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Co-Designing Caregiver Support Groups: Rapid Review with a Non-Profit Organization

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ABSTRACT

This rapid review aims to synthesize literature on co-designing support groups for caregivers of older adults, focusing on how caregivers are involved in the co-design process. This synthesis is undertaken in collaboration with the Saskatoon Council on Aging to inform the development of caregiver support groups. Guided by the Cochrane Rapid Reviews Methods Group, this review follows a streamlined evidence synthesis approach. Our search strategy was run on June 5, 2023, on the MEDLINE, EMBASE, CINAHL, Cochrane CENTRAL, and PsycINFO databases. Three studies met the inclusion criteria, highlighting the importance of comprehensive initiatives and peer support. Key findings include the necessity of tailoring support groups to caregivers' specific needs and preferences, the combination of online and offline support, and the importance of cultural sensitivity in service design. Methodological approaches to co-design varied across studies, with each emphasizing the importance of iterative feedback loops and engagement with diverse caregiver groups. The review underscores the value of co-designed support groups in effectively meeting caregivers' needs. Engaging caregivers in the design process ensures that support groups are tailored to their requirements and empowers them to shape their support systems. The insights from this review can guide future co-design efforts, enhancing caregiver support initiatives.

Introduction

Population aging is a global phenomenon that has led to an increasing need for informal caregivers to support older adults (World Health Organization, 2020). As the number of older adults continues to grow, it becomes more crucial to address the support needs of caregivers who play a vital role in providing assistance to the population that is growing in age. Previous literature has highlighted the challenges faced by caregivers and the importance of providing them with adequate support (Hall et al., 2022; Lindeza et al., 2024;

Phillips et al., 2023; Raj et al., 2022). Moreover, caregivers have expressed a keen interest in engaging in research and development efforts to improve their caregiving experiences (Bowness et al., 2024; Hall & Holtslander, 2022; Hall et al., 2024; Kolade et al., 2024). Caregiving has been conceptually defined (Hermanns & Mastel-Smith, 2012) as:

> "the process of helping another person who is unable to do for themselves in a 'holistic' (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotional skills, knowledge, time, and an emotional connection with the care recipient." (p. 15)

This definition suggests that caregiving is an act that requires skill, social engagement capacity, and a worldview focused on seeking community or building networks. As a measure of seeking and building, support groups for caregivers provide a valuable platform for sharing experiences, acquiring knowledge, and accessing emotional support (Lauritzen et al., 2022). Support groups typically encompass various activities and initiatives that address the diverse needs of caregivers (Gardiner et al., 2018; Smolej et al., 2023). Some examples of activities include group discussions, educational workshops, skill-building exercises, self-care strategy learning, and information sharing on available resources (Gardiner et al., 2018; Hall et al., 2022; Hughes et al., 2023; Stawnychy et al., 2021). Support groups for caregivers can strengthen the caregiver's motivation to continue providing care and compensate for their decreased involvement in social networks due to caregiving responsibilities (Moss et al., 2019). Furthermore, support groups provide opportunities for caregivers to express their negative feelings and receive validation from other caregivers who experience similar situations. The sessions can be facilitated in person but are increasingly being delivered in online formats (Ploeg et al., 2017, 2018). Since social support is ascertained to be preventative for caregiver burden and stress (Coe & Neufeld, 1999; De Maria et al., 2020; Swinkels et al., 2019), support groups are a critical initiatives (also known as *interventions*) to ensuring the wellness of caregivers.

To maximize the effectiveness, relevance, and uptake of support groups, it is essential to involve caregivers in their co-design (Sheridan et al., 2017). Co-design is a collaborative approach and creative process where stakeholders, such as caregivers, work together with research teams to improve services or develop support initiatives (Robert et al., 2022; Vargas et al., 2022). Co-design focuses on partnership and collaboration from the initial design phase and emphasizes equal and equitable relationships between end-users and researchers, fostering mutual learning, trust, and reciprocity (Carroll et al., 2021; Sakaguchi-Tang et al., 2021). Similarly, co-production involves and emphasizes active contribution of end-users in the development of an initiative, rather than passive recipients of the initiative once it has been produced (Bandola-Gill et al., 2023; Egilstrød et al., 2023; Robert et al., 2022) and is

often used synonymously with co-design (Masterson et al., 2022). These participatory approaches have been increasingly used to engage older adults in the design and development of support initiatives and technologies (Sakaguchi-Tang et al., 2021). Co-design methods have shown promise in creating more effective and user-friendly solutions by leveraging the unique perspectives and experiences of older adults (Bielinska et al., 2022; Cole et al., 2022; Janols et al., 2022; Valaitis et al., 2019). By involving older adults and caregivers throughout the design and implementation process, researchers can create initiatives that are not only user-centred, but also more likely to be adopted and maintained in real-world settings (Sakaguchi-Tang et al., 2021).

The principles of co-design recognize that people are creative and that they are experts in their own lives (Blomkamp, 2018). As such, policies, services, and initiatives should be designed by people with relevant lived experience (Blomkamp, 2018). By actively engaging caregivers in the design process, their unique perspectives and insights can be incorporated, which is critical to ensuring that the support groups align with their specific needs, preferences, and priorities (Hall et al., 2022). Co-designing support groups with caregivers also promotes a sense of ownership (Ibitoye et al., 2023), empowering the caregivers to take an active role in shaping their support systems. Ultimately, co-design enhances the value and impact of support initiatives (Ibitoye et al., 2023; Sheridan et al., 2017). However, it is important to note that the "success" and effectiveness of co-designed initiatives is dependent on the delivery of the initiative (Man et al., 2019). As such, co-design processes may enhance the value of initiatives, but only if it is undertaken meaningfully. This not only involves engaging with co-design participants and gathering feedback, but also measuring outcomes (Man et al., 2019). Co-design researchers must ask themselves "how have participants of the co-design project and the resulting initiative been influenced in the short- and long-term?"

In response to the identified needs and preferences of caregivers, this rapid review synthesized existing literature related to the co-design of support groups specifically designed for caregivers of older adults. This review was undertaken in collaboration with a non-profit organization, the Saskatoon Council on Aging (SCOA), which is an organization committed to enhancing the well-being and meeting the unique needs of caregivers of older adults. By conducting this rapid review, we sought to inform the organization's efforts to engage caregivers as active participants in co-designing support groups tailored to their requirements.

Non-profit organization (stakeholder) partner

Rapid reviews are driven by the need for timely evidence for decision-making purposes (Garritty et al., 2021). Stakeholders define the need for a rapid review and are engaged with in the review process to set and refine the research

question, eligibility criteria, and outcomes of interest (Garritty et al., 2021). The purpose of this rapid review was driven by a non-profit organization in Saskatchewan, Canada, called the Saskatoon Council on Aging (SCOA). SCOA is a community-driven non-profit organization that focuses on healthy aging for adults 55 years and older (Saskatoon Council on Aging, 2024).

In 2020, SCOA began growing their sub-initiative, the Saskatoon Caregiver Information and Support Centre (SCISC). Focus groups were conducted with caregivers of older adults in Saskatoon, Saskatchewan and key priorities were defined for caregiver needs (Hall & Holtslander, 2022). Findings were implemented into a grant application to the Petro-Canada CareMakers Foundation, from which SCOA received an initial $110,000 grant to grow the SCISC. Although the SCISC had initially been formed in 2000, SCOA began prioritizing the development of the centre by hiring a registered social worker to act as a caregiver coordinator (LM) and a caregiver coordinator assistant to facilitate activities (JW). SCOA has since been able to use funding to hire a second registered social worker as a caregiver coordinator (MH) to work with caregivers in the Saskatoon community and surrounding areas. To date, SCOA has received over $360,000 in funding for the SCISC from the Petro-Canada CareMakers Foundation. Further support for SCOA's caregiver centre initiative has been garnered from the Saskatchewan Blue Cross to print and distribute SCOA's Caregiver Orientation Guide (Saskatoon Council on Aging, 2022) – a resource that was determined as a need from a previous scoping review of caregiver-identified priorities for support (Hall et al., 2022).

In June 2023, doctoral student researchers SH and EL were contacted by SCOA to assist in determining how to co-design support groups for caregivers in the community, as a new SCISC initiative. To incorporate plans for co-designing support groups into their 2024 application to the Petro-Canada CareMaker's Foundation, we conducted this rapid review to collate the evidence on co-designed support groups for caregivers of older adults. Our findings have since been implemented into the 2024 application, which is pending result as of September 2024. In this manuscript, we aim to share our findings and provide valuable insights into the involvement of caregivers in co-designing support groups, as well as the key features and components of these co-designed support initiatives.

Theoretical framework

This rapid review is framed theoretically by Conservation of Social Resources Theory (Hobfoll et al., 1990). This theory suggests that social support is a central building block of health and well-being (Hobfoll et al., 1990) and an individual who has sufficient resources, such as access to support groups with relevant content, is better at meeting challenges and mitigating stress (Hobfoll & Lilly, 1993). Support groups

allow for the exchange of resources among caregivers, such as advice, emotional support, and practical tips (Hobfoll, 2001). Furthermore, conserving social resources via support groups helps individuals to build resilience and coping strategies (Hobfoll, 2002). Co-designing support groups with active involvement from caregivers ensures that the initiatives are tailored to their specific needs and preferences, making the support more relevant and effective (Hobfoll et al., 1998). Previous research has highlighted the importance of personalized support in enhancing caregiver satisfaction and engagement with support group activities (Coon et al., 2003).

Methods

This rapid review follows the guidance and methodology provided by the Cochrane Rapid Reviews Methods Group (Garritty et al., 2021). Rapid reviews streamline evidence synthesis, which includes identifying, organizing, and synthesizing findings in a compressed timeline (Garritty et al., 2021; Tricco et al., 2017). We chose this approach because the non-profit organization we partnered with for this project (SCOA) needed to expedite forming a support group development plan to include in their grant application to the Petro-Canada CareMakers Foundation. To ensure rigor, this rapid review also adheres to the PRISMA-S reporting guidelines (Rethlefsen et al., 2021).

Setting the research question – topic refinement

Stakeholders from the non-profit organization (LM and JW) and the primary author (SH) met on June 1, 2023, via Zoom video conferencing to discuss the needs and goals of the organization and set priorities for the rapid review. In collaboration with the non-profit organization, we developed our research question for this rapid review, which is: "What methodologies are used to engage with caregivers of older adults in co-designing support groups?" We hypothesized that some studies that develop support group initiatives may be of qualitative and mixed method design. Therefore, we structured this review using the SPIDER approach, which is used to craft research questions when the goal of a review is to synthesize qualitative and mixed methods evidence (Cooke et al., 2012). The SPIDER variables are: (1) *sample*, where in this review, the sample is caregivers of older adults; (2) *phenomenon of interest*, which are support groups (either in-person or internet-mediated); (3) *design*, in which studies that employ a co-design approach to support group development were searched for; (4) *evaluation*, where critique in some form is reported from caregivers, which may include whether their needs were met; and (5) *research type*, which was inclusive of qualitative and mixed methods

studies. To answer our research questions, we selected and synthesized litera-
ture using the following inclusion criteria:

- Published original research of any design, including other reviews, con-
ference abstracts and dissertations.
- Sample of participants is caregivers of older adults. The World Health
Organization (2020) considers older adults to be age 60 + . For the
purpose of this review, we included studies that reported care recipients'
mean age to be >55 years. Studies that narratively reported that the
caregivers were caring for older adults were also included.
- Caregivers of older adults are engaged in the development and co-design
of the support group initiative, including its structure, activities, and
delivery.

Exclusion criteria for this rapid review were:

- Study protocols and incomplete work.
- Sample of participants is NOT caregivers of older adults.
- Caregivers were not engaged in the development and co-design of the
support group initiative.

Setting eligibility criteria

We limited the publication language to English only, as is recommended by
Garritty et al. (2021) to enhance the streamlined process of a rapid review. It is
also recommended in the rapid review guidelines by Garritty et al. (2021) to
place emphasis on higher quality study designs, such as systematic reviews and
randomized controlled trials. With that being said, due to the nature of the
research questions for this rapid review, we expected to find more studies that
employed qualitative, mixed methods, or quasi-experimental design.
Therefore, we did not limit our inclusion criteria to any specific study design.

Searching

The search strategy for this rapid review was crafted by the lead author SH,
who is experienced in conducting literature reviews and knowledge synth-
eses (Haase et al., 2021; Hall et al., 2022). Our MEDLINE search strategy is
presented in Table 1. All three search strategies are provided in
Supplementary File 1. Five electronic databases were searched on June 5,
2023. MEDLINE (OVID interface), EMBASE (OVID interface), and
Cochrane CENTRAL (Clarivate interface) were searched due to the neces-
sity of including these databases per the Cochrane rapid review method
guidelines (Garritty et al., 2021). Searching of specialized databases is

Table 1. MEDLINE (OVID Interface) search strategy. Conducted June 5, 2023.

	Searches	Results
1	Exp Aged/	3448418
2	(older* or elder* or senior* or geriatric or aged).ti,ab.	1220190
3	1 or 2	4069911
4	Exp Caregivers/	49605
5	(caregiver* or care giver* or carer* or caregiving or care partner* or care-partner*).ti,ab.	95487
6	4 or 5	104585
7	Exp Support Groups/	10712
8	(support group* or support network* or social intervention* or peer to peer or peer support or forum* or p2p or discussion group*).ti,ab.	34122
9	7 or 8	42077
10	3 and 6 and 9	1072

recommended for certain topics (Garritty et al., 2021). Due to the nature of the research questions and the field of research this rapid review intended to explore, we chose to also search CINAHL (EbscoHOST interface) and PsycINFO (OVID interface). Regarding date limits, none were placed on four of the five databases searched. However, Cochrane CENTRAL indexes records from several unpublished and incomplete sources. Furthermore, controlled trials were not the expected study design for inclusion within this review. As such, for our Cochrane CENTRAL search strategy, we imposed a date restriction to limit records to the last two years.

Supplemental searching of grey literature is suggested to be limited in rapid reviews. At the recommendation of a health sciences librarian (KR), we omitted the search of grey literature due to time constraints. Although also not required for rapid reviews, we did choose to search the reference lists of the studies included from an initial round of screening due to the availability of time and resources. We used CitationChaser software (Haddaway et al., 2021) on June 7, 2023 to search the references listed in the records included after the initial round of full text screening, as well as articles that cited those included records.

Study selection

Records were exported from databases and uploaded to Covidence systematic review software for screening of titles and abstracts, and subsequently full texts, carried out by SH and EL. We used the Covidence function for de-duplication of records. Our screening procedure is demonstrated in a Covidence-generated PRISMA flow diagram (Figure 1).

Data extraction

A single reviewer (SH) extracted data from the included records using a piloted form, developed by SH and EL. Records included in this review had the following data extracted in Microsoft Excel: author, year, place of study, study
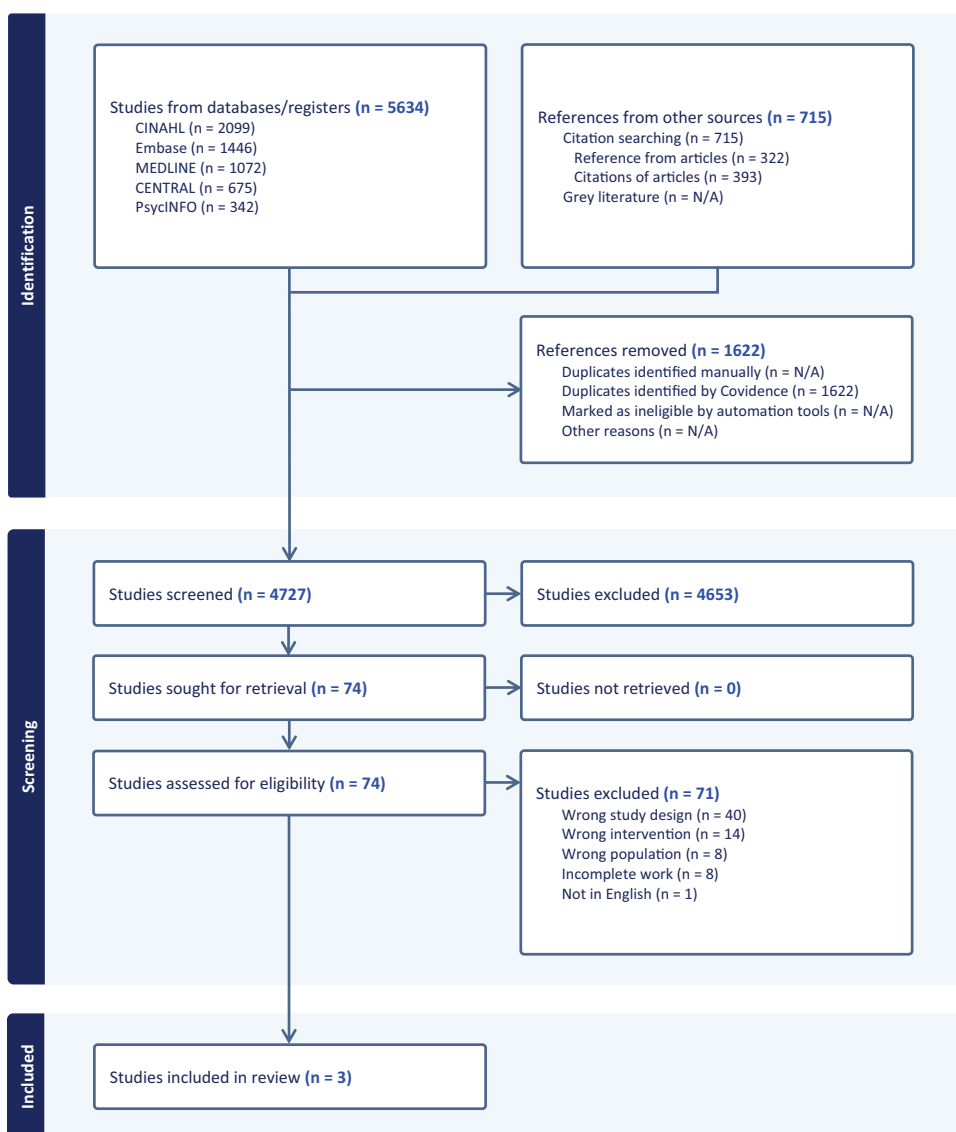
Figure 1 PRISMA 2020 flow diagram generated in Covidence.

design, sample size, care recipient medical condition, relationship of caregiver to care recipient, method of researcher interaction, mode of support group delivery, purpose/aim of study, study themes/categories, support group activities, relevant outcomes, and implications and/or recommendations.

Risk of bias assessment

Garritty et al. (2021) recommend assessing for risk of bias using a validated tool for the included study designs. For this rapid review, we used the Mixed

Methods Appraisal Tool (MMAT, version 2018), which is a critical appraisal tool that is designed for the appraisal stage of mixed studies reviews (Hong et al., 2018). The MMAT allows for the appraisal of methodological quality of qualitative, quantitative (RCTs, non-randomized, quantitative descriptive studies), and mixed methods studies (Hong et al., 2018), making it an ideal tool for the risk of bias assessment in this rapid review. SH and EL conducted the risk of bias assessment independently and limited ratings to the relevant outcomes, with a focus on outcomes most important to the planning of a co-design activity.

Synthesis

Our extraction tables and the included articles were imported into NVivo 12.7.0 qualitative data analysis software (QSR International Pty Ltd., 2019) to inductively create codes based on the included study findings using the method of descriptive analysis (Loeb et al., 2017). SH conducted the descriptive analysis independently and the synthesis was reviewed against the included articles by EL. Lastly, insights from the co-author stakeholders LM, JW, and MH were sought and a narrative of the insights was prepared for our discussion.

Results

Study selection

Figure 1 presents our PRISMA flow diagram. After screening 4727 titles and abstracts and 74 full texts, a total of three studies met inclusion criteria for this rapid review. Exclusion often occurred due to the wrong intervention type, typically an internet-based support initiative that lacked clarity on whether it involved interactive or two-way communication necessary for support groups. If the internet support initiative demonstrated a clear communication pathway among participants, such as through a discussion forum, it was considered for inclusion. Studies were most often excluded for incorrect study design, such as when the support group initiative had already been developed by the research team, lacking caregiver input. Specifically, older literature seemed to use a more authoritative approach to designing support groups, where the structure of the support group was pre-designed, and participants were invited to evaluate the group but not be part of its conception.

Risk of bias assessment

The Mixed Methods Appraisal Tool (MMAT) was applied to assess the methodological quality of three included studies, which were all qualitative in methodology. The application of the MMAT revealed that all three studies lacked clear research questions but presented findings that addressed their respective research aims. Each study utilized appropriate qualitative

approaches and data collection methods, ensuring the derivation and interpretation of findings were well substantiated by data.

Study characteristics

Table 2 presents the included studies' characteristics. Included studies were all published between 2019 and 2021. Two studies employed qualitative methodologies, while the third used a mixed methods approach. Participant samples were consistently > 50% female. Numbers of participants ranged from $N = 6$ to $N = 26$. When reported, the majority of caregivers were spousal caregivers, followed by adult children being the second most common relationship between caregiver and care recipient. Studies used either co-design workshops, individual semi-structured interviews, or a combination of both. Interestingly, none of the included articles used reporting guidelines, such as the Standards for Reporting Qualitative Research (SRQR; O'Brien et al., 2014) or, more specifically, the Guidance for Reporting Involvement of Patients and Public (GRIPP2), which is used to enhance the consistency of patient and public involvement, including co-design approaches(Staniszewska et al., 2017).

Descriptive analysis

Summary of findings from included studies

Table 3 presents a summary of the included studies' findings. Authors of the three studies developed and described themes, which highlighted the multifaceted challenges faced by caregivers, underscoring the importance of comprehensive support initiatives and peer support. Collectively, these studies advocate for the comprehensiveness of support initiatives, the combination of online and offline support, and the necessity of tailoring programs to local specificities, providing a foundation for inclusive, adaptive, and culturally sensitive caregiver support initiatives.

Banbury et al. (2021) aimed to create a peer support program for informal dementia carers in Australia. Through a co-design process that included gathering the lived experiences of carers, they identified major challenges such as difficulties in getting assessments, worries about the future, managing consultations, dealing with family dynamics, and social isolation. The result was a telehealth program with eight key discussion topics, ranging from health literacy to support networks. Participants reported high levels of connectedness and knowledge transfer, demonstrating the effectiveness of the co-designed approach in building a supportive and practical program that carers could readily adopt.

Davies et al. (2019) focused on developing a prototype website to support family caregivers of persons with dementia nearing the end of life. It was found

Table 2. Study Characteristics.

Author (Citation #)	Year	Place of Study	Study Design	Sample Size	% Female	Average Age of Caregiver	Care Recipient Medical Condition	Relationship of Caregiver to Care Recipient	Method of Researcher Interaction	Mode of Support Group Delivery
Banbury et al. (2021)	2021	Australia	Qualitative	6	50	66.7	Dementia	Spouse = 50% Adult child = 16% Sibling = 16% NR = 16%	Co-design meetings and subsequent semi-structured interview	Telehealth peer support
Davies et al. (2019)	2019	United Kingdom	Qualitative	11	73	74	Dementia	Spouse = 55% Adult child = 45%	Individual interviews	Online support initiative
Graffigna et al. (2021)	2021	Italy	Mixed methods	26	72	Ranges reported	Non-Specific	Not Reported	Quantitative survey in phase 1, co-design workshops in phase 2	Online support initiative and WhatsApp group chat for caregivers

Table 3. Study Findings.

Author (Citation #)	Year	Aim of Study	Study Themes or Categories	Support Group Activities	Relevant Outcomes	Implications/Recommendations/ Conclusions
Banbury et al. (2021)	2021	Develop an Australian peer support program with informal dementia carers (hereafter referred to as carers) by examining lived experiences using a co-design process.	(1) Difficulty getting an assessment/ diagnosis exacerbated by GP's unconvinced a problem exists and long wait lists. (2) Worry about the future/plans (3) Providing information during a consultation when the person being cared for is present (4) Dealing with difficult family members (5) Social isolation/ loneliness (carer and the person with dementia)	The process identified eight key topics to be included in a program to be delivered by telehealth. Weekly Discussion Topics: 1) Getting to know you 2) Navigating the health and social care systems 3) Caring for the carer 4) Being an advocate 5) Health literacy 6) Care managing 7) Support networks 8) Changes in relationships	All participants reported high levels of group connectedness, feeling supported and transfer of knowledge and skills. The co-design development of the program through tight loops of co-creative development and co-evaluation ensured that not only the content but also the group setting, and technology is developed and trialed as planned for implementation of the program. As such the co-designed support initiative is something that carers can use and adopt and is truly innovative.	The inclusion of carers from different locations strengthens the program's appropriateness across the country. This study demonstrated that safe and cohesive relationships can be developed using telehealth and through the co-design process long-lasting peer support virtual networks can be built.

Table 3. (Continued).

Author (Citation #)	Year	Aim of Study	Study Themes or Categories	Support Group Activities	Relevant Outcomes	Implications/Recommendations/ Conclusions
Davies et al. (2019)	2019	Report the development and presents the core targets and components of a prototype website to support family caregivers of a person with dementia toward the end of life.	(1) Feeling prepared and equipped (2) feeling connected and supported (3) valuing themselves as a caregiver and an individual (4) maintaining control of the caring situation and being the coordinator of care	Online support initative provides an opportunity to identify other caregivers for support and discussion, either privately or within a group Support was able to be provided online though peer interaction and contact with professionals. Opportunities to engage with other caregivers in the same situation as them and in a group situation, appeared more beneficial. Interaction with professionals was a positive experience for caregivers, however views were mixed on receiving this online.	This paper provides a clear and transparent process for developing an internet-based support initiative, providing an example for others developing digital or internet-based support initiative. A key finding is that online support alone is not enough, there needs to be either face to face contact or telephone contact.	1) Allowing time for iterations is vital in the development of all complex support initiatives; however, the development of online support initiatives, such as websites requires much more time and emphasis needs to be placed on the earlier phases of development. 2) A pragmatic approach to co-production may be needed for caregiver populations. Individual meetings are valuable. Researchers should not assume that co-production panels and group meetings are required for robust methods. Individual meetings reduce the burden on caregivers and allows for fast paced support initiative development, minimizing delays to the overall research project. 3) Synthesis of a variety of data sources is often not well reported in support initiative development. The use of tabulation, adopting a matrix approach to display findings allows clear comparison of evidence.

(Continued)

Table 3. (Continued).

Author (Citation #)	Year	Aim of Study	Study Themes or Categories	Support Group Activities	Relevant Outcomes	Implications/Recommendations/ Conclusions
Graffigna et al. (2021)	2021	Co-produce new services with local service providers and family caregivers to ensure aging-in-place processes and to strengthen families' inclusion and engagement.	(1) Need for information (2) Best practices for sharing needs (3) Emotional needs	Dedicated website to inform caregivers and relatives Information brochures Information delivery about available servicesOnline group for sharing concerns Training coursesProfessional psychological support within support group	1) Direct achievements: factors that impacted directly on family caregivers or service providers (e.g., increased levels of trust between caregivers and service providers) 2) Indirect achievements: actual or potential indirect impacts on one or more actors in the service ecosystem (e.g. increased motivation of service providers following direct collaboration in co-producing a new service)	The process itself can be considered a good practice for innovating the healthcare and welfare support dedicated to aging in place initiatives. Moving for the deep analysis of the population characteristics, of their caregiving burden, service usage levels and expectations of support was then possible to directly engage family caregivers in the co-design of a new social service able to truly answer their needs and expectations, in a full sensitiveness to the cultural and anthropological specificities of their local community.

that caregivers needed to feel prepared, supported, valued, and in control of the caregiving situation. The online support initiative provided opportunities for caregivers to connect with others in similar situations and interact with professionals. However, the study noted that while online support was beneficial, it should be supplemented with face-to-face or telephone contact. This research emphasized the importance of a thorough, iterative development process for online support tools and suggested that individual meetings could be more effective than group sessions for certain caregiver populations.

Graffigna et al. (2021) co-designed new services with local providers and family caregivers to enhance aging-in-place processes. They identified the need for information, best practices for sharing needs, and emotional support. The study found both direct benefits, like increased trust between caregivers and service providers, and indirect benefits, such as heightened motivation among service providers. This approach was tailored to the cultural and anthropological specifics of rural communities.

Methodological approaches to co-design
The included studies took unique approaches to co-designing their support groups. Banbury et al. (2021) used the Double Diamond model (UK Design Council, 2015) for co-design, Davies et al. (2019) followed an iterative approach for support initiative development and testing, and Graffigna et al. (2021) conducted a comprehensive community-based research project with quantitative and qualitative components. The Double Diamond model employed by Banbury et al. (2021) guided their co-design process in four phases: discover, define, develop, and deliver. The "discover" phase involved exploring problems, gathering insights, and generating ideas. In the "define" phase, problems were refined to provide a framework. The "develop" phase focused on creating and exploring solutions, while the "deliver" phase involved testing and evaluating the service, improving parts that worked and rejecting those that did not. The Double Diamond model approach used by Banbury et al. (2021) facilitated a structured co-design process starting from broad exploration of problems and user needs, narrowing down to define specific issues, creating a wide range of solutions, and finally converging to refine and test the service.

Davies et al. (2019) grounded their approach in combining interviews, literature review, and theory, refined through a nominal group process, and culminated in testing the prototype with a diverse sample of family caregivers. They used an iterative approach and "co-production" (often considered synonymous with co-design) methods in four stages for their development process. In stage 1, they synthesized data from interviews, systematic reviews, and theory to identify the prototype's targets, which occurred prior to engaging with stakeholders in the co-design process. Stage 2 involved identifying initiative targets and components through a research development group, in

which participants were involved in workshopping the development of the initiative. In stage 3, they developed the initiative prototype based on the earlier stages and follow-up meetings were conducted with members of the research development group to ensure caregiver perspectives were represented accurately and effectively. Finally, in stage 4, user testing was conducted with family caregivers of people with dementia, with a focus on recruiting diverse participants.

Lastly, Graffigna et al. (2021) conducted a community-based participatory research project involving four main phases. In phase 1, they performed a quantitative analysis of caregiver needs, services usage, and costs. This phase included a quantitative survey and database secondary analysis. Phase 2 involved co-design workshops with caregivers and local stakeholders to generate ideas and insights for a new caregiver service. Workshop transcripts were qualitatively analyzed to synthesize participants' contributions and create a prototype. Phase 3 comprised piloting and preliminary assessment of the service's feasibility, initially in face-to-face and later in an online format due to the COVID-19 pandemic. Phase 4 assessed the transferability of the project to other regions, involving structured interviews and a SWOT analysis with social and welfare service providers.

Across the three studies, several commonalities were observed in the methodological frameworks. Each study emphasized the importance of engaging with the target population from the outset and employing iterative feedback loops. The studies consistently applied a blend of quantitative and qualitative methods to gather data, refine support initiatives, and evaluate outcomes. Banbury et al. (2021) and Davies et al. (2019) shared similar sequential models guiding their development process. However, while Banbury et al. (2021) model emphasized the shift between divergent and convergent thinking, Davies et al. (2019) focused on the nominal group process to refine their support initiative. Graffigna et al. (2021) extended beyond development to consider the transferability of their support initiative, a step not explicitly mentioned in the other two studies. This aspect highlights the importance of adapting initiatives to different contexts and evaluating their broader applicability.

A critical aspect in the methodologies was the engagement of diverse user groups. Davies et al. (2019) demonstrated this by recruiting a purposively sampled group of caregivers with varied internet usage and backgrounds. Graffigna et al. (2021) targeted family caregivers using both home care services and local nursing homes, aiming to understand a spectrum of caregiving experiences and needs. This diversity was key to ensuring that the developed services would be applicable and responsive to a wide range of caregiver situations. The studies encountered and addressed several challenges. For instance, Davies et al. (2019) found difficulty in recruiting low-internet-usage caregivers, highlighting the potential digital divide in accessing caregiver

support. Graffigna et al. (2021) faced the challenge of the COVID-19 pandemic, which required them to shift their services online. These challenges necessitated flexibility and adaptation in their methodologies. In summary, these three studies employed different methodologies to address specific research questions, and each study provided valuable insights and outcomes related to their respective research goals.

Benefits and challenges

Benefits of approaches. Authors of the three included studies reflected on the benefits of their approaches. Co-design methods used by Banbury et al. (2021) facilitated the inclusion of a diverse range of stakeholders, ensuring that the resulting solutions were user-centred and innovative. This process promoted social capital and empowered co-design participants (Banbury et al., 2021). In the study by Davies et al. (2019), the iterative nature of co-design involving regular feedback and refinement, helped to create their prototype initiative that was grounded in the real-life experiences and needs of the end-users. Leveraging technology for accessibility in the co-design process enabled participation from geographically dispersed caregivers, which would not have been possible to accomplish with in-person meetings alone. This was particularly beneficial in ensuring broader inclusivity and overcoming the challenges posed by caregivers' limited time and mobility (Banbury et al., 2021). This diversity was recognized in the study by Graffigna et al. (2021), where participants noted the diversity of their experiences as a strength, providing a rich base for collective problem-solving and empathy.

Challenges of approaches. Technological barriers created a challenge in the studies by Banbury et al. (2021) and Graffigna et al. (2021), which included environmental issues that caused connectivity problems. Other minor issues in connectivity required patience and troubleshooting, which could have been planned for in advance (Banbury et al., 2021). Furthermore, varying levels of technological literacy in participants created the challenge of ensuring consistent participation from caregivers, especially those less familiar with digital tools (Graffigna et al., 2021). There was also a challenge of process understanding, where some participants expressed the desire for more information about co-design itself, suggesting that providing comprehensive initial training and ongoing support could enhance engagement and effectiveness (Banbury et al., 2021; Davies et al., 2019; Graffigna et al., 2021).

Discussion

The successful co-design of support groups for caregivers of older adults is hinged on several critical factors. Firstly, engaging a diverse group of users from the outset ensures that the developed services cater to a wide range of

caregiver situations and needs. This approach not only enhances the relevance and effectiveness of the support groups but also promotes a sense of ownership and empowerment among caregivers. Included studies in this rapid review emphasized the importance of iterative feedback loops in the design process, enabling continuous refinement of the support group initiatives. This iterative approach highlights the dynamic nature of co-design, where caregivers' ongoing input shapes the evolution of the support group. Another key feature is adaptability, crucial for addressing unforeseen challenges such as technological barriers or external factors like the COVID-19 pandemic. The need for flexibility was evident in the challenges faced by the studies in recruiting low-internet-usage caregivers or shifting services online during the pandemic. Therefore, co-design processes must be equipped to adapt to varying circumstances and caregiver demographics.

The collaborative approach used in co-design thrives in fields beyond that of just caregiving. Co-design methods with older adults specifically are increasingly employed in research initiatives (Bielinska et al., 2022; Cole et al., 2022; Janols et al., 2022; Valaitis et al., 2019). In community development, co-design allows residents to actively participate in shaping their environments, ensuring that outcomes reflect the community's needs and values (Calvo & De Rosa, 2017). This inclusive process fosters ownership and sustainability of initiatives. Similarly, in education, co-design involves students and educators in curriculum development, creating learning experiences that are relevant and responsive to the learners' contexts (Ahmadi, 2023). Thus, co-design practices emphasize the importance of integrating diverse perspectives and leveraging collective expertise. Applying the principles of co-design to caregiver support groups could revolutionize their effectiveness. By engaging stakeholders in the co-design of support initiatives, tailored resources and programs can be developed that directly address the nuanced challenges caregivers face. The co-design approach also ensures that the solutions are not only practical, but empathetic and understanding of the caregivers' experiences.

While co-design offers numerous advantages, certain pitfalls need to be considered. A lack of adaptability can hinder the effectiveness of support groups. Including end users in assessing the best type of technology for support initiative delivery is also essential and often overlooked (Eyles et al., 2016). Overcoming such challenges requires a flexible approach to design and delivery. Another potential pitfall in co-design is the underrepresentation of certain groups, which, in the case of this review, can result in support groups that do not fully address the diverse needs of the end-user community. Limited stakeholder engagement has been found to be a challenge in other support initiative co-design work (Andersen & Mosleh, 2021; Eyles et al., 2016; Noorbergen et al., 2021). However, as previously mentioned, involving stakeholders with diverse interests, perspectives, and agendas is critical and actually enhances the innovation of co-designed support initiatives (Andersen & Mosleh, 2021). More research is necessary to

determine the optimal approach to co-design when engaging with a heterogenous group of stakeholders, such as care recipients and health care professionals in one setting (Slattery et al., 2020).

Stakeholder insights

The co-authors from SCOA (LM, JW, and MH) provided valuable insights regarding the rapid review on co-designing support groups with caregivers. SCOA recognized the urgent need for co-design in developing support systems, emphasizing the importance of involving caregivers in every step to ensure the support initiatives are effectively tailored to their needs. SCOA sees co-design as a way to foster a sense of ownership among caregivers and to ensure the development of effective, inclusive, and responsive support systems. SCOA's concerns about the overwhelming nature of creating support groups without a clear methodological system in place was evident. SCOA sees the potential in leveraging the findings from this rapid review to secure funding and validate their efforts in building a caregiver community. This shift aligns with one of their organizational goals of enhancing health literacy and the lives of both caregivers and care recipients. SCOA aims to increase health literacy and engage with caregivers in a way that is driven by their lived experiences. The organization envisions caregivers actively participating in creating activities. This vision is supported by the review's findings on the importance of engaging diverse caregiver groups in the co-design process.

SCOA is proud of their current engagement with caregivers, but note a drop-off in outcomes, particularly in the effectiveness of their support initiatives. This rapid review supports this observation by underscoring the importance of designing support systems that are both inclusive and responsive to caregivers' needs. The review is also seen as a valuable tool for backing SCOA's caregiver support initiatives, providing evidence-based support for their initiatives. Moreover, SCOA is keen on understanding how to leverage the review to improve their support systems. SCOA is particularly keen on the Double Diamond method (Banbury et al., 2021; UK Design Council, 2015) highlighted in the review, recognizing the need for a bottom-up rather than top-down approach in designing support systems. The emphasis is on starting at a grassroots level, involving service users and people with lived experience in the design process. This rapid review's insights into co-design methodologies are seen as pivotal in shaping SCOA's future strategies, driving them toward a more intentional, collaborative approach that fully engages caregivers in the creation of support systems.

An ongoing challenge identified by SCOA is the retention of caregivers in their community. SCOA sees the importance of establishing a system that fosters the creation of a sustainable caregiver community. SCOA stakeholders are keen on taking the next steps, using the insights from this rapid review to

inform the development of more effective support groups. This aligns with the review's findings, which advocate for the involvement of caregivers in the co-design process to develop support initiatives that are practical and empathetic to their experiences. SCOA also discussed the formation of a caregiver advisory council, which aligns with the review's emphasis on engaging diverse user groups to ensure the development of services that cater to a wide range of caregiver situations and needs. Among our team, there is a consensus to favor designs that involve end-users and those who will benefit from the support services. Lastly, SCOA expressed concern about the reliance on informal caregivers by governments and the need for systemic changes. SCOA acknowledges the challenges caregivers face, especially considering that family and friend caregivers carry a substantial burden of the healthcare system. While support groups provide some relief, broader systemic changes are necessary for lasting impact.

Implications and future research

This review revealed a surprising scarcity of literature on co-designing support groups for caregivers of older adults, with only three articles identified. This gap is particularly striking given the growing interest in caregiving research and the increasing population of older adults. There is a pressing need for more comprehensive research in this area to develop a deeper understanding of effective co-design practices and to explore new avenues for caregiver support. The findings from this review have significant implications for the development of caregiver support groups. First, the effectiveness of co-design methodologies in developing support services is evident. Engaging caregivers from the outset in a structured, iterative process can lead to more inclusive and responsive services. This approach should be considered a best practice in the development of caregiver support initiatives. Moreover, the need to balance online and offline support methods is clear. While online support initiatives offer convenience and a broad reach, they might not be sufficient on their own. A combination of both, tailored to the specific needs and circumstances of caregivers, is likely to be more effective. Another key implication is the importance of cultural sensitivity and local context in service design. Tailoring support initiatives to meet the unique needs of different caregiver communities can enhance their effectiveness and acceptance.

Future research should explore diverse co-design methodologies, perhaps integrating emerging technologies to enhance the engagement and feedback process. Investigating how different co-design frameworks perform in various cultural and social contexts would be valuable. Longitudinal studies are needed to assess the long-term effectiveness of co-designed caregiver support groups. This includes evaluating caregiver satisfaction, caregiver burden, and the impact on care recipients. Future studies should also focus on the optimal

combination of online and offline support methods. This includes under-standing how different demographic groups interact with technology and how online platforms can be made more accessible and effective. Studies need to recognize the existence of a digital divide, especially among caregivers with low internet usage. Research is needed to find effective ways to reach and support these caregivers. Lastly, future work should aim to involve a broader range of stakeholders, including healthcare professionals, policymakers, and caregivers themselves, to ensure that the co-designed services cater to a wide range of needs and perspectives.

Strengths and limitations

This review addresses a timely and critical issue, given the aging global population and the increasing reliance on caregivers. The collaboration with the non-profit organization, SCOA, implied practical implications and real-world applicability of our review's findings. However, there are limitations to rapid reviews. The limitations of our rapid review are notably linked to the intrinsic constraints of rapid review methodology and scope decisions. Due to the rapid nature of this review, grey literature was omitted, and there may have been more instances of co-designed support groups within this omitted literature. Language limitations, with the review confined to English-only publications, pose a significant barrier to inclusivity by potentially disregard-ing valuable international research and diverse perspectives on caregiver support. Lastly, this review's findings were somewhat narrow due to the relatively low number of included studies ($N = 3$). Therefore, the evidence presented could be considered inconclusive in terms of comprehensiveness of methodological approaches to co-designing support groups with caregivers.

Conclusion

The integration of the methodological approaches used in the three included studies suggests that future research and support initiatives in this area would benefit from flexible co-design processes that actively involve caregivers and consider the transferability of services to different contexts. The emphasis on iterative processes and engagement with diverse populations stands as a foundational principle for the develop-ment of effective caregiver support groups. This rapid review underscores the value of co-design in developing support groups for caregivers of older adults. The engagement of caregivers in the design process not only ensures that their specific needs are met but also empowers them to take an active role in shaping their support systems. While challenges exist, the potential benefits of co-designed support groups are substantial,

offering a pathway to more effective, inclusive, and responsive caregiver support initiatives.

Our partner stakeholder organization, the Saskatoon Council on Aging, values this rapid review as a foundational resource for developing a plan to craft effective support groups for caregivers. SCOA is committed to applying the principles of co-design and adapting these to their unique context. We envision a path forward in creating more empathetic, practical, and caregiver-centric support systems, as indicated by this rapid review's findings. SCOA's ultimate goal remains enhancing the lives of caregivers and their care recipients, while advocating for broader systemic changes to support this vulnerable population. As the demand for caregiver support continues to grow, the insights from this review will be instrumental in guiding future co-design efforts and enhancing the well-being of caregivers and their recipients alike.

Acknowledgments

Disclosure statement

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