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A Qualitative Study Assessing Organizational Readiness to Implement Caregiver Support Programs

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Complete List of Authors:	Tseung, Victrine; University of Toronto Faculty of Medicine, Rehabilitation Sciences Institute Jaglal, Susan; University of Toronto, Physical Therapy; Toronto Rehabilitation Institute Salbach, Nancy; University of Toronto, Physical Therapy; Toronto Rehabilitation Institute Cameron, Jill; University of Toronto, Department of Occupational Science and Occupational Therapy; Toronto Rehabilitation Institute
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Running Head: Organizational Implementation of Caregiver Programs

Title: A Qualitative Study Assessing Organizational Readiness to Implement Caregiver Support Programs

Authors: Victrine Tseung, PhD, Susan B Jaglal, PhD, Nancy M Salbach, PhD, and Jill I Cameron, PhD

Victrine Tseung, PhD
Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto
160-500 University Ave
Toronto, ON. Canada
v.tseung@utoronto.ca

Susan Jaglal, PhD FCAHS
Toronto Rehabilitation Institute-UHN Chair
Department of Physical Therapy, University of Toronto
Associate Academic Director of Research TRI-UHN
160-500 University Ave
Toronto, ON M5G 1V7
Susan.jaglal@utoronto.ca

Nancy M. Salbach, PhD

Department of Physical Therapy, University of Toronto

160-500 University Avenue

Toronto, ON M5G 1V7 Canada

Nancy.salbach@utoronto.ca

Corresponding Author: Jill I. Cameron, PhD FAHA

Department of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto

160-500 University Ave.

Toronto, ON M5G 1V7 Canada

416-978-2041 (office)

Jill.cameron@utoronto.ca

Affiliate Scientist, UHN-Toronto Rehabilitation Institute

Twitter: @caregiving_UofT

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Abstract

Objective: To qualitatively explore factors affecting implementation of caregiver support programs in health care institutions in a regional stroke system.

Design: A qualitative descriptive study with the Ontario Stroke System (OSS) was conducted. Data were collected through focus groups and in-depth interviews. Transcripts were coded and analyzed using inductive thematic analysis.

Setting: Regional Stroke System, Ontario, Canada.

Participants: OSS stakeholders including medical directors, executives, program directors, education coordinators, rehabilitation and community and long-term care specialists, primary care leaders, and health care professionals.

Intervention: Not applicable.

Main Outcome Measures: Data collection explored perceptions of the need for caregiver support programs and factors that may affect their implementation.

Results: Four focus groups (n=43) and 29 interviews were completed. Analyses identified themes related to: 1) evidence that a caregiver program will improve health and health system outcomes; 2) personnel requirements; 3) barriers associated with current billing and referral processes; and 4) integration with current practice and existing workflow processes.

Conclusions: Implementation strategies to adopt caregiver programs into clinical practice should incorporate evidence and consider personnel and existing workflow processes.

Keywords: caregivers, stroke, organizations, qualitative research

Abbreviations:

OSS – Ontario Stroke System

FG – Focus Group

HCP – Health Care Professionals

MD – Medical Directors

RE – Regional Health Executives

PL – Primary Care Leaders

PRISMA – Program of Research to Integrate the Services for the Maintenance of Autonomy

ADLs – Activities of Daily Living

Article Summary

Strengths and Limitations of this study

- Our study used in-depth qualitative methods to be the first study to explore organizational considerations for implementing caregiver programs in a regional stroke system.
- Our study included 72 participants reflecting key stakeholder groups responsible for supporting caregivers and implementing caregiver programs within institutions.
- Additional stakeholder groups (e.g., hospital managers) could have provided additional perspectives on caregiver program implementation.
- More in-depth probing of the specific challenges experienced in rural areas would have expanded our findings.

Introduction

Family caregivers play a central role in the recovery, rehabilitation, and community re-integration of individuals who experience a stroke. Numerous studies have documented the negative impact providing care can have on caregiver health and wellbeing (1, 2). Previous literature recommends the use of multi-component interventions (3) that cross the care continuum (4, 5) to meet caregivers' needs for support. However, caregivers are not benefiting from these programs, as they are not being incorporated into standard clinical practice (6, 7). Research from the United Kingdom, identified program and system level factors that limited the implementation of a stroke caregiver program into clinical practice (8, 9). Participants reported lack of time and individuals responsible for ensuring implementation as limiting factors. Our research with the Ontario Stroke System (OSS) (10, 11) has indicated a need to understand implementation of caregiver programs within institutions. Therefore, the objective of this study was to examine factors that influence implementation of caregiver programs within institutions.

Methods

Design

We conducted a qualitative descriptive study (12) and used the used the SRQR reporting guidelines (13). Participants were recruited from the OSS – regional system of stroke care. Institutional ethics boards, including the University of Toronto Research Ethics Board, approved the study. All participants provided written consent. This study was situated in the Knowledge-to-Action Framework's (14) barrier assessment step to identify facilitators and barriers in the local context. The Consolidated Framework for Implementation Research (15) informed data collection.

Patient and Public Involvement

Patients and the public were not involved in the design of this research. Participants, as described below, were involved in this research through in-depth interviews and focus groups where they contributed their thoughts about caregivers and program implementation. Findings have been presented at local and national stroke conferences which is commonly attended by many participants They will receive copies of publications.

Participants

Participants were recruited from the 11 OSS regions including: Program Directors, Rehabilitation Specialists, Community and Long-Term Care Specialists, Education Coordinators, Medical Directors, and health care professionals providing stroke care in acute, rehabilitation, and community settings, and from the broader health care system including regional health executives, and primary care leaders.

Data Collection

Participants were asked to discuss: 1) perceptions of the availability, importance, and effectiveness of caregiver programs; 2) current practices related to caregiver education and support; and 3) program level implementation considerations. Qualitative interviews and focus groups were audio-recorded, transcribed verbatim, reviewed for accuracy, and de-identified. Data can be accessed by contacting the corresponding author.

Data Analysis

Data was analyzed using inductive thematic analysis (16) and facilitated using NVivo (17). To maximize the credibility of the findings, all authors reviewed data and contributed to theme generation (18).

Results

Four focus groups (n=43) and 29 interviews yielded 72 participants (see tables 1 and 2). Four themes related to: 1) need for evidence that a caregiver program will improve patient and caregiver health and health system outcomes after “real world” implementation; 2) personnel requirements; 3) barriers associated with current billing and referral processes; and 4) integration with current practice and workflow processes. Participant quotations from focus groups (FG) and interviews with health care professionals (HCP), medical directors (MD), regional health executives (RE), and primary care leaders (PL) are identified by number.

Table 1: Professional role of participants: A summary of study participants’ professional roles.

Participant Group	**Number of Participants (n=72)***
Regional/District Program Directors (FG)	19
Community and Long-Term Care Specialists (FG)	7
Regional Education Coordinators (FG)	7
Regional Rehabilitation Specialists (FG)	11
Regional Medical Directors (INT)	2
Health Region Executives (INT)	4

Participant Group	**Number of Participants (n=72)***
Health Region Primary Care Leads (INT)	4
Health Care Professionals (INT)	19

Abbreviations: FG, focus group; INT, interview.

*One participant had a dual role.

Table 2: Health Care Professionals by Sector and Occupation: A summary of study participants' clinical sector and profession.

Health Care Professionals by Sector and Occupation (N=19)	
Sector	**Number of Participants**
Acute	5
Rehabilitation	7
Community	6
Private	1
Profession	
Occupational Therapist	5
Physical Therapist	4
Speech Language Pathologist	3
Physiatrist/Recreational Therapist/Stroke Care Navigator	3
Registered Nurse	2
Social Worker	2

Theme 1: Need for evidence that a caregiver program will improve patient and caregiver health and health system outcomes after "real world" implementation

Participants discussed the role of evidence, including program evaluation, to support funding, implementation, and sustainability of caregiver programs. Participants suggest stakeholders differ in their preferences for process (e.g., program attendance) or outcomes (e.g., health and health system outcomes) data. For example, some prefer numerical data to support implementation (e.g., program attendance) while others are looking for success stories (e.g., patient stories). The following quotation describes the roles of pilot testing and program evaluation to sustain implementation in practice:

> But the point I'm trying to get across is that…the organization if they see…there's research to back up the effectiveness of it [caregiver program]…then they'll pilot it… to see if it's working, and then…upper management…they'll look at the number of people who are taking advantage of the programs cause it all comes down to numbers for organizations, right. And...if it is working right then that pilot program can become…a regular program that the hospital runs and incorporates as a part of their budget. (HCP 19)

Theme 2: Personnel Requirements

Many participants agreed that existing team members would not be able to assume this added responsibility so a new role was needed. In terms of creating a new role, three considerations were discussed: 1) similarity with existing roles; 2) integration into a community-based navigator role; and 3) integration into health care teams in acute and rehabilitation settings. A few participants highlighted the overlap with existing roles (e.g., community care case managers) so this role would need to be clearly defined:

> …defining whose role is what and again who's responsible for what, because if you're doing a quarter of the discharge planner's job and you're doing thirty percent of the family doctor's job…there's too much duplication in the hospital and in the health care. (HCP 15)

Some participants spoke about the navigator role in which an individual supports patients and families in the community. Perspectives differed as to the possibility of integrating caregiver support into this role as their availability and function varied by region: "…not every region has a navigator…and those that do they function very differently" (FG 3).

Participants questioned the feasibility of having a position that crosses care environments because current practice does not include contact with patients and their caregivers after they leave the institution. While they indicated the desire for a single point of contact for caregiver support, they spoke about the challenge of determining funding sources and sustainability with current fiscal restraints. The following quotation raises the issue of funding and ownership for this role, particularly in cases where acute and rehabilitation care are separate institutions:

> This acute person follows the patient through their rehab stay to community…how does that work when it's [rehab] a separate facility? Like the ownership … that's why the idea of dedicated resources seems to be a good fit to overcome that barrier because if you think about it, if someone's being paid by [hospital A] to handle [hospital A] patients and…and they're off to another…that's what I'm thinking is a barrier for you… (FG 4)

The increasingly large caseload this single person would have to manage was also mentioned as a concern for the feasibility of this approach: "…just by the nature of the beast it's most likely that you're going to…need a few of these individuals…because their caseload is going to just get bigger and bigger…" (FG 4). Instead, some participants suggested that caregiver support be organized by care environment with health care teams picking up the education where the last team finished. The following quotation provides an example: “I can see it working as…the stroke nurse’s role to take it from point A to point B and then…it would be the social worker and rehab’s role to be from this section to this section and then it would be the community navigator or the outpatient OT…to be taken to the next stage…” (FG 3).

In addition, some participants felt that it may be more likely to be funded if it was used region-wide. However, in geographically larger stroke regions, it would be very challenging for one individual to cover the entire region:

> And the individual has to be a regional resource versus organizational. So they can’t necessarily belong to a specific hospital but they have to have the capacity to cover a region and be flexible in that…which is a barrier up north. (FG 2)

Participants had different perspectives regarding the role of health care professionals in providing caregiver support. This individual would need to be knowledgeable about acute care, rehabilitation, and community care and to stay up-to-date with community resources. He or she would have counseling skills and a good understanding of each of the disciplines on the health care team. Some participants provided examples of specific health care professionals they perceived to be most appropriate for this role, including occupational therapists, social workers, nurses, and other allied health professionals.

Participants questioned the use of trained volunteers or non-health care professionals. Some of the regional health executives discussed the limited availability and high costs of health care professionals as the main reasons to consider volunteers. The following quotation highlights this point: “So it may be a costly model if the person is a health care professional. There may be other models where you use peers, somebody who’s had a similar experience or volunteers who have been trained” (RE 4). However, there might be instances when the issues facing the families are predominantly medical in nature, and these personnel may not be able to address such issues:

> …the challenge would be and we've seen it with community navigators when it's an orphan patient and we have a community navigator following them but all their issues are medical…that community navigator is not equipped to provide advice or to plan any intervention other than to say go to a walk in clinic or et cetera. And that then it becomes a challenge for both parties. (FG 1)

Theme 3: Barriers associated with current billing and referral processes

Participants agreed that existing infrastructure should incorporate caregiver programs. However, participants identified several challenges. Health care professionals and Rehabilitation Specialists suggested that organizational referral criteria and government-funded health insurance precludes caregivers from being formal units of care. One participant explained that there are community-based activities that would be appropriate for the patient-caregiver dyad, but because the organization's mandate is to provide services to individuals with disabilities and there is no billing structure for services provided to caregivers, caregivers are not included. The following quotation demonstrates how the current billing structure and referral criteria hinder the provision of caregiver support within health care organizations:

> Let's say we register the caregiver as a patient, then they need a chart. Then they need space in health records. Like then we have to track them that way…if the caregiver now becomes the patient then you need to refer them to mental health if that's the issue. Do you know what I mean...So whether or not our institution would adopt that would be really interesting to see. I doubt it…Cause then a cost comes in. (HCP 10)

Theme 4: Integration with current practice and existing workflow processes

Participants discussed four facilitators to the integration of caregiver support into current practice and existing workflow processes. Potential challenges were also discussed.

First, participants suggested the caregiver support role should become part of routine practice. This approach may overcome limited therapist time to provide support in both inpatient and community care.

Second, participants were concerned with incorporating caregiver support into patient charts. A few participants indicated that there are no places in patient charts to document the specific education provided. If education became required practice, the tendency might be to provide the support for the sake of checking off the box as opposed to paying attention to the content, timing, or the readiness of the caregiver to receive this information. The following quotation underscores the challenges with incorporating caregiver support into existing documentation, particularly when these programs cross care environments:

> …so if there is a way to [tick off] have you done your section of [caregiver program] …you would almost have to be embedded in documentation somehow too so that it is not missed and that would be hard because… once that patient is gone, so is their chart…you are not even supposed to go into the chart after… (FG 3)

Third, participants emphasized communication between the individual providing caregiver support and the rest of the care team to ensure consistency and continuity in messaging to caregivers. This was noted as a challenge in community care because team members do not necessarily communicate with one another or know who else is working with the patient.

Lastly, participants highlighted the importance of having a formalized and structured approach to guide implementation. This would require ready-made materials that can be adapted to local contexts, developing a clear referral and monitoring system, setting target user criteria, and establishing a mechanism for re-accessing caregivers if they initially decline the program. Participants suggested some health care professions would need education and tools to assess caregivers' needs and provide appropriate supports. Training may also enhance soft skills as many health care professionals may be more comfortable with the more technical aspects of their clinical work.

Discussion

The objective of this study was to identify factors that influence implementation of caregiver programs within institutions. The four themes suggest that the availability of evidence to support program outcomes, personnel requirements, and a supportive structure including billing, workflow and resources are important for caregiver program implementation.

As we aim to support transitions across the care continuum (4, 5, 19, 20), our findings suggest one potential approach to implementing a program that crosses care environments. This would involve offering a program across care environments with health care teams picking up the education where the last team finished. Caregivers, however, prefer having one individual provide support across the care continuum (21). One possible solution to address these differences in perspectives comes from the aging literature. Stroke care could adopt an integrated service delivery model such as one proposed for the frail elderly. The PRISMA (Program of Research to Integrate the Services for the Maintenance of Autonomy) model uses case managers to coordinate and monitor the needs of frail elderly across care environments and has demonstrated positive impacts on patient and caregiver health, and health care utilization (22, 23). The applicability of this service delivery model to stroke care warrants further consideration.

Participant responses indicated that occupational therapists are one of the health care professionals who would be suitable to deliver caregiver support. Occupational therapists are a core member of multi-disciplinary stroke teams and they contribute to caregiver training (e.g., teaching ADLs) (24, 25). Beyond training in ADLs, occupational therapists' training in mental health and meaningful occupations prepares them for addressing the psychosocial effects of caregiving (24). There is a need to address caregivers' needs such that they are able to maintain both their own health and engagement in valued activities and provide care for their loved ones (26). This previous research (26) and our study findings highlight occupational therapists as a potential source of support for caregivers.

Current billing structures and referral criteria preclude the provision of services to caregivers in standard clinical practice. This suggests a need to expand organizational structures for billing, referral and documentation to include caregiver support. As demonstrated in the PRISMA model, information systems (e.g., computerized client chart that is available across organizations) can be developed to overcome organizational structures (22). The integration of caregivers into information systems can facilitate program implementation (9).

Article Summary

Strengths and Limitations of this study

- Our study used in-depth qualitative methods to be the first study to explore organizational considerations for implementing caregiver programs in a regional stroke system.
- Our study included 72 participants reflecting key stakeholder groups responsible for supporting caregivers and implementing caregiver programs within institutions.

- Additional stakeholder groups (e.g., hospital managers) could have provided additional perspectives on caregiver program implementation.
- More in-depth probing of the specific challenges experienced in rural areas would have expanded our findings.

In summary, our study was one of the first to examine implementation of caregiver programs within a regional stroke system. It adds to the existing literature by delineating implementation considerations and highlighting the potential role for occupational therapists as providers of caregiver support.

Conflict of Interest

Authors have no conflicts of interest to declare.

Author Contributions

VT contributed to the project conceptualization and design, data acquisition and qualitative interviewing, coding and data analysis, theme generation, drafting and revising the manuscript.

SJ contributed to project conceptualization and design, qualitative data analysis, theme generation and revisions to the final manuscript.

NMS contributed to project conceptualization and design, qualitative data analysis, theme generation and revisions to the final manuscript.

JIC contributed to the project conceptualization and design, qualitative data analysis, theme generation, drafting and revising the manuscript.

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Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 6
Purpose or research question - Purpose of the study and specific objectives or questions	Page 6

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 6
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	n/a
Context - Setting/site and salient contextual factors; rationale**	Page 6
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 7
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 6
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 7

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 7
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 7
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 7
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 7
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 7

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 8-15
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pages 8-15

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 15-16
Limitations - Trustworthiness and limitations of findings	Pages 16-17

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	n/a
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Title page

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

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Authors: Victrine Tseung, PhD, Susan B Jaglal, PhD, Nancy M Salbach, PhD, and Jill I Cameron, PhD

Victrine Tseung, PhD

Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto

160-500 University Ave

Toronto, ON. Canada

v.tseung@utoronto.ca

Susan Jaglal, PhD FCAHS

Toronto Rehabilitation Institute-UHN Chair

Department of Physical Therapy, University of Toronto

Associate Academic Director of Research TRI-UHN

160-500 University Ave

Toronto, ON M5G 1V7

Susan.jaglal@utoronto.ca

Nancy M. Salbach, PhD

Department of Physical Therapy, University of Toronto

160-500 University Avenue

Toronto, ON M5G 1V7 Canada

Nancy.salbach@utoronto.ca

Corresponding Author: Jill I. Cameron, PhD FAHA

Department of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto

160-500 University Ave.

Toronto, ON M5G 1V7 Canada

416-978-2041 (office)

Jill.cameron@utoronto.ca

Affiliate Scientist, UHN-Toronto Rehabilitation Institute

Twitter: @caregiving_UofT

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Intervention: Not applicable.

Main Outcome Measures: Data collection explored perceptions of the need for caregiver support programs and factors that may affect their implementation.

Results: Four focus groups (n=43) and 29 interviews were completed. Analyses identified themes related to: 1) evidence that a caregiver program will improve health and health system outcomes; 2) personnel requirements; 3) barriers associated with current billing and referral processes; and 4) integration with current practice and existing workflow processes.

Conclusions: Implementation strategies to adopt caregiver programs into clinical practice should incorporate evidence and consider personnel and existing workflow processes.

Keywords*:* caregivers, stroke, organizations, qualitative research

Abbreviations:

OSS – Ontario Stroke System

FG – Focus Group

HCP – Health Care Professionals

MD – Medical Directors

RE – Regional Health Executives

PL – Primary Care Leaders

PRISMA – Program of Research to Integrate the Services for the Maintenance of Autonomy

ADLs – Activities of Daily Living

Article Summary

Strengths and Limitations of this study

- Our study used in-depth qualitative methods to explore organizational considerations for implementing caregiver programs in a regional stroke system.
- Our study included 72 participants reflecting key stakeholder groups responsible for supporting caregivers and implementing caregiver programs within institutions.
- We did not systematically obtain data related to years of experience in specific roles.
- Additional stakeholder groups (e.g., hospital managers) could have provided additional perspectives on caregiver program implementation.
- More in-depth probing of the specific challenges experienced in rural areas would have expanded our findings.

Introduction

Family caregivers play a central role in the recovery, rehabilitation, and community re-integration of individuals who experience a stroke. Numerous studies have documented the negative impact providing care can have on caregiver health and wellbeing (1, 2). Previous literature suggest that 30-33% of caregivers experience depression (3). Taking on the caregiver role can also impact other aspects of a caregiver's life, including leisure, relationships, and work. Relatives who assumed the caregiver role had increased responsibilities, decreased leisure activities and negative changes in their relationships, and the impact on their lives can still be present after a year post-stroke (4). A study conducted in the United States found that the indirect costs associated with caregiving (e.g., traveling time, out-of-pocket expenses) amounted to $5,669 per caregiver per year, and costs of total lost productivity amounted to more than $10,000 per year per employed caregiver (5). Taken together, the caregiver role affects many aspects of a caregiver's life and education and support has the potential to enhance their abilities to take on and sustain this important role.

Previous literature recommends the use of multi-component interventions (6) that cross the care continuum (7, 8) to meet caregivers' needs for support. Multicomponent interventions include at least two of the following: information provision (e.g., community resources), emotional support and counseling (e.g., support groups, professional support) and skills training (physical care, problem solving) (6). For example, the 'Timing It Right' Family Stroke Family Support program is a multicomponent intervention that is delivered by a health care professional (stroke support person), who meets with the caregiver in-person in acute care and then follows up with six monthly telephone meetings to discuss caregiver's support needs and potential strategies to meet these needs (7, 8). However, caregivers are not benefiting from these programs, as they are not being incorporated into standard clinical practice (9, 10). Research from the United Kingdom identified program and system level factors that limited the implementation of a stroke caregiver program into clinical practice (11, 12). Participants reported lack of time and individuals responsible for ensuring implementation as limiting factors.

Caregiver program implementation has been studied in the context of dementia caregiving. Although there are more than 200 efficacious dementia caregiver programs, only 6 have been integrated into practice (13). The need to identify contextual factors that may influence implementation has emerged as an emerging research field and an important step towards effective integration into practice (13). Previous studies undertook process evaluations during caregiver program implementation (e.g., (11, 12, 14)). However, the current study aimed to identify factors that may influence implementation in real-world settings prior to developing or testing an implementation strategy (15). Our research to date with the Ontario Stroke System (OSS) (16, 17) has indicated a need to understand implementation of caregiver programs within institutions. Therefore, the objective of this qualitative descriptive study was to examine program level factors (i.e., within institutions) that influence local implementation of caregiver programs in the context of a regional stroke system. For the purposes of this study, a caregiver education and support program was defined as a structured, time-limited intervention with a basic protocol and program materials. A program consists of one or more of the following: education, training and support.

Methods

Design

We conducted a qualitative descriptive study (18) and used the SRQR reporting guidelines (19). A qualitative approach is used when the purpose is to understand a specific phenomenon for which there has been limited research and the important variables to explore are unclear (20). There are no previous studies that have examined the implementation of caregiver education and support in standard clinical practice within the Canadian context. Specifically, a qualitative descriptive study design is particularly suited when producing a comprehensive description of participant perceptions of a specific phenomenon because data analysis and interpretation stays close to the data and participant perceptions are considered to be accurate and truthful reflections of the reality of the phenomenon (i.e., caregiver program implementation) (18). Participants were recruited from the OSS – regional system of stroke care in the province of Ontario. The OSS is publicly funded, includes 11 geographical regions, and provides specialized stroke care across the continuum. Each region includes a Regional Stroke Centre or Enhanced District Stroke Centre, community hospitals, rehabilitation hospitals, community-based providers and pre-hospital providers (21). Some of the regions are large encompassing rural areas and some are small and urban. There are 9 Regional Stroke Centres, 2 Enhanced District Stroke Centres, 16 District Stroke Centres, and 24 secondary prevention clinics (21). Institutional ethics boards, including the University of Toronto Research Ethics Board, approved the study. All participants provided written consent. This study was situated in the Knowledge-to-Action Framework’s (22) barrier assessment step to identify facilitators and barriers in the local context. The Consolidated Framework for Implementation Research (23) informed data collection.

Patient and Public Involvement

Patients and the public were not involved in the design of this research. Participants, as described below, were involved in this research through in-depth interviews and focus groups where they contributed their thoughts about caregivers and program implementation. Findings have been presented at local and national stroke conferences which is commonly attended by many participants and they will receive copies of publications.

Participants

Participants were recruited from the 11 OSS regions including: Program Directors, Rehabilitation Specialists, Community and Long-Term Care Specialists, Education Coordinators, Medical Directors, and health care professionals providing stroke care in acute, rehabilitation, and community settings, and from the broader health care system including regional health executives, and primary care leaders. Regional Rehabilitation Specialists, Professional Education Coordinators, Community and Long-Term Care Specialists, and Regional/District Program Directors were invited by the corresponding author via email to participate in a focus group as part of regularly scheduled group meetings. Regional Medical Directors, health executives, and primary care leaders were invited by the corresponding author via email to participate in an interview. OSS Education Coordinators assisted with recruitment of health care professionals by emailing the study invitation to attendees of their education sessions. The primary author then coordinated and conducted all interviews and focus groups.

None of the members of the research team had any formal relationships with the participants. The corresponding author has shared their research with members of the Ontario Stroke System through invited presentations and workshops.

Data Collection

Participants were asked to discuss: 1) perceptions of the availability, importance, and effectiveness of caregiver programs; 2) current practices related to caregiver education and support; and 3) program level implementation considerations. The focus group and interview questions incorporated the domains of the Consolidated Framework for Implementation Research (CFIR) (23) to explore how individual and institution-level factors influence caregiver program implementation (see supplemental appendix). For example, individual level factors such as understanding of caregiver needs, the institution's ability to address caregiver needs, and the evidence base for caregiver programs can all influence program implementation (23). Participants were asked to reflect on all caregiver programs in general and then more specifically on caregiver programs that cross care environments using the Timing It Right Stroke Family Support Program (7, 8) as an example. Focus groups were conducted in person at the local Heart and Stroke Foundation office and interviews were conducted by telephone. The primary author collected all data and is an occupational therapist and doctoral candidate with training in qualitative interviewing. Data collection took place over the course of four months and ended when data saturation was reached. Qualitative, semi-structured interviews and focus groups were audio-recorded, transcribed verbatim, reviewed for accuracy, and de-identified.

Data Analysis

Qualitative thematic analysis is commonly used to analyze data in qualitative descriptive studies (18). Data were analyzed using inductive thematic analysis (24) and facilitated using NVivo (25). The first author coded all of the data and all authors reviewed the data and contributed to theme generation. Reflexive notes and field notes were taken throughout data collection and analysis to ensure the dependability and confirmability of the findings (18). To maximize the credibility of the findings, all authors reviewed data and contributed to theme generation (26).

Results

Four focus groups (n=43) and 29 individual interviews yielded 72 participants (see tables 1 and 2). Four themes related to: 1) need for evidence that a caregiver program will improve patient and caregiver health and health system outcomes after "real world" implementation; 2) personnel requirements; 3) barriers associated with current billing and referral processes; and 4) integration with current practice and workflow processes. Participant quotations from focus groups (FG) and interviews with health care professionals (HCP), medical directors (MD), regional health executives (RE), and primary care leaders (PL) are identified by number.

Table 1: Professional role of participants: A summary of study participants' professional roles.

Participant Group	**Number (%) of Participants (n=72)***
Regional/District Program Directors	19 (26%)
Community and Long-Term Care	7 (10%)
Regional Education Coordinators	7 (10%)
Regional Rehabilitation Specialists	11 (15%)
Regional Medical Directors (INT)	2 (3%)
Health Region Executives (INT)	4 (6%)

Participant Group	**Number (%) of Participants (n=72)***
Health Region Primary Care Leads	4 (6%)
Health Care Professionals (INT)	19 (26%)

Abbreviations: FG, focus group; INT, interview.

*One participant had a dual role.

Table 2: Health Care Professionals by Sector and Occupation: A summary of study participants' clinical sector and profession.

Health Care Professionals by Sector and Occupation	
Sector	**Number (%) of Participants (N=19)**
Acute	5 (26%)
Rehabilitation	7 (37%)
Community	6 (32%)
Private	1 (5%)
Profession	
Occupational Therapist	5 (26%)
Physical Therapist	4 (21%)
Speech Language Pathologist	3 (16%0
Physiatrist/Recreational Therapist/Stroke Care Navigator	3 (16%)
Registered Nurse	2 (11%)
Social Worker	2 (11%)

Theme 1: Need for evidence that a caregiver program will improve patient and caregiver health and health system outcomes after "real world" implementation

Participants discussed the role of evidence, including program evaluation, to support funding, implementation, and sustainability of caregiver programs. Participants suggest stakeholders differ in their preferences for process (e.g., program attendance) or outcomes (e.g., health and health system outcomes) data. For example, some prefer numerical data to support implementation (e.g., program attendance) while others are looking for success stories (e.g., patient stories). The following quotation describes the roles of pilot testing and program evaluation to sustain implementation in practice:

> But the point I'm trying to get across is that…the organization if they see…there's research to back up the effectiveness of it [caregiver program]…then they'll pilot it… to see if it's working, and then…upper management…they'll look at the number of people who are taking advantage of the programs cause it all comes down to numbers for organizations, right. And...if it is working right then that pilot program can become…a regular program that the hospital runs and incorporates as a part of their budget. (HCP 19)

Theme 2: Personnel Requirements

Many participants agreed that existing team members would not be able to assume this added responsibility so a new role was needed. In terms of creating a new role, three considerations were discussed: 1) similarity with existing roles; 2) integration into a community-based navigator role; and 3) integration into health care teams in acute and rehabilitation settings. A few participants highlighted the overlap with existing roles (e.g., community care case managers) so this role would need to be clearly defined:

> …defining whose role is what and again who's responsible for what, because if you're doing a quarter of the discharge planner's job and you're doing thirty percent of the family doctor's job…there's too much duplication in the hospital and in the health care. (HCP 15)

Some participants spoke about the navigator role in which an individual supports patients and families in the community. Perspectives differed as to the possibility of integrating caregiver support into this role as their availability and function varied by region: "…not every region has a navigator…and those that do they function very differently" (FG 3).

Participants questioned the feasibility of having a position that crosses care environments because current practice does not include contact with patients and their caregivers after they leave the institution. While they indicated the desire for a single point of contact for caregiver support, they spoke about the challenge of determining funding sources and sustainability with current fiscal restraints. The following quotation raises the issue of funding and ownership for this role, particularly in cases where acute and rehabilitation care are separate institutions:

> This acute person follows the patient through their rehab stay to community…how does that work when it's [rehab] a separate facility? Like the ownership … that's why the idea of dedicated resources seems to be a good fit to overcome that barrier because if you think about it, if someone's being paid by [hospital A] to handle [hospital A] patients and…and they're off to another…that's what I'm thinking is a barrier for you… (FG 4)

The increasingly large caseload this single person would have to manage was also mentioned as a concern for the feasibility of this approach: "…just by the nature of the beast it's most likely that you're going to…need a few of these individuals…because their caseload is going to just get bigger and bigger…" (FG 4). Instead, some participants suggested that caregiver support be organized by care environment with health care teams picking up the education where the last team finished. The following quotation provides an example: "I can see it working as…the stroke nurse's role to take it from point A to point B and then…it would be the social worker and rehab's role to be from this section to this section and then it would be the community navigator or the outpatient OT…to be taken to the next stage…" (FG 3).

In addition, some participants felt that it may be more likely to be funded if it was used region-wide. However, in geographically larger stroke regions, it would be very challenging for one individual to cover the entire region:

> And the individual has to be a regional resource versus organizational. So they can't necessarily belong to a specific hospital but they have to have the capacity to cover a region and be flexible in that…which is a barrier up north. (FG 2)

Participants had different perspectives regarding the role of health care professionals in providing caregiver support. This individual would need to be knowledgeable about acute care, rehabilitation, and community care and to stay up-to-date with community resources. He or she would have counseling skills and a good understanding of each of the disciplines on the health care team. Some participants provided examples of specific health care professionals they perceived to be most appropriate for this role, including occupational therapists, social workers, nurses, and other allied health professionals.

Participants questioned the use of trained volunteers or non-health care professionals. Some of the regional health executives discussed the limited availability and high costs of health care professionals as the main reasons to consider volunteers. The following quotation highlights this point: "So it may be a costly model if the person is a health care professional. There may be other models where you use peers, somebody who's had a similar experience or volunteers who have been trained" (RE 4). However, there might be instances when the issues facing the families are predominantly medical in nature, and these personnel may not be able to address such issues:

> …the challenge would be and we've seen it with community navigators when it's an orphan patient and we have a community navigator following them but all their issues are medical…that community navigator is not equipped to provide advice or to plan any intervention other than to say go to a walk in clinic or et cetera. And that then it becomes a challenge for both parties. (FG 1)

Theme 3: Barriers associated with current billing and referral processes

Participants agreed that existing infrastructure should incorporate caregiver programs. However, participants identified several challenges. Health care professionals and Rehabilitation Specialists suggested that organizational referral criteria and government-funded health insurance precludes caregivers from being formal units of care. One participant explained that there are community-based activities that would be appropriate for the patient-caregiver dyad, but because the organization's mandate is to provide services to individuals with disabilities and there is no billing structure for services provided to caregivers, caregivers are not included. The following quotation demonstrates how the current billing structure and referral criteria hinder the provision of caregiver support within health care organizations:

> Let's say we register the caregiver as a patient, then they need a chart. Then they need space in health records. Like then we have to track them that way…if the caregiver now becomes the patient then you need to refer them to mental health if that's the issue. Do you know what I mean...So whether or not our institution would adopt that would be really interesting to see. I doubt it…Cause then a cost comes in. (HCP 10)

Theme 4: Integration with current practice and existing workflow processes

Participants discussed four facilitators to the integration of caregiver support into current practice and existing workflow processes. Potential challenges were also discussed.

First, participants suggested the caregiver support role should become part of routine practice. This approach may overcome limited therapist time to provide support in both inpatient and community care.

Second, participants were concerned with incorporating caregiver support into patient charts. A few participants indicated that there are no places in patient charts to document the specific education provided. If education became required practice, the tendency might be to provide the support for the sake of checking off the box as opposed to paying attention to the content, timing, or the readiness of the caregiver to receive this information. The following quotation underscores the challenges with incorporating caregiver support into existing documentation, particularly when these programs cross care environments:

> …so if there is a way to [tick off] have you done your section of [caregiver program] …you would almost have to be embedded in documentation somehow too so that it is not missed and that would be hard because… once that patient is gone, so is their chart…you are not even supposed to go into the chart after… (FG 3)

Third, participants emphasized communication between the individual providing caregiver support and the rest of the care team to ensure consistency and continuity in messaging to caregivers. This was noted as a challenge in community care because team members do not necessarily communicate with one another or know who else is working with the patient.

Lastly, participants highlighted the importance of having a formalized and structured approach to guide implementation. This would require ready-made materials that can be adapted to local contexts, developing a clear referral and monitoring system, setting target user criteria, and establishing a mechanism for re-accessing caregivers if they initially decline the program. Participants suggested some health care professions would need education and tools to assess caregivers' needs and provide appropriate supports. Training may also enhance soft skills as many health care professionals may be more comfortable with the more technical aspects of their clinical work.

Discussion

The objective of this study was to identify factors that influence implementation of caregiver programs within institutions. The four themes suggest that the availability of evidence to support program outcomes, personnel requirements, and a supportive structure including billing, workflow and resources are important for caregiver program implementation.

As we aim to support transitions across the care continuum (7, 8, 27, 28), our findings suggest one potential approach to implementing a program that crosses care environments. This would involve offering a program across care environments with health care teams picking up the education where the last team finished. Caregivers, however, prefer having one individual provide support across the care continuum (29). One possible solution to address these differences in perspectives comes from the aging literature. Stroke care could adopt an integrated service delivery model such as one proposed for the frail elderly. The PRISMA (Program of Research to Integrate the Services for the Maintenance of Autonomy) model uses case managers to coordinate and monitor the needs of frail elderly across care environments and has demonstrated positive impacts on patient and caregiver health, and health care utilization (30, 31). The applicability of this service delivery model to stroke care warrants further consideration. Participant responses indicated that various health care professionals would be suitable to provide support to caregivers. One example is occupational therapists where previous literature suggests that occupational therapists can serve an important role in addressing the needs of caregivers (32). Occupational therapists are a core member of multi-disciplinary stroke teams and they contribute to caregiver training (e.g., teaching ADLs) (33, 34). Beyond training in ADLs, occupational therapists' training in mental health and meaningful occupations prepares them for addressing the psychosocial effects of caregiving (33). There is a need to address caregivers' needs such that they are able to maintain both their own health and engagement in valued activities and provide care for their loved ones (4). This previous research (4) and our study findings highlight occupational therapists as a potential source of support for caregivers.

Current billing structures and referral criteria preclude the provision of services to caregivers in standard clinical practice. This suggests a need to expand organizational structures for billing, referral and documentation to include caregiver support. As demonstrated in the PRISMA model, information systems (e.g., computerized client chart that is available across organizations) can be developed to overcome organizational structures (30). The integration of caregivers into information systems can facilitate program implementation (12).

Strengths and Limitations

Our study used in-depth qualitative methods to explore organizational considerations for implementing caregiver programs in a regional stroke system. Our study included 72 participants reflecting key stakeholder groups responsible for supporting caregivers and implementing caregiver programs within institutions. We did not systematically obtain data related to years of experience in specific roles. Additional stakeholder groups (e.g., hospital managers) could have provided additional perspectives on caregiver program implementation. More in-depth probing of the specific challenges experienced in rural areas would have expanded our findings.

In summary, our study was one of the first to examine implementation of caregiver programs within a regional stroke system. It adds to the existing literature by delineating implementation considerations and highlighting the potential role for occupational therapists and other health care professionals as providers of caregiver support.

Conflict of Interest

Authors have no conflicts of interest to declare.

Author Contributions

VT contributed to the project conceptualization and design, data acquisition and qualitative interviewing, coding and data analysis, theme generation, drafting and revising the manuscript.

SJ contributed to project conceptualization and design, qualitative data analysis, theme generation and revisions to the final manuscript.

NMS contributed to project conceptualization and design, qualitative data analysis, theme generation and revisions to the final manuscript.

JIC contributed to the project conceptualization and design, qualitative data analysis, theme generation, drafting and revising the manuscript.

Data Availability

Data may be accessed by contacting the corresponding author.

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Appendix I Interview/Focus Group Guides for Qualitative Descriptive Study

Focus Group Questions – Regional Community and Long-Term Care Specialists

1. What are your perceptions of caregiver education and support programs in terms of their utility, effectiveness and importance?
2. Please think about the programs you have implemented for patient education, caregiver education or caregiver support.
    a. How did you go about implementing these programs?
    b. What was your experience with implementing these programs?
    c. If you have not implemented these types of programs, why?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care to start providing support and to provide them with the program guide. The stroke support person will then conduct monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one;
    a. What factors would facilitate your region to implement this type of program?
    b. What factors would hinder your region from implementing this type of program?
    c. How could these factors be overcome?
4. What other thoughts do you have about meeting the needs of family caregivers?

Ending Question

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Focus Group Questions – Regional Education Coordinators

1. In your region, what has been one key challenge to educating health care professionals to implement best practice recommendations in clinical practice?
2. Please think about the health care professional education initiatives you have implemented. How have these initiatives address the provision of patient and family education across the care continuum?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care to start providing support and to provide them with the program guide. The stroke support person will then conduct monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one; how could this type of program be incorporated into your regional education initiatives to facilitate its implementation into clinical practice?
4. What other thoughts do you have about meeting the needs of family caregivers?

<u>Ending Question</u>

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Focus Group Questions – Regional/District Program Directors

1. What are your perceptions of caregiver education and support programs in terms of their utility, effectiveness and importance?
2. What programs have you implemented for patient education, caregiver education or caregiver support?
    a. How did you go about implementing these programs?
    b. What was your experience with implementing these programs?
    c. If you have not implemented these types of programs, why?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care, provides them with the program guide, and then conducts monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one;
    a. What factors would facilitate your region/district to implement this type of program?
    b. What factors would hinder your region/district from implementing this type of program?
    c. How could these factors be overcome?
4. What other thoughts do you have about meeting the needs of family caregivers?

<u>Ending Question</u>

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Focus Group Questions – Regional Rehabilitation Specialists

1. What are your perceptions of caregiver education and support programs in terms of their utility, effectiveness and importance?
2. Please think about the programs you have implemented for patient education, caregiver education or caregiver support.
    a. How did you go about implementing these programs?
    b. What was your experience with implementing these programs?
    c. If you have not implemented these types of programs, why?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care to start providing support and to provide them with the program guide. The stroke support person will then conduct monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one;
    a. What factors would facilitate your region to implement this type of program?
    b. What factors would hinder your region from implementing this type of program?
    c. How could these factors be overcome?
4. What other thoughts do you have about meeting the needs of family caregivers?

<u>**Ending Question**</u>

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Interview Guide – Health Care Professional Questions

1. Please tell us who you are, your professional training, and your role in the Ontario Stroke System.
2. Can you describe your involvement with family caregivers to stroke survivors?
3. What education and supports do family caregivers receive in your institution?
    a. What is done well?
    b. What could be done better?
    c. What are your institution's future plans for offering programs to family caregivers?
4. What are your perceptions of caregiver education and support programs in terms of their utility and effectiveness?
    a. Do you think your perceptions are in line with the perception of the health care organization you are currently in?
    b. If not, in what ways are they different?
    c. What factors would help your health care organization adopt family caregiver education and support programs into practice?
    d. What factors are hindering your health care organization from adopting family caregiver education and support programs into practice?
    e. What solutions would you propose to address these factors?
5. Our caregiver education and support program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments; what factors would influence your health care organization to adopt this program?
    a. What would be some of the barriers to adopting this program? What solutions would you propose to address these barriers?
6. What other thoughts do you have about meeting the needs of family caregivers?

Ending Questions

7. If you could make one change to the health care system to make things better for family caregivers, what would that change be?

8. Do you have any final thoughts for me today?

Thank you for taking the time to participate and share your thoughts.

Interview Guide – Local Health Integration Network Executive

1. Please tell me about your professional training and your role in the Local Health Integration Network
2. What are your perceptions of the need for, availability, and effectiveness of caregiver education and support programs?
3. What initiatives specifically targeting family caregivers are in place or in development? Can you describe them?
4. One model of a caregiver education and support program uses a stroke support person (health care professional) to provide family caregivers with education and support starting in acute care by meeting with them in person and then calling them monthly for approximately the first six months post stroke.
    a. What could facilitate the implementation of this program into practice across your LHIN?
    b. What could hinder the implementation of this program into practice across your LHIN?
    c. What solutions would you propose to address these barriers?

Ending Questions

5. What other thoughts do you have about meeting the needs of family caregivers?
6. If you could make one change to the health care system to make things better for family caregivers, what would that change be?
7. Do you have any final thoughts for me today?

Thank you for taking the time to participate and share your thoughts.

Interview Guide – Local Health Integration Networks (LHIN) Primary Care Leads

1. How did the LHIN primary care leads group come about? Please describe your role as the primary care lead.
2. What initiatives specifically targeting family caregivers are in place or in development? Can you describe them?
3. How would caregiver education and support programs fit into primary care across your LHIN?
    a. What factors would help the implementation of family caregiver education and support programs into practice?
    b. What factors would hinder the implementation of family caregiver education and support programs into practice?
    c. What solutions would you propose to address these factors?

Ending Questions

4. What other thoughts do you have about meeting the needs of family caregivers?
5. If you could make one change to the health care system to make things better for family caregivers, what would that change be?
6. Do you have any final thoughts for me today?

Thank you for taking the time to participate and share your thoughts.

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Title and abstract

	Page/line no(s).
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 6-7
Purpose or research question - Purpose of the study and specific objectives or questions	Page 7

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 8
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	n/a
Context - Setting/site and salient contextual factors; rationale**	Page 8
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 9
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 8
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 10

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 10
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 9
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 10-11
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 10-11
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 10-11

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 11-19
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pages 11-19

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 19-21
Limitations - Trustworthiness and limitations of findings	Pages 20

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	n/a
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 2

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
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BMJ Open

A Qualitative Study Assessing Organizational Readiness to Implement Caregiver Support Programs in Ontario, Canada

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Running Head: Organizational Implementation of Caregiver Programs

Title: A Qualitative Study Assessing Organizational Readiness to Implement Caregiver Support Programs in Ontario, Canada.

Authors: Victrine Tseung, PhD, Susan B Jaglal, PhD, Nancy M Salbach, PhD, and Jill I Cameron, PhD

Victrine Tseung, PhD

Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto

160-500 University Ave

Toronto, ON. Canada

v.tseung@utoronto.ca

Susan Jaglal, PhD FCAHS

Toronto Rehabilitation Institute-UHN Chair

Department of Physical Therapy, University of Toronto

Associate Academic Director of Research TRI-UHN

160-500 University Ave

Toronto, ON M5G 1V7

Susan.jaglal@utoronto.ca

Nancy M. Salbach, PhD

Department of Physical Therapy, University of Toronto

160-500 University Avenue

Toronto, ON M5G 1V7 Canada

Nancy.salbach@utoronto.ca

Corresponding Author: Jill I. Cameron, PhD FAHA

Department of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto

160-500 University Ave.

Toronto, ON M5G 1V7 Canada

416-978-2041 (office)

Jill.cameron@utoronto.ca

Affiliate Scientist, UHN-Toronto Rehabilitation Institute

Twitter: @caregiving_UofT

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Word Count: 2541

Tables: 2

Abstract

Objective: To qualitatively explore factors affecting implementation of caregiver support programs in health care institutions in a regional stroke system.

Design: A qualitative descriptive study with the Ontario Stroke System (OSS) was conducted. Data were collected through focus groups and in-depth interviews. Transcripts were coded and analyzed using inductive thematic analysis.

Setting: Regional Stroke System, Ontario, Canada.

Participants: OSS stakeholders including medical directors, executives, program directors, education coordinators, rehabilitation and community and long-term care specialists, primary care leaders, and health care professionals.

Intervention: Not applicable.

Main Outcome Measures: Data collection explored perceptions of the need for caregiver support programs and factors that may affect their implementation.

Results: Four focus groups (n=43) and 29 interviews were completed. Analyses identified themes related to: 1) evidence that a caregiver program will improve health and health system outcomes; 2) personnel requirements; 3) barriers associated with current billing and referral processes; and 4) integration with current practice and existing workflow processes.

Conclusions: Implementation strategies to adopt caregiver programs into clinical practice should incorporate evidence and consider personnel and existing workflow processes.

Keywords: caregivers, stroke, organizations, qualitative research

Abbreviations:

OSS – Ontario Stroke System

FG – Focus Group

HCP – Health Care Professionals

MD – Medical Directors

RE – Regional Health Executives

PL – Primary Care Leaders

PRISMA – Program of Research to Integrate the Services for the Maintenance of Autonomy

ADLs – Activities of Daily Living

Article Summary

Strengths and Limitations of this study

- Our study used in-depth qualitative methods to explore organizational considerations for implementing caregiver programs in a regional stroke system.
- Our study included 72 participants reflecting key stakeholder groups responsible for supporting caregivers and implementing caregiver programs within institutions.
- We did not systematically obtain data related to years of experience in specific roles.
- Additional stakeholder groups (e.g., hospital managers) could have provided additional perspectives on caregiver program implementation.
- More in-depth probing of the specific challenges experienced in rural areas would have expanded our findings.

Introduction

Family caregivers play a central role in the recovery, rehabilitation, and community re-integration of individuals who experience a stroke. Numerous studies have documented the negative impact providing care can have on caregiver health and wellbeing (1, 2). Previous literature suggest that 12-25% of caregivers experience depression (3, 4) and caregiver burden is positively associated with depression symptoms (5). Taking on the caregiver role can also impact other aspects of a caregiver's life, including leisure, relationships, and work. Relatives who assumed the caregiver role have increased responsibilities, decreased leisure activities and negative changes in their relationships, and the impact on their lives can still be present after a year post-stroke (6). A study conducted in the United States found that the indirect costs associated with caregiving (e.g., traveling time, out-of-pocket expenses) amounted to $5,669 per caregiver per year, and costs of total lost productivity amounted to more than $10,000 per year per employed caregiver (7). Taken together, the caregiver role affects many aspects of a caregiver's life and education and support has the potential to enhance their abilities to take on and sustain this important role.

Previous literature recommends the use of multi-component interventions (8) that cross the care continuum (9, 10) to meet caregivers' needs for support. Multicomponent interventions include at least two of the following: information provision (e.g., community resources), emotional support and counseling (e.g., support groups, professional support) and skills training (physical care, problem solving) (8). For example, the 'Timing It Right' Family Stroke Family Support program is a multicomponent intervention that is delivered by a health care professional (stroke support person), who meets with the caregiver in-person in acute care and then follows up with six monthly telephone meetings to discuss caregiver's support needs and potential strategies to meet these needs (9, 10). However, caregivers are not benefiting from these programs, as they are not being incorporated into standard clinical practice (11, 12). Research from the United Kingdom identified program and system level factors that limited the implementation of a stroke caregiver program into clinical practice (13, 14). Participants reported lack of time and individuals responsible for ensuring implementation as limiting factors.

Caregiver program implementation has been studied in the context of dementia caregiving. Although there are more than 200 efficacious dementia caregiver programs, only 6 have been integrated into practice (15). The need to identify contextual factors that may influence implementation has emerged as an emerging research field and an important step towards effective integration into practice (15). Previous studies undertook process evaluations during caregiver program implementation (e.g., (13, 14, 16)). However, the current study aimed to identify factors that may influence implementation in real-world settings prior to developing or testing an implementation strategy (17). Our research to date with the Ontario Stroke System (OSS) (18, 19) has indicated a need to understand implementation of caregiver programs within institutions. Therefore, the objective of this qualitative descriptive study was to examine program level factors (i.e., within institutions) that influence local implementation of caregiver programs in the context of a regional stroke system. For the purposes of this study, a caregiver education and support program was defined as a structured, time-limited intervention with a basic protocol and program materials. A program consists of one or more of the following: education, training and support.

Methods

Design

We conducted a qualitative descriptive study (20) and used the SRQR reporting guidelines (21). A qualitative approach is used when the purpose is to understand a specific phenomenon for which there has been limited research and the important variables to explore are unclear (22). There are no previous studies that have examined the implementation of caregiver education and support in standard clinical practice within the Canadian context. Specifically, a qualitative descriptive study design is particularly suited when producing a comprehensive description of participant perceptions of a specific phenomenon because data analysis and interpretation stays close to the data and participant perceptions are considered to be accurate and truthful reflections of the reality of the phenomenon (i.e., caregiver program implementation) (20). Participants were recruited from the OSS – regional system of stroke care in the province of Ontario. The OSS is publicly funded, includes 11 geographical regions, and provides specialized stroke care across the continuum. Each region includes a Regional Stroke Centre or Enhanced District Stroke Centre, community hospitals, rehabilitation hospitals, community-based providers and pre-hospital providers (23). Some of the regions are large encompassing rural areas and some are small and urban. There are 9 Regional Stroke Centres, 2 Enhanced District Stroke Centres, 16 District Stroke Centres, and 24 secondary prevention clinics (23). Institutional ethics boards, including the University of Toronto Research Ethics Board, approved the study. All participants provided written consent. This study was situated in the Knowledge-to-Action Framework's (24) barrier assessment step to identify facilitators and barriers in the local context. The Consolidated Framework for Implementation Research (25) informed data collection.

Patient and Public Involvement

Patients and the public were not involved in the design of this research. Participants, as described below, were involved in this research through in-depth interviews and focus groups where they contributed their thoughts about caregivers and program implementation. Findings have been presented at local and national stroke conferences which is commonly attended by many participants and they will receive copies of publications.

Participants

Participants were recruited from the 11 OSS regions including: Program Directors, Rehabilitation Specialists, Community and Long-Term Care Specialists, Education Coordinators, Medical Directors, and health care professionals providing stroke care in acute, rehabilitation, and community settings, and from the broader health care system including regional health executives, and primary care leaders. Regional Rehabilitation Specialists, Professional Education Coordinators, Community and Long-Term Care Specialists, and Regional/District Program Directors were invited by the corresponding author via email to participate in a focus group as part of regularly scheduled group meetings. Regional Medical Directors, health executives, and primary care leaders were invited by the corresponding author via email to participate in an interview. OSS Education Coordinators assisted with recruitment of health care professionals by emailing the study invitation to attendees of their education sessions. The primary author then coordinated and conducted all interviews and focus groups.

None of the members of the research team had any formal relationships with the participants. The corresponding author has shared their research with members of the Ontario Stroke System through invited presentations and workshops.

Data Collection

Participants were asked to discuss: 1) perceptions of the availability, importance, and effectiveness of caregiver programs; 2) current practices related to caregiver education and support; and 3) program level implementation considerations. The focus group and interview questions incorporated the domains of the Consolidated Framework for Implementation Research (CFIR) (25) to explore how individual and institution-level factors influence caregiver program implementation (see supplemental appendix). For example, individual level factors such as understanding of caregiver needs, the institution's ability to address caregiver needs, and the evidence base for caregiver programs can all influence program implementation (25). Participants were asked to reflect on all caregiver programs in general and then more specifically on caregiver programs that cross care environments using the Timing It Right Stroke Family Support Program (9, 10) as an example. Focus groups were conducted in person at the local Heart and Stroke Foundation office and interviews were conducted by telephone. The primary author collected all data and is an occupational therapist and doctoral candidate with training in qualitative interviewing. Data collection took place over the course of four months and ended when data saturation was reached. Qualitative, semi-structured interviews and focus groups were audio-recorded, transcribed verbatim, reviewed for accuracy, and de-identified.

Data Analysis

Qualitative thematic analysis is commonly used to analyze data in qualitative descriptive studies (20). Data were analyzed using inductive thematic analysis (26) and facilitated using NVivo (27). The first author coded all of the data and all authors reviewed the data and contributed to theme generation. Reflexive notes and field notes were taken throughout data collection and analysis to ensure the dependability and confirmability of the findings (20). To maximize the credibility of the findings, all authors reviewed data and contributed to theme generation (28).

Results

Four focus groups (n=43) and 29 individual interviews yielded 72 participants (see tables 1 and 2). Four themes related to: 1) need for evidence that a caregiver program will improve patient and caregiver health and health system outcomes after "real world" implementation; 2) personnel requirements; 3) barriers associated with current billing and referral processes; and 4) integration with current practice and workflow processes. Participant quotations from focus groups (FG) and interviews with health care professionals (HCP), medical directors (MD), regional health executives (RE), and primary care leaders (PL) are identified by number.

Table 1: Professional role of participants: A summary of study participants' professional roles.

Participant Group	**Number (%) of Participants (n=72)***
Regional/District Program Directors	19 (26%)
Community and Long-Term Care	7 (10%)
Regional Education Coordinators	7 (10%)
Regional Rehabilitation Specialists	11 (15%)
Regional Medical Directors (INT)	2 (3%)
Health Region Executives (INT)	4 (6%)

Participant Group	**Number (%) of Participants (n=72)***
Health Region Primary Care Leads	4 (6%)
Health Care Professionals (INT)	19 (26%)

Abbreviations: FG, focus group; INT, interview.

*One participant had a dual role.

Table 2: Health Care Professionals by Sector and Occupation: A summary of study participants' clinical sector and profession.

Health Care Professionals by Sector and Occupation	
Sector	**Number (%) of Participants (N=19)**
Acute	5 (26%)
Rehabilitation	7 (37%)
Community	6 (32%)
Private	1 (5%)
Profession	
Occupational Therapist	5 (26%)
Physical Therapist	4 (21%)
Speech Language Pathologist	3 (16%0
Physiatrist/Recreational Therapist/Stroke Care Navigator	3 (16%)
Registered Nurse	2 (11%)
Social Worker	2 (11%)

Theme 1: Need for evidence that a caregiver program will improve patient and caregiver health and health system outcomes after "real world" implementation

Participants discussed the role of evidence, including program evaluation, to support funding, implementation, and sustainability of caregiver programs. Participants suggest stakeholders differ in their preferences for process (e.g., program attendance) or outcomes (e.g., health and health system outcomes) data. For example, some prefer numerical data to support implementation (e.g., program attendance) while others are looking for success stories (e.g., patient stories). The following quotation describes the roles of pilot testing and program evaluation to sustain implementation in practice:

> But the point I'm trying to get across is that…the organization if they see…there's research to back up the effectiveness of it [caregiver program]…then they'll pilot it… to see if it's working, and then…upper management…they'll look at the number of people who are taking advantage of the programs cause it all comes down to numbers for organizations, right. And...if it is working right then that pilot program can become…a regular program that the hospital runs and incorporates as a part of their budget. (HCP 19)

Theme 2: Personnel Requirements

Many participants agreed that existing team members would not be able to assume this added responsibility so a new role was needed. In terms of creating a new role, three considerations were discussed: 1) similarity with existing roles; 2) integration into a community-based navigator role; and 3) integration into health care teams in acute and rehabilitation settings. A few participants highlighted the overlap with existing roles (e.g., community care case managers) so this role would need to be clearly defined:

> …defining whose role is what and again who's responsible for what, because if you're doing a quarter of the discharge planner's job and you're doing thirty percent of the family doctor's job…there's too much duplication in the hospital and in the health care. (HCP 15)

Some participants spoke about the navigator role in which an individual supports patients and families in the community. Perspectives differed as to the possibility of integrating caregiver support into this role as their availability and function varied by region: "…not every region has a navigator…and those that do they function very differently" (FG 3).

Participants questioned the feasibility of having a position that crosses care environments because current practice does not include contact with patients and their caregivers after they leave the institution. While they indicated the desire for a single point of contact for caregiver support, they spoke about the challenge of determining funding sources and sustainability with current fiscal restraints. The following quotation raises the issue of funding and ownership for this role, particularly in cases where acute and rehabilitation care are separate institutions:

> This acute person follows the patient through their rehab stay to community…how does that work when it's [rehab] a separate facility? Like the ownership … that's why the idea of dedicated resources seems to be a good fit to overcome that barrier because if you think about it, if someone's being paid by [hospital A] to handle [hospital A] patients and…and they're off to another…that's what I'm thinking is a barrier for you… (FG 4)

The increasingly large caseload this single person would have to manage was also mentioned as a concern for the feasibility of this approach*:* "…just by the nature of the beast it's most likely that you're going to…need a few of these individuals…because their caseload is going to just get bigger and bigger…" (FG 4). Instead, some participants suggested that caregiver support be organized by care environment with health care teams picking up the education where the last team finished. The following quotation provides an example: "I can see it working as…the stroke nurse's role to take it from point A to point B and then…it would be the social worker and rehab's role to be from this section to this section and then it would be the community navigator or the outpatient OT…to be taken to the next stage…" (FG 3).

In addition, some participants felt that it may be more likely to be funded if it was used region-wide. However, in geographically larger stroke regions, it would be very challenging for one individual to cover the entire region:

> And the individual has to be a regional resource versus organizational. So they can't necessarily belong to a specific hospital but they have to have the capacity to cover a region and be flexible in that…which is a barrier up north. (FG 2)

Participants had different perspectives regarding the role of health care professionals in providing caregiver support. This individual would need to be knowledgeable about acute care, rehabilitation, and community care and to stay up-to-date with community resources. He or she would have counseling skills and a good understanding of each of the disciplines on the health care team. Some participants provided examples of specific health care professionals they perceived to be most appropriate for this role, including occupational therapists, social workers, nurses, and other allied health professionals.

Participants questioned the use of trained volunteers or non-health care professionals. Some of the regional health executives discussed the limited availability and high costs of health care professionals as the main reasons to consider volunteers. The following quotation highlights this point: "So it may be a costly model if the person is a health care professional. There may be other models where you use peers, somebody who's had a similar experience or volunteers who have been trained" (RE 4). However, there might be instances when the issues facing the families are predominantly medical in nature, and these personnel may not be able to address such issues:

> …the challenge would be and we've seen it with community navigators when it's an orphan patient and we have a community navigator following them but all their issues are medical…that community navigator is not equipped to provide advice or to plan any intervention other than to say go to a walk in clinic or et cetera. And that then it becomes a challenge for both parties. (FG 1)

Theme 3: Barriers associated with current billing and referral processes

Participants agreed that existing infrastructure should incorporate caregiver programs. However, participants identified several challenges. Health care professionals and Rehabilitation Specialists suggested that organizational referral criteria and government-funded health insurance precludes caregivers from being formal units of care. One participant explained that there are community-based activities that would be appropriate for the patient-caregiver dyad, but because the organization's mandate is to provide services to individuals with disabilities and there is no billing structure for services provided to caregivers, caregivers are not included. The following quotation demonstrates how the current billing structure and referral criteria hinder the provision of caregiver support within health care organizations:

> Let's say we register the caregiver as a patient, then they need a chart. Then they need space in health records. Like then we have to track them that way…if the caregiver now becomes the patient then you need to refer them to mental health if that's the issue. Do you know what I mean...So whether or not our institution would adopt that would be really interesting to see. I doubt it…Cause then a cost comes in. (HCP 10)

Theme 4: Integration with current practice and existing workflow processes

Participants discussed four facilitators to the integration of caregiver support into current practice and existing workflow processes. Potential challenges were also discussed.

First, participants suggested the caregiver support role should become part of routine practice. This approach may overcome limited therapist time to provide support in both inpatient and community care.

Second, participants were concerned with incorporating caregiver support into patient charts. A few participants indicated that there are no places in patient charts to document the specific education provided. If education became required practice, the tendency might be to provide the support for the sake of checking off the box as opposed to paying attention to the content, timing, or the readiness of the caregiver to receive this information. The following quotation underscores the challenges with incorporating caregiver support into existing documentation, particularly when these programs cross care environments:

> …so if there is a way to [tick off] have you done your section of [caregiver program] …you would almost have to be embedded in documentation somehow too so that it is not missed and that would be hard because… once that patient is gone, so is their chart…you are not even supposed to go into the chart after… (FG 3)

Third, participants emphasized communication between the individual providing caregiver support and the rest of the care team to ensure consistency and continuity in messaging to caregivers. This was noted as a challenge in community care because team members do not necessarily communicate with one another or know who else is working with the patient.

Lastly, participants highlighted the importance of having a formalized and structured approach to guide implementation. This would require ready-made materials that can be adapted to local contexts, developing a clear referral and monitoring system, setting target user criteria, and establishing a mechanism for re-accessing caregivers if they initially decline the program. Participants suggested some health care professions would need education and tools to assess caregivers' needs and provide appropriate supports. Training may also enhance soft skills as many health care professionals may be more comfortable with the more technical aspects of their clinical work.

Discussion

The objective of this study was to identify factors that influence implementation of caregiver programs within institutions. The four themes suggest that the availability of evidence to support program outcomes, personnel requirements, and a supportive structure including billing, workflow and resources are important for caregiver program implementation.

As we aim to support transitions across the care continuum (9, 10, 29, 30), our findings suggest one potential approach to implementing a program that crosses care environments. This would involve offering a program across care environments with health care teams picking up the education where the last team finished. Caregivers, however, prefer having one individual provide support across the care continuum (31). One possible solution to address these differences in perspectives comes from the aging literature. Stroke care could adopt an integrated service delivery model such as one proposed for the frail elderly. The PRISMA (Program of Research to Integrate the Services for the Maintenance of Autonomy) model uses case managers to coordinate and monitor the needs of frail elderly across care environments and has demonstrated positive impacts on patient and caregiver health, and health care utilization (32, 33). The applicability of this service delivery model to stroke care warrants further consideration. Participant responses indicated that various health care professionals would be suitable to provide support to caregivers. One example is occupational therapists where previous literature suggests that occupational therapists can serve an important role in addressing the needs of caregivers (34). Occupational therapists are a core member of multi-disciplinary stroke teams and they contribute to caregiver training (e.g., teaching ADLs) (35, 36). Beyond training in ADLs, occupational therapists' training in mental health and meaningful occupations prepares them for addressing the psychosocial effects of caregiving (35). There is a need to address caregivers' needs such that they are able to maintain both their own health and engagement in valued activities and provide care for their loved ones (6). This previous research (6) and our study findings highlight occupational therapists as a potential source of support for caregivers.

Current billing structures and referral criteria preclude the provision of services to caregivers in standard clinical practice. This suggests a need to expand organizational structures for billing, referral and documentation to include caregiver support. As demonstrated in the PRISMA model, information systems (e.g., computerized client chart that is available across organizations) can be developed to overcome organizational structures (32). The integration of caregivers into information systems can facilitate program implementation (14).

Strengths and Limitations

Our study used in-depth qualitative methods to explore organizational considerations for implementing caregiver programs in a regional stroke system. Our study included 72 participants reflecting key stakeholder groups responsible for supporting caregivers and implementing caregiver programs within institutions. We did not systematically obtain data related to years of experience in specific roles. Additional stakeholder groups (e.g., hospital managers) could have provided additional perspectives on caregiver program implementation. More in-depth probing of the specific challenges experienced in rural areas would have expanded our findings.

In summary, our study was one of the first to examine implementation of caregiver programs within a regional stroke system. It adds to the existing literature by delineating implementation considerations and highlighting the potential role for occupational therapists and other health care professionals as providers of caregiver support.

Conflict of Interest

Authors have no conflicts of interest to declare.

Author Contributions

VT contributed to the project conceptualization and design, data acquisition and qualitative interviewing, coding and data analysis, theme generation, drafting and revising the manuscript.

SJ contributed to project conceptualization and design, qualitative data analysis, theme generation and revisions to the final manuscript.

NMS contributed to project conceptualization and design, qualitative data analysis, theme generation and revisions to the final manuscript.

JIC contributed to the project conceptualization and design, qualitative data analysis, theme generation, drafting and revising the manuscript.

Data Availability

Data may be accessed by contacting the corresponding author.

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Appendix I Interview/Focus Group Guides for Qualitative Descriptive Study

Focus Group Questions – Regional Community and Long-Term Care Specialists

1. What are your perceptions of caregiver education and support programs in terms of their utility, effectiveness and importance?
2. Please think about the programs you have implemented for patient education, caregiver education or caregiver support.
    a. How did you go about implementing these programs?
    b. What was your experience with implementing these programs?
    c. If you have not implemented these types of programs, why?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care to start providing support and to provide them with the program guide. The stroke support person will then conduct monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one;
    a. What factors would facilitate your region to implement this type of program?
    b. What factors would hinder your region from implementing this type of program?
    c. How could these factors be overcome?
4. What other thoughts do you have about meeting the needs of family caregivers?

Ending Question

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Focus Group Questions – Regional Education Coordinators

1. In your region, what has been one key challenge to educating health care professionals to implement best practice recommendations in clinical practice?
2. Please think about the health care professional education initiatives you have implemented. How have these initiatives address the provision of patient and family education across the care continuum?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care to start providing support and to provide them with the program guide. The stroke support person will then conduct monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one; how could this type of program be incorporated into your regional education initiatives to facilitate its implementation into clinical practice?
4. What other thoughts do you have about meeting the needs of family caregivers?

<u>Ending Question</u>

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Focus Group Questions – Regional/District Program Directors

1. What are your perceptions of caregiver education and support programs in terms of their utility, effectiveness and importance?
2. What programs have you implemented for patient education, caregiver education or caregiver support?
    a. How did you go about implementing these programs?
    b. What was your experience with implementing these programs?
    c. If you have not implemented these types of programs, why?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care, provides them with the program guide, and then conducts monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one;
    a. What factors would facilitate your region/district to implement this type of program?
    b. What factors would hinder your region/district from implementing this type of program?
    c. How could these factors be overcome?
4. What other thoughts do you have about meeting the needs of family caregivers?

<u>Ending Question</u>

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Focus Group Questions – Regional Rehabilitation Specialists

1. What are your perceptions of caregiver education and support programs in terms of their utility, effectiveness and importance?
2. Please think about the programs you have implemented for patient education, caregiver education or caregiver support.
    a. How did you go about implementing these programs?
    b. What was your experience with implementing these programs?
    c. If you have not implemented these types of programs, why?
3. The Timing It Right Stroke Family Support Program is an example of a structured caregiver program. The program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments. The stroke support person meets with family caregivers in acute care to start providing support and to provide them with the program guide. The stroke support person will then conduct monthly follow-up telephone calls to address their support needs and to go over relevant information in the guide. The stroke support person follows family caregivers for approximately the first six months post stroke. This program aims to provide timely and tailored education and support to family caregivers. If you consider a structured caregiver support program like this one;
    a. What factors would facilitate your region to implement this type of program?
    b. What factors would hinder your region from implementing this type of program?
    c. How could these factors be overcome?
4. What other thoughts do you have about meeting the needs of family caregivers?

<u>Ending Question</u>

5. Do you have any final thoughts for us today?

Thank you for taking the time to participate and share your thoughts with us.

Interview Guide – Health Care Professional Questions

1. Please tell us who you are, your professional training, and your role in the Ontario Stroke System.
2. Can you describe your involvement with family caregivers to stroke survivors?
3. What education and supports do family caregivers receive in your institution?
    a. What is done well?
    b. What could be done better?
    c. What are your institution's future plans for offering programs to family caregivers?
4. What are your perceptions of caregiver education and support programs in terms of their utility and effectiveness?
    a. Do you think your perceptions are in line with the perception of the health care organization you are currently in?
    b. If not, in what ways are they different?
    c. What factors would help your health care organization adopt family caregiver education and support programs into practice?
    d. What factors are hindering your health care organization from adopting family caregiver education and support programs into practice?
    e. What solutions would you propose to address these factors?
5. Our caregiver education and support program uses a stroke support person (health care professional) to provide family caregivers with education and support in person and by telephone across care environments; what factors would influence your health care organization to adopt this program?
    a. What would be some of the barriers to adopting this program? What solutions would you propose to address these barriers?
6. What other thoughts do you have about meeting the needs of family caregivers?

<u>Ending Questions</u>

7. If you could make one change to the health care system to make things better for family caregivers, what would that change be?

8. Do you have any final thoughts for me today?

Thank you for taking the time to participate and share your thoughts.

Interview Guide – Local Health Integration Network Executive

1. Please tell me about your professional training and your role in the Local Health Integration Network
2. What are your perceptions of the need for, availability, and effectiveness of caregiver education and support programs?
3. What initiatives specifically targeting family caregivers are in place or in development? Can you describe them?
4. One model of a caregiver education and support program uses a stroke support person (health care professional) to provide family caregivers with education and support starting in acute care by meeting with them in person and then calling them monthly for approximately the first six months post stroke.
    a. What could facilitate the implementation of this program into practice across your LHIN?
    b. What could hinder the implementation of this program into practice across your LHIN?
    c. What solutions would you propose to address these barriers?

Ending Questions

5. What other thoughts do you have about meeting the needs of family caregivers?
6. If you could make one change to the health care system to make things better for family caregivers, what would that change be?
7. Do you have any final thoughts for me today?

Thank you for taking the time to participate and share your thoughts.

Interview Guide – Local Health Integration Networks (LHIN) Primary Care Leads

1. How did the LHIN primary care leads group come about? Please describe your role as the primary care lead.
2. What initiatives specifically targeting family caregivers are in place or in development? Can you describe them?
3. How would caregiver education and support programs fit into primary care across your LHIN?
    a. What factors would help the implementation of family caregiver education and support programs into practice?
    b. What factors would hinder the implementation of family caregiver education and support programs into practice?
    c. What solutions would you propose to address these factors?

Ending Questions

4. What other thoughts do you have about meeting the needs of family caregivers?
5. If you could make one change to the health care system to make things better for family caregivers, what would that change be?
6. Do you have any final thoughts for me today?

Thank you for taking the time to participate and share your thoughts.

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 3

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 6-7
Purpose or research question - Purpose of the study and specific objectives or questions	Page 7

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 8
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	n/a
Context - Setting/site and salient contextual factors; rationale**	Page 8
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 9
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 8
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 10

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 10
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 9
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 10-11
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 10-11
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 10-11

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 11-19
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pages 11-19

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 19-21
Limitations - Trustworthiness and limitations of findings	Pages 20

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	n/a
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 2

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388