grey literature is provided in **Appendix D**. One-on-one peer support represented the second most common type of peer support available to caregivers in Canada. One-on-one peer support offers services to caregivers on an individual basis by connecting them with people who understand their challenges and share similar experiences (57). These one-on-one meetings are flexible, informal in nature and can take place in person, over the phone, online, or a combination of these options. Regardless of the method of delivery, the overarching goal is to provide caregivers with emotional support, offer encouragement, social connection, share ideas for coping, and help guide them through system/service navigation (57,58).

Most one-on-one peer support services available in Canada are spearheaded by health-based organizations and involve a matching process facilitated by the host organization whereby a caregiver is matched with a trained peer volunteer based on similarity in experience. In many cases, such as the Peer Match Program run by the MS (multiple sclerosis) Society of Canada, these peer supporters are trained to provide assistance, advice, and information about system navigation, services, and resources (59). Most organizations in Canada provide support specifically targeted at the type of care recipient the caregiver is caring for. For example, the Canadian Pulmonary Fibrosis Foundation provides one-on-one support through email and telephone calls specifically to caregivers of patients suffering from pulmonary fibrosis (60). Similar types of services are also available to caregivers of patients with cancer, multiple sclerosis, Crohn's disease, ulcerative colitis, liver disease and those caring for the elderly. A small number of services provide assistance to all caregivers, regardless of the type of caregiving involved.

Telephone and email modalities made up the majority of this category and thus, most of these services are available to caregivers across Canada. For example, the Canadian Cancer Society provides a nation-wide peer support program where facilitators match clients with a trained volunteer based on similarity in cancer experience (58). In Central and Western Canada (namely Ontario, Quebec, Manitoba, and British Columbia), there were some resources that served caregivers in their specific region. For example, Caregiving with Confidence is an organization that provides one-on-one telephone support services to caregivers residing in the city of Winnipeg, Manitoba (61). All other regions in Canada lacked this type of area-specific resource.

Peer Support in Groups

Peer support for caregivers in Canada is most commonly delivered in a group format. Throughout the country, health-based and grassroots organizations offer peer support primarily to groups of caregivers in the form of peer support groups, educational workshops, and activity-based (or creative) support groups. Groups can take on one of these formats or combine multiple approaches. Regardless of the program structure, these groups share an overarching objective of bringing caregivers together to learn from and support one another. Depending on the type of program, caregivers are invited to attend alone or with the care recipient. Like one-on-one supports, programs can be open to all caregivers, or be tailored to specific caregivers based on the condition or health needs of the care recipient. The programs are frequently facilitated by an experienced health professional (e.g., social worker) and/or trained volunteer with lived experience caregiving.

Support groups

Peer support groups are voluntary gatherings of individuals who meet to share their experiences and to support one another as they face challenges (62). In Canada, this appears to be the dominant form of peer support for caregivers and is available to varying degrees and formats, in all provinces and territories. The identified peer support groups were both formal or informal in nature, and often hosted free-of-charge at an organization, community centre, or health centre. Many of the in-person support groups occur on a weekly or monthly basis, offering an opportunity to participate in supportive and non-judgemental discussion. For example, Caregivers Nova Scotia offers peer support groups throughout the province to all caregivers, facilitated by a staff member with relevant caregiving experience (63). Some organizations also offer phone-based or virtual peer support groups for caregivers that are often moderated by a trained health professional for an extended period of time. For example, Baycrest Health Sciences (Ontario) offers an Online Caregiver Support Group for family and caregivers affected by a person with dementia. These groups meet for 8 to 10 consecutive weeks using videoconferencing software (64). Other types of virtual groups were also identified, some of which are entirely text-based. Among these is Cancer Chat Canada, which runs online peer support groups where caregivers and others affected by cancer meet on a weekly basis at a designated time in an online chat room (65). Regardless of the delivery format, these groups are all intended to reduce caregiver isolation through the creation of various communities of support.

Educational workshops

Another identified group-based peer support available to caregivers in Canada is educational or informational support groups. In addition to bringing caregivers together into a supportive environment, these groups focus on supporting caregivers' learning needs, building their caregiving skillset, and providing tools for self-care. These groups take the form of single- or multi-session workshops or series of "educational support groups" on a range of topics. For example, Ami Quebec offers workshops for caregivers of people with mental illness to learn more about the condition, support family members and caregivers, practice meditation and resilience training, and develop coping skills (66). To facilitate participation, some workshops are offered online like Caregivers Alberta's Compass for Caregivers Program, a nine-module workshop that provides instruction on managing guilt, grief and stress, improving communication, navigating the system, and planning for the future (67).

Activity-based/recreational programs

Activity-based support groups for caregivers were identified to a lesser extent throughout Canada. These programs can take a variety of forms and generally involve bringing caregivers together to participate in a social activity that moves beyond discussion alone. For example, the Commox Valley Senior Support Society in British Columbia offers a range of peer support programs for caregivers. Among these is the Creative Caregivers program, which is an arts-focused group that helps caregivers explore their creativity through art, music, storytelling, relaxation, and meditation (68). Arts-based programming and drumming circles are also offered through various Wellspring chapters (Canada-wide network for cancer support). Some organizations offer larger-scale events to caregivers and their families where they can socialize. Among these are the Alzheimer Society of New Brunswick's Memory Cafes, which are free monthly group events with guest speakers and entertainment for people affected by dementia (69).

Training

Peer support training programs are also available to caregivers who are looking to become peer group facilitators or mentors. These programs are designed to provide training delivered by an experienced facilitator or professional, and often have an associated cost or a set amount of volunteer time commitment required. The identified training programs were all located in the Western provinces. For example, Caregivers Alberta runs a full-day facilitator training program for caregivers, focusing on self-care, wellness, and supportive sharing (67). However, some websites advertised volunteer opportunities for peers that would include some training but did not constitute an explicit training program.

Social Media and Discussion Forums

Social media platforms and discussion forums are utilized as a medium to seek and provide support for caregivers. The Canadian Caregiver Network created Huddol, an online social network to bring caregivers together to share experiences (70). Like other social media platforms, Huddol includes chat functions and communities (groups) focused on specific needs that users can join, all while maintaining anonymity. Some organizations are present on Huddol and have created their own community groups (e.g., Huntington Society of Canada, ALS Society of Quebec). Other organizations were found to directly host discussion forums or Facebook groups for people to openly share experiences, problem-solve, and connect with others. Examples include the Leukemia and Lymphoma Society of Canada, Caregiving Matters, Cancer Connection (Canadian Cancer Society), Support 4 Caregivers (Craig's Cause Pancreatic Cancer Society), Age Village, and PH Warriors (Pulmonary Hypertension Association of Canada).

Other Supports

Other peer-based or peer-informed supports are also available to caregivers across Canada. These include repositories of resources developed by some caregivers for other caregivers, which may not involve direct contact between caregivers. For example, Health Experiences Canada has put together a range of video interviews with caregivers who share their experiences about being a caregiver and accessing resources and professional services (71). In the videos, caregivers also discuss the impact of being a caregiver and offer advice to other caregivers, health professionals, and others with a general interest. Another example is the "Caregivers Out of Isolation" program offered by the Seniors Resource Centre in Newfoundland and Labrador, which provides information, support, and referral services.

Conclusions

This rapid review of the recent academic and grey literature sought to characterize the landscape of peer caregiver support initiatives in Canada and abroad, and to identify features and approaches that may be effective in meeting caregiver needs. Through a synthesis of mixed methods academic literature, we were able to gain insight into the mechanisms of peer support interventions. Although we found many Canadian programs in the grey literature, the academic literature review captured only two studies from Canada, both focusing on online support groups for caregivers of persons with dementia (19) and cancer (20). This discrepancy may reflect an interest in implementing peer caregiver support programs in Canada, yet relatively limited evaluative evidence supporting their effectiveness. Older adults and those with dementia were overrepresented among care recipient populations, which may not be surprising, as age-related needs comprise the most common issues requiring caregiving help (2). Intervention formats within the academic and grey literature were also similar, spanning one-on-one and group-based peer supports. While overall, most Canadian initiatives were led by health sector organizations, such as hospitals and charitable/advocacy groups, group-based supports revealed more grassroots and informal efforts. We present the following key findings to help optimize peer support programs:

1. Meeting the caregivers' informational needs: General online information may be sought early in the caregiving process and should be evidence-based and practical. Specific, individualized healthcare advice may be preferred at advanced disease stages. Informational support may serve different purposes depending on care recipients' conditions (e.g., provide hope that an individual with mental illness will get better; reassure that a child with developmental disability is progressing adequately for their age; help cope with the care recipient's deteriorating health status due to terminal illness).

2. Teaching skills relevant to caregiving tasks: Individuals tend to assume the caregiving role after a sudden event, without receiving formal training (3). Caregivers thus appreciate learning about disease care, coping strategies, family communication, and self-care. Understanding care recipients' perspectives also helped caregivers adapt to challenges. Developing these skills may result in lower stress and improved self-efficacy, which may have a "ripple effect" on the care recipients' wellbeing.

3. Peer-based emotional support: Peers were often preferred to health professionals as sources of emotional support, because health professionals may "understand but […] not share the same suffering" (35). Caregivers valued reflecting on their own experiences when supporting others, though establishing healthy boundaries is warranted. Ensuring an open and private space (online and in-person) for caregivers to connect is important. Peer support groups of similar age and gender may be preferred by some caregivers; inclusion of more experienced caregivers may provide foresight regarding what to expect next.

4. Instrumental support: Caregivers expected to receive tangible and concrete supports, including respite care, referrals to health and community resources, and transportation support. One-on-one peer mentoring interventions may be a well-suited vehicle for such approaches, though more original investigations are needed to support their implementation.

5. Flexible intervention delivery approaches: Caregivers manage many competing priorities; remote/virtual peer support systems were thus viewed positively due to their flexibility. In-person support groups should also be flexible in their curricula to accommodate caregivers' dynamic circumstances and changing needs.

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Appendix A. Detailed Methodology

Rapid Scoping Review

We followed an established five-step methodological framework for scoping reviews, which involves defining a research question, identifying relevant studies using a comprehensive electronic database search strategy, study selection against the eligibility criteria, data charting, and data collation and synthesis (72,73). We adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Extension for Scoping Reviews (PRISMA-ScR) reporting guidelines (74).

Information sources

We searched MEDLINE (Ovid), PsycINFO (Ovid), and CINAHL-Plus (EBSCO) using a combination of database-specific syntax (e.g., Medical Subject Headings, MeSH) and text-words related to the following concepts: (1) informal caregivers and (2) peer support. The following limits were applied to the search strings: publication year 2017-2020, English-language, and human subjects. CINAHL-Plus also allowed to exclude sources indexed in MEDLINE, to minimize inclusion of duplicates. A validated trials filter consisting of MeSH terms and text-words was added to the MEDLINE search strategy (75,76). The database search was first developed in MEDLINE and subsequently translated into other database-specific syntax. All final electronic database searches were conducted and exported on January 16, 2020. To ensure literature saturation, the database search was supplemented by handsearching and snowballing techniques.

Study selection process

Records were imported from each electronic database into a web-based systematic review management software, Covidence (www.covidence.org), to remove duplicate citations and perform citation screening. Citations were screened sequentially in two phases: (1) titles and abstracts and (2) full-text articles. All reviewers were first trained on a random sample of 20 titles and abstracts and 10 full-text articles to pilot the selection criteria. As suggested by the Cochrane Collaboration Handbook for Systematic Reviews of Interventions (77), inter-rater agreement was calculated at both stages using Krippendorff's alpha statistic[3] to serve as an indicator of whether further reviewer training and discussion about the selection criteria were needed. Krippendorff's alpha values range between 0 and 1, indicating agreement beyond that attributable to chance (78,79). The calculated alpha statistic was 0.281 for the title and abstract screening pilot sample and 0.383 for the full-text screening pilot sample; both values were below Krippendorff's acceptability threshold (alpha ≥ 0.667), suggesting suboptimal agreement (78). Selection decisions were thoroughly discussed with the study team, the reasons for disagreements were explored, and a consensus document was prepared and circulated to clarify inconsistencies.

Citations were then divided among five reviewers (DB, MK, MMV, NG, SN) for title/abstract and full-text article screening. The titles and abstracts of citations whose eligibility was uncertain (rated "maybe") were passed directly to full-text review. The results of full-text review were cross-checked in their entirety by the lead author (DB). Studies were excluded if they met one or more of the following selection criteria: (1) the study did not describe or evaluate an intervention or program; (2) peer-to-peer caregiver support was not a goal of the intervention or program; (3) caregivers were not the target population receiving the

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[3] ReCal Calculator for Nominal, Ordinal, Interval, and Ratio-Level Data: http://dfreelon.org/recal/recal-oir.php

intervention or program; (4) the study jurisdiction was not part of the OECD; (5) the publication type was not an original and primary peer-reviewed source (e.g., conference proceedings, literature reviews, editorials, thesis dissertations, books); (6) the full-text of the source was not accessible through the university library. The detailed selection process is presented in the PRISMA flow diagram in **Appendix B**.

Data extraction and synthesis

Data extraction was completed by five reviewers (DB, MK, MMV, NG, SN). Data items included study objectives, study designs, intervention jurisdictions/settings, features of the intervention or program of interest (with comparison group, if applicable), target population characteristics, and intervention impacts on outcomes. One reviewer (MMV) extracted definitions for the terms "informal caregiver" and "peer support" from all studies, whether explicit or implicit (e.g., in study background/context, participant eligibility criteria, or discussion of main findings). The extracted data were collated and reviewed thoroughly by one author (DB) to address any ambiguities and to identify salient patterns, which were used to derive an analytical framework. A thematic analysis was then undertaken (DB, MK), where data were charted and grouped according to the following framework components:

- *Intervention formats*: The format of intervention delivery was categorized as: (1) peer mentoring and befriending, (2) support groups and workshops, (3) recreational programs, and (4) social media platforms.
- *Types of peer support*: Interventions could provide multiple types of peer support, including: (1) informational support, (2) instructional support, (3) emotional support, and (4) instrumental support. This categorization was adapted from a framework developed by Hoagwood et al. (2010) to describe family support programs in children's mental health (80). Within each category, subthemes pertaining to best practices were elucidated inductively. These peer support types and definitions are presented in **Table A1**.

A summary of the scoping review results is presented in **Appendix C**.

Table A1. Types of peer support

Type of peer support	Definition
Informational support	Provision of education and resources about illness progression and impact, treatment options, health/social services, as well as avenues for advocacy (e.g., rights, policies, legislation, and entitlements).
Instructional support	Provision of coaching and instruction regarding skill development related to caregiver duties or self-care.
Emotional support	Shared communication between peer caregivers that aims to foster mutual feelings of validation, affirmation, understanding, and appreciation.
Instrumental support	Concrete provision of services from peer-to-peer, which may take the form of respite care, transportation, or purchasing of groceries or medications.

Adapted from: Hoagwood et al. (2010) (80). [4]

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[4] The Hoagwood et al. (2010) framework includes a fifth category, "advocacy support," defined as the provision of specific information about rights and resources (e.g., legislation, entitlements), provision of direct advocacy to obtain services for the caregiver or the care recipient, or skill building to develop the caregiver as an advocate at policy and service system levels. As none of the included articles appeared to meaningfully discuss peer caregiver support meeting this definition, we did not include it in the analysis.

Grey Literature Review

To describe the current landscape of peer-to-peer caregiver supports in Canada, research team members (MR, SC, JL) performed targeted Google web searches for peer caregiver supports and organizations in each province and territory (key terms included peer support, peer support group, self-help group, caregiver support, etc.). We then reviewed program and resource lists from Canadian caregiving organizations and key resources (Carers Canada, The Change Foundation, Canadian Virtual Hospice, Family Caregivers of British Columbia [FCBC], Caregivers Alberta, The Ontario Caregiver Organization, Caregivers Nova Scotia, Senior Resource Network of Manitoba, the Saskatoon Caregiver Information and Support Centre), searched for caregiver supports in health-related organizations (e.g., Alzheimer Society of Canada, ALS Society of Canada, Canadian Cancer Society, Parkinson Society of Canada), searched for caregiver supports in health-related organizations, and analyzed a cross-section of Twitter data[5] to uncover additional supports and organizations. Network members of the NAO were also consulted for local insights and resources to facilitate the search. Supports were excluded if they were not current; not targeted to caregivers; not described in the public domain; not created or targeted to Canada; if there was insufficient information on the program; and/or if the program did not aim to provide or facilitate peer-to-peer interaction and support.

The resulting programs from the search were examined to determine whether they met the inclusion criteria for the review. The included supports were organized into five categories based on shared key themes, including: (1) one-on-one supports (e.g., mentorships, helplines); (2) group supports (e.g., peer support groups, workshops, activity-based programs); (3) training opportunities to facilitate peer programming; (4) social media platforms and discussion forums; and (5) other support types and relevant resources. This thematic grouping aligned closely with the academic review literature and validated by peer support group documents (e.g., BC Ministry of Health, Mental Health Commission of Canada).

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[5] Twitter data was collected and analyzed using Netlytic, an open-source software tool. Supplementary information available upon request.
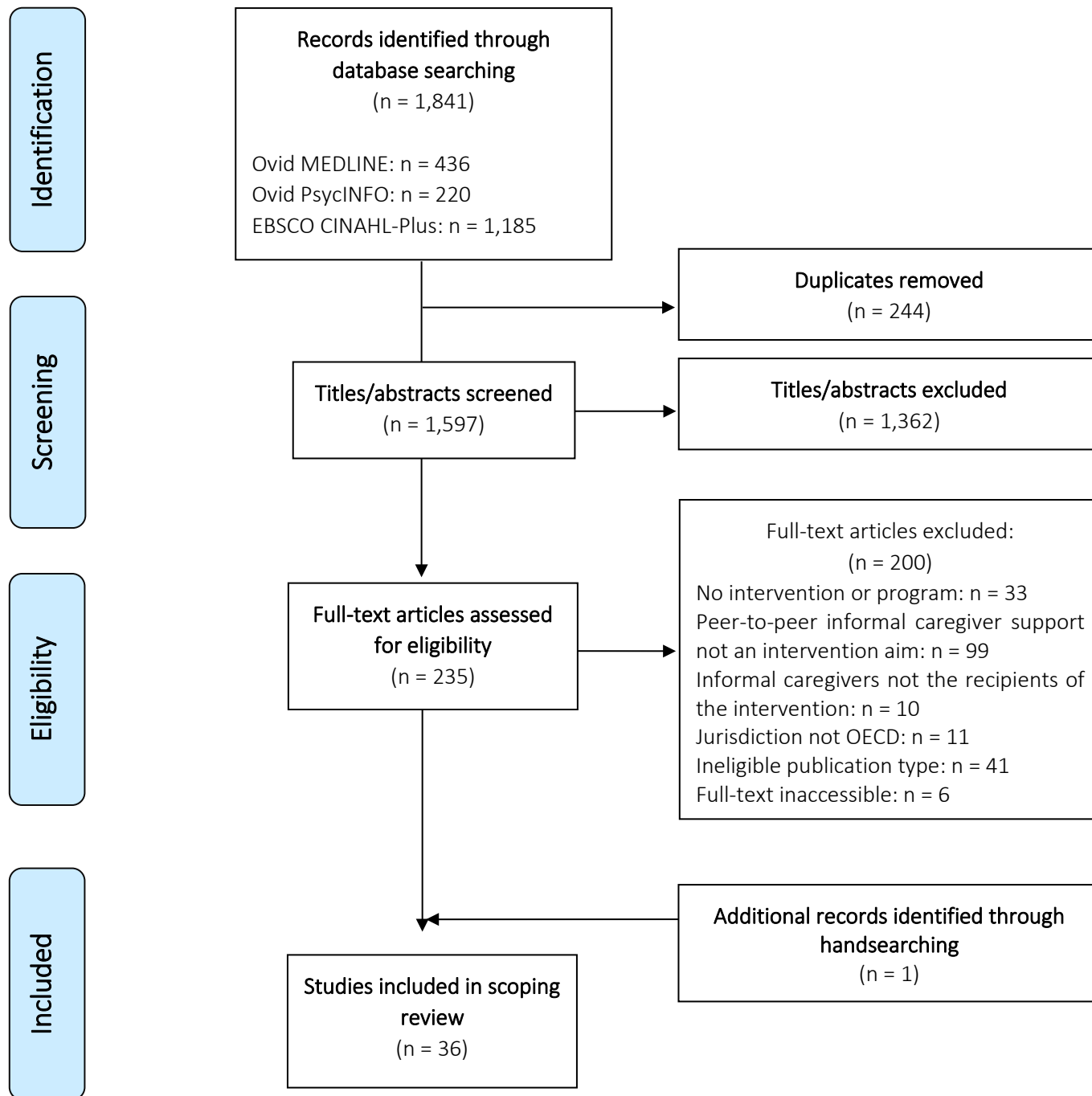
Electronic Database Search Strategy

Electronic database search strategy (last updated January 16, 2020).

SEARCH	SYNTAX	RESULTS
Ovid MEDLINE **(n = 436)**	1. exp Caregivers/ and (exp Family/ or exp Spouses/ or exp Parents/ or exp Friend/ or exp Voluntary Workers/)	11,201
	2. ((informal or non-formal or non formal or nonformal or unpaid or nonpaid or non-paid or non paid or nonprofessional or non-professional or non professional or lay or family or familial or families or spous* or partner* or parent* or kin or friend* or neighbo?r* or volunt*) adj (caregiver or caregivers or caregiving or care giver or care givers or care giving or care-giver or care-givers or care-giving or caretaker or caretakers or caretaking or care taker or care takers or care taking or care-taker or care-takers or care-taking or carer or carers)).tw,kf.	15,904
	3. exp Social Support/ or exp Peer Group/ or exp Social Networking/	89,421
	4. (befriend* or ((support* or counsel* or help* or network* or assist*) adj (peer or peers or peer-led or peer-to-peer or lay or mentor* or volunt* or buddy or buddies or mutual or social or psychosocial or psycho-social or online or internet or telephone or phone or group*))).tw,kf.	16,159
	5. randomized controlled trial.pt.	498,799
	6. controlled clinical trial.pt.	93,524
	7. multicenter study.pt.	264,906
	8. pragmatic clinical trial.pt.	1,280
	9. (randomis* or randomiz* or randomly).ti,ab.	870,475
	10. groups.ab.	1,996,902
	11. (trial or multicenter or multi center or multicentre or multi centre).ti.	250,591
	12. (intervention? or effect? or impact? or controlled or control group? or (before adj5 after) or (pre adj5 post) or ((pretest or pre test) and (posttest or post test)) or quasiexperiment* or quasi experiment* or pseudo experiment* or pseudoexperiment* or evaluat* or time series or time point? or repeated measur*).ti,ab.	9,354,793
	13. non-randomized controlled trials as topic/	
	14. interrupted time series analysis/	611
	15. controlled before-after studies/	752
	16. 1 or 2	472
	17. 3 or 4	23,608
	18. or/5-16 [trials filter – based on EPOC]	102,042
	19. 16 and 17 [no date, language, study design restrictions]	10,426,620
	20. 16 and 17 and 18 [with trials filter, no date or language restrictions]	4,119
	21. limit 20 to (english language and humans and yr="2017 -Current")	2,577
		436
Ovid PsycINFO **(n = 220)**	1. exp Caregivers/ and (exp Spouses/ or exp Family/ or exp Parents/ or exp Friendship/ or exp Volunteers/)	10,549
	2. ((informal or non-formal or non formal or nonformal or unpaid or nonpaid or non-paid or non paid or nonprofessional or non-professional or non professional or lay or family or familial or families or spous* or partner* or parent* or kin or friend* or neighbo?r* or volunt*) adj (caregiver or caregivers or caregiving or care giver or care givers or care giving or care-giver or care-givers or care-giving or caretaker or caretakers or caretaking or care taker or care takers or care taking or care-taker or care-takers or care-taking or carer or carers)).ti,ab.	11,979
	3. exp Social Support/ or exp Peers/ or exp Peer Relations/ or exp Peer Counseling/ or exp Social Networks/	
	4. (befriend* or ((support* or counsel* or help* or network* or assist*) adj (peer or peers or peer-led or peer-to-peer or lay or mentor* or volunt* or buddy or buddies or mutual or	79,518

	social or psychosocial or psycho-social or online or internet or telephone or phone or group*))).ti,ab.	18,213
	5. 1 or 2	19,183
	6. 3 or 4	94,413
	7. 5 and 6	1,818
	8. limit 7 to (human and english language and yr="2017 -Current")	220
EBSCO CINAHL-Plus **(n = 1,185)**	S1. (MH "Caregivers")	31,817
	S2. TI ((informal or non-formal or non formal or nonformal or unpaid or nonpaid or non-paid or non paid or nonprofessional or non-professional or non professional or lay or family or familial or families or spous* or partner* or parent* or kin or friend* or neighbo?r* or volunt*) N1 (caregiver or caregivers or caregiving or care giver or care givers or care giving or care-giver or care-givers or care-giving or caretaker or caretakers or caretaking or care taker or care takers or care taking or care-taker or care-takers or care-taking or carer or carers)) or AB ((informal or non-formal or non formal or nonformal or unpaid or nonpaid or non-paid or non paid or nonprofessional or non-professional or non professional or lay or family or spouse or spousal or spouses or partner or partners or parent or parents or parental or kin or friend or friends or neighbor?r* or volunt*) N1 (caregiver or caregivers or caregiving or care giver or care givers or care giving or care-giver or care-givers or care-giving or caretaker or caretakers or caretaking or care taker or care takers or care taking or care-taker or care-takers or care-taking or carer or carers))	17,282
	S3. (MH "Support, Psychosocial+") OR (MH "Caregiver Support")	74,409
	S4. (MH "Peer Group") OR (MH "Peer Counseling")	12,765
	S5. TI (befriend* or ((support* or counsel* or help* or network* or assist*) N1 (peer or peers or peer-led or peer-to-peer or lay or mentor* or volunt* or buddy or buddies or mutual or social or psychosocial or psycho-social or online or internet or telephone or phone or group*))) or AB (befriend* or ((support* or counsel* or help* or network* or assist*) N1 (peer or peers or peer-led or peer-to-peer or lay or mentor* or volunt* or buddy or buddies or mutual or social or psychosocial or psycho-social or online or internet or telephone or phone or group*)))	58,647
	S6. S1 OR S2	40,037
	S7. S3 OR S4 OR S5	120,808
	S8. S6 AND S7;	8,108
	S9. S6 and S7; Limiters - Published Date: 20170101-20200131; Exclude MEDLINE records; Human; Language: English	1,185

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Appendix B. PRISMA Study Selection Flowchart

Identification

Records identified through database searching
(n = 1,841)

Ovid MEDLINE: n = 436
Ovid PsycINFO: n = 220
EBSCO CINAHL-Plus: n = 1,185

Duplicates removed
(n = 244)

Screening

Titles/abstracts screened
(n = 1,597)

Titles/abstracts excluded
(n = 1,362)

Eligibility

Full-text articles assessed for eligibility
(n = 235)

Full-text articles excluded:
(n = 200)
No intervention or program: n = 33
Peer-to-peer informal caregiver support not an intervention aim: n = 99
Informal caregivers not the recipients of the intervention: n = 10
Jurisdiction not OECD: n = 11
Ineligible publication type: n = 41
Full-text inaccessible: n = 6

Included

Additional records identified through handsearching
(n = 1)

Studies included in scoping review
(n = 36)

Adapted from: Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med*. 2009 Jul 1;6(7):e1000097. doi:10.1371/journal.pmed1000097

Appendix C. Summary of the Review Literature

Definitions

Informal caregivers

Eleven studies mentioned that caregivers were family members providing informal or unpaid care to the care recipient (19,20,35,36,48,49,51,53,55,56), while another 16 studies only mentioned that caregivers were family members of the care recipient (21,30–32,34,37–41,43–45,47,52,54). Three studies did not provide any further definition for the terms "caregiver" or "support person" (29,42,46); nonetheless, caregiver samples of most studies predominantly included adult family members (see **Table C1**). Five studies provided the most comprehensive and explicit definitions of caregivers; all of these definitions noted that caregivers were family members, friends, and neighbours providing ongoing emotional, financial, and practical care to an individual with a long-term health condition on an informal and uncompensated basis, outside of the clinical setting (22–26). While there is no consensus definition of informal caregiving, our findings align with the broad definition developed by the Change Foundation (2015), which defined informal caregivers as the "family, friends, [and] neighbours who provide critical and ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, disability, or end of life circumstances" (27).

Peer caregivers or peer support

Among the included studies, 24 (67%) specifically used the term "peer," while others tended to simply refer to "other caregivers." Most definitions were implicit, with studies alluding to caregiver-to-caregiver interaction (e.g., engaging in discussions, sharing resources, and providing emotional support) (23,34,36,38,42,44,47,52); individuals with similar caregiving experiences, roles, needs, or circumstances (37,40,45,49,50,54); or individuals of shared membership within a caregiver organization or network (35,51,53). Some studies also contrasted the involvement of other caregivers in providing support from that of health professionals (20,55).

Nine studies provided an explicit definition of peer caregivers. Interestingly, all but two of these focused on caregivers of either children/youth (28–31) or family members/relatives (21,22,32) with severe mental health issues. All of these studies consistently defined peer caregivers as those with the "lived experience" of caring for the identified care recipient population (i.e., individuals with mental health issues). Some of these studies also employed an intervention-specific term to refer to peer caregivers, such as Parent Support Providers (28), Parent Peer Support Partners (29), Family Peer Advocates (30), or Carer Peer Support Workers (22). Of the two studies not focused on mental health, one mentioned that "peer patrons" (moderators of an online caregiver forum) were those with extensive caregiving experience and a willingness to share resources to support others (24); while the other provided a general definition of a peer caregiver as one who "has faced the same significant challenges as the [peer] support recipient and serves as a mentor to that individual" (12). Although there is no consensus definition of peer support, our findings agree with the broad definition developed by the Mental Health Commission of Canada, where peer support is a "supportive relationship between people who have a lived experience in common" (33).

Table C1. Characteristics of studies identified in scoping review

Study characteristic	No. (%)	Study characteristic	No. (%)
Jurisdiction		**Care recipient health condition**	
Australia	2 (6%)	Dementia	17 (47%)
Austria	1 (3%)	Mental illness (child and youth)	4 (11%)
Canada	2 (6%)	Mental illness (mixed populations)	2 (6%)
Italy	1 (3%)	Advanced cancer (adults)	2 (6%)
Netherlands	1 (3%)	Amyotrophic lateral sclerosis (ALS)	2 (6%)
New Zealand	1 (3%)	Developmental disabilities (child)	2 (6%)
Sweden	1 (3%)	Chronic illness (adults)	2 (6%)
United Kingdom	6 (17%)	Elder care	2 (6%)
United States	20 (56%)	Military veterans	2 (6%)
		Genetic health conditions (child)	1 (3%)
Study design*			
Qualitative study	19 (53%)	**Caregiver relationship to care recipient**	
Mixed methods	9 (25%)	Adult family members (partners/spouses, parents/guardians, adult children)	26 (72%)
Quasi-experimental	10 (28%)		
RCT	3 (8%)		
Cross-sectional	1 (3%)	Young family members (young children, siblings)	3 (8%)
Pilot and feasibility study	11 (31%)		
		Family members, not specified	3 (8%)
Intervention initiator or funder		Not reported	4 (11%)
Non-profit organization	14 (39%)		
Hospital or healthcare organization	8 (22%)	**Caregiver sample >50% women**	23 (64%)
Government agency	4 (11%)		
Caregivers/grassroots	4 (11%)		
University	2 (3%)		
Not reported	4 (11%)		

N = 36

*Studies can belong to multiple categories (e.g., quasi-experimental or RCT designs could employ mixed methods).

Table C2. Detailed breakdown of studies in analytic framework

Intervention formats	Study	Types of peer support			
		Informational (n = 25)	Instructional (n = 21)	Emotional (n = 20)	Instrumental (n = 4)
Peer mentoring and befriending (n = 6)	Anthony 2019 (28)		✓		
	Gopalan 2017 (29)	✓	✓	✓	✓
	Jamison 2017 (30)	✓	✓		
	Mosher 2018 (34)		✓		
	Smith 2018 (12)			✓	
	Visa 2019 (22)	✓	✓	✓	✓
Support groups and educational workshops (n = 14)	Bailey 2017 (41)	✓	✓		
	Biello 2019 (23)	✓	✓	✓	
	Gossink 2018 (38)	✓			
	Han 2018 (36)	✓	✓	✓	
	Chiocchi 2019 (21)	✓			
	Cipolletta 2019 (35)	✓	✓	✓	
	Damianakis 2018 (19)		✓		
	Moebs 2017 (42)		✓	✓	
	Rubin 2018 (31)	✓	✓	✓	
	Poyner-Del Vento 2018 (43)	✓	✓		
	Paun 2019 (39)		✓		
	Serwe 2017 (25)	✓		✓	
	Sharaievska 2018 (37)	✓		✓	✓
	Ufer 2018 (40)	✓			
Activity-based/ recreational programs (n = 5)	Akhtar 2017 (48)	✓		✓	
	Kavanaugh 2018 (44)		✓		
	Mittelman 2018 (47)		✓		
	Nagl-Cupal 2019 (45)			✓	
	Ovenden 2019 (46)			✓	✓
Social media platforms and discussion forums (n = 11)	Anderson 2017 (49)	✓		✓	
	Andersson 2016 (54)	✓			
	Gleeson 2017* (32)	✓		✓	
	Male 2017* (20)			✓	
	Dam 2017* (51)	✓		✓	
	Davies 2019* (52)	✓	✓	✓	
	Diefenbeck 2017 (55)	✓	✓	✓	
	Friedman 2018 (53)	✓			
	Narasimha 2019 (24)	✓	✓	✓	
	Vaughan 2018 (26)	✓			
	Wilkerson 2018 (50)		✓		

Checkmark (✓) indicates that a type of support is a component of intervention activities or intended/perceived impacts.
* Early-stage or pilot evaluations that did not extensively comment on impacts related to the type of peer support.

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Table C3. Summary of studies identified in scoping review

Author/ Year	Jurisdiction (Country)	Methods	Sample	Intervention description	Summary of Key Findings
Akhtar 2017	England	Qualitative (semi-structured interviews)	Caregivers of relatives with dementia (n=11)	Dementia Cafés: Monthly two-hour meetings at a regular venue (a library or church hall). Meetings allow informal socialization with peers and are a source of useful information about dementia and services available.	Carers had an overwhelming appreciation of the cafes and what they offered. Café coordinators also played an important part in the carers' experiences and were regarded positively. Recommendations included those about recruitment and training of café coordinators, how cafes present themselves and their services, and how they can offer dedicated support for informal carers.
Anderson 2017	United States (US)	Content analysis (online blogs)	Blogs written by caregivers of persons with dementia (n=9)	Online blogs: Blogs written by caregivers of persons with dementia were analyzed to explore how they are part of the caregiving experience. Blogs allow for peer involvement and support. The use of blogs by caregivers to cope with caring for a person with dementia was measured.	Blogs were found to be part of the caregiving experience in four ways: (1) social support through communication and engagement; (2) information gathering and seeking; (3) reminiscing and legacy building; and (4) altruism. Understanding the ways in which caregivers use social media may help facilitate interventions and services aimed at improving caregiver burden and quality of life.
Andersson 2016	Sweden	Content analysis (semi-structured interviews, explorative descriptive)	Working caregivers of an older family member (n=9)	A Good Place (AGP): A web-based information and communication technologies (ICT) family carer support network. AGP enables information and communication transfer between and within groups of family carers and practitioners.	Three main themes depicted the experience of having access to AGP, describing it as a support hub to connect with peers for emotional and informational support; as relevant in changing life circumstances; and indicating it was an accessible, complimentary means of support that allowed caregivers to balance their various obligations better. This also reinforced working carers' sense of competence, helping them to meet caregiving demands and see positive aspects in their situation. Low levels of digital skills and anxieties about using computer-based supports were barriers. The authors suggest that web-based support should be introduced in a timely manner and more accurately meet their unique needs.
Anthony 2019	US	Pretest-posttest feasibility study	Caregivers of children and youth with mental health challenges	Peer delivered, family-to-family (F2F) support: Supports were provided by parents with lived experience of raising a child or	Authors found evidence to suggest that time spent in family support services leads to improvement in key F2F goals that have the potential to improve service

		Psychometric validation Study period: 3-months, 6-months follow-up	(n=319)	youth with emotional, behavioral (including substance use), and/or mental health challenges. The Family Journey Assessment (validated tool developed to evaluate F2F programs) tracked caregiver progress toward self-advocacy and self-efficacy.	engagement and mental health literacy, reduce stress, increase support, and enhance recognition of need. Moreover, the study showed that the more time families spend in F2F, the less they need peer supporter input to achieve their goals.
Bailey 2017	United Kingdom (UK)	Quasi-experimental, mixed methods	Caregivers of individuals with dementia (n=20)	Carer Support Group: Both the Carer Support Group (CSG) program and the Cognitive Stimulation Therapy (CST) interventions consisted of 10, parallel two-hour sessions, delivered over a five-week period in separate rooms. The CST involved reminiscence sessions, discussions about current affairs, hobbies, places, and activities. The CSG sessions included education about dementia and how it affects behaviour and cognition, information on how to handle issues such as repeated questions, and opportunity for peer support and discussions. Additionally, each CSG session began with feedback on the previous week's CST session.	The carers who attended CSG sessions found them valuable. This study found strong evidence from carers' narratives that they felt it was beneficial. Becoming a carer had affected some participants' personal identity with evidence that they viewed caring in terms of adopting a parental role, consequently losing their personal identity as a spouse or child. The impact of a loss of identity and social role, linked with an enforced adoption of a new unwanted identity (carer), cannot be under-estimated and participants' narratives contained examples of loss, grief, resentment, and associated guilt. A valuable facet of the CSG was that the support sessions gave carers the opportunity to "be themselves", to re-engage with their "pre-carer identity" and interact with others as a person in their own right. The empathy group members experienced was crucial in this process, suggesting that specific groups for dementia carers would be more beneficial than a generic support group.
Biello 2019	US	Qualitative (semi-structured interviews) Study period: November 2016 – February 2017	Caregivers of veterans with dementia (n=11)	The Cognitive Disorders Specialty Care Education Center of Excellence (COE): A multi-component intervention for primary caregivers that includes visits with staff social workers, resource referrals, and an evidence-based psychoeducational program (the Savvy Caregiver Program). The COE caregiver intervention components evaluated were the Savvy Caregiver Program, a 5-to-6-session psychoeducational training aimed at preparing dementia caregivers for the challenges of neurocognitive decline; the	Overall, opinions of COE caregiver support services were positive. Major themes revealed include: information about dementia; social support; focus on care-giver efficacy; application of behavioral strategies; and emphasis on caregiver well-being. Identified gaps and recommended future COE services include additional information on dementia, additional support for individual caregiver challenges, offer practical and logistical support, and improve availability of formal caregiver program.

				Tele-Savvy Program, a tablet- and internet-based remote adaptation of the Savvy Caregiver Program; caregiver visits and telephone calls with COE staff members; and referrals to internal or external resources.	
Chiocchi 2019	UK	Quasi-experimental Study period: September 2014 – June 2017	Carers of a family member with a mental health diagnosis and who may also experience psychosis or personality disorder. (n=60)	Training Education and Support Program: co-delivered program that comprised of 20 two-hour training sessions, two educational awareness sessions, five sessions of group-based learning, and a 12-module problem solving skills enhancement program.	Results indicated improved mental health wellbeing, reduced burden, and increased family empowerment. The program also suggests a positive, incremental affect as demonstrated through outcome measurement at five timepoints.
Cipolletta 2018	Italy	Qualitative (semi-structured interviews) Content analysis	People with amyotrophic lateral sclerosis (ALS) and their family caregivers (n=12)	Support groups: Ten 1.5-hour group support sessions (one for caregivers and one for adult children). Group work aimed to foster the creation of social networks among peers, share their problems and cope with their sense of helplessness, contain their anguish, and promote more adaptive caring roles.	The results showed a difference between caregivers who are partners and those who are children of patients with ALS and between caregivers of relatives at different stages of the illness. Comparison with peers and providing each other with mutual support helped participants feel less alone, allowed them to exchange information and advice, and helped them to improve their self-esteem and self-efficacy. Participants would recommend the groups to other caregivers of ALS. Involving communities in caregiver supports is useful to create new networks and activate personal and social resources for wellbeing.
Dam 2017	Netherlands	Quasi-experimental, mixed methods Study period: 16 weeks	Caregivers of people with dementia (n=25)	Inlife: A web-based platform that promotes social support, positive interactions, and access to information within the dementia caregiver social network.	High-active Inlife users showed less decline after 16 weeks in perceived family support than the low-active users. High-active Inlife user group had significantly lower levels of received support compared to the low-active Inlife user group. Improvements in feelings of competence and a decrease in feelings of loneliness (in the high-active Inlife users).
Damianakis 2018	Canada	Content analysis (support groups)	Spousal care givers of persons with Alzheimer's disease (AD) or frontotemporal	Caring for Others: Ten weekly 1-hour online video conferencing support groups and links to disease-specific information, private e-mail, and a question-and-answer forum. Focused on helping caregivers tolerate and	Caregivers discussed their experiences of the emotional, physical, and social impact of caring for a person with AD or FTD. Spirituality and meaning making was apparent throughout the caregiving experience and related coping strategies.

			dementia (FTD) (n=24)	manage the anxiety associated with the care recipient's condition.	
Davies 2019	UK	iKT/developmental evaluation	Caregivers of individuals with dementia (n=11)	Developed and tested a website prototype. The website included information on what to expect toward the end of life, planning, looking after yourself (the caregiver), day-to-day of caring, preparing for death, communication, financial information, talk to a professional option, chat to a carer option, and local support. The peer element included the option to chat to a carer online and a video of a carer providing information/education about each topic of interest.	Emergent themes reflect challenges faced by caregivers related to preparedness, feeling connected and supported, self-value, and maintaining control.
Diefenbeck 2017	US	Content analysis	Caregivers of individuals with chronic illness (n=16)	Online Support Group: Researchers examined the content themes emerging from a non-facilitated, peer-only, unstructured, asynchronous Online Support Group (OSG) for caregivers of chronically ill individuals. Each OSG was conducted in a self-help format for the 16-week enrollment period.	The reported findings suggest that caregiving can be difficult work and may exact an emotional toll; caregivers need time to adapt to their role and often need a platform to vent about fear, anxiety and frustration, and seek specific advice or problem solving. Caregivers also found opportunities to share the silver linings of the caregiver experience.
Friedman 2018	US	Survey (self-report) Study period: baseline, 3 months after baseline, 6 months after baseline	Family caregivers of military veterans with disabilities (n=242)	Online support groups for military caregivers (Military and Veteran Caregiver Network (MVCN), Hidden Heroes, Operation Family Caregiver, the Caregiver Action Network, Blue Star Families, American Legion Auxiliary): the MVCN is an online peer support program established in 2016 for military caregivers. Hidden Heroes is a non-profit military caregiver support organization that has an online forum. The rest are private Facebook groups.	Military caregivers with the greatest caregiving demands, those who assisted with more tasks, and those spending ≥60 hours per week on caregiving duties were most likely to post in or visit online peer support groups on a weekly basis or more often. Caring for a veteran with a neurological or psychological condition was also positively and significantly related to visiting an online community support group, indicating a greater need of support.
Gleeson 2017	Australia	Quasi-experimental	Caregivers of a young relative (12–25 years old) receiving treatment for depression or anxiety, of at least 16 years old, English	Meridian: An online application that creates an online therapeutic environment. Meridian is available to carers 24-hours/day and integrates therapy content, expert and peer moderation, and social networking.	A high proportion of participants were motivated to maintain regular contact with the system. There were moderate correlations with reductions in stress and use of the system.

				speaker (n=29)	
Gopalan 2017	US	Qualitative (semi-structured interviews) Study period: June - August 2014	Caregivers to youth who were previously consented to participate in the longitudinal evaluation of MD CARES (n=35)	Parent Peer Support: Monthly face-to-face meetings to collectively review youth and family strengths, identify priority needs, develop and oversee implementation of individualized care plans, monitor progress, and revise care when needed.	Major themes captured caregivers' expectations for PPS, reasons for accepting or refusing PPS, and perceptions of PPS impact. Caregivers indicated that the PPS provided many benefits for themselves, youth in the care, and their families. Perceived need, the desire for shared experiences and knowledge, and assistance in accessing resources, facilitated accepting the PPS service. Barriers included inaccurate expectations of PPS, time limitations of services, escalating youth behavior, scheduling conflicts, perceived unresponsiveness, and caregivers feeling overwhelmed by the number of providers.
Gossink 2018	Netherlands	Randomized controlled trial (RCT); Explorative mixed methods pilot study Study period: Six months	Caregivers of dementia patients dealing with frontal behavioural problems (N=30; intervention group n=15, control group n=15)	Support program: Five in-person sessions comprised of psychoeducation by a medical specialist, peer social support, and learning new coping strategies through cognitive behavioural therapy. The control group received regular visits with a medical specialist.	Sense of competence improved in caregivers who participated in the intervention. Caregivers in the intervention group most appreciated the internal support and mutual recognition between caregivers. The most supportive parts of the program were the psychoeducation and behavioural cognitive therapy. The authors could not conclude that the intervention improved caregiver burden, perceived stress, and depressed mood. However, caregivers who received support did experience some benefit regarding mood and perceived stress.
Han 2018	US	Qualitative interviews Study period: Older volunteers: February - March 2016 Caregivers: February 2017	People with early to middle stages of dementia and their caregivers (n=12)	Stepping Stones: Weekly 1.5 hour-meetings for people with dementia (PwD) and their caregivers in separate groups. The activity group for PwD aimed to provide opportunities for social interaction. The support group for caregivers aimed to provide support and education.	Stepping Stones was founded to promote participation of PwD and fulfill a deep need of family caregivers. Caregivers reported that some of the program features made it unique and distinct from other programs, and well organized and structured.
Jamison 2017	US	RCT Study period: Six months	Caregivers to children with Autism spectrum disorder (ASD) diagnosis (n=39)	Family peer advocates (FPA): Parents met with assigned FPA in 12 meetings. They identified the needs of the family, provide education and support, and identify appropriate resources based on needs.	Focused contact with an FPA significantly decreased caregiver stress compared to control group. No significant changes in either group on measures of caregiver support, empowerment, or

				Control group: parents received the standard of care provided for autism-related services: referrals to resources and supports.	service utilization. Both groups showed increased ASD knowledge over time.
Kavanaugh 2018	US	Qualitative feasibility study Study period: One day	Youth caregivers (aged 8-18) of family member with Amyotrophic Lateral Sclerosis (ALS), between the ages of 8–18	Formal training protocol: Four 45-minute modules to develop skills, peer support, and normalizing experiences. Modules: improve family utilization of ASD services, have a positive impact on caregiver knowledge and treatment options, and improve family stress and caregiver perceptions of family support and empowerment.	The peer group experiential young caregiver model is feasible for both youth and therapists. Participants found benefit, skill acquisition, and mastery by asking questions, teaching back skills to the group and engaging with peers. The authors report that this project demonstrates young caregivers will participate in training and engage with "like" peer groups.
Male 2017	Canada	Content analysis (transcripts of support groups)	Caregiver of individuals with advanced cancer (=25)	Cancer Chat Canada: 8-11 weekly 90-minute sessions in a closed membership online support group. Free platform that offers real-time, professionally facilitated support groups for caregivers.	Results provide a comprehensive overview of the online facilitator's role which may be integral to meaningful group interaction. Facilitators maximized the utility of their respective online groups through structuring and guiding, actively scanning, and modulating the experience.
Mittelman 2018	US	Quasi-experimental, mixed methods pilot study	Informal caregivers and persons with early to middle stage dementia (n=10 dyads)	The Unforgettables: 13 weekly two-hour rehearses in a chorus, and a final concert, as a means of improving their quality of life and social connectedness. Rehearsals were divided into two parts by a 15-minute break. Couples took turns hosting the break by bringing refreshments for everyone. This allowed for social interactions amongst caregivers and those with dementia.	Quality of life and communication with members of the chorus improved for the people with dementia. For caregivers, self-esteem was the only outcome that improved. Caregivers enjoyed sharing an experience with others like themselves, the challenge of learning new songs and singing techniques and took pleasure in the activity itself, and valued the social support of the group, the group atmosphere, and the sense of community. Qualitative outcomes suggest that both caregivers and people with dementia had positive reactions, but quantitative results suggest a greater benefit for the people with dementia.
Moebs 2017	New Zealand	Qualitative interviews Study period: April 2012 - June 2013	Caregivers of individuals living with dementia (n=15)	Coping with Forgetfulness Group: Dyads of people living with cognitive impairment and caregivers who attended the Coping with Forgetfulness Group program were invited to take part in individual interviews. The	Caregivers reported benefit from learning about memory problems and sharing their challenges with other caregivers in a comforting environment. Caregivers value the informational and emotional support, whereas participants living with cognitive

				"Coping with Forgetfulness Group" is a weekly nine-week group cognitive rehabilitation program for individuals with memory problems and their caregivers.	impairment emphasized benefit of relational and practical aspects.
Mosher 2018	US	RCT	Advanced gastrointestinal cancer patients and caregivers (n=50 patient-caregiver dyads)	Patients and caregivers were randomly assigned to a five-session, telephone-based coping skills intervention or a peer helping + coping skills intervention. Peer helping involved contributing to handouts on coping skills for other families coping with cancer.	Small effects in favor of the coping skills group were found regarding meaning in life/peace at one- and five-weeks post-intervention. Other outcomes did not vary as a function of group assignment, with both groups showing small decreases in patient and caregiver fatigue and caregiver distress and burden. Authors report that the study supports the feasibility and acceptability of five-session, telephone-based dyadic coping skills interventions.
Nagl-Cupal 2019	Austria	Qualitative (semi-structured interviews), content analysis	Young caregivers aged 10 to 14 years (n=11) and parents with severe or chronic illness	Recreational camp for young caregivers: The two-week camp aimed to provide children from 10 to 14 years a respite time from caring and from their often-difficult private circumstances. It is held annually in varying locations and provides leisure time with a broad variety of outdoor and group-oriented activities. In an individual or group setting, the children can voluntarily have conversations about their situation at home.	This study described the experiences of children and their parents with a summer camp for young caregivers. A notable observation was that the "real" conversations about the children's experiences took place mostly unwatched, in the children's sleeping rooms and in private. The camp gave children a glimpse of another way of living that cannot be maintained at home, and parents noticed a positive change when their children came home from camp. Authors suggest that these findings indicate that camps can make an important contribution to addressing young carers' needs in addition to more sustainable relief measures.
Narasimha 2019	US	Content analysis from online portal (ALZConnected.org) Study period: December 2017 - January 2018	Posts on the Caregiver's forum from informal caregivers of Alzheimer's patients (n=10 conversational threads)	Online peer support group: The online portal developed by the Alzheimer's Association was moderated by an administrator. Peer patrons posted content on online portals, including a Caregiver's Forum.	The analysis revealed five themes related to content of peer interaction with others, including advice provider, information source, shoulder to cry on, portal star, and caregiver advocate. Peer patrons were found to be predominantly advice providers for all caregiving matters while communicating with others, making peers a large information source. Many comments were found to also have an aspect of emotional support.
Ovenden 2019	UK	Qualitative (semi-structured interviews)	People with dementia (n=6), carers n =10) and the group organizers	Boccia: a modified form of indoor bowls, is a team game, which involves throwing coloured balls at a target ball (jack) from a seated position. The researcher attended	The unique nature of Boccia reportedly helped to provide physical and mental stimulation as being part of an inclusive and enjoyable group. Participation at the weekly group helped in "the

			(n=6)	group sessions over a period of six weeks and observed the Boccia games.	struggle of being a caregiver" where carers had a period of respite while others care for or played Boccia with their spouse.
Paun 2019	US	Quasi-experimental, mixed methods	Caregivers of individuals with dementia (=5)	Chronic Grief Management (live-streaming, online intervention program): survey and focus groups with five family caregivers from suburban long-term care facility specializing in care of individuals with ADHD for assessment of participants at baseline and at the end of the Chronic Grief Management - live-streaming, online intervention program. The CGMI-V follows a standardized intervention manual and comprises approximately 60-minute sessions delivered weekly for eight consecutive weeks.	All caregivers agreed that the online environment did not interfere with their ability to relate to one another emotionally, especially because they could see each other via live-streaming video. Caregivers acknowledged that the live-streaming, group-based intervention helped them feel less alone in their caregiving experience and also made them feel less guilty about having placed their family members in long-term care.
Poyner-Del Vento 2018	US	Mixed methods	Caregivers of veterans with dementia (n=7)	The Caregivers' Attachment and Relationship Education (C.A.R.E.): an eight-session group therapy developed for caregivers of individuals with Parkinson's disease.	At one-month follow-up, caregivers who initially reported mild or greater levels of caregiver burden demonstrated statistically reliable declines in psychological distress, relationship distress, or both. Post treatment surveys indicated positive perceptions in overall helpfulness of treatment goals, as well as positive changes in insight and behaviors.
Rubin 2018	US	Quasi-experimental, no baseline, no control	Caregivers of child and youth mental health issues (n=145; n=196)	Siblings participated in a structured support group that enabled them to share their stories and learn coping skills. Caregivers were provided with a psychoeducation curriculum in a group facilitated by a parent mentor. At the end of each session, participants completed surveys which included questions on demographics, satisfaction, knowledge learned, and anticipated changes in behavior as the result of participating in the intervention.	Caregivers indicated that the emotional support provided by the group was significant to them, and reported: • Gaining useful parenting strategies to better support the siblings • Increased understanding of the impact of mental illness on siblings; and • A reduction in feelings of isolation, and improved access to resources. Siblings reported: • Feeling relieved and better understood • Learning new coping skills; and • Found validation and support through sharing their experiences in a group setting. Not only was the emotional support perceived to be helpful, but learning about their sibling's situation and discussing coping strategies was important.

Serwe 2017	US	Qualitative pilot study (focus groups)	Caregivers who completed a 6-week telehealth program (n=4)	Telehealth Powerful Tools for Caregivers (PTC): The education-based wellness program was delivered in six, 90-minute weekly sessions following the scripted format used for the face-to-face PTC program, with minor changes. Participants received one in-person training session on VSee software use before the program began and were provided a hard-copy VSee user guide, a custom-created document to help participants use the software required to participate in the telehealth PTC program, and a folder containing printed handouts for the PTC class series.	Overall, participants reported a positive experience and findings indicate that telehealth was effective in both promoting learning and facilitating relationships. Two major themes emerged that reflected the participants' experiences of the program and telehealth, and the lessons learned. There were minimal challenges using telehealth that were resolved easily, like audio feedback.
Sharaievska 2018	US	Qualitative (semi-structured interviews)	Caregivers of children with a developmental disability (n=8)	Online and offline support groups: The grassroots initiatives described in this study were created by parents of children with developmental disabilities, who were interviewed for this study. Online support groups were developed after a parent created a blog and built a list of followers. Information about blogs and online support groups was shared by word of mouth, including suggestions from physicians. Offline support groups were developed by parents seeking opportunities to connect with other families in similar circumstances. These support groups met once a month to discuss various topics or host events/leisure activities.	The study revealed that caregivers saw online and offline support groups as playing important but different roles in their lives and the lives of their families. Online support groups were particularly appreciated during the initial steps of learning about a child's disability when caregivers felt isolated and eager to learn more. During that stage, online support groups offered them volumes of valuable information and access to people across the world who go through similar experiences. Offline support groups offered participants of this study a sense of strong connection and belonging, and allowed them to spend time with other adults and learn about resources available in their community. The mothers also appreciated the opportunity provided to the children with disabilities and their siblings to make friends and spend time together.
Smith 2018	England	Qualitative, cross-sectional (in-depth, semi-structured interviews)	Befrienders (n=7) and peer supporters (n=3) to carers of people with dementia; half of the sample were former carers	Peers and befrienders are trained by organizations to support other carers of people with dementia on a volunteer basis.	Findings showed that volunteers benefitted from their role due to the "two-way" flow of support. Experiential similarity and having common interests with carers were considered important to the development of mutually beneficial relationships. Volunteers perceived that carers gained emotional and social support, which in turn improved the carers' coping ability. Being able to see positive

					changes to carers' lives was important for volunteers to gain enjoyment and satisfaction from their role. Challenges identified by volunteers, included dealing with carers' emotions.
Ufer 2018	US (7 states)	Quasi-experimental pilot evaluation	Caregivers of children with genetic conditions and other special health care needs from 7 states (n=190)	The Care Coordination: Empowering Families (CCEF) training provides families with the knowledge, tools, and resources to engage with health, education, and family support systems. The eight-hour interactive training includes eight core training components with 16 learning objectives. The training also provides an opportunity to learn practical information and be inspired by others with similar experiences.	Families who attended the training report being the primary source of care coordination for their children and 83.7% see their role in their child's healthcare changing as a result of the training. The findings suggest that peer support and communication with providers increased as a result of the training over the course of the study and impacted how the family interacts with the child's doctor. Families also reported system-level improvements one year later compared to the pre-training assessment.
Vaughan 2018	US	Quasi experimental, mixed methods (surveys, focus groups, and interviews) Study period: Six months follow-up (enrollment September 2016-February 2017)	MVCN users which were primarily caregivers (survey n=217, focus groups n=11, interviews n=4)	Military and Veteran Caregiver Network (MVCN): web platform, currently administered by the American Red Cross. Caregivers can post in forums, exchange information/resources, attend webchats and webinars, send direct messages, and interact with trained peer and professional moderators. Comparison group: Members of caregiver organizations other than MVCN (e.g., Hidden Heroes, Operation Family Caregiver at the Rosalynn Carter Institute for Caregiving, the Caregiver Action Network, Blue Star Families, and the American Legion Auxiliary).	Survey findings showed infrequent use, with 60.7% caregivers (128/211) visiting the website once a month or less, and passively, with a minority (32/144, 22.2%) of users (i.e., those who had visited the website at least once during the past three months, N=144) posting comments or links to the network. Nonetheless, most users (121/144, 84.0%) endorsed moderate or greater satisfaction with the website on the survey. Focus group and interview participants reported benefiting from passive use of the website (e.g., reading posts, looking for specific resources). Perceived benefits included the hub nature of the website, containing multiple resources; privacy and safety, as only approved users could access posts; and sense of anonymity. The largely passive engagement was a hindrance to receiving adequate peer support.
Visa 2019	Australia	Qualitative (semi-structured interviews) pilot study	Carers of service users attending a community mental health clinic and received a CPSW service within the last 5-10 months (n=20)	The Carer Peer Support Workers (CPSW) pilot program: Provides emotional, financial, and informational support. CPSWs are people with lived experience as family carers of persons with a mental illness, and are employed to provide the support to other carers and family members.	The study highlighted how mental health services could best utilize and benefit from CPSWs. Results found that carers were generally positive about the CPSW's emotional support, practical support, shared lived experience and mutual under-standing, and the "ripple effect" the support had on service users; some felt that the support was unnecessary either due to believing it may not have a lasting effect, that the focus should have been on the

				Follow-up: 5-10 months after their last contact with the service.	service user, or that they previously received enough support. To be most useful, the nature of the carer peer support work should be tailored to the specific needs of the carers.
Wilkerson 2018	US	Mixed methods: online surveys, semi-structured interviews Pretest-posttest	Informal caregivers of people with AD (n=12)	The Friendsourced Peer Support (FPS) intervention was hosted online through two closed Facebook groups. Over six-weeks, participants were asked to interact with peer caregivers in the group by posting questions and responding to comments. A moderator facilitated group participation through weekly prompts and individual e-mails. Follow-up occurred six weeks after the completion of the intervention.	After a six-week intervention, caregivers were found to have significantly decreased burden and perceived stress scores, and significantly increased emotional and informational support scores. Qualitative data analysis of the intervention identified positive effects in acquiring new caregiving knowledge and its application. Findings demonstrated that joining social network groups through friend-sourcing was feasible for AD caregivers who were familiar with social media, and can provide another means of guiding the development of their personal support networks.

List of abbreviations: AD (Alzheimer's Disease); AGP (*A Good Place);* ALS (Amyotrophic Lateral Sclerosis); FTD (frontotemporal dementia); ICT (Information and Communication Technologies); FPS (Friendsourced Peer Support); RCT (Randomized Control Trial); UK (United Kingdom); US (United Sates)

Appendix D: Summary of the Grey Literature

Table D1. One-on-one supports

Program name/Host	Jurisdiction	Target caregiving population	Delivery/Facilitation details	Type(s) of support
1:1 Caregiver Peer Support, MS Society of Canada	Canada (national)	Multiple Sclerosis caregivers	Telephone/ Internet	Emotional; Informational
Caregiver Support Helpline, L'Appui pour les proches aidants d'aînés	Quebec	Caregivers of older adults	Telephone	Informational (referral)
CPFF Peer Support, Canadian Pulmonary Fibrosis Foundation	Canada (national)	Pulmonary fibrosis (PF) patients, caregivers, family/ friends of someone living with PF	Email/Telephone	Emotional; Informational
Direct Support for Individuals and Families, Seniors Come Share Society	British Columbia	Caregivers of older adults	In person	Informational
Gusty Peer Support, Crohn's and Colitis Canada	Canada (national)	Crohn's and Colitis patients and their caregivers	Email	Emotional; Informational
Keeping in Touch (KIT) Program, Cowichan Family Caregivers Support Society	Vancouver Island, British Columbia	Caregiving families	Unclear	Emotional
One2One Peer Support, Bladder Cancer Canada	Canada (national)	Bladder cancer patients and their caregivers	Unclear	Informational (advice)
One-to-one Caregiver Support, Cowichan Family Caregivers Support Society	Vancouver Island, British Columbia	All caregivers	Telephone/ In-person	Emotional; Informational (system navigation)
Pancreatic Peer Support, Wellspring Cancer Support Network in partnership with Pancreatic Cancer Canada	Ontario	Pancreatic cancer patients and their caregivers	Telephone/ Video Conference/ In-person	Informational (system navigation, advice)
Patti Robinson Kaufmann First Connection Program, Leukemia & Lymphoma Society of Canada	Canada (national)	Blood-related cancer patients and their caregivers	Telephone	Emotional
Peer Match Program, Canadian Cancer Society	Canada (national)	Cancer patients and their caregivers	Telephone	Emotional; Informational
Peer Support, Wellspring Cancer Support Network	Ontario	Cancer patients and their caregivers	In-person	Emotional; Informational (system navigation)
Peer-to-Peer, Lung Cancer Canada	Canada (national)	Lung cancer patients and their caregivers	Telephone/Email	Emotional; Informational
Project for Caregivers Individual Support, Centre de bénévolat SARPAD	Quebec	Caregivers of older adults	Unclear	Informational (system navigation)
Telephone Support, Caring with Confidence	Manitoba	Caregivers of older adults	Telephone	Emotional
The Caregiver Exchange, thehealthline.ca/ LHIN	Ontario	All caregivers	Telephone/ Internet	Informational (system navigation)

Program name/Host	Jurisdiction	Target caregiving population	Delivery/Facilitation details	Type(s) of support
The Peer Support Network, Canadian Liver Foundation	Canada (national)	Liver disease patients and their caregivers	Telephone	Emotional; Informational
Time out for Caregivers, Caring with Confidence	Manitoba	Caregivers of older adults	In-person	Emotional; Instrumental (respite)

Table D2. Group supports

Program name/Host	Jurisdiction	Target caregiving population	Delivery/Facilitation details	Type(s) of support
Afterstroke Support Groups, March of Dimes	Alberta, British Columbia, Manitoba, New Brunswick, Nova Scotia, Ontario, Quebec, Saskatchewan	Caregivers of stroke survivors	In-person Facilitator unspecified	Emotional; Informational
Alzheimer/Dementia Family Caregiver Support Group, Unclear	Yukon	Caregivers of people with Alzheimer's	In person	Emotional; Informational (system navigation)
Annapolis County Canadian Mental Health Association Mental Health Support Group, Canadian Mental Health Association	Nova Scotia	Caregivers of people with mental illness	In person	Emotional
Association Quebecoise des Personnes Aphasiques	Quebec	Caregivers of people with Aphasia	In person Professional-led	Informational (educational); Emotional
Autism Nova Scotia Support Group, Autism Nova Scotia	Nova Scotia	Caregivers of people with Autism	In person	Emotional; Informational; Activity-based (monthly social events like dances and picnics)
Bipolar Disorder Peer Support Group, Mood Disorders Association of Nova Scotia	Nova Scotia	Caregivers of people with mental illness	In person	Emotional
Brain Injury Caregiver Support Group, Brain Injury Society of Toronto	Ontario	Caregivers of people living with acquired or traumatic brain injury	In person Peer-led	Emotional
Bridge to Hope, Eating Disorder Foundation of Newfoundland	Newfoundland	Caregivers of people with eating disorders	In person	Emotional; Informational (system navigation)
Campbell River Caregiver Support Group, Family Caregivers Society of British Columbia	British Columbia	All caregivers	In person Professional-led	Emotional; Informational (system navigation)
Cancer Chat Canada, De Souza Institute	Canada (national)	Caregivers of people with cancer	Online Professional-led	Emotional
Care for the Caregiver, Five Hills Health Region	Saskatchewan	All caregivers	In person Facilitator unspecified	Emotional; Informational (educational)

Care Partners Peer Support Program, CNIB Foundation	Canada (national)	Caregivers of people with vision loss	In person/ Phone Professional-led	Emotional; Informational (educational - skill development)
Caregiver 101, Matthews House Hospice	Ontario	Unspecified	In person Facilitator unspecified	Informational (educational -skill development)
Caregiver Connection, Ripple Connection Support Centre	Alberta	Caregivers of people with mental illness	In person	Emotional; Informational (system navigation)
Caregiver Connections: Drop-in Support Group, Canadian Mental Health Association	Alberta	Caregivers of people with mental illness	In person	Emotional
Caregiver Expo, Burnaby Seniors Outreach Services Society	British Columbia	All caregivers	In person No facilitator	Emotional; Informational; Activity-based (conference day)
Caregiver Support and Outreach, Seniors Come Share Society	British Columbia	Caregivers of older adults	In person	Emotional; Informational
Caregiver Support Community, Caregivers Alberta	Alberta	All caregivers	In person Trained facilitator	Emotional; Informational
Caregiver Support Group, Alzheimer Society of British Columbia	British Columbia	Caregivers of people with Alzheimer's	In person	Emotional; Informational
Caregiver Support Group, Alzheimer Society of Nova Scotia	Nova Scotia	Caregivers of people with Alzheimer's	In person Facilitator unspecified	Emotional support
Caregiver Support Group, Burnaby Seniors Outreach Services Society	British Columbia	All caregivers	In person Professional or peer-led	Emotional support
Caregiver Support Group, Family Caregivers of BC	British Columbia	All caregivers	Unclear	Emotional support
Caregiver Support Group, Fetal Alcohol Syndrome Society Yukon	Yukon	Caregivers of people with FASD	In person	Emotional; Informational
Caregiver Support Group, Frog Hollow House	British Columbia	Caregivers of older adults	In person	Emotional
Caregiver Support Group, Matthews House Hospice	Ontario	Caregivers of someone with a life limiting illness	In person Volunteer-led	Emotional; Activity-based (lunch)
Caregiver Support Group, Mental Health Services Nova Scotia Health	Nova Scotia	Caregivers of people with mental illness	Unclear	Unclear
Caregiver Support Group, Mount Pleasant Neighbourhood House	British Columbia	Caregivers of people with chronic and/or disabling conditions	In person Peer-led	Emotional; Informational (system navigation, coping)
Caregiver Support Group, Parkinson Canada	Nova Scotia	Caregivers of people with Parkinson's	In person Facilitator unspecified	Emotional
Caregiver Support Group, Schizophrenia Society of New Brunswick	New Brunswick	Caregivers of people with long-term mental illness	In person	Emotional
Caregiver Support Groups, Alzheimer Society of Newfoundland and Labrador	Newfoundland and Labrador	Caregivers of people with Alzheimer's	In person	Emotional; Informational

Caregiver Support Groups, Alzheimer Society of PEI	Prince Edward Island	Caregivers of people with Alzheimer's	In person	Emotional; Informational
Caregiver Support Groups, Caregivers Network for East Jootenay Seniors	British Columbia	Caregivers of older adults	In person	Emotional; Informational (skill-building, system navigation)
Caregiver Support Groups, Comox Valley Senior Support Society	British Columbia	Caregivers of older adults	In person	Emotional
Caregiver Support Groups, Saskatoon Health Region	Saskatchewan	All caregivers	In person	Emotional
Caregiver Support Network, Alzheimer Society of New Brunswick	New Brunswick	Caregivers of people with Alzheimer's	In person	Emotional; Informational
Caregiver Support Program, Vancouver Coastal Health	British Columbia	All caregivers	In person	Emotional; Informational; Advocacy
Caregiver Support, Community Support Connections	Ontario	All caregivers	In person Professional-led	Emotional; Informational
Caregiver Tele-Group Support, Caregivers Nova Scotia	Nova Scotia	All caregivers	Online Peer-led	Emotional; Informational
Caregiver Virtual Support Group, Brain Tumour Foundation	Canada (national)	Caregivers of people with brain tumours	Online Volunteer-led	Emotional; Informational
Caregiver's Support Group, Canadian Mental Health Association	Yukon	Caregivers of people with mental illness	In person Professional- and Peer-led	Emotional; Informational
Caregivers and Alzheimer's Support Group, Salt Spring Seniors Centre	British Columbia	Caregivers of older adults and people with Alzheimer's	In person	Emotional; Informational
Caregivers Connect, Ridge Meadows Seniors Society	British Columbia	Caregivers of older adults living at home	In-person	Emotional; Informational
Caregivers Connect: Finding Sanctuary, Wellspring	Alberta	Caregivers of people with cancer	In person	Emotional
Caregivers Connect: Support and Relaxation, Wellspring	Ontario	Caregivers of people with cancer	In person	Emotional
Caregivers Network of Surrey/Delta Support Group, Seniors Come Share Society	British Columbia	Caregivers of people with chronic or long-term illness, disability or frailty	In person	Emotional; Informational (system navigation)
Carrefour des femmes de Saint Leonard	Quebec	Women who are caregivers	In person	Emotional; Informational (educational); Activity-based (coffee meetings)
Centre de benevolat SARPAD	Quebec	Caregivers of seniors	In person/ Phone Facilitator unspecified	Education
Centre de Soutien Entr'aidant	Quebec	Caregivers of older adults and adults approaching the end-of-life	In person Professional-led	Emotional; Informational (educational); Activity-based (coffee meetings)

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Clare Ostomy Support Group, Ostomy Canada	Nova Scotia	Caregivers of people who have undergone ostomy surgery	In person Professional-led	Emotional; Informational (educational)
CMHA Family Program, Canadian Mental Health Association PEI	Prince Edward Island	Caregivers of people with mental illness	In person Professional-led and Peer-led	Informational (skill development)
Colchester Stroke Club Support Group, Colchester Stroke Club	Nova Scotia	Caregivers of stroke survivors	In person	Emotional; Informational
COMPASS for the Caregiver, Caregivers Alberta	Alberta	All caregivers	In person Peer-led	Informational (educational, skill development)
Dementia Caregiver Group, Western Ottawa Community Resource Centre	Ontario	Caregivers of people with Dementia	In person Facilitator unspecified	Emotional
Dissociative Identity Disorder (DID) Support Group for Families, Ottawa Anxiety and Trauma Clinic	Ontario	Caregivers and family members of people with Dissociative Identity Disorder	In person Peer-led	Emotional
Drum for Joy, Wellspring	Alberta	Caregivers of people with cancer	In-person Professional-led	Emotional; Activity-based (drum circle)
Enhancing Care for Ontario Dementia Care Partners, The Reitman Centre at Sinai Health System	Ontario	Caregivers of people with Dementia	In person/ Online	Informational (educational, skill development, information sharing)
Families Supporting Families Support Group, Eating Disorder Foundation of Newfoundland and Labrador	Newfoundland and Labrador	Caregivers of people with eating disorders	In-person	Emotional; Informational (system navigation)
Family & Friends Support Group, Hopewell	Ontario	Caregivers of people affected by eating disorders	In person Professional-led	Emotional; Informational (educational, skill development)
Family and Caregiver Support Group, South Vancouver Neighbourhood House	British Columbia	Caregivers of an ailing loved one	In-person	Emotional
Family and Friends Peer Support Groups, Eating Disorders Nova Scotia	Nova Scotia	Caregivers of people with eating disorders	In-person Peer-led	Emotional; Informational
Family Caregiver Support Group, Alberni Hospice	British Columbia	Caregivers of older adults	In person	Emotional; Informational (system navigation)
Family Caregivers Voice	Ontario	All caregivers	Unclear Peer-led	Advocacy
Family Education and Support Group, Stella's Place	Ontario	Caregivers of young adults with mental illness	Unclear	Emotional; Informational
Family Matters Peer Support and Recovery Program, Mood Disorders Association of Ontario; NAMI Ontario	Ontario	Caregivers of people with mood disorders	Unclear	Emotional; Informational (educational)
Family Support Group, Cornwall & District	Ontario	Caregivers of people with mental illness	In-person Facilitator unspecified	Emotional

Family Support Group, Laing House	Nova Scotia	Caregivers of people with mental illness	In-person Unspecified facilitator; Guest speakers	Emotional; Informational (educational, system navigation)
Family Support Group, Mood Disorders Ottawa	Ontario	Caregivers of people with mood disorders	In person Facilitator unspecified	Emotional; Informational
Family Support Groups, Leukemia & Lymphoma Society of Canada	Canada (national)	Caregivers of people with blood-related cancer	In person Professional-led	Emotional
Family Support Groups, Reconnect Community Health Services	Ontario	Caregivers of people with mental illness	In person Led by Family Support Workers	Emotional
Family Support, Durham Mental Health Services	Ontario	Caregivers of people with mental illness	In person Facilitator unspecified	Emotional; Informational
Family-to-Family Education Course, Parents for Children's Mental Health	Ontario	Caregivers of people with serious mental illness	Unclear Professional- and peer-led	Educational; Informational (information sharing, skill development)
For Caregivers Only, Wellspring	Alberta	Caregivers of people with cancer	In-person Professional- and peer-led	Educational; Informational (information sharing, skill development)
Forensic Family Support Group, Royal Ottawa Mental Health Center	Ontario	Caregivers of individuals involved in the forensic mental health system	In person	Emotional
Fredericton and District Ostomy Association Support Group, Ostomy Canada	New Brunswick	Caregivers of people who have had ostomy surgery	In person Professional- and peer-led	Emotional; Informational (educational)
Friends & Family Mental Illness, Capital Region Mental Health and Addictions Association	New Brunswick	Caregivers of people with mental illness	In-person	Emotional
General Caregiver Support Group, Western Ottawa Community Resource Centre	Ontario	All caregivers	In-person Facilitator unspecified	Emotional
Greater Moncton Self-Help Group, MS Society Greater Moncton Chapter	New Brunswick	Caregivers of people with Multiple Sclerosis	In-person Facilitator unspecified	Emotional
Group Supports, Groupe des Aidants du Sud-Ouest	Quebec	All caregivers	In person	Emotional; Informational (educational)
Group Supports, Hayn Doun Family Support Services	Quebec	Caregivers of seniors	In-person	Emotional; Informational (skill development); Activity-based (caregivers and volunteer chefs prepare meals)
Group Supports, Reseau d'Action pour les Aidants to Jeanne-Mance	Quebec	Caregivers of older adults	In-person	Emotional; Informational (educational)
IDEAS Family Support Group, Schizophrenia Society of Ontario	Ontario	Caregivers of people with Schizophrenia	Unclear	Emotional; Informational; Activity-based (evening presentations)

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In person Support Groups, Pulmonary Hypertension Association of Canada	British Columbia, Manitoba, Ontario, Quebec and Nova Scotia	Caregivers of people with Pulmonary Hypertension	In-person; Peer-led	Emotional; Informational (educational)
INCA Quebec	Quebec	Caregivers of people with vision impairment	In-person	Emotional; Informational
Kawartha Lakes Parents, Families and Caregivers Group, Community Living Trent Highlands	Ontario	Caregivers of people with developmental disabilities	In person Facilitator unspecified	Emotional; Informational
Lanark County Family Peer Support Group, Open Doors	Ontario	Caregivers of people with mental illness	In-person	Emotional; Informational
Le Temps d'une Pause	Quebec	Caregivers of people with moderate to severe cognitive impairments	In person Professional-led	Educational; Informational (skill development)
Living with Cancer Support Group, Canadian Cancer Society	Nova Scotia	Caregivers of people with cancer	In-person	Emotional
Living with Stroke Program, Heart and Stroke Foundation	Canada (national)	Caregivers of stroke survivors	In-person Professional and peer-led	Emotional; Informational/educational
McCormick Caregiver Support Group, McCormick Dementia Services	Ontario	Caregivers of people with Dementia	In-person Facilitator unspecified	Emotional; Informational
Memory Café, Alzheimer Society of New Brunswick	New Brunswick	Caregivers of people with Alzheimer's	In-person Volunteer-led	Emotional; Informational (education); Activity-based (conference and entertainment)
Mental Health & Addictions Support Group for Family and Friends, Schizophrenia Society of Nova Scotia	Nova Scotia	Caregivers of people with Schizophrenia	In-person	Emotional; Informational (education, skill development)
Mental Illness Family Education & Support Group, Schizophrenia Society of Nova Scotia	Nova Scotia	Caregivers of people with mental illness	In-person	Emotional; Informational (educational)
Nipissing Family Peer Support Services, ConnexOntario	Ontario	Family and caregivers of people with mental illness	Unclear Facilitator unspecified	Emotional; Informational (education); Consultation and community development
Online Support Group, Kidney Foundation	Canada (national)	Caregivers of people with Chronic Kidney Disease	Online	Emotional; Informational
Ottawa OCD Patient/Family Support Group, OCD Ottawa	Ontario	Caregivers of people with Obsessive Compulsive Disorder	In-person Peer-led	Emotional
Parent 2 Parent, Rare Disease Network	British Columbia, Yukon, Ontario,	Caregivers of people with rare diseases	In-person Peer-led	Emotional

	Quebec, Newfoundland			
Parent and Family Support Group Teleconference, CNIB Foundation	Canada (national)	Caregivers of children with vision loss	Online Facilitator unspecified	Emotional; Informational (system navigation)
Parent Support Group, Halifax Association for Community Living	Nova Scotia	Parents of children with developmental disabilities	In-person	Emotional
Parent Support Groups, Autism Society Newfoundland and Labrador	Newfoundland and Labrador	Caregivers/parents of children with Autism	In-person Professional and peer-led	Emotional; Informational
Parent/Caregiver Support Group, Parents' Lifelines of Eastern Ontario	Ontario	Caregivers of people facing mental health challenges	In-person Facilitator unspecified	Emotional; Informational
Peer Caregiver Support Group, Parent Support Association of Calgary	Canada (national)	Caregivers of youth and young adults with Fetal Alcohol Spectrum Disorders	In-person Led by a parent advocate	Emotional; Informational
Peer Support Group, Ostomy Canada	Prince Edward Island	Caregivers of people who have undergone ostomy surgery	In-person Professional and peer-led	Emotional; Informational (education, information sharing)
Peer Support Group, Stroke Recovery Association of Manitoba Office	Manitoba	Caregivers of stroke survivors	In person Facilitator unspecified	Emotional
Peer Support Groups, Caregivers Nova Scotia	Nova Scotia	All caregivers	In person Peer-led	Emotional; Informational
Peer Support Groups, Federation of Quebec Alzheimer Societies	Quebec	Caregivers of people with Dementia	In-person Facilitator unspecified	Emotional
Peer Support Program, Alzheimer Society of Manitoba	Manitoba	Caregivers of people with Dementia	In-person/telephone	Emotional
Peer Support Program, Amyotrophic Lateral Sclerosis (ALS) Society of Manitoba	Manitoba	Caregivers of people with ALS	In-person	Emotional
Peer Support Program, Arthritis Society of Manitoba	Manitoba	Caregivers of people with arthritis	In-person	Emotional
Peer Support Program, Canadian Cancer Society	Manitoba	Caregivers of people with cancer	Telephone Peer-led	Emotional
Peer Support Program, CancerCare Manitoba	Manitoba	Caregivers of people with cancer	In-person	Emotional
Peer Support, Hospice PEI	Prince Edward Island	Family and caregivers who have recently experienced a loss	In-person	Emotional
Post Polio Support Group, March of Dimes	Prince Edward Island	Caregivers of people impacted by Polio	Unclear	Emotional; Informational (skill development)
Powerful Tools for Caregivers, Matthews House Hospice	Ontario	All caregivers	In-person Peer-led	Emotional; Informational (skill development)
Quilting for Wellness, Wellspring	Ontario	Caregivers of people with cancer	In-person Peer-led	Emotional; Informational (skill development); Activity-based (quilting)

Scleroderma Support Group, Scleroderma Society of Nova Scotia	Nova Scotia	Caregivers of people with Scleroderma and Lupus	In-person Peer-led	Emotional support
Social Support Group for Clients & Caregivers, MS Society Grand River Chapter	Nova Scotia	Caregivers of people with Multiple Sclerosis	In-person	Emotional; Informational/educational
South Delta Caregivers Network Education and Support Group, Delta Hospice Society	British Columbia	Caregivers of people who are frail, elderly, chronically ill, or have a disability	In-person	Emotional; Informational/educational (system navigation)
St John Area Multiple Myeloma Support Group, Myeloma Canada	New Brunswick	Caregivers of people with Multiple Myeloma	In-person	Emotional
Strengthening Families Together, Schizophrenia Society of Ontario	Ontario	Caregivers of people with Schizophrenia	Unclear	Emotional; Informational/educational
Sudbury OCD Parent Peer Support, International OCD Foundation	Ontario	Families and caregivers of kids or teens with OCD	In-person Peer-led	Emotional
Support for Caregivers, CIUSSS de l'Ouest-de-l'Ile-de-Montreal	Quebec	All caregivers	In-person Professional-led	Emotional; Informational (education); Activity-based (art and health workshops, conferences)
Support Group and Art Therapy, Association Quebecoise des Parents et Amis de la Personne Atteinte de Maladie Mentale	Quebec	Caregivers of people with mental illness	In-person Facilitator unspecified	Emotional; Informational (education information sharing); Activity-based (art therapy)
Support Group, Annapolis Valley Health Seniors	Nova Scotia	Caregivers of people with Dementia	In-person	Emotional
Support Group, Asperger Manitoba Inc.	Manitoba	Caregivers and parents of adults with Asperger's	I In-person	Emotional
Support Group, Brain Injury Association of Nova Scotia	Nova Scotia	Caregivers of people with brain injuries	In-person	Emotional
Support Group, Caregiving with Confidence	Manitoba	Caregivers of older adults	In-person Volunteer-led	Emotional
Support Group, Cowican Family Caregiver Support Society	British Columbia	All caregivers	In-person	Emotional
Support Group, Parents Supporting Parents Society	Nova Scotia	Parents of children with special needs	In-person	Emotional
Support Group, Parkinson Quebec	Quebec	Caregivers of people with Parkinson's	In-person	Emotional; Informational
Support Groups, VON and South West Health	Nova Scotia	All caregivers	In-person	Emotional
Support4Caregivers, Craig's Cause Pancreatic Cancer Society	Canada (national)	Caregivers of people with pancreatic cancer	Online Facilitated by professionals	Emotional

Survivor and Caregiver Support Group, Brain Injury Association Sudbury & District	Ontario	Survivors of brain injury, their caregivers, family and friends	In-person Facilitator unspecified	Emotional; Informational/educational
Telephone Support Groups, Pulmonary Hypertension Association of Canada	Canada (national)	Parents of children with Pulmonary Hypertension	Telephone Peer-led	Emotional; Informational
The Kitchen is Open Caregiver Coffee Group	Alberta	All caregivers	In-person Peer-led	Emotional; Activity-based (coffee meetings)
The Powerhouse Project, Young Caregivers Association	Ontario	Young caregivers	In person Facilitator unspecified	Emotional; Informational (education, skill development)
Various Peer Supports, Alzheimer Society	Quebec	Caregivers of people with Dementia	In person	Emotional; Informational; Activity-based (meditation)
Various Support Groups, Ami Quebec	Quebec	Caregivers of people with mental illness	In person Facilitator unspecified	Emotional
Various Support Groups, Wellspring	Alberta, Ontario, Nova Scotia, Prince Edward Island	Caregivers of people with cancer	In person Peer-led	Emotional
Various Supports, Yee Hong Centre for Geriatric Care	Ontario	Caregivers of older Chinese Canadians	Unclear	Emotional; Informational/educational
Virtual Caregiver Support Group, Brain Tumour Foundation of Canada	Canada (national)	Caregivers of people with brain tumours	Online Peer-led	Emotional
West Carleton Caregiver Support Group, Western Ottawa Community Resource Centre	Ontario	All caregivers	In person Facilitator unspecified	Emotional
Yellowknife Care Partner Support Group, Alzheimer Society of Alberta and Northwest Territories	Yellowknife	Caregivers of people with Alzheimer's	Unclear	Emotional; Informational (coping)

Table D3. Training

Program name/Host	Jurisdiction	Target caregiving population	Delivery/Facilitation details	Description
COMPASS for the Caregiver: Facilitator Training, Caregivers Alberta	Alberta	All caregivers	In-person Professional-led	Program facilitator training course
Facilitator training: Caregiver Support Groups, Family Caregivers of British Columbia	British Columbia	All caregivers	In person Professional-led	Peer support group facilitator training
Caregiver Support Group Facilitator, Alzheimer Society of British Columbia	British Columbia	Caregivers of Alzheimer patients	In person Professional-led	Peer support group facilitator training

Table D4. Social media and discussion forums

Program name/Host	Jurisdiction	Target caregiving population	Delivery/Facilitation details	Type(s) of support
Huddol, Canadian Caregiver Network	Canada (national)	All caregivers	Online social network application	Emotional; Informational
CancerConnection.ca, Canadian Cancer Society	Canada (national)	Caregivers of people with cancer, cancer patients and survivors	Online community, Moderated	Emotional; Informational
LLS Community[6], Leukemia and Lymphoma Society of Canada	Canada (national)	Caregivers of people with blood-related cancer	Online community, Moderated	Emotional; Informational
Canadian Virtual Hospice	Canada (national)	All caregivers	Online discussion forum, Moderated	Emotional; Informational
Caregivers Forum, Age Village	Canada (national), French	Caregivers of people with Alzheimer's	Online discussion forum, Moderated	Emotional; Informational
Atlantic Canada's PH Warriors, Pulmonary Hypertension Association of Canada	Newfoundland and Labrador	Caregivers of people with pulmonary hypertension	Facebook group, Moderated	Emotional; Informational
Private Facebook Support Groups, Brain Tumour Foundation of Canada	Canada (national)	Brain tumor patients, survivors, parents, and caregivers	Facebook group, Moderated	Emotional; Informational

Table D5. Other supports

Program name/Host	Jurisdiction	Target caregiving population	Delivery/Facilitation details	Type(s) of support
Caregiver Out of Isolation Program, Senior Resource Centre	Newfoundland and Labrador	Caregivers of seniors	Online	Informational (resource platform)
Caregiver Support Groups, The Oasis in Kanata	Ontario	Caregivers of people with mental illness	Online	Informational (list of caregiver support groups available near Ottawa)
Caregiver Support Portals, Hospice Palliative Care Ontario	Ontario	All caregivers	Online, Co-created with caregivers	Informational
Caregiver Supports, Ontario Peer Development Initiative	Ontario	Caregivers of people with mental illness	Online	Informational (list of caregiver support groups available in Ontario)
Caregivers' Circle, Community Wellness Centre (Jeffery Hale Community Partners)	Greater Quebec Area	English-speaking caregivers	Online	Informational (e-newsletter, caregiving handbook, resource guides)
Elizz, Saint Elizabeth Health Care	Canada (national)	All caregivers	Online	Emotional; Informational (blog and resource platform)
Various Caregiver Supports, L'Appui pour les Proches Aidants D'aines	Quebec	All caregivers	Online	Informational (resource directory of caregiver supports

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[6] Formerly the LLS Blood Cancer Discussion Board for caregivers.

Table D6. Breakdown of peer supports identified in grey sources by care recipient health condition

Care recipient health condition	Count
Unspecified or non-specific health condition	37
Mental health (including eating disorders, mood disorders, dissociative identity disorder, OCD, schizophrenia, and individuals in the forensic mental health system)	36
Cancer	21
Older adults/seniors	18
Alzheimer's, dementia and cognitive impairment	19
Developmental disabilities and children with special needs (including Asperger syndrome, and FASD)	8
Autoimmune disorders (including Multiple Sclerosis, scleroderma and lupus)	4
Brain injuries (including acquired or traumatic) and aphasia	4
Stroke survivors	4
Brain tumour	3
Chronic, long-term or life-limiting illness, or disability (any condition, unspecified)	3
Ostomy surgery	3
Pulmonary hypertension	3
Vision loss or impairment	3
Parkinson's	2
ALS	1
Arthritis	1
Crohn's and colitis	1
Chronic kidney disease	1
Liver disease	1
Polio	1
Pulmonary fibrosis	1
Rare diseases	1

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