

The role of community during critical care transitions from hospital-to-home: a rapid review of evidence involving stroke caregivers

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Abstract

Purpose – Stroke care transitions, particularly from hospital to home, place significant demands on essential care partners (ECPs) (caregivers) – commonly family or friends – who provide unpaid support without adequate training or resources. Despite their critical role, few transitional care interventions adequately support ECPs. This rapid review aims to identify and synthesize community-involved and intersectoral care transition interventions that include stroke ECPs, in alignment with the Discharge Assistance and Supports at Home (DASH) model's principles of cross-sector collaboration, volunteerism and leisure as a modality of care.

Design/methodology/approach – A rapid review was conducted following updated Cochrane guidance for effectiveness reviews and PRISMA-P reporting standards. Searches were conducted across multiple databases, and studies were screened, extracted and synthesized. Eligible studies included interventions that engaged ECPs in post-stroke care transitions and involved community-based organizations, volunteers or leisure-based approaches. Data were analysed thematically.

Findings – The findings of the rapid review identified the settings and contexts of the interventions – including when, where, with whom and how they were implemented – as well as the nature of the interventions, key human factors such as facilitators, the involvement of community-based organizations, volunteers and leisure activities, and critical insights into what worked, for whom and why.

Research limitations/implications – Three key insights emerged from this rapid review to inform better support for ECPs: first, a growing yet underdeveloped shift towards tailored, ECP-centred approaches as essential – not optional – components of stroke care; second, the reinforcing cycle between education, support and self-care; and third, the importance of embedding transitional interventions within broader intersectoral health system and community contexts. These insights from this rapid review will inform the development of a research agenda aimed at identifying and addressing the specific supports ECPs require during critical transition periods – particularly the shift from hospital to home.



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Originality/value – This rapid review offers a novel synthesis of stroke care transition interventions that meaningfully engage ECPs through community involvement, cross-sector collaboration and leisure-based approaches – an underexplored area in current literature. By aligning findings with the DASH model, the review advances understanding of how volunteerism and community assets can support ECPs during hospital-to-home transitions. The study highlights a critical shift towards ECP-centred care, emphasizing the need for systemic, tailored supports. These insights contribute original value by informing future research and practice that recognize ECPs as essential stakeholders in post-stroke recovery, not merely as informal or peripheral caregivers.

Keywords Essential care partners (caregivers), Post-discharge stroke recovery, Critical care transitions, Hospital-to-home transitions, Community support, Volunteers, Rapid review

Paper type Research article

Introduction

In Canada, a stroke occurs in a hospital or emergency department approximately every five minutes, affecting an estimated 108,707 individuals annually who require complex care (Holodinsky *et al.*, 2023). In high-income countries like Canada, advances in prevention, treatment and neurorehabilitation have reduced stroke-related mortality and disability (Katan and Luft, 2018), resulting in up to 80% of stroke survivors being discharged home (Mountain *et al.*, 2020). Higher discharge rates place significant pressure on essential care partners (ECPs), also known as caregivers – often family members or friends, most commonly middle-aged women – who provide comprehensive, unpaid support during critical care transitions such as hospital-to-home (Bates, 2024; CCCE, 2024). ECPs are placed in roles for which they are unprepared or inadequately trained, resulting in significant burdens that impact their well-being and limit their time, energy and capacity for self-care (Andrew *et al.*, 2015; Garnett *et al.*, 2022; Kokorelias *et al.*, 2020). Despite the indispensable role that ECPs play in the recovery journey, and the growing reliance on them within healthcare systems to support individuals transitioning home after discharge, few integrated support strategies – defined as coordinated systems of care, resources and guidance – are available to help ECPs manage the complex care needs that arise during critical care transitions (Camak, 2015; Chen *et al.*, 2021; Singh *et al.*, 2022).

The Discharge Assistance and Supports at Home (DASH) model, developed by Nelson *et al.* (2024a, b), illustrates how cross-sector collaboration and community-driven approaches can generate practical, action-oriented responses to the needs of stroke survivors during care transitions. Developed in partnership with a community-based, non-governmental organization, DASH leverages community resources and volunteer support to strengthen post-discharge care (Nelson *et al.*, 2024a, b). However, a notable limitation of the model in its current structure is its limited focus on ECPs, which constrains understanding of how their practical and psychosocial needs might be more effectively addressed during key transition periods. To address this gap in stroke care, the purpose of the current review is to explore transitional care interventions that include stroke ECPs, to identify how and in what capacity principles of the DASH model – particularly intersectoral partnerships involving community-based organizations, volunteers and the use of leisure as a modality of care – have been utilized. Insights from this review will enhance understanding of how stroke care pathways can more intentionally support ECPs during care transitions by highlighting promising intersectoral and community-involved strategies that address both the practical demands and overall well-being of ECPs, while informing future care models aimed at reducing caregiver burden.

Background information

Evolving role of ECPs

Following hospital discharge, ECPs become the primary providers of daily care for stroke survivors throughout the transition period and into long-term recovery (Cameron *et al.*, 2016; Lindblom, 2021; Pucciarelli *et al.*, 2018). ECPs are most tasked with managing financial concerns, medications and appointments and ongoing practical and emotional support (Bakas *et al.*, 2014, 2017; Kokorelias *et al.*, 2020; Lutz *et al.*, 2011) and experience task-shifting

burdens, where responsibilities such as childcare, household management or elder care – once shared – become solely theirs (Jammal *et al.*, 2024; Pope *et al.*, 2022). ECPs assume caregiving responsibilities without sufficient education, training or preparation (Bates, 2024; Lutz *et al.*, 2011) and with limited coordinated support and guidance across the continuum of care (Chen *et al.*, 2021; Singh *et al.*, 2022). Given the vital contributions ECPs make in supporting stroke survivors through critical care transitions like hospital-to-home, it is essential to prioritize their needs within discharge and transitional care planning processes (Lin *et al.*, 2022a).

Caregiving impacts on social and leisure activities

While the physical and emotional demands of caregiving are well documented – manifesting as increased stress, low mood and reduced quality of life and overall well-being (Barber *et al.*, 2024; Hu *et al.*, 2018; McCauley *et al.*, 2021; Kokorelias *et al.*, 2020) – less attention has been given to the social and leisure dimensions of their well-being (Chen *et al.*, 2016; Gough *et al.*, 2022; King *et al.*, 2019; Markle Reid *et al.*, 2023). Caregiving disrupts not only ECPs' relationships with the loved one they are supporting (Leighton *et al.*, 2025a) but also disrupts other valued social roles and leisure activities that provide joy, identity and a sense of personal balance (Leighton *et al.*, 2025a; Shi *et al.*, 2025). Such social and leisure disruptions lead to isolation, role loss and a diminished sense of meaning and fulfilment (Iso-Ahola and Baumeister, 2023). While increasing recognition is being given to the importance of social activity and community reintegration for stroke survivors as a critical part of recovery (Mountain *et al.*, 2020), there remains limited focus on the needs of ECPs who also require opportunities to reintegrate meaningfully to support their identity, sense of belonging and well-being beyond the caregiving role. Recognizing and supporting the social and leisure aspects of ECPs' lives is essential to fostering their resilience and sustaining their long-term capacity to provide care.

Gaps in transitional care processes

The hospital-to-home transition is widely recognized as a vulnerable period for both stroke survivors and their ECPs, who must quickly adapt to new routines of care while continuing rehabilitation (Chen *et al.*, 2016). Transitional care interventions – such as navigation support, transition coaching and health coaching – have been proven effective to assist individuals and their families through significant shifts in care settings, like hospital-to-home transitions (Howitt *et al.*, 2024). There is also evidence that structured education, as well as psychosocial interventions that provide emotional support and practical skill development during discharge and transition processes, can lead to better health outcomes, reduced stress, higher-quality discharges and improved overall quality of life for both stroke survivors and ECPs (Chen *et al.*, 2021; Crocker *et al.*, 2021; Forster *et al.*, 2012; Mou *et al.*, 2021; O'Callaghan *et al.*, 2022). For example, discharge interventions that blend in-person engagement with at-home or telephone follow-up have shown promise in maintaining continuity of care (Liebzeit *et al.*, 2021; Marston *et al.*, 2023). As well, peer support has been found to significantly reduce caregiver stress, depression and burden (Putra *et al.*, 2024). Despite growing recognition of the importance of transitional care, significant gaps remain in discharge and transition planning, particularly as they relate to the needs of ECPs (Chen *et al.*, 2021; Mou *et al.*, 2021; O'Callaghan *et al.*, 2022).

Although early supported discharge policies and interventions can effectively promote faster transitions to home- and community-based recovery and reduce hospital stay costs (Osbourne and Neville, 2019; Suksatan and Tankumpuan, 2022; Youens *et al.*, 2019), they often leave ECPs with inadequate time and support to prepare for the complex responsibilities of caregiving during critical care transitions (Chen *et al.*, 2021) – contributing to peak burden periods following discharge (Lin *et al.*, 2022a). Current transitional and discharge planning processes focus primarily on stroke survivors, overlooking the essential role and support needs of ECPs, resulting in guidance that fails to address their concerns or prepare them for complex caregiving responsibilities (Chen *et al.*, 2021; Lin *et al.*, 2022a; Lutz *et al.*, 2011). Best practice

guidelines therefore recommend timely, targeted education and support for both survivors and caregivers to ease critical care transitions (Cameron *et al.*, 2016; Mountain *et al.*, 2020). When adequately prepared, ECPs demonstrate greater confidence, stronger problem-solving abilities and are less likely to experience the negative physical, emotional and psychological impacts of caregiving (Chartrand *et al.*, 2023).

Role of intersectoral partnerships on transitional care

Recently, there has been growing recognition of the potential for intersectoral partnerships – particularly with community-based organizations (CBOs) and the voluntary sector – to strengthen healthcare transitions (Nelson *et al.*, 2024a, b). If integrated into health system processes, intersectoral partnerships can play a pivotal role in addressing unmet needs through innovative care models (Nelson *et al.*, 2024b). Yet, there remains a critical gap in understanding the role these sectors can play in bolstering the capacity and well-being of individuals navigating critical care transitions. The authors are currently leading a research project to evaluate the effectiveness of a DASH framework, in partnership with March of Dimes Canada (MODC), a national, non-profit organization and leading disability service provider in Canada that delivers community-based programs to support people with disabilities, their families and caregivers (March of Dimes Canada, 2026). Through this partnership, MODC delivers volunteer-based home visits offering practical and psychosocial support to stroke survivors following discharge (Nelson *et al.*, 2024a). A noted gap in the current work is the exploration of how the DASH framework can be adapted to also support stroke survivors' ECPs. To address this gap, this rapid review sought to identify how, and in what capacity, CBOs, volunteers and leisure-based approaches are currently being leveraged to support ECPs of stroke survivors during transitions in care. The outcome of this review will inform a research agenda that leverages the DASH framework to centre the needs of ECPs and guide the development of inclusive, sustainable, equitable and caregiver-centred transitional care practices.

Methods

This review followed the updated Cochrane guidance for conducting rapid reviews of effectiveness, which outlines a five-step process: refining the topic, conducting searches, selecting studies, extracting data and synthesizing findings (Garrity *et al.*, 2021). We also adhered to the PRISMA-P guidelines to ensure procedural rigour (Shamseer *et al.*, 2015). This review was registered on February 5, 2025, with the Open Science Framework (OSF) registry (registry DOI: <https://osf.io/ygsne/>), and the protocol was previously published (Leighton *et al.*, 2025b). This study did not require ethics board approval, as it did not involve human or animal subjects.

Step one: topic refinement

We conducted a rapid review to better understand how CBOs, volunteers as human resources and leisure activities support ECPs during critical care transitions. To guide this review, the authors identified the following research questions using aspects of the population, concept and context (PCC):

- (1) What existing community-involved or -led interventions (*concept*) have been used to support stroke ECPs (*population*) during critical care transitions to home (*context*)?
 - To what extent do these interventions include intersectoral partnerships?
 - To what extent do these interventions include volunteers as human resources?
 - To what extent do these interventions include leisure-based modalities?

Step two: Searches

An information specialist (CW) developed the search strategy in collaboration with the first author (JL), beginning with an initial search of Ovid MEDLINE in January 2025 to identify relevant articles. Text words from titles and abstracts, along with index terms used to describe the studies, informed the development of a comprehensive search. The full and final search syntax is provided in Supplemental File 1. This strategy was then adapted for use across the following databases: Medline, Cochrane, Embase, CINAHL, Pubmed. The search was limited to studies published in English and covered the period from the inception of each database to January 2025.

Step three: study selection

Results from all databases were combined and imported into Covidence to support screening, data extraction and remove duplicates. Prior to beginning the screening process, two reviewers (JL & MS) piloted a sample of 10 titles and abstracts using the predefined screening criteria to assess inter-rater agreement. Discrepancies were resolved through discussion and consensus. A second pilot of 30 records was then conducted, resulting in minimal disagreement between reviewers. Following pilot testing, all titles and abstracts were screened independently by both reviewers using the following inclusion criteria: (1) published in English in a peer-reviewed journal, (2) inclusion of stroke ECPs (caregivers) in the intervention and (3) inclusion of an intervention with a component of discharge or transitional care planning (see [Table 1](#)).

In the second stage, both reviewers (JL & MS) independently screened the full texts of records identified as potentially eligible during the title and abstract review. The study selection process is summarized in the PRISMA flowchart shown in [Figure 1](#). This rapid review included studies of all design types; however, non-peer-reviewed articles, case examples, dissertations and commentaries were excluded.

Step four: data extraction

The data extraction form was piloted by two authors (JL & MS) and subsequently expanded to capture additional relevant details. Following guidelines for conducting rapid reviews ([Garrity et al., 2021](#)), a single reviewer (JL) extracted data from all included records using Covidence software. Key data categories included: authors, year, geographic location, study

Table 1. Study selection eligibility criteria

<i>Eligibility criteria</i>	
Included	Excluded
<p><i>Population: Stroke Caregivers</i></p> <ul style="list-style-type: none"> • Sources that include ECPs (caregivers) who are supporting someone who has experienced a stroke in a caregiving capacity <p>OR</p> <ul style="list-style-type: none"> • include both stroke caregivers and survivors <p><i>Concept: Hospital Discharge Planning or Transitions-to-Home Support</i></p> <ul style="list-style-type: none"> • Defined as an intervention, strategy, program, or service that involves components to support hospital discharge or transitions-to-home <p><i>Context: Critical transitions</i></p> <ul style="list-style-type: none"> • Defined as a transition from a healthcare setting/ context to home (e.g. hospital/acute or in-patient to home) • Sources that are academic literature (i.e. studies, conceptual papers, systemic reviews) • Sources from any geographic region • Sources were not limited in time range 	<ul style="list-style-type: none"> • Sources in which caregivers are not explicitly mentioned <p>OR</p> <ul style="list-style-type: none"> • sources that do not include stroke care populations <ul style="list-style-type: none"> • Interventions that do not include hospital discharge planning or transitions-to-home support <ul style="list-style-type: none"> • Interventions that occur during hospitalization or in-patient care OR do not focus on transitions to home <ul style="list-style-type: none"> • Sources with insufficient details to meaningfully meet the scoping review objectives • Sources without English language full text

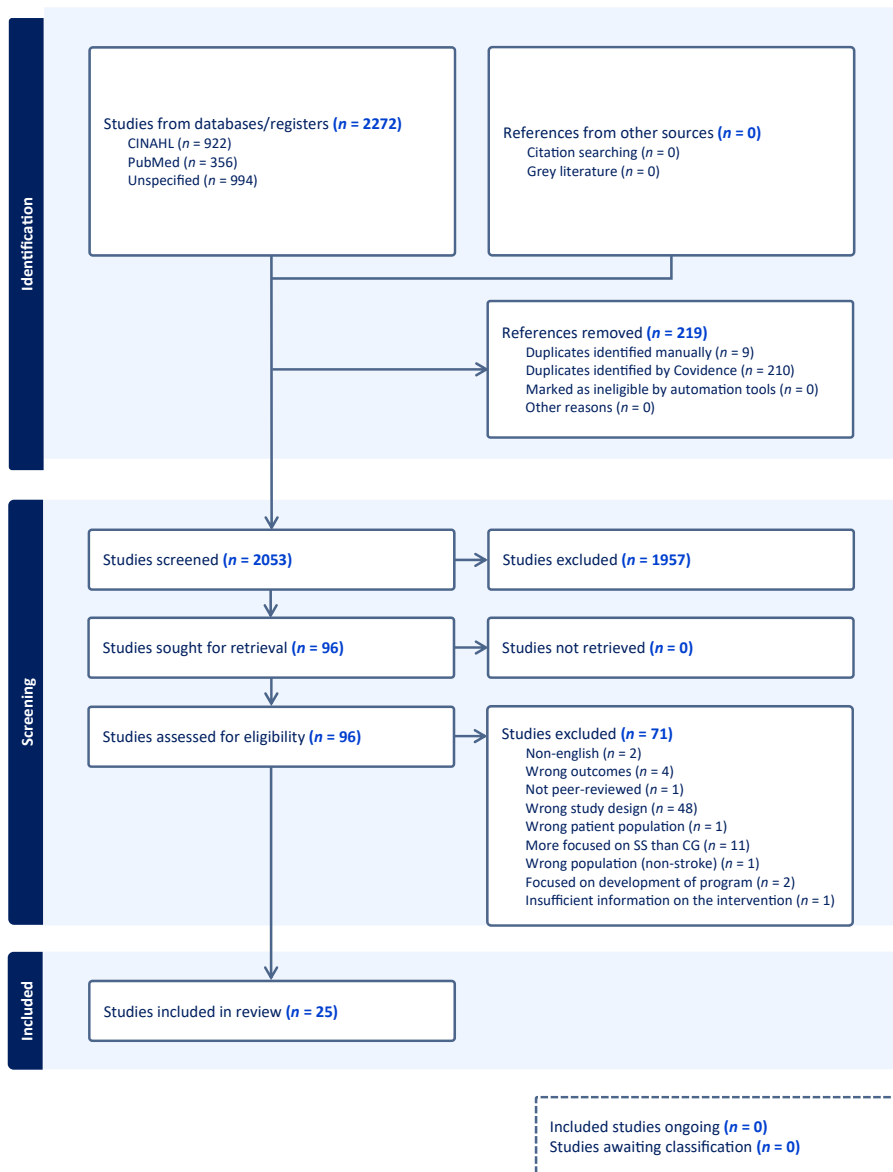


Figure 1. Prisma flowchart diagram

type, intervention components, intervention setting, mode of delivery, facilitators, target population, sample size, involvement of CBOs, use of volunteers, inclusion of leisure components, outcome measures, main findings, reported limitations and suggested future directions. The first author (JL) also verified the extracted data for accuracy and completeness.

Step five: synthesizing the findings

After data extraction, all information was collated into an Excel spreadsheet for analysis. A descriptive content analysis approach (Tricco *et al.*, 2015) was used to synthesize findings, guided by a 5W framework (what, where, when, why and how). The synthesis was structured around the review objectives, research questions and the *a priori* defined concepts of population (stroke ECPs), concept (discharge and transition-to-home support) and context (critical care transitions from hospital-based care to home).

Results: caregiver-centred transitional support interventions

As illustrated in Figure 1, the initial search yielded 2,272 results. After removing 216 duplicate entries, 2056 unique records underwent title/abstract screening. At this stage, 1965 entries were excluded, leaving 91 records for a full-text review. Seventy studies were excluded at this stage, resulting in a total of 25 studies meeting the inclusion criteria. Reasons for exclusion varied, with most ($n = 49$) being the wrong study design, followed by wrong target population ($n = 12$), wrong study outcomes ($n = 6$) non-English presentation ($n = 2$) or insufficient information on the intervention ($n = 1$) (see Table 2 for an overview of the data extraction and Supplemental Material 2 for the expanded data extraction chart).

To synthesize the findings of this review, we describe and contextualize the caregiver-included interventions designed to support the transition from hospital-to-home following stroke. Here, we speak to the settings and contexts of the intervention, its core components and delivery methods, the key human actors involved (e.g. facilitators, peers, volunteers), as well as key learnings about what worked, for whom and why.

The setting and context: when, where, who and how?

The studies included in this review spanned from 2002 to 2024, with a noticeable increase in publications from 2020 onward ($n = 13$). Of the interventions specifically targeting the needs of ECPs, only one study was published in 2015 (Cameron *et al.*, 2016), with the remaining five emerging after 2019 (Araújo *et al.*, 2018; Bierhals *et al.*, 2023; Ferguson *et al.*, 2020; Jarvis *et al.*, 2019; Vielvoye *et al.*, 2023). The studies represent a range of geographical locations, most frequently in the United States ($n = 4$) (Lutz *et al.*, 2023; Ostwald *et al.*, 2014; Pittharapong *et al.*, 2017; Woodward *et al.*, 2021), China ($n = 4$) (Mou *et al.*, 2022; Lin *et al.*, 2022b; Ng *et al.*, 2005; Ramazanu *et al.*, 2021), Canada ($n = 3$) (Cameron *et al.*, 2015; Egan *et al.*, 2010; Ritsma *et al.*, 2023) and Taiwan ($n = 3$) (Kuo *et al.*, 2024; Shyu *et al.*, 2008, 2010). Just over half of the studies ($n = 14$) employed multi-setting interventions, involving more than one care setting – such as hospital and home environments – while 11 focused on a single hospital or home environment only. Notably, most studies ($n = 18$) included the home setting post-discharge, aiming to address the needs of ECPs within their living environment. Sample sizes varied widely, ranging from 14 to 1,228 participants, encompassing stroke survivors, ECPs and healthcare workers. Most interventions ($n = 19$) targeted the ECP-stroke survivor dyad, whereas a smaller number ($n = 6$) focused exclusively on ECPs as the primary recipients of tailored support interventions.

For methodological approaches, most studies ($n = 14$) used randomized controlled trials to assess intervention effectiveness, while only one (Vielvoye *et al.*, 2023) employed a qualitative design to capture participants lived experiences. Intervention delivery methods consisted of nearly half of the conducted in-person ($n = 10$), and nine combining in-person and telephone-based approaches. Fifteen interventions began pre-discharge, with 12 continuing into the post-discharge period. Five were limited to the pre-discharge phase; nine were initiated post-discharge without prior in-hospital/acute components.

The interventions in action: what?

The interventions described across the included studies reflected a wide range of caregiver-centred supports, primarily falling into three overlapping categories: education and resources,

Table 2. Overview of rapid review study results

Author and year	Country	Study design	Location and mode of delivery	Target population and sample size	Involvement of CBOs? In what capacity?	Involvement of volunteers? In what capacity?	Involvement of leisure? In what capacity?
Vielvoye et al. (2023)	The Netherlands	Qualitative	Hospital and Home; In-person	CG only; 18 CG	No	No	No
Nazari et al. (2024)	Iran	Randomized Controlled Trial	Hospital and Home; Virtual (Video Call/ Conferencing); Phone	CG and SS; 60 (30 SS and CG intervention group; 30 SS and CG control group)	Yes; Education on how and when to contact community services	No	No
Kuo et al. (2024)	Taiwan	Quasi-experimental	Inpatient and Home; In-person; Virtual (Video Call/ Conferencing)	CG and SS; 105 (54 SS and CG intervention group; 51 SS and CG control group)	No	No	No
Kalra et al. (2004)	England	Randomized Control Trial	Inpatient and Home; In-person	CG and SS; 300 (151 CG intervention group; 149 CG control group)	No	No	No
Jarvis et al. (2019)	United Kingdom (Scotland)	Exploratory	Hospital/Acute only; In-person	CG only; 89 CGs	No	No	No
Mou et al. (2022)	China	Randomized Control Trial	Inpatient and Home; In-person; Phone	CG and SS; 40 (20 SS and CG intervention group; 20 SS and CG control group)	No	No	No
Bierhals et al. (2023)	Brazil	Randomized Control Trial	Home only; In-person	CG only; 48 (24 CG intervention group; 24 CG control group)	No	No	No

(continued)

Table 2. Continued

Author and year	Country	Study design	Location and mode of delivery	Target population and sample size	Involvement of CBOs? In what capacity?	Involvement of volunteers? In what capacity?	Involvement of leisure? In what capacity?
Egan et al. (2010)	Canada	Exploratory	Community setting only; In-person	CG and SS; 73 (41 SS and 32 CG)	Yes; Recruitment through CBO (organizational newsletter, phone calls, local news posting). Referral of community programs that suited needs/interests of participant	No	Yes; Evaluation of leisure participation during assessment. Referral to sustainable leisure pursuits
Aguirrezabal et al. (2013)	Spain	Nonrandomized, Control	Hospital/Acute only; In-person	CG and SS; 150 (76 SS and 73 CG intervention group; 74 SS and 33 CG control group)	No	No	No
Pitthayapong et al. (2017)	Thailand	Quasi-experimental	Community/ Outpatient and Home; In-person	CG and SS; 62 (31 SS and CG intervention group; 31 SS and CG control group)	No	No	No
Ferguson et al. (2020)	United States	Nonrandomized, Longitudinal	Hospital/Acute only; In-person	CG only; 27 CG	Yes; List of community resources (such as stroke support groups) available post-discharge	No	Yes; Resource document listed leisure-based modalities for self-care (e.g. exercise, music, deep breathing)
Ramazanu et al. (2021)	China	Interpretive, Descriptive	Inpatient only; In-person	CG and SS; 14 (7 SS and 7 CG)	No	No	No

(continued)

Table 2. Continued

Author and year	Country	Study design	Location and mode of delivery	Target population and sample size	Involvement of CBOs? In what capacity?	Involvement of volunteers? In what capacity?	Involvement of leisure? In what capacity?
Ritsma et al. (2023)	Canada	Effectiveness	Inpatient only; In-person; Virtual (Video Call/ Conferencing)	CG and SS; 48 SS and CG	No	No	No
Ng et al. (2005)	China	Prospective	Home only; In-person; Phone	CG and SS; 144 SS and CG)	No	No	No
Hosseini et al. (2022)	Iran	Randomized Control Trial	Home only; Phone	CG and SS; 72 (36 SS and CG intervention group; 34 SS and CG control group)	No	No	No
Bitek and Erol (2023)	Turkey	Randomized Control Trial	Hospital and Home; In-person; Phone	CG and SS; 69 (34 SS and CG intervention group; 35 SS and CG control group)	No	No	No
Lincoln et al. (2003)	United Kingdom (England)	Randomized Control Trial	Inpatient and Home; In-person; Phone	CG and SS; 250 (126 SS and CG intervention group; 124 SS and CG control group)	Yes; Information package provided by CBO	No	No
Shyu et al. (2008)	Taiwan	Randomized Experimental	Hospital and Home; In-person; Phone	CG and SS; 201 (97 SS and CG intervention group; 104 SS and control group)	No	No	No
Shyu et al. (2010)	Taiwan	Clinical Trial	Hospital and Home; In-person; Phone	CG and SS; 201 (97 SS and CG intervention group; 104 SS and control group)	No	No	No
Cameron et al. (2015)	Canada	Randomized Control Trial	Hospital and Home; In-person; Phone	CG only; 31 (10 CG standard care; 10 CG self-directed intervention; 11 CG SSP-directed intervention)	No	No	No

(continued)

Table 2. Continued

Author and year	Country	Study design	Location and mode of delivery	Target population and sample size	Involvement of CBOs? In what capacity?	Involvement of volunteers? In what capacity?	Involvement of leisure? In what capacity?
Lutz et al. (2023)	United States	Pragmatic Cluster-randomized Trial	Community/ Outpatient and Home; In-person; Phone	CG and SS; 1,228 (1722 SS and CG intervention group; 2486 SS and CG control group)	No	No	No
Ostwald et al. (2014)	United States	Randomized Trial	Home only; In-person; Mail	CG and SS; 159 (79 SS and CG home-based intervention group; 80 SS and CG mailed intervention control group)	Yes; Personalized letters included links to support groups	No	Yes; Personalized letters included tips for leisure activity adaptations
Lin et al. (2022b)	China	Randomized Control Trial	Hospital/acute and Outpatient; In-person; Phone	CG and SS; 140 (70 SS and CG intervention group; 70 SS and CG control group)	No	No	No
Araújo et al. (2018)	Portugal	Quasi-experimental	Community/ Outpatient and Home; In-person	CG only; 174 (85 intervention group; 89 control group)	No	No	No
Woodward et al. (2021)	United States	Randomized Control Trial	Home only; In-person; Virtual (Video Call/ Conferencing); Phone	CG and SS; 169 (57 CG intervention; 54 CG intervention + website resource; 58 CG control usual care)	No	No	No

Note(s): CG, caregiver; SS, stroke survivor

psychosocial support and discharge support at home. Educational components addressed stroke-related knowledge, including stroke care and recovery (e.g. symptoms, complications) (Araújo *et al.*, 2018; Bitek and Erol, 2023; Egan *et al.*, 2010; Ferguson *et al.*, 2020; Hosseini *et al.*, 2022; Kuo *et al.*, 2024; Lin *et al.*, 2022b; Mou *et al.*, 2022; Nazari *et al.*, 2024; Ostwald *et al.*, 2014; Pitthayapong *et al.*, 2017; Ramazanu *et al.*, 2021; Ritsma *et al.*, 2023; Shyu *et al.*, 2008, 2010), rehabilitation (Bitek and Erol, 2023; Cameron *et al.*, 2015; Kuo *et al.*, 2024; Lin *et al.*, 2022b; Lutz *et al.*, 2023; Nazari *et al.*, 2024; Pitthayapong *et al.*, 2017), medication management (Ferguson *et al.*, 2020; Lutz *et al.*, 2023; Ostwald *et al.*, 2014) and nutrition (Araújo *et al.*, 2018; Pitthayapong *et al.*, 2017; Shyu *et al.*, 2008). Psychosocial components focused on emotional health and coping strategies (Shyu *et al.*, 2010; Lin *et al.*, 2022b), psychosocial education and adjustment (Cameron *et al.*, 2015; Hosseini *et al.*, 2022; Ostwald *et al.*, 2014), access to peer support groups (Aguirrezabal *et al.*, 2013; Ferguson *et al.*, 2020) and stress-reduction techniques (Lin *et al.*, 2022b; Ramazanu *et al.*, 2021). Only three studies (Egan *et al.*, 2010; Ferguson *et al.*, 2020; Ostwald *et al.*, 2014) referenced leisure modalities – one involved an assessment of leisure participation as part of the intervention (Egan *et al.*, 2010), and two included leisure-based self-care activities, such as journaling or deep breathing, within educational resources as tools for community re-integration or stress relief (Ferguson *et al.*, 2020; Ostwald *et al.*, 2014). Finally, most interventions focused on discharge planning and preparation during the pre-discharge phase, including activities such as home adaptation and service referrals (Aguirrezabal *et al.*, 2013; Bitek and Erol, 2023; Egan *et al.*, 2010; Lincoln *et al.*, 2003; Lin *et al.*, 2022b; Lutz *et al.*, 2023; Nazari *et al.*, 2024; Ostwald *et al.*, 2014; Ritsma *et al.*, 2023; Shyu *et al.*, 2008, 2010; Woodward *et al.*, 2021). Other interventions helped facilitate community re-integration by connecting ECPs with local programs (Ferguson *et al.*, 2020; Hosseini *et al.*, 2022; Lincoln *et al.*, 2003; Kalra *et al.*, 2004; Ritsma *et al.*, 2023; Woodward *et al.*, 2021). Interventions that extended in-person support into the home beyond hospital-based often combined aspects of educational and psychosocial components – reinforcing caregiving skills (Araújo *et al.*, 2018; Kalra *et al.*, 2004; Mou *et al.*, 2022; Woodward *et al.*, 2021), addressing post-discharge challenges (Bierhals *et al.*, 2023; Kuo *et al.*, 2024; Lincoln *et al.*, 2003; Mou *et al.*, 2022; Ostwald *et al.*, 2014), offering tailored ECP training (Araújo *et al.*, 2018; Bierhals *et al.*, 2023; Lincoln *et al.*, 2003) and linking ECPs to local resources (Bitek and Erol, 2023; Ostwald *et al.*, 2014).

Seventeen of the interventions adopted a tailored approach, designed to meet the unique needs of ECPs and/or stroke survivors (Aguirrezabal *et al.*, 2013; Bierhals *et al.*, 2023; Bitek and Erol, 2023; Cameron *et al.*, 2015; Egan *et al.*, 2010; Ferguson *et al.*, 2020; Hosseini *et al.*, 2022; Jarvis *et al.*, 2019; Kalra *et al.*, 2004; Kuo *et al.*, 2024; Lin *et al.*, 2022b; Lincoln *et al.*, 2003; Lutz *et al.*, 2023; Mou *et al.*, 2022; Ng *et al.*, 2005; Pitthayapong *et al.*, 2017; Ramazanu *et al.*, 2021; Ritsma *et al.*, 2023; Shyu *et al.*, 2008/2010; Woodward *et al.*, 2021) while nine were standardized, offering the same content, training and support to all participants. Nine studies included a material resource, such as booklets or handbooks (Bitek and Erol, 2023; Cameron *et al.*, 2015; Ferguson *et al.*, 2020; Kalra *et al.*, 2004; Mou *et al.*, 2022; Nazari *et al.*, 2024; Ostwald *et al.*, 2014; Woodward *et al.*, 2021), six provided practical hands-on training (Araújo *et al.*, 2018; Jarvis *et al.*, 2019; Kalra *et al.*, 2004; Ng *et al.*, 2005; Pitthayapong *et al.*, 2017; Vielvoye *et al.*, 2023), and two featured a digital component, such as a mobile app or WhatsApp communication (Nazari *et al.*, 2024; Vielvoye *et al.*, 2023).

The human element: facilitators, community-based partners and volunteers

Most interventions ($n = 17$) were facilitated by interdisciplinary care providers, including occupational therapists, physiotherapists, psychologists and nurses. Two interventions were delivered by a research team member (Ferguson *et al.*, 2020; Pitthayapong *et al.*, 2017), while five did not specify who facilitated the intervention. Most studies did not involve a CBO or intersectoral partnership to support home and community care transition. However, five studies (Egan *et al.*, 2010; Ferguson *et al.*, 2020; Lincoln *et al.*, 2003; Nazari *et al.*, 2024;

[Ostwald et al., 2014](#)) referenced or involved CBOs, by providing participants with information on how to contact relevant services ([Nazari et al., 2024](#)) or by listing CBOs among the local resources available for follow-up or connection ([Ferguson et al., 2020](#); [Ostwald et al., 2014](#)). One study utilized a CBO to assist with participant recruitment through channels such as newsletters and email distribution ([Egan et al., 2010](#)), and one incorporated a CBO-produced educational resource (e.g. a magazine) as part of the intervention ([Lincoln et al., 2003](#)). When specified, the CBOs involved were non-profit organizations, including the Stroke Survivors' Association of Ottawa ([Egan et al., 2010](#)) and Stroke Association UK ([Lincoln et al., 2003](#)). Notably, none of the 25 studies used volunteers as part of the intervention team or as a human resource to support delivery.

Key learnings: what worked, for whom and why?

[Vielvoye et al. \(2023\)](#) defined peak burden for caregivers as being experienced at two key time points: in the days or weeks leading up to discharge and around six weeks post-discharge, when ECPs reported feeling overwhelmed by their new caregiving responsibilities ([Vielvoye et al., 2023](#)). Interventions incorporating educational components effectively increased ECP preparedness for caregiving duties ([Aguirrezabal et al., 2013](#); [Jarvis et al., 2019](#); [Kuo et al., 2024](#); [Nazari et al., 2024](#); [Pitthayapong et al., 2017](#); [Ritsma et al., 2023](#); [Vielvoye et al., 2023](#)). At the same time, those that included practical, hands-on support helped build confidence, autonomy and a sense of mastery in the caregiving role ([Aguirrezabal et al., 2013](#); [Bierhals et al., 2023](#); [Ferguson et al., 2020](#); [Jarvis et al., 2019](#); [Kalra et al., 2004](#); [Kuo et al., 2024](#); [Lin et al., 2022b](#); [Lincoln et al., 2003](#); [Mou et al., 2022](#); [Nazari et al., 2024](#); [Ostwald et al., 2014](#); [Ritsma et al., 2023](#); [Shyu et al., 2008](#); [Vielvoye et al., 2023](#)). Several studies showed that interventions with targeted components that were more personalized to the needs of the stroke survivor-ECP dyads successfully reduced ECP burden ([Aguirrezabal et al., 2013](#); [Bierhals et al., 2023](#); [Ferguson et al., 2020](#); [Jarvis et al., 2019](#); [Kalra et al., 2004](#); [Kuo et al., 2024](#); [Lin et al., 2022b](#); [Mou et al., 2022](#); [Nazari et al., 2024](#); [Ritsma et al., 2023](#); [Shyu et al., 2008](#); [Vielvoye et al., 2023](#); [Woodward et al., 2021](#)), which helped enhance caregiver competence in one study ([Ng et al., 2005](#)). Tailored or individualized interventions that addressed the unique needs of the ECP and/or stroke survivor dyad were described as beneficial as they aligned with the dyad's current capacities, preferences and stage in the recovery process, allowing care to be delivered in a way that was both relevant and responsive to their evolving circumstances ([Egan et al., 2010](#); [Ramazanu et al., 2021](#); [Shyu et al., 2010](#); [Cameron et al., 2015](#)). ECP-tailored interventions were also described as cost-effective and feasible ([Ferguson et al., 2020](#); [Jarvis et al., 2019](#); [Kalra et al., 2004](#)), contributing to earlier stroke survivor discharge ([Jarvis et al., 2019](#)), fewer medical complications ([Pitthayapong et al., 2017](#)) and reduced rates of re-hospitalization ([Shyu et al., 2010](#)). Interventions that included external or digital resources were considered sustainable and accessible, allowing ECPs to obtain information and support at any stage of the transition process ([Aguirrezabal et al., 2013](#); [Kuo et al., 2024](#)).

In several studies, ECPs expressed a desire for more confidence in navigating and accessing post-discharge services ([Jarvis et al., 2019](#)), often reporting a lack of awareness about available resources and how to connect with them ([Egan et al., 2010](#)). Interventions that guided community supports, such as CBOs, were perceived as helpful in easing the transition to home and improving community re-integration ([Lincoln et al., 2003](#)). Programmes that addressed ECP social needs ([Aguirrezabal et al., 2013](#); [Bierhals et al., 2023](#); [Kalra et al., 2004](#); [Kuo et al., 2024](#); [Ostwald et al., 2014](#)) demonstrated improvements in quality of life ([Bierhals et al., 2023](#); [Kalra et al., 2004](#); [Kuo et al., 2024](#)) and reductions in loneliness and helplessness ([Aguirrezabal et al., 2013](#)). Although featured in only one study, a peer-support programme was found to reduce caregiver strain and enhance well-being ([Kuo et al., 2024](#)). Interventions that fostered open communication between ECPs and stroke survivors created opportunities for connection and mutual support during a period often marked by disconnection ([Ramazanu](#)

et al., 2021). Notably, one study specifically identified that improved confidence among ECPs was linked to their ability to participate in self-care activities (Ng *et al.*, 2005), such as leisure.

Discussion and reflections on ECP-centred transitional support

Three emerging learnings stand out to us for how to better support ECPs from this rapid review: the growing, but still underdeveloped, shift towards tailored, ECP-centred approaches as an essential – rather than optional – element of stroke care; the reinforcing relationship between education, support and self-care as a cycle; and the need to integrate transitional interventions within broader health system and community contexts.

Centred, not sidelined: tailoring transitional support for ECPs

Of the 25 studies included in this rapid review, only six focused exclusively on ECPs, all of which were published since 2015 – highlighting a recent and growing interest in supporting ECPs and reflecting a broader shift in care systems towards recognizing their essential role in ensuring continuity of care across hospital, home and community settings. Despite growing recognition of ECPs' importance, many transitional care interventions continue to sideline their needs, treating them as secondary to those of stroke survivors rather than as a distinct group with evolving challenges and needs (Hahn-Goldberg *et al.*, 2018; Lin *et al.*, 2022a; Zhan *et al.*, 2022). This is reflected in this review as only 6 of the 25 studies that exclusively focused on the unique care needs of ECPs. Among the 19 studies that addressed the stroke survivor–ECP dyad, the emphasis was primarily on the survivor's care needs or on preparing ECPs to provide care, rather than on supporting the ECPs themselves. While these supports are undoubtedly important, they often overlook the broader and more complex needs of ECPs who must navigate identity and role changes, social disconnection, limited access to community resources and competing life demands such as employment, financial pressures, household responsibilities and additional caregiving roles during the transition from hospital-to-home (Ferguson *et al.*, 2020; Cameron *et al.*, 2015; Lutz *et al.*, 2023). Even comprehensive interventions, such as those by Mou *et al.* (2022) and Vielvoye *et al.* (2023), which aimed to build ECP confidence through education and training, left many ECPs feeling emotionally overwhelmed at discharge.

Consistent with previous research on transitional care interventions, our findings highlight that tailored approaches – those that identify and address the unique and evolving needs of each stroke survivor and/or ECP dyad – are commonly associated with positive caregiver-reported outcomes, such as improved preparedness and reduced perceived strain (Chen *et al.*, 2016). For example, Jarvis *et al.* (2019) found that ECPs who received targeted support tailored to their situation felt more prepared for their caregiving roles and reported lower levels of strain. Across studies included in this review, tailored interventions were described as acceptable and beneficial by ECPs, particularly in relation to enhanced preparedness and perceived support (Cameron *et al.*, 2015; Egan *et al.*, 2010; Jarvis *et al.*, 2019; Ramazanu *et al.*, 2021; Shyu *et al.*, 2010). Rather than demonstrating comparative superiority, these findings suggest a growing recognition of the importance of responsive, individualized support approaches that acknowledge ECPs as essential partners in stroke care and recovery. Achieving effective and sustainable care transitions depends on centring ECPs by recognizing their emotional well-being, life demands and caregiving capacity, while designing supports that reflect these realities (Mitchell *et al.*, 2018). The findings of this rapid review complement existing literature by identifying how education and practical training can function not only as tools to enhance caregiving skills but also as entry points into a reinforcing cycle that enables ECPs to attend to their own well-being and engage in self-care.

The cycle of ECP knowledge, support and self-care

Our findings identify peak periods of heightened caregiver burden – specifically in the days leading up to discharge and at six weeks post-discharge (Vielvoye *et al.*, 2023) – which aligns

with a previous qualitative longitudinal study by [Lin et al. \(2022b\)](#), describing a “crisis at home” in which caregivers experienced significant burden following discharge. This burden includes not only the need for education and practical skills to support stroke survivors ([Ritsma et al., 2023](#)) but also the emotional and psychosocial toll on caregivers, who must navigate feelings of overwhelm, grief and anxiety during their own transitional journey ([Cameron et al., 2015](#); [Egan et al., 2010](#); [Ramazanu et al., 2021](#)). This finding helps pinpoint critical moments within the discharge and transition journey when ECPs most need targeted support strategies – not only to care for their loved one, in this case the stroke survivor but also to attend to their own self-care and wellness needs.

Many interventions reviewed in this study incorporated educational and practical support that improved caregivers’ confidence, autonomy and a sense of mastery in their new roles. For example, [Lin et al. \(2022b\)](#) implemented a health coaching intervention prior to discharge – covering topics such as transitional care goals, self-care skills, home modifications, physical functioning, medication management and stroke-related risk prevention. Caregivers who participated reported significantly reduced caregiver burden at both 12 and 24 weeks, demonstrating the potential of such support to ease caregiving stress ([Lin et al., 2022b](#)). Consistent with previous studies involving stroke survivors, these findings highlight that the inclusion of interprofessional care teams offers a multidisciplinary approach that more effectively addresses the full spectrum of health and well-being needs ([Liu et al., 2025](#); [Lowther et al., 2021](#); [Parmar et al., 2025](#)). Furthermore, this review demonstrates that enhancing caregiver preparedness through education is a cost-effective and feasible strategy, associated with fewer medical complications and reduced re-hospitalization rates – findings that align with previous research involving older adults and individuals living with chronic heart conditions ([Osborne and Neville, 2019](#); [Suksatan and Tankumpuan, 2022](#)).

Previous research has identified social and leisure needs as a persistent gap in service delivery during the transition from hospital to home ([Chen et al., 2016](#); [Gough et al., 2022](#); [Markle Reid et al., 2023](#); [King et al., 2019](#)). This gap was also evident in this review, as only a limited number of interventions specifically addressed the social and emotional needs of ECPs, with those that did reporting improvements in quality of life ([Bierhals et al., 2023](#); [Jarvis et al., 2019](#); [Kalra et al., 2004](#)) and reductions in loneliness and helplessness ([Aguirrezabal et al., 2013](#)). For instance, [Kuo et al. \(2024\)](#) utilized an online peer support network, while [Ramazanu et al. \(2021\)](#) created spaces for ECPs and stroke survivors to openly discuss personal concerns and connect with others in similar roles. These findings echo those of [Markle Reid et al. \(2023\)](#) that there is a critical need to strengthen partnerships between health and social services – particularly during care transitions from hospital to home – to ensure that social and leisure needs are also adequately addressed.

Notably, one study included in this review found that as stroke survivors regained the ability to perform self-care activities, both they and their caregivers reported increased confidence in the transition to and return home from the hospital ([Ng et al., 2005](#)). While these findings highlight stroke survivors’ capacity for self-care, we propose that a similar dynamic may apply to ECPs as reflected in [Ramazanu et al.’s \(2021\)](#) qualitative study, which demonstrated ECPs growing recognition of the importance of self-care as essential to sustaining caregiving responsibilities. This suggests a mutually reinforcing cycle during critical care transitions; through education and practical training, stroke survivors and ECPs can build skills and confidence that create space for ECPs to prioritize self-care.

ECPs commonly neglect their well-being to prioritize the care needs of their loved ones ([Garnett et al., 2022](#); [Kokorelias et al., 2020](#)). Leisure-based self-care activities – such as gentle movement like yoga, reflective practices like journaling and spiritual activities like meditation or spending time in nature – have demonstrated healing benefits that help individuals cope with difficult times ([Harmon and Kyle, 2022](#); [Leighton et al., 2021](#); [Yuen et al., 2021](#)), including critical moments like discharge and transition for stroke survivors and their ECPs. Yet, despite the clear value of leisure-based coping, very few interventions in this review explicitly incorporated leisure as a core component of ECP support. Only a few

interventions addressed leisure and/or self-care; for example, [Ferguson et al. \(2020\)](#) provided ECPs with a resource document listing self-care activity (e.g. exercise, music, deep breathing). Still, they found no significant reduction in ECP stress ([Ferguson et al., 2020](#)). This raises an important consideration: could integrating leisure-based self-care coping strategies more intentionally alongside education and practical training better address ECPs emotional and psychosocial needs during the discharge and transition period?

Care in context: integrating transitional support across health and community systems

Recent scholarship has highlighted the potential of CBOs and the voluntary sector in supporting hospital-to-home transitions ([Nelson et al., 2024a, b](#)). In this review, [Lincoln et al. \(2003\)](#) identified that interventions offering information on community supports were valued by ECPs and stroke survivors for aiding community reintegration. While a handful of interventions incorporated or referenced CBOs ([Egan et al., 2010](#); [Ferguson et al., 2020](#); [Lincoln et al., 2003](#); [Nazari et al., 2024](#); [Ostwald et al., 2014](#)), their involvement was often minimal, limited to roles such as assisting with participant recruitment or being listed as external resources for participants to explore independently. Only three studies in this review ([Ferguson et al., 2020](#); [Nazari et al., 2024](#); [Ostwald et al., 2014](#)) provided tailored information about CBOs, including [Ostwald et al. \(2014\)](#), who sent personalized letters detailing local services. While these approaches are helpful, they fall short of true integration.

Without embedding CBOs meaningfully into the intervention process, many ECPs lack the time, energy or confidence to independently seek out community-based supports and resources – an issue echoed by [Jarvis et al. \(2019\)](#), where ECPs expressed a need for greater confidence in navigating post-discharge services. To move beyond superficial references to community resources, discharge and transitional care models must intentionally integrate CBOs and provide clear guidance for ECPs to access and engage with these supports – an approach strongly emphasized in the recent Canadian best practice recommendations for rehabilitation, recovery and community participation following stroke ([Mountain et al., 2020](#)). A recent scoping review by [Choi et al. \(2024\)](#), suggests that when ECPs caring for an older adult with a chronic illness are knowledgeable about local resources and confident in accessing them, they are more likely to utilize these supports, thereby improving both their own well-being and the recovery outcomes of their loved ones. While these findings point to potential value, they do not permit conclusions about the relative effectiveness of specific intervention types. Interestingly, the few studies that addressed leisure and social connection identified in our review – through online peer support or community-based groups – also discussed the role of CBOs. This conceptual overlap suggests an emerging alignment rather than evidence of greater effectiveness, highlighting a promising direction for future research focused on social wellness, peer support and community participation.

The absence of the voluntary sector – particularly trained volunteers – as active contributors to transitional care across all studies in this review represents a missed opportunity. This finding aligns with a previous scoping review of people living with dementia, which identified volunteers as valuable resources in reducing emergency department and hospital admissions and as effective facilitators of interventions that improve care transitions ([Bharmal et al., 2025](#)). Organizations such as MODC have already deployed trained volunteers who can serve as peer navigators or community facilitators post-discharge ([MODC, 2026](#)). This suggests an untapped role for CBOs and the broader voluntary sector in supporting stroke ECPs through discharge and transitional care, as they navigate available resources and adapt to evolving caregiving responsibilities – paralleling the kinds of services described by [Nelson et al. \(2024a, b\)](#) as beneficial for stroke survivors.

In addition to integrating community and voluntary sector resources, interventions extending beyond the hospital setting into home care contexts were described as useful and acceptable by ECPs as they engaged multiple sectors of care and addressed emerging practical and emotional challenges. This review also highlights the value of interventions offering

external resources – such as handbooks or digital platforms for connection and information-seeking – in assisting ECPs to manage caregiving responsibilities while balancing competing life demands, consistent with prior studies on transitional care interventions (Singh *et al.*, 2022; Fuller *et al.*, 2020). Rather than demonstrating comparative effectiveness, these findings underscore the importance of continuity and contextual relevance in transitional support. Overall, the evidence suggests that support for ECPs must extend beyond discharge and be embedded in home and community contexts to align with ECPs lived realities and evolving needs.

Lessons not yet learned: limitations and future directions in ECP care

Across the studies included in this review, several limitations may hinder the generalizability, interpretability and long-term applicability of the findings. Many studies relied on small, non-representative samples, often drawn from a single hospital or region, limiting the diversity and generalizability of results. Short follow-up periods, missing baseline data and high attrition further reduced the reliability of outcomes and limited insight into the sustained impacts of interventions. Implementation challenges were also noted, including variation in delivery, poor uptake and limited fidelity assessments, raising concerns about reproducibility and real-world feasibility. Methodological constraints, such as reliance on self-reported measures, unvalidated tools and non-randomized designs, introduced risks of bias and weakened the strength of causal claims.

To address these gaps, the study authors recommended several future directions. These include recruiting more diverse samples (Bitek and Erol, 2023; Ferguson *et al.*, 2020), conducting long-term evaluations (ideally beyond 12 months) (Ng *et al.*, 2005) and assessing broader outcomes such as cost-effectiveness, caregiver burden, and healthcare use. Methodological improvements, such as reducing selection bias, ensuring baseline data collection, and controlling for confounding factors, were also emphasized (Nazari *et al.*, 2024; Shyu *et al.*, 2008/2010). Greater attention to flexible delivery models, including digital or hybrid approaches, was encouraged to enhance accessibility and participation (Vielvoye *et al.*, 2023; Ritsma *et al.*, 2023). As well, integrating interventions within broader health systems and community contexts was critical to achieving scalable, team-based models of caregiver support.

Next steps and future directions

This manuscript presents the findings of a rapid review to address the proposed research questions. As we reflect on these findings, one key area that demands attention is the equity issues faced by ECPs, particularly those from underserved and marginalized communities. There is a clear need to explore how CBOs can take a more intentional role in delivering culturally relevant and accessible caregiver support – for example, by offering resources in multiple languages or implementing care coordinator roles to improve navigation within Indigenous communities. Based on our analysis of the data collected to address our research questions, we found that discussion of health equity, cultural considerations and Indigenous communities was very limited. To explore these important issues further, we will be expanding this work into a realist review – in partnership with marginalized and underrepresented communities to identify how intersecting factors – such as place of residence, race/ethnicity, socioeconomic status and social capital – influence both access to and the effectiveness of ECP support interventions. In addition to equity considerations, an emerging area of interest is whether increased confidence in managing care tasks during critical care transitions creates the opportunity and capacity for respite for ECPs to prioritize their own self-care and well-being.

The insights gained from this review will guide the development of a research agenda for the first author (JL) focused on identifying and addressing the specific supports ECPs need during critical transition periods, particularly from hospital-to-home. Central to this agenda is the advancement of integrated care models that incorporate the strengths of CBOs and the

Limitations

This rapid review has several methodological limitations that should be considered when interpreting the findings. The review was restricted to English-language publications, which may have excluded relevant evidence from non-English-speaking contexts and limited the global applicability of the findings. While dual screening was conducted at the title and abstract stage, full-text screening and data extraction were completed by a single reviewer with verification by a second reviewer, introducing the potential for selection or interpretive bias despite alignment with rapid review guidance. In addition, the descriptive content analysis relied on author interpretation of heterogeneous study designs, outcomes and intervention descriptions, which may have influenced how findings were categorized and synthesized. This review did not include a formal quality appraisal or comparative effectiveness analysis; therefore, conclusions should be interpreted as descriptive rather than causal or comparative. Finally, the rapid review approach prioritizes breadth and timeliness over depth, which may have limited detailed examination of individual intervention mechanisms, underscoring the need for future systematic or realist reviews to build on these findings.

Conclusion

Effective stroke recovery and health system sustainability relies on recognizing ECPs as essential partners in care whose well-being must be integrated into transitional care planning during critical care transitions. Three key insights emerged from this review. First, transitional care interventions must be tailored to ECPs' unique needs and include them meaningfully in planning and decision-making. Second, providing ECPs with adequate preparation, resources and emotional support enhances their confidence and capacity to manage caregiving demands, reducing burnout and improving sustainability. Third, support for ECPs must extend beyond hospital discharge and be embedded within a broader, community-based continuum of care. CBOs and trained volunteers remain underutilized assets in delivering localized, person-centred support. To ensure long-term impact, ECP interventions must be embedded within coordinated health and social care systems that bridge institutional care and everyday life, making support for ECPs both scalable and sustainable.

Patient or public contribution

The public was not directly involved in this research project. One member of our research team – and a listed co-author on this manuscript (BLP) – is a person with lived experience as a stroke caregiver. Their perspective informed all phases of the study, including the initial design and development of the research questions, data analysis and the review of the final manuscript.

Supplementary material

The supplementary material for this article can be found online.

References

- Aguirrezabal, A., Duarte, E., Rueda, N., Cervantes, C., Marco, E. and Escalada, F. (2013), "Effects of information and training provision in satisfaction of patients and carers in stroke rehabilitation", *NeuroRehabilitation*, Vol. 33 No. 4, pp. 639-647, doi: [10.3233/nre-130989](https://doi.org/10.3233/nre-130989).
- Andrew, N.E., Kilkenny, M.F., Naylor, R., Purvis, T. and Cadilhac, D.A. (2015), "The relationship between caregiver impacts and the unmet needs of survivors of stroke", *Patient Preference and Adherence*, pp. 1065-1073, doi: [10.2147/ppa.s85147](https://doi.org/10.2147/ppa.s85147).

- Araújo, O., Lage, I., Cabrita, J. and Teixeira, L. (2018), "Training informal caregivers to care for older people after stroke: a quasi-experimental study", *Journal of Advanced Nursing*, Vol. 74 No. 9, pp. 2196-2206, doi: [10.1111/jan.13714](https://doi.org/10.1111/jan.13714).
- Bakas, T., Clark, P.C., Kelly Hayes, M., King, R.B., Lutz, B.J. and Miller, E.L. (2014), "Evidence for stroke family caregiver and dyad interventions: a statement for healthcare professionals from the American heart association and American stroke association", *Stroke*, Vol. 45 No. 9, pp. 2836-2852, doi: [10.1161/STR.0000000000000033](https://doi.org/10.1161/STR.0000000000000033).
- Bakas, T., McCarthy, M. and Miller, E.T. (2017), "Update on the state of the evidence for stroke family caregiver and dyad interventions", *Stroke*, Vol. 48 No. 5, pp. e122-e125, doi: [10.1161/STROKEAHA.117.016052](https://doi.org/10.1161/STROKEAHA.117.016052).
- Barber, B.V., Gregg, E.E., Drake, E.K., Macdonald, M., Hickey, M., Flynn, C., Moody, E., Gallant, S.M., McConnell, E. and Weeks, L.E. (2024), "Transitional care programs for older adults moving from hospital to home in Canada: a systematic review of text and opinion", *PLOS One*, Vol. 19 No. 7, e0307306, doi: [10.1371/journal.pone.0307306](https://doi.org/10.1371/journal.pone.0307306).
- Bates, L. (2024), "Who care for our caregivers? Building the evidence for change", *Journal of Recovery in Mental Health*, Vol. 7 No. 2, pp. 8-13, doi: [10.33137/jrmh.v7i2.43069](https://doi.org/10.33137/jrmh.v7i2.43069).
- Bharmal, S., Nelson, M. and Saragosa, M. (2025), "Volunteer-supported care transition interventions for people living with dementia: a secondary analysis of a scoping review", *International Journal of Integrated Care*, Vol. 25 No. 2, p. 16, doi: [10.5334/ijic.9056](https://doi.org/10.5334/ijic.9056).
- Bierhals, C.C.B.K., Dal Pizzol, F.L.F., Low, G., Day, C.B., Santos, N.O.D. and Paskulin, L.M.G. (2023), "Quality of life in caregivers of aged stroke survivors in Southern Brazil: a randomized clinical trial", *Revista Latino-Americana de Enfermagem*, Vol. 31, e3657, doi: [10.1590/1518-8345.5935.3657](https://doi.org/10.1590/1518-8345.5935.3657).
- Bitek, D.E. and Erol, O. (2023), "The effect of discharge training and telephone counseling service on patients' functional status and caregiver burden after stroke: a randomized controlled trial", *Neurology Asia*, Vol. 28 No. 3, pp. 583-592, doi: [10.54029/2023xmx](https://doi.org/10.54029/2023xmx).
- Camak, D.J. (2015), "Addressing the burden of stroke caregivers: a literature review", *Journal of Clinical Nursing*, Vol. 24 Nos 17-18, pp. 2376-2382, doi: [10.1111/jocn.12884](https://doi.org/10.1111/jocn.12884).
- Cameron, J.I., Naglie, G., Green, T.L., Gignac, M.A., Bayley, M., Huijbregts, M. and Czerwonka, A. (2015), "A feasibility and pilot randomized controlled trial of the 'timing it right stroke family support program'", *Clinical Rehabilitation*, Vol. 29 No. 11, pp. 1129-1140, doi: [10.1177/0269215514564897](https://doi.org/10.1177/0269215514564897).
- Cameron, J.I., O'Connell, C., Foley, N., Salter, K., Booth, R., Boyle, R., Cheung, D., Cooper, N., Corriveau, H., Dowlatshahi, D., Dulude, A., Flaherty, P., Glasser, E., Gubitza, G., Hebert, D., Holzmann, J., Hurteau, P., Lamy, E., LeClaire, S., McMillan, T., Murray, J., Scarfone, D., Smith, E.E., Shum, V., Taylor, K., Taylor, T., Yanchula, C., Teasell, R. and Lindsay, P. (2016), "Canadian stroke best practice recommendations: managing transitions of care following stroke — guidelines update 2016", *International Journal of Stroke*, Vol. 11 No. 7, pp. 807-822, doi: [10.1177/1747493016660102](https://doi.org/10.1177/1747493016660102).
- Canadian Centre for Caregiving Excellence (2024), "Caring in Canada: survey insights from caregivers and care providers across Canada", available at: https://canadiancaregiving.org/wp-content/uploads/2024/06/CCCE_Caring-in-Canada.pdf (accessed 10 August 2025).
- Chartrand, J., Shea, B., Hutton, B., Dingwall, O., Kakkar, A., Chartrand, M. and Backman, C. (2023), "Patient and family centred care transition interventions for adults: a systematic review and meta-analysis of RCTs", *International Journal for Quality in Health Care*, Vol. 35 No. 4, mzad102, doi: [10.1093/intqhc/mzad102](https://doi.org/10.1093/intqhc/mzad102).
- Chen, L., Xiao, L.D. and De Bellis, A. (2016), "First time stroke survivors' and caregivers' perceptions of being engaged in rehabilitation", *Journal of Advanced Nursing*, Vol. 72 No. 1, pp. 73-84, doi: [10.1111/jan.12819](https://doi.org/10.1111/jan.12819).
- Chen, L., Xiao, L.D., Chamberlain, D. and Newman, P. (2021), "Enablers and barriers in hospital to home transitional care for stroke survivors and caregivers: a systematic review", *Journal of Clinical Nursing*, Vol. 30 Nos 19-20, pp. 2786-2807, doi: [10.1111/jocn.15807](https://doi.org/10.1111/jocn.15807).

- Choi, J.Y., Lee, S.H. and Yu, S. (2024), "Exploring factors influencing caregiver burden: a systematic review of family caregivers of older adults with chronic illness in local communities", *Healthcare*, Vol. 12 No. 10, p. 1002, doi: [10.3390/healthcare12101002](https://doi.org/10.3390/healthcare12101002).
- Crocker, T.F., Brown, L., Lam, N., Wray, F., Knapp, P. and Forster, A. (2021), "Information provision for stroke survivors and their carers", *Cochrane Database of Systematic Reviews*, Vol. 2021 No. 5, doi: [10.1002/14651858.CD001919.pub4](https://doi.org/10.1002/14651858.CD001919.pub4).
- Egan, M., Anderson, S. and McTaggart, J. (2010), "Community navigation for stroke survivors and their care partners: description and evaluation", *Topics in Stroke Rehabilitation*, Vol. 17 No. 3, pp. 183-190, doi: [10.1310/tsr1703-183](https://doi.org/10.1310/tsr1703-183).
- Ferguson, L., Perera, A., Farhad, M., Parwaiz, A. and Stutzman, S.E. (2020), "Alleviating care partner post-stroke stress through education", *Journal of Neuroscience Nursing*, Vol. 52 No. 3, pp. 117-121, doi: [10.1097/jnn.0000000000000510](https://doi.org/10.1097/jnn.0000000000000510).
- Forster, A., Brown, L., Smith, J., House, A., Knapp, P., Wright, J.J. and Young, J. (2012), "Information provision for stroke survivors and their caregivers", *Cochrane Database of Systematic Reviews*, Vol. 2012, doi: [10.1002/14651858.CD001919.pub3](https://doi.org/10.1002/14651858.CD001919.pub3).
- Fuller, T.E., Pong, D.D., Piniella, N., Pardo, M., Bessa, N., Yoon, C., Dalal, A.K. and Schnipper, J.L. (2020), "Interactive digital health tools to engage patients and caregivers in discharge preparation: implementation study", *Journal of Medical Internet Research*, Vol. 22 No. 4, e15573, doi: [10.2196/15573](https://doi.org/10.2196/15573).
- Garnett, A., Ploeg, J., Markle Reid, M. and Strachan, P.H. (2022), "Factors impacting the access and use of formal health and social services by caregivers of stroke survivors: an interpretive description study", *BMC Health Services Research*, Vol. 22 No. 1, p. 433, doi: [10.1186/s12913-022-07804-x](https://doi.org/10.1186/s12913-022-07804-x).
- Garrity, C., Gartlehner, G., Nussbaumer-Streit, B., King, V.J., Hamel, C., Kamel, C. and Stevens, A. (2021), "Cochrane rapid reviews methods group offers evidence-informed guidance to conduct rapid reviews", *Journal of Clinical Epidemiology*, Vol. 130, pp. 13-22, doi: [10.1016/j.jclinepi.2020.10.007](https://doi.org/10.1016/j.jclinepi.2020.10.007).
- Gough, C., Baker, N., Weber, H., Lewis, L.K., Barr, C., Maeder, A. and George, S. (2022), "Integrating community participation in the transition of older adults from hospital to home: a scoping review", *Disability and Rehabilitation*, Vol. 44 No. 17, pp. 4896-4908, doi: [10.1080/09638288.2021.1912197](https://doi.org/10.1080/09638288.2021.1912197).
- Hahn-Goldberg, S., Jeffs, L., Troup, A., Kubba, R. and Okrainec, K. (2018), "'We are doing it together': the integral role of caregivers in a patients' transition home from the medicine unit", *PLoS One*, Vol. 13 No. 5, e0197831, doi: [10.1371/journal.pone.0197831](https://doi.org/10.1371/journal.pone.0197831).
- Harmon, J. and Kyle, G. (2022), "Connecting to the trail: natural spaces as places of healing", *Leisure Sciences*, Vol. 44 No. 8, pp. 1112-1127, doi: [10.1080/01490400.2020.1712282](https://doi.org/10.1080/01490400.2020.1712282).
- Holodinsky, J.K., Lindsay, P., Amy, Y.X., Ganesh, A., Joundi, R.A. and Hill, M.D. (2023), "Estimating the number of hospital or emergency department presentations for stroke in Canada", *Canadian Journal of Neurological Sciences*, Vol. 50 No. 6, pp. 820-825.
- Hosseini, A., Sharifi, N., Dehghanrad, F. and Sharifipour, E. (2022), "Effect of telenursing on caregiver burden of care and incidence of some complications in patients with acute stroke discharged from neurological wards: a randomized control trial", *Shiraz E-Medical Journal*, Vol. 23 No. 8, doi: [10.5812/semj-123479](https://doi.org/10.5812/semj-123479).
- Howitt, L., Jacob, G., Zucal, G., Smith, J., Crocker-Ellacott, R. and Sharkey, S. (2024), "Navigation support during transitions in care for persons with complex care needs: a systematic review", *Healthcare*, Vol. 12 No. 18, p. 1814, doi: [10.3390/healthcare12181814](https://doi.org/10.3390/healthcare12181814).
- Hu, P., Yang, Q., Kong, L., Hu, L. and Zeng, L. (2018), "Relationship between the anxiety/depression and care burden of the major caregiver of stroke patients", *Medicine*, Vol. 97 No. 40, e12638, doi: [10.1097/md.00000000000012638](https://doi.org/10.1097/md.00000000000012638).
- Iso-Ahola, S.E. and Baumeister, R.F. (2023), "Leisure and meaning in life", *Frontiers in Psychology*, Vol. 14, 1074649, doi: [10.3389/fpsyg.2023.1074649](https://doi.org/10.3389/fpsyg.2023.1074649).

- Jammal, M., Kolt, G.S., Liu, K.P., Dennaoui, N. and George, E.S. (2024), "The impact of caregiving on the roles and valued activities of stroke carers: a systematic review of qualitative studies", *PLOS One*, Vol. 19 No. 5, e0304501, doi: [10.1371/journal.pone.0304501](https://doi.org/10.1371/journal.pone.0304501).
- Jarvis, A., Smith, M., McAlpine, L. and Gillespie, D.C. (2019), "Caring for the carer of someone who has had a stroke: findings from an innovative project", *International Journal of Therapy and Rehabilitation*, Vol. 26 No. 8, pp. 1-11, doi: [10.12968/ijtr.2017.0167](https://doi.org/10.12968/ijtr.2017.0167).
- Kalra, L., Evans, A., Perez, I., Melbourn, A., Patel, A., Knapp, M. and Donaldson, N. (2004), "Training carers of stroke patients: randomised controlled trial", *BMJ*, Vol. 328 No. 7448, p. 1099, doi: [10.1136/bmj.328.7448.1099](https://doi.org/10.1136/bmj.328.7448.1099).
- Katan, M. and Luft, A. (2018), "Global burden of stroke", *Seminars in Neurology*, Vol. 38 No. 2, pp. 208-211, doi: [10.1055/s-0038-1649503](https://doi.org/10.1055/s-0038-1649503).
- King, J., O'Neill, B., Ramsay, P., Linden, M.A., Darweish Medniuk, A., Outtrim, J. and Blackwood, B. (2019), "Identifying patients' support needs following critical illness: a scoping review of the qualitative literature", *Critical Care*, Vol. 23 No. 1, p. 187, doi: [10.1186/s13054-019-2441-6](https://doi.org/10.1186/s13054-019-2441-6).
- Kokorelias, K.M., Lu, F.K., Santos, J.R., Xu, Y., Leung, R. and Cameron, J.I. (2020), "'Caregiving is a full time job' impacting stroke caregivers' health and well being: a qualitative meta synthesis", *Health and Social Care in the Community*, Vol. 28 No. 2, pp. 325-340, doi: [10.1111/hsc.12895](https://doi.org/10.1111/hsc.12895).
- Kuo, W.Y., Chen, C.Y., Wang, J., Wang, C.M., Chen, M.C. and Chang, T.Y. (2024), "Evaluating the combination of in-person and electronic social networking services for family caregivers of stroke survivors: a quasi-experimental analysis", *Journal of Nursing Scholarship*, Vol. 57 No. 2, pp. 216-227, doi: [10.1111/jnu.13022](https://doi.org/10.1111/jnu.13022).
- Leighton, J., Lopez, K.J. and Johnson, C.W. (2021), "'There is always progress to be made': reflective narratives on outdoor therapeutic recreation for mental health support", *Therapeutic Recreation Journal*, Vol. 55 No. 2, pp. 185-203, doi: [10.18666/TRJ-2021-V55-12-10653](https://doi.org/10.18666/TRJ-2021-V55-12-10653).
- Leighton, J., Nelson, M.L., Sheppard, C.L., Wasilewski, M., Reis, L., Vijayakumar, A., Simpson, R., Robinson, L.L., Levy, C., Steinberg, R. and Goulding, S. (2025a), "'You're alive, but are you living?' Exploring long COVID (LC)'s impact on social and leisure well-being for individuals and caregivers", *Psychology and Health*, pp. 1-21, doi: [10.1080/08870446.2025.2552233](https://doi.org/10.1080/08870446.2025.2552233).
- Leighton, J., Saragosa, M., Nelson, M.L.A., Ludwig Prout, B. and MacEachern, E. (2025b), "Community-involved care transition interventions to support essential care partners of stroke survivors: a rapid review protocol", *BMJ Open*, Vol. 15 No. 11, e100720.
- Liebzeit, D., Rutkowski, R., Arbaje, A.I., Fields, B. and Werner, N.E. (2021), "A scoping review of interventions for older adults transitioning from hospital to home", *Journal of the American Geriatrics Society*, Vol. 69 No. 10, pp. 2950-2962, doi: [10.1111/jgs.17323](https://doi.org/10.1111/jgs.17323).
- Lin, S., Wang, C., Wang, Q., Xie, S., Tu, Q., Zhang, H., Peng, M., Zhou, J. and Redfern, J. (2022a), "The experience of stroke survivors and caregivers during hospital to home transitional care: a qualitative longitudinal study", *International Journal of Nursing Studies*, Vol. 130, 104213, doi: [10.1016/j.ijnurstu.2022.104213](https://doi.org/10.1016/j.ijnurstu.2022.104213).
- Lin, S., Xiao, L.D., Chamberlain, D., Ullah, S., Wang, Y., Shen, Y., Chen, Z. and Wu, M. (2022b), "Nurse-led health coaching programme to improve hospital-to-home transitional care for stroke survivors: a randomised controlled trial", *Patient Education and Counselling*, Vol. 105 No. 4, pp. 917-925.
- Lincoln, N.B., Francis, V.M., Lilley, S.A., Sharma, J.C. and Summerfield, M. (2003), "Evaluation of a stroke family support organiser: a randomized controlled trial", *Stroke*, Vol. 34 No. 1, pp. 116-121, doi: [10.1161/01.str.0000047850.33686.32](https://doi.org/10.1161/01.str.0000047850.33686.32).
- Lindblom, S. (2021), "Understanding the links: the exploration of care transitions between hospital and continued rehabilitation in the home after stroke", Doctoral dissertation, Karolinska Institute, Sweden.
- Liu, B., Cai, J. and Zhou, L. (2025), "Effectiveness of integrated care models for stroke patients: a systematic review and meta-analysis", *Journal of Nursing Scholarship*, Vol. 57 No. 2, pp. 266-297, doi: [10.1111/jnu.13027](https://doi.org/10.1111/jnu.13027).

- Lowther, H.J., Harrison, J., Hill, J.E., Gaskins, N.J., Lazo, K.C., Clegg, A.J., Watkins, C.L., Garrett, H., Gibson, J.M.E. and Lightbody, C.E. (2021), "The effectiveness of quality improvement collaboratives in improving stroke care and the facilitators and barriers to their implementation: a systematic review", *Implementation Science*, Vol. 16 No. 1, p. 95, doi: [10.1186/s13012-021-01162-8](https://doi.org/10.1186/s13012-021-01162-8).
- Lutz, B.J., Young, M.E., Cox, K.J., Martz, C. and Rae Creasy, K. (2011), "The crisis of stroke: experiences of patients and their family caregivers", *Topics in Stroke Rehabilitation*, Vol. 18 No. 6, pp. 786-797, doi: [10.1310/tsr1806-786](https://doi.org/10.1310/tsr1806-786).
- Lutz, B.J., Kucharska-Newton, A.M., Jones, S.B., Psioda, M.A., Gesell, S.B., Coleman, S.W., Duncan, P.W., Radman, M.D., Levy, S., Bettger, J.P., Freburger, J.K., Chou, A., Celestino, J., Rosamond, W.D. and Bushnell, C.D. (2023), "Familial caregiving following stroke: findings from the comprehensive post-acute stroke services (COMPASS) pragmatic cluster randomized transitional care study", *Topics in Stroke Rehabilitation*, Vol. 30 No. 5, pp. 436-447, doi: [10.1080/10749357.2022.2077520](https://doi.org/10.1080/10749357.2022.2077520).
- March of Dimes Canada (2026), "Home", available at: <https://www.marchofdimes.ca/en-ca> (accessed 27 June 2025).
- Markle Reid, M., Fisher, K., Walker, K.M., Beauchamp, M., Cameron, J.I., Dayler, D., Whitmore, C., Gafni, A., Ganann, R., Hajas, K., Koetsier, B., Mahony, R., Pollard, C., Prescott, J. and Rooke, T. (2023), "The stroke transitional care intervention for older adults with stroke and multimorbidity: a multisite pragmatic randomized controlled trial", *BMC Geriatrics*, Vol. 23 No. 1, p. 687, doi: [10.1186/s12877-023-04403-1](https://doi.org/10.1186/s12877-023-04403-1).
- Marston, C., Morgan, D.D., Philip, J. and Agar, M. (2023), "Supporting carers as patients move between hospital and home: a systematic review of interventions to support these transitions in care", *Journal of Palliative Medicine*, Vol. 26 No. 2, pp. 270-298, doi: [10.1089/jpm.2022.0221](https://doi.org/10.1089/jpm.2022.0221).
- McCauley, R., McQuillan, R., Ryan, K. and Foley, G. (2021), "Mutual support between patients and family caregivers in palliative care: a systematic review and narrative synthesis", *Palliative Medicine*, Vol. 35 No. 5, pp. 875-885, doi: [10.1177/0269216321999962](https://doi.org/10.1177/0269216321999962).
- Mitchell, S.E., Laurens, V., Weigel, G.M., Hirschman, K.B., Scott, A.M., Nguyen, H.Q., Jack, B.W., Laird, L., Levine, C., Davis, T.C., Gass, B., Shaid, E., Li, J. and Williams, M.V. (2018), "Care transitions from patient and caregiver perspectives", *The Annals of Family Medicine*, Vol. 16 No. 3, pp. 225-231, doi: [10.1370/afm.2222](https://doi.org/10.1370/afm.2222).
- Mou, H., Wong, M.S. and Chien, W.T. (2021), "Effectiveness of dyadic psychoeducational intervention for stroke survivors and family caregivers on functional and psychosocial health: a systematic review and meta-analysis", *International Journal of Nursing Studies*, Vol. 120, 103969, doi: [10.1016/j.ijnurstu.2021.103969](https://doi.org/10.1016/j.ijnurstu.2021.103969).
- Mou, H., Lam, S.K.K. and Chien, W.T. (2022), "Effects of a family-focused dyadic psychoeducational intervention for stroke survivors and their family caregivers: a pilot study", *BMC Nursing*, Vol. 21 No. 1, p. 364, doi: [10.1186/s12912-022-01145-0](https://doi.org/10.1186/s12912-022-01145-0).
- Mountain, A., Patrice Lindsay, M., Teasell, R., Salbach, N.M., de Jong, A., Foley, N., Bhogal, S., Bains, N., Bowes, R., Cheung, D., Corriveau, H., Joseph, L., Lesko, D., Millar, A., Parappilly, B., Pikula, A., Scarfone, D., Rochette, A., Taylor, T., Vallentin, T., Dowlatshahi, D., Gubituz, G., Casaubon, L.K. and Cameron, J.I. (2020), "Canadian stroke best practice Recommendations: rehabilitation, recovery and community participation following stroke. Part two: transitions and community participation following stroke", *International Journal of Stroke*, Vol. 15 No. 7, pp. 789-806, doi: [10.1177/1747493019897847](https://doi.org/10.1177/1747493019897847).
- Nazari, A.M., Abbaszadeh, A., Kazemi, R., Yousofvand, V. and Zandi, M. (2024), "The effect of online training based on stroke educational program on patient's quality of life and caregiver's care burden: a randomized controlled trial", *BMC Nursing*, Vol. 23 No. 1, p. 958, doi: [10.1186/s12912-024-02629-x](https://doi.org/10.1186/s12912-024-02629-x).
- Nelson, M.L., Saragosa, M., Singh, H. and Yi, J. (2024a), "Examining the role of third sector organization volunteers in facilitating hospital to home transitions for older adults – a collective case study", *International Journal of Integrated Care*, Vol. 24 No. 1, p. 16, doi: [10.5334/ijic.7670](https://doi.org/10.5334/ijic.7670).

- Nelson, M.L., Saragosa, M. and Miller, R. (2024b), "The third sector in integrated care: partner, provider, or both?", *International Journal of Integrated Care*, Vol. 24 No. 3, p. 9, doi: [10.5334/ijic.8149](https://doi.org/10.5334/ijic.8149).
- Ng, S., Chu, M., Wu, A. and Cheung, P. (2005), "Effectiveness of home-based occupational therapy for early discharged patients with stroke", *Hong Kong Journal of Occupational Therapy*, Vol. 15 No. 1, pp. 27-36, doi: [10.1016/s1569-1861\(09\)70031-2](https://doi.org/10.1016/s1569-1861(09)70031-2).
- Osborne, C.L. and Neville, M. (2019), "Understanding the experience of early supported discharge from the perspective of patients with stroke and their carers and health care providers: a qualitative review", *Nursing Clinics of North America*, Vol. 54 No. 3, pp. 367-384, doi: [10.1016/j.cnur.2019.04.006](https://doi.org/10.1016/j.cnur.2019.04.006).
- Ostwald, S.K., Godwin, K.M., Cron, S.G., Kelley, C.P., Hersch, G. and Davis, S. (2014), "Home-based psychoeducational and mailed information programs for stroke caregiving dyads post discharge: a randomized trial", *Disability and Rehabilitation*, Vol. 36 No. 1, pp. 55-62, doi: [10.3109/09638288.2013.777806](https://doi.org/10.3109/09638288.2013.777806).
- O'Callaghan, G., Fahy, M., Murphy, P., Langhorne, P., Galvin, R. and Horgan, F. (2022), "Effectiveness of interventions to support the transition home after acute stroke: a systematic review and meta-analysis", *BMC Health Services Research*, Vol. 22 No. 1, p. 1095, doi: [10.1186/s12913-022-08473-6](https://doi.org/10.1186/s12913-022-08473-6).
- Parmar, J., L'Heureux, T., Lewanczuk, R., Lee, J., Charles, L., Sproule, L., Anderson, S., Chaudhuri, E.R., Berry, J., Shapkin, K., Powell, L., Nicholas, D., Tarnowski, G., Leslie, M., Lobchuk, M., Kaattari, J., Porter, A., Ewa, V., Podlosky, L., Pei, J., Mosaico, S., Penner, J. and Saunders, S. (2025), "Transforming care through co-design: developing inclusive caregiver-centered education in healthcare", *Healthcare*, Vol. 13 No. 3, p. 254, doi: [10.3390/healthcare13030254](https://doi.org/10.3390/healthcare13030254).
- Pitthayapong, S., Thiangtam, W., Powwattana, A., Leelacharas, S. and Waters, C.M. (2017), "A community-based program for family caregivers for post-stroke survivors in Thailand", *Asian Nursing Research*, Vol. 11 No. 2, pp. 150-157, doi: [10.1016/j.anr.2017.05.009](https://doi.org/10.1016/j.anr.2017.05.009).
- Pope, N.D., Baldwin, P.K., Gibson, A. and Smith, K. (2022), "Becoming a caregiver: experiences of young adults moving into family caregiving roles", *Journal of Adult Development*, Vol. 29 No. 2, pp. 147-158, doi: [10.1007/s10804-021-09391-3](https://doi.org/10.1007/s10804-021-09391-3).
- Pucciarelli, G., Ausili, D., Galbussera, A.A., Rebori, P., Savini, S., Simeone, S., Alvaro, R. and Vellone, E. (2018), "Quality of life, anxiety, depression and burden among stroke caregivers: a longitudinal, observational multicentre study", *Journal of Advanced Nursing*, Vol. 74 No. 8, pp. 1875-1887, doi: [10.1111/jan.13695](https://doi.org/10.1111/jan.13695).
- Putra, K.A.N., Suyasa, I.G.P.D., Kamaryati, N.P. and Dharmapatni, N.W.K. (2024), "Development of a self care guideline to prevent rehospitalization in stroke patients: a modified Delphi study", *Jurnal Ners*, Vol. 19 No. 1, pp. 21-30, doi: [10.20473/jn.v19i1.48937](https://doi.org/10.20473/jn.v19i1.48937).
- Ramazanu, S., Chiang, V.C.L. and Valimaki, M. (2021), "The experiences and evaluation of a complex intervention for couples coping with stroke", *Journal of Neuroscience Nursing*, Vol. 53 No. 1, pp. 18-23, doi: [10.1097/jnn.0000000000000564](https://doi.org/10.1097/jnn.0000000000000564).
- Ritsma, B.R., Gariscsak, P.J., Vyas, A., Chan Nguyen, S. and Appireddy, R. (2023), "The virtual family conference in stroke rehabilitation: education, preparation and transition planning", *Clinical Rehabilitation*, Vol. 37 No. 8, pp. 1099-1110, doi: [10.1177/02692155221146448](https://doi.org/10.1177/02692155221146448).
- Shamseer, L., Moher, D., Clarke, M., Liberati, A., Petticrew, M., Shekelle, P. and Stewart, L.A., PRISMA-P Group (2015), "Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation", *BMJ*, Vol. 350 jan02 1, p. g7647, doi: [10.1136/bmj.g7647](https://doi.org/10.1136/bmj.g7647).
- Shi, J.M., Wang, K., Yoo, D.W., Karkar, R. and Saha, K. (2025), "Balancing caregiving and self care: exploring mental health needs of Alzheimer's and dementia caregivers", arXiv preprint, arXiv: 2506.14196.
- Shyu, Y.I.L., Chen, M.C., Chen, S.T., Wang, H.P. and Shao, J.H. (2008), "A family caregiver-oriented discharge planning program for older stroke patients and their family caregivers", *Journal of Clinical Nursing*, Vol. 17 No. 18, pp. 2497-2508, doi: [10.1111/j.1365-2702.2008.02450.x](https://doi.org/10.1111/j.1365-2702.2008.02450.x).

- Shyu, Y.I.L., Kuo, L.M., Chen, M.C. and Chen, S.T. (2010), "A clinical trial of an individualised intervention programme for family caregivers of older stroke victims in Taiwan", *Journal of Clinical Nursing*, Vol. 19 Nos 11-12, pp. 1675-1685, doi: [10.1111/j.1365-2702.2009.03124.x](https://doi.org/10.1111/j.1365-2702.2009.03124.x).
- Singh, H., Nguyen, T., Hahn Goldberg, S., Lewis Fung, S., Smith Bayley, S. and Nelson, M.L. (2022), "A qualitative study exploring the experiences of individuals living with stroke and their caregivers with community based poststroke services: a critical need for action", *PLOS One*, Vol. 17 No. 10, e0275673, doi: [10.1371/journal.pone.0275673](https://doi.org/10.1371/journal.pone.0275673).
- Suksatan, W. and Tankumpuan, T. (2022), "The effectiveness of transition care interventions from hospital to home on rehospitalization in older patients with heart failure: an integrative review", *Home Health Care Management and Practice*, Vol. 34 No. 1, pp. 63-71, doi: [10.1177/108482232111023887](https://doi.org/10.1177/108482232111023887).
- Tricco, A.C., Antony, J., Zarin, W., Striffler, L., Ghassemi, M., Ivory, J., Straus, S.E., Hutton, B. and Moher, D. (2015), "A scoping review of rapid review methods", *BMC Medicine*, Vol. 13 No. 1, p. 224, doi: [10.1186/s12916-015-0465-6](https://doi.org/10.1186/s12916-015-0465-6).
- Vielvoye, M., Nanninga, C.S., Achterberg, W.P. and Caljouw, M.A. (2023), "Informal caregiver stroke program in geriatric rehabilitation of stroke patients: a qualitative study", *Journal of Clinical Medicine*, Vol. 12 No. 9, p. 3085, doi: [10.3390/jcm12093085](https://doi.org/10.3390/jcm12093085).
- Woodward, A.T., Fritz, M.C., Hughes, A.K., Coursaris, C.K., Swierenga, S.J., Freddolino, P.P. and Reeves, M.J. (2021), "Effect of transitional care stroke case management interventions on caregiver outcomes: the MISTT randomized trial", *Social Work in Health Care*, Vol. 60 No. 10, pp. 642-655, doi: [10.1080/00981389.2021.2009958](https://doi.org/10.1080/00981389.2021.2009958).
- Youens, D., Parsons, R., Toye, C., Slatyer, S., Aoun, S., Hill, K.D., Moorin, R., Maher, S., Davis, S. and Osseiran-Moisson, R. (2019), "The cost effectiveness of a telephone-based intervention to support caregivers of older people discharged from hospital", *BMC Geriatrics*, Vol. 19 No. 1, p. 68, doi: [10.1186/s12877-019-1085-3](https://doi.org/10.1186/s12877-019-1085-3).
- Yuen, F., Ranahan, P., Linds, W. and Goulet, L. (2021), "Leisure, cultural continuity and life promotion", *Annals of Leisure Research*, Vol. 24 No. 1, pp. 92-113, doi: [10.1080/11745398.2019.1653778](https://doi.org/10.1080/11745398.2019.1653778).
- Zhan, Y., Yu, J., Chen, Y., Liu, Y., Wang, Y., Wan, Y. and Li, S. (2022), "Family caregivers' experiences and needs of transitional care during the transfer from intensive care unit to a general ward: a qualitative study", *Journal of Nursing Management*, Vol. 30 No. 2, pp. 592-599, doi: [10.1111/jonm.13518](https://doi.org/10.1111/jonm.13518).

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