
Exploring Health Care Providers' Perceptions of the Needs of Stroke Carers: Informing Development of an Optimal Health Program

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Background: Health care provider experiences of the carer have been researched, but little is written about how these can inform development of support programs. **Objectives:** This study aimed to (1) explore health care provider perceptions of stroke carer roles and support needs and (2) examine carer needs across the stroke care trajectory to assist with development of an Optimal Health Program (OHP) to support carers. This study is part of a staged program of research that will evaluate and refine the OHP. **Methods:** Four dual-moderated semi-structured focus groups of stroke health care providers across acute, subacute, and community rehabilitation services were conducted. Facilitators used a semi-structured focus group schedule to guide discussion. Sessions were recorded, transcribed, and analyzed using thematic and content analysis. **Results:** Three key themes emerged: transition, information, and impact of stroke. A number of subthemes highlighted the distinct roles of health care providers and carers. Specific elements of the OHP were identified as having the potential to advance support for carers across the stroke care trajectory. **Discussion:** Findings support the integration of an OHP for carers within existing stroke care services in Australian public hospital and community settings. **Conclusion:** This study suggests how health care provider experiences could inform a self-management OHP to assist carers in navigating stroke services and to address their health-related concerns. **Key words:** carers, carer support, focus groups, health care provider, optimal health, stroke

Stroke is a chronic illness that places a significant burden on individuals, families, and communities internationally.^{1,2} The primary responsibility of providing care often falls to family and significant others, often with one person carrying out the majority of caregiving duties.^{3,4} A variety of health care providers are involved in stroke rehabilitation, including medical and nursing professionals, allied health care practitioners,

and mental health clinicians. Health care providers are perceived as a source of support and information not only for people with stroke, but also for their carers,⁵ but there is limited research in which providers are included as study participants and questioned about their perceptions of stroke carers' roles and needs.⁶⁻⁸ Clarifying their views could inform programs designed to address gaps in stroke services specific to carer support.

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Health Care Providers' Perspective

In a Canadian setting, Cameron et al⁷ interviewed stroke family caregivers and health care providers across acute, rehabilitation, and community services. Framework analysis identified 3 key themes: type and intensity of support, who provides support and how, and what and whom is the primary focus of care. There was consensus that less information is needed during the acute phase of diagnosis but more information is needed during the preparation and transitioning to discharge home. Carers tended to feel overwhelmed by medical information, and health care providers felt uncertain about when caregivers were ready to receive information. Carer participants also indicated that support of family and friends decreased over time. Health care providers and caregivers agreed that the patient should be the focus of care at diagnosis and stabilization, and that caregivers should be increasingly prioritized with preparation for discharge. Health care providers and caregivers highlighted different challenges during the preparation process. For health care providers, this was accessing caregivers during business hours; for caregivers, challenges were feeling they did not have a voice in home care service decisions. These themes indicate that caregiver needs and health care provider roles change across the illness trajectory.

In the United Kingdom, Morris, Payne, and Lambert⁶ conducted focus groups to explore the stroke care experiences of patients, carers, and health care providers. Thematic analysis revealed 6 themes: stroke service as specialist service, splits or separations in services, availability of care, consistency of care, staff morale, and wish for change/recommendations. In terms of a specialist service, health care providers believed that the ward environment could offer emotional support by linking patients and carers with people in similar positions. Carers and health care professionals in this study noted their concerns about the lack of availability of staff and the impact on recovery if, for instance, patients missed an occupational therapy or physiotherapy session.

In another UK-based study, Greenwood et al⁸ explored the perceptions of primary care practitioners and carers of stroke survivors

regarding general practice teams and support measures for carers. Results were gathered through semi-structured interviews. Practitioners concurred that although general practice was an appropriate place to provide support, practitioners found it difficult to identify carers' needs, particularly because carers did not tend to present to the practice asking for help, preferring to "go it alone." Practitioners also saw their roles as reactive rather than proactively seeking out carers' needs, mainly due to time constraints in seeing to both patient and carer needs. Provider and carer participants also had similar views about carer training, which might involve a variety of components such as practical training (eg, diet, using aids) and support for problems associated with caring such as depression. Although these findings are insightful, it is less clear whether they translate to Australian public health care settings, but they do highlight the difficulty of supporting and engaging carers.

Carers of People with Stroke

Stroke can have significant psychological impact on carers who often feel unprepared to deal with the physical, cognitive, and emotional demands.^{9,10} The nonprofessional carer role is complex and the care burden is under-recognized; often carers do not get what they need in terms of support and information.^{11,12} Carers often experience adverse health effects and have high rates of depression,¹³ anxiety,¹⁴ cardiovascular disease,¹⁵ and mortality.¹⁶ They may also have to reduce their occupational and social activities.¹⁷

Robinson et al¹⁸ reviewed the literature and highlighted carers' needs for information, ways to manage stress and depression (eg, through relaxation methods), social support, health maintenance, and problem-solving skills. Ski and O'Connell¹⁰ conducted a longitudinal study in metropolitan Victoria, Australia, to explore the impact of the caring role on stroke carers. The most consistently reported concern was lack of follow-up for initiating home rehabilitation. Findings suggested that early discharge combined with lack of appropriate planning can contribute to carer burden. Similar findings were noted by Perry and Middleton¹⁹ in a study of 32 Australian

stroke carers who were interviewed by telephone 1 and 3 months post discharge. In particular, the main concerns of carers were preparation for life after discharge and the need for information, which was sometimes believed to be inadequate.

Optimal Health Program

The Optimal Health Program (OHP) is a multidisciplinary collaborative therapy and self-efficacy intervention to support people with mental or physical illness.²⁰⁻²² The program promotes hope, growth, and partnership²⁰⁻²² by providing a comprehensive therapeutic approach for consumers, clinicians, service providers, and others to work systematically toward the achievement of optimal health outcomes.²¹ The concepts of self-efficacy and care coordination are integral components of the OHP. The OHP model is focused on well-being with a capacity to include additional components addressing particular mental or physical health problems. The OHP is delivered in 10 sequential sessions comprising: (1) interagency collaboration, (2) care coordination,^{23,24} and (3) support information and identification of community support and a booster. See **Table 1** for OHP session topics.

Other psychosocial interventions to support informal carers of stroke survivors have shown promising results.²³⁻²⁵ However, we are not aware of any programs that integrate carer interventions with care coordination in Australia. There is a gap in knowledge about how health care providers’ perceptions inform the implementation of carer support programs. Our research explores health care providers’ experiences to assist in identifying strategies for customizing the OHP to support carers of people with stroke. This study is part of a wider program of research designed to inform the adaptation of the OHP for carers of people with stroke. The self-management foundations of the OHP are particularly relevant for carers who provide the majority of care, especially after the transition away from formal services. The collaborative team focus of the OHP also provides an environment for carers that facilitates their ability to develop confidence, learn strategies for self-care, and identify where to obtain further assistance if required. Our aims were to (1) explore

health care providers’ perceptions of the stroke carer role and carer support needs across the stroke care trajectory and (2) identify strategies for the modification of the OHP such that it could be integrated into existing stroke health services.

Methods

Participants and setting

A purposive sampling strategy was used to recruit 23 health care providers who represented a range of disciplines. Inclusion criteria were being employed with a Victorian public health service in stroke care, age greater than 18 years, and ability to converse in English. All medical, nursing, and allied health care providers were invited to participate, and there was no requirement for participants to have a specific level or number

Table 1. Revised Optimal Health Program

Session	Key session topics	Objectives
1	Introduction: What is health ?	Understanding our behavior and our health
2	Optimal Health Wheel	Understanding the 6 areas of health: social, physical, emotional, intellectual, employment (engagement), and spiritual (values)
3	I Can Do Model Part 1 Health Plan 1: Managing optimal health	Strengths and vulnerabilities – understanding a balance
4	I Can Do Model Part 2 Health Plan 2: Managing suboptimal health	Stressors and strategies – understanding and monitoring impact
5	Medication	Understanding medication, physical health, and metabolic monitoring
6	Collaborative partners & strategies Health Plan 3: Episode of illness	Identifying key partnership and supports
7	Change enhancement	Understanding past events and defining change
8	Visioning and goal setting	Creative problem solving and planning
9	Building health plans	Health plans 1, 2, & 3 – maintaining well-being
10	Booster: What is my health like now ?	Reviewing health plans and reflecting on achievements

of years of experience. Four focus groups were conducted at 4 clinical settings: 1 group from acute care, 2 from subacute care (rehabilitation and transitional care), and 1 from community rehabilitation. The average focus group duration was 54 minutes. **Table 2** presents the breakdown of disciplines represented by participants in each focus group. Medical providers were approached but were unable to attend the focus groups.

Design

A cross-sectional qualitative focus group design was used, with dual-moderated focus groups.²⁶

Procedure

This study was approved by the relevant human research ethics committee. We reviewed the relevant literature and developed a semi-structured focus group schedule. All participants provided written informed consent; participant identifiers were removed before data analysis. Nurse unit managers were approached and assisted in identifying staff who were eligible for the study and arranging focus group times and locations. To maximize a range of responses, we conducted focus groups in key service areas including acute, subacute, and community stroke services and we targeted staff from each professional discipline (eg, physiotherapy). Data saturation was achieved when no new themes emerged across focus groups.

Table 2. Breakdown of focus group participants by sex and discipline

Group	n	Sex (M/F)	Disciplines
Acute	8	2/6	Dietician, Occupational Therapy, Nursing, Pastoral Care, Physiotherapy, Social Work
Subacute rehabilitation	7	1/6	Nursing, Nurse Unit Manager, Physiotherapy, Social Work, Speech Pathology
Subacute transitional care	5	0/5	Case Manager–Social Work, Team Leader–Social Work
Community rehabilitation	3	0/3	Occupational Therapy, Social Work, Speech Pathology

A dual-moderator approach was used; the second moderator was able to ask probing questions and keep detailed notes contemporaneously with the interview, something noted as lacking in single-facilitator focus group approaches.²⁷ The moderators were researchers with qualitative research and group work experience. Focus groups were audiorecorded and transcribed verbatim. Field notes were kept, and debriefing sessions between facilitators were held after interviews. All notes informed data analysis.

Data analysis

Four researchers independently analyzed, coded (identifying key passages and words), and categorized (classifying key passages and words within themes) verbatim transcription, drawing on pragmatic thematic analysis to form emergent themes. The pragmatic data analysis approach of Halcomb and Davidson²⁸ was used for the purpose of focus group data analysis. This 6-stage approach is illustrated in **Figure 1**. Participant responses were explored in more detail after focus groups

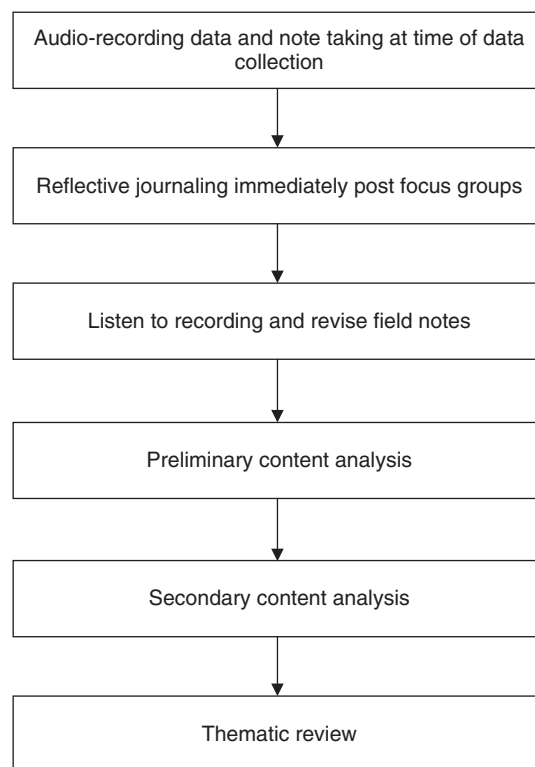


Figure 1. Pragmatic data analysis as described by Halcomb and Davidson.²⁸

were conducted. A further review of notes was undertaken immediately after the focus groups were conducted. Then audiotapes were reviewed to ensure the accuracy of notes taken. Transcripts were re-reviewed and common responses were grouped to form themes. Four fellow researchers reviewed the notes and listened to the audiotapes for secondary validation of themes. Then the data were linked to findings from the associated literature. After initial data analysis was complete, the 4 researchers met to discuss their findings and arrive at a consensus.

Results

Three major themes emerged, each incorporating subthemes (Table 3). The themes were transition, information, and impact of stroke. To identify various health care settings/groups, the following classifications are used: acute unit (A), subacute rehabilitation (SA1), subacute transitional care (SA2), and community rehabilitation (CR). Clinical applicability of the OHP is presented for each of the key themes.

Key theme: Transition

Participants discussed transitions in the stroke trajectory including progression from symptoms to stroke diagnosis and transition from acute care to subacute care and to home. The groups also identified transitions that occurred as individuals adopted a caring role. Two subthemes emerged

Table 3. Themes and subthemes derived from data analysis

Themes	Subthemes
Transition	Health care providers' role across stages of the stroke trajectory Carers' transition to a caring role and how this role changes over time
Information	Delivery of information by health care providers Carers' responses to information and difficulties comprehending implications
Impact of stroke	Health care providers' role in supporting the carer and person with stroke and maintaining hope Carers' experiences of the impact of stroke

reflecting health care providers' views of their professional roles and their views of the carers' role.

Subtheme: Transition in health care providers' role

There was consensus that support for carers of patients with stroke by health care providers across the trajectory is crucial. Participants acknowledged that their roles could be challenged by workload.

I would like to give more time to families but feel constrained by my workload for the shift and sometimes you see husbands or wives or carers and you know in your heart they are finding things difficult and that is very hard and I feel it's part of my work... (SA1)

Participants identified how lack of access to counselling support affected daily work.

I think the support around the emotional journey, both client and families is a big gap because if we had access to psychology or counselling we could start educating about stroke... offering what they need as things change such as adjusting to their emotions. (CR)

Each of the participant groups highlighted challenges in supporting carers and people with stroke who are transitioning to discharge home and identified where access to services was time limited.

There is dependence and reliance which is difficult to navigate, mainly because people need long-term support and we are the end of the line as community rehabilitation. Especially discharge conversation. "Yeah but where are we going? We still need support with this." There is still much more improvement to make which is right but there is no one else. (CR)

Subtheme: Transition in carers' role

Participants described the process of taking on a caring role, how this changed across the illness trajectory, and how this role can be difficult to accept.

I think lots of people struggle with that notion of being a carer straight up, and the adjustment period is a process of weeks and sometimes longer. (SA1)

Participants also highlighted how people identify with their caring role.

I think that carers of stroke in particular and other conditions that might be chronic is that most people from my experience don't identify themselves as a carer but as a husband or wife or daughter... (SA1)

Participants reported that financial disadvantage is a major challenge confronting carers in the transition to home.

The financial disadvantage of the client is the biggest hurdle... if you have a family that can buy a lifting machine and a special bed and employ a physio so they can get a better outcome, they have the potential to have a better outcome than those who are lower socioeconomic... (SA2)

The groups acknowledged that the caring role unfolds alongside life stage transitions. There was agreement that stroke could interrupt the carers' plans for the future.

They had dreams and plans for retirement, concrete plans and "next year we will go here, here and here" and the loss of that when the husband had a stroke was incredibly devastating because all of the plans stopped... (SA2)

The groups discussed the transitions in the carers' capacity to cope and how expectations can be challenged as carers recognize the extent of demands.

I have had family say "this is absolutely what I want and I want to devote my life to meeting their needs" and six months later they may say "actually this is very difficult and we need assistance and respite." (A)

Key theme: Information

Participants discussed the role of information based on their experiences of using information to educate carers and people with stroke. Two subthemes emerged.

Subtheme: Health care providers' delivery of information

There was consensus that information should be reinforced throughout care pathways. The timing of information provision was highlighted as a challenge.

After people have been coming to the rehab centre after six-months they are still not ready to take on some information and not ready to engage in a certain group...that is a challenge, the timing and information and when are people ready to accept things. (CR)

Participants acknowledged that information should target individual needs and not be overwhelming. The groups acknowledged how carers' grief and adjustment can guide information provision.

It depends where the carer is in regards to their grief and adjustment and I find that you might tell them the same information every week depending if they can take it in or not. (SA1)

Participants spoke of managing information requests from carers and stroke survivors. Acute health care providers noted that when prognosis was uncertain, they tended to provide less specific information.

I think being vague is better than being concrete and giving wrong answers. (A)

The rehabilitation groups highlighted the practical, future-focused information provided to patients and carers in preparation for hospital discharge.

You try to provide education and strategies for communication at home and provide examples to support someone to be independent in the community and at home. (CR)

Subtheme: Carers' responses to information and difficulties comprehending implications

There was consensus that carers who are experiencing heightened levels of stress have difficulty retaining verbal information.

It is hard for them to take it all in, in the beginning they are so stressed and so anxious they can't retain the information and that is why I think it is important that it [information] is reinforced for them. (A)

The groups discussed how written and oral modes of information can be combined.

I can't remember whether it was 20% or 25% of information people are given verbally is retained...but it goes up when you give them written information coupled with verbal which is why we give family members or carers the family meeting minutes. (SA1)

Key theme: Impact of stroke

Participants clarified their perception of the impact of stroke on patients and carers. This included carers' responses to uncertainty and loss associated with the stroke.

Subtheme: Health care providers' role in supporting the carer

Participants emphasized the importance of validating and listening to carers' experiences.

There was consensus on the need to maintain hope for patients and carers.

Yeah, that is one thing, giving them hope, that's one thing we are really good at as a team we never, never extinguish hope. It may look bleak but we never extinguish that hope. (SA1)

Participants spoke of how understanding and supporting carers can be a subtle process.

I think a lot of what we do in terms of carers is subtle supportive counselling...just trying to have an understanding to know what it might be like to walk in their shoes. (SA2)

This subtheme overlaps with the transition theme, where participants highlighted how they support carers in different ways across the stroke trajectory.

Subtheme: Carers' experiences of the impact of stroke

There was consensus that stroke contributes to uncertainty for carers across the illness trajectory.

There is uncertainty and fear they are facing and what does it mean for the future. I think for me the thing I am aware of is the sense of loss people experience and the uncertainty. (A)

There was acknowledgment that carers face multiple losses and that changes in their relationships with the stroke survivors are arguably one of the most challenging consequences of stroke.

One of the hardest things to cope with particularly if there are significant personality changes is that sense of "I have lost this person, who is this new person who I have to take care of? I have lost my husband and I don't know who it is." (SA1)

This concept of loss overlaps with the transition theme that highlighted the losses that are experienced across life stage transitions. Participants acknowledged that carers can experience anger and resentment toward the stroke survivor.

I have worked with some clients in this program and the carers were not sad, were not uncaring, but angry at their spouse and very highly functional in both cases and now were in position that they couldn't do anything and they had to put their lives on hold. Who'll care for them? And they were stuck there within the anger and their anger was pushed onto their partner who had the stroke. (SA2)

The groups acknowledged the impact of carers' experiences of loss before the stroke.

Carers have their issues before the person had their stroke and it pushes them to the limit of what their capacity is. They might not have been managing with what they had before and this comes and just tops it off. (CR)

Groups highlighted how stroke can affect the patients' capacity to earn income, which has adverse effects on both the patients and carers.

They have gone from having quite a good lifestyle, mortgage, to the main income holder staying home, the wife the carer, and going to a pension and then lose the house. (CR)

Discussion

Summary of main findings

This study explored health care providers' perceptions of the role of stroke carers and their needs for support. The findings, consistent with results of previous research, highlight the multifaceted nature of stroke health care providers' experiences.⁶⁻⁸ Three key themes were identified: transition, information, and impact of stroke. These are discussed along with implications for practice and integration of the OHP into existing stroke services.

The theme of transition included subthemes centered on the changes over time in the roles of the health care providers and carers. Participants acknowledged their roles supporting carers at different stages of the illness. These findings are congruent with research acknowledging the roles of different disciplines in supporting carers' changing needs.⁷ Similar to findings by Morris, Payne, and Lambert,⁶ participants in this study highlighted concerns around availability of care on the wards and the impact this might have on the ability to provide supports to carers and patients. Participants emphasized discharge home as a crucial stage for supporting carers. The importance of care at discharge home and follow-up was also noted in a previous Australian study.¹⁰ A study by Cameron et al⁷ also highlighted how carers needed more information during this period as compared to the time of diagnosis. By simultaneously facilitating carer and health care provider focus groups, Cameron et al⁷ were able to compare and contrast their different perspectives on carer support needs and recommend a family-centered model of care to address the changing needs of carers over time. The exploration of the perspectives of carers and patients with stroke forms part of the next stages of our research in informing the

application of OHP to this population with a unique focus on well-being and self-efficacy.

Participants acknowledged the transition of persons taking on a caring role and how their role evolves across the stroke care trajectory. They clarified how carers and stroke survivors experience interruptions to life stage transitions. This is consistent with results of a qualitative study of family caregivers in Italy that highlighted carers' newly acquired roles and support needs.²⁹ Within this transition theme, our participants reported that carers may not ask for help until months down the track, preferring to devote themselves to the caring role. This concept of "going it alone" was also described by the primary care practitioners in a study by Greenwood et al.⁸

The second major theme was information. The subthemes included the delivery of information by the health care provider and the carers' responses, including the implications of their difficulties in comprehending the information. Such themes have been observed in the stroke carer literature, including the role of information in improving carers' knowledge of stroke and their satisfaction with treatment.^{6,7} Our findings were particularly consistent with those of Cameron et al,⁷ who found that health care providers struggled with decisions about how and when to deliver stroke-related information to carers. Similarly, our participants identified challenges with information provision, most notably related to the timing and amount of information provided.

The third major theme was impact of stroke. This theme incorporated the subthemes of the health care providers' role in supporting carers and maintaining hope and the carers' experiences of the impact of stroke. Findings highlighted the uncertainty, shock, and loss carers experience after stroke, which parallels the literature reporting the importance of supporting carers' emotional needs.^{7,16,17} Like our participants, health care providers in a study by Morris, Payne, and Lambert⁶ acknowledged their role in facilitating emotional support, specifically the importance of facilitating peer support between patients and families on the wards. It is important to note, however, that participants in the study by Morris, Payne, and Lambert⁶ were asked primarily service-based questions (eg, nature of the service, possible improvements), and there was less focus on exploring specific perceptions of the carer role.

Therefore, participants in our study were more primed to speak about their perceptions of the carers and carers' role in terms of aspects such as emotional support.

The emotional impact of stroke was noted by Gosman-Hedström and Dahlin-Ivanoff³ who found that mastering an uncertain, unpredictable life was the dominant theme for older females caring for partners with stroke, whereas a study by Jones and Morris³⁰ of adult stroke survivors and their parent carers highlighted carers' emotional turmoil, including chronic grief and distress.

Given the consistent findings from this and previous studies, it is possible that health care providers throughout the world have similar views about carers' roles and their needs in relation to the stroke setting. An interesting finding in our study was the lack of discussion about the positive experiences of caring. A systematic review revealed that carers reported positive experiences including increased self-esteem and feeling appreciated.³¹ One possibility is that participants did not perceive "positives" or assumed the study focus was challenges, despite the neutral focus group questions (eg, "What are your thoughts about the role of the carer?").

OHP clinical applications and integration across existing stroke services

Transition

Participants identified challenges to providing and accessing support for carers, particularly in the discharge to home. The OHP can be delivered by a range of health care providers, and it targets individual carer needs.^{20,21} Training health care providers in the OHP across acute, subacute, and community services could improve consistency in the provision of carer support across stroke pathways. The OHP can be flexibly delivered, depending on changing carer needs, and can be offered at all stages of the care trajectory. OHP can be delivered in the community and homes or by videoconferencing.

Information

The OHP can be tailored to include illness-related information such as that from the National Stroke Foundation. The OHP is flexible, and

information can be staged across the trajectory at appropriate times and in coordination with multidisciplinary teams. The OHP provides participants and facilitators with written session material, including regular reviews of previous sessions for consolidation of progress. The OHP includes a self-care booklet designed specifically for stroke carers, containing information on lifestyle, communication skills, and how to seek psychological and peer support. There is a pocket-sized health journal to record appointments and contacts. In concrete terms, the adaptation of the OHP may incorporate stroke-specific information from the National Stroke Foundation such as stroke symptoms and means of prevention. The OHP may integrate information about carer stress and the types of psychological therapy available for ongoing support to address the impact of stroke.

Impact of stroke

The OHP provides a formal setting in which carers' experiences of uncertainty can be heard and validated. This complements the compassion and understanding that are provided by multidisciplinary teams, facilitating carers' growth and self-awareness. This forum also acknowledges carers' multiple and preexisting losses that accompany the stroke experience. The OHP can flexibly focus on the issues of most concern for carers, including those that occur before the stroke. In relation to financial burden, the OHP uses telephone or videoconferencing sessions to reach socially isolated and economically disadvantaged people.

Limitations of this study and strengths for future directions

Our sample was specific to an Australian metropolitan public health service. Therefore, findings may not be transferable to other health care settings as there are different models of postacute stroke care across Australia and internationally. We did not include the carers' or stroke survivors' perceptions. We are addressing this gap by studying carers' perceptions through individual and focus group interviews and comparing data with results of this study.

A trial of the revised OHP is the next step in integrating the OHP into public and community health care settings to support carers of people with stroke. We will develop OHP training modules to train professionals across Australia in delivering the OHP to carers to expand the potential benefits of the OHP.

Conclusion

Health care providers in this study highlight 3 key areas for carers of stroke survivors: (1) transitions through care to home, (2) the delivery and receipt of information, and (3) the impact of stroke. In adapting the OHP, it will therefore be important to stage information across the illness trajectory, be flexible with support during transitions, and balance practical tools with space for empathic communication around the impact of stroke. By exploring the experiences of health care providers, this study has suggested how an OHP can be tailored to support carers of people with stroke and how it can be integrated into existing Australian public health care settings. Further research on the OHP will help refine its applicability for supporting carers of people with stroke by applying a psycho-educational model that focuses on improving the self-efficacy and well-being of the carer.

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