

ORIGINAL REPORT

ACTUAL AND IDEAL SERVICES IN ACUTE CARE AND REHABILITATION FOR RELATIVES POST-STROKE FROM THREE PERSPECTIVES: RELATIVES, STROKE CLIENTS AND HEALTH PROFESSIONALS

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Objective: To document the gap between actual and desired ideal services for relatives post-stroke from 3 perspectives: relatives, stroke clients and health professionals.

Methods: A two-phase qualitative design and consisting of in-depth interviews (Phase 1) and 3 focus groups (Phase 2). The interview sample consisted of 25 relatives (mean age 53.4 (standard deviation 12.7); women=21/25) and 16 individuals with a first stroke (mean age=55.7 (standard deviation 11.2); women=7/16). The focus group sample size varied from 5 to 7 participants. An interview guide validated by experts was used. Audio content was transcribed verbatim and rigorously analyzed by two team members.

Results: Services received by relatives are diversified, and relatives' perceptions range from receiving no services to being satisfied with services received. Even when participants were satisfied, ideal services were still desired: they would have liked to receive services earlier and without having to seek. Four main factors emerged as influencing the amount and quality of services received, including the individual's ability to seek.

Conclusions: A gap remains between actual and ideal services for relatives post-stroke. It is crucial to legitimized relatives' role as clients and to systematically assess the patient's social environment in order to provide services in accordance with needs.

Key words: family; stroke; health services; acute care; rehabilitation, qualitative study.

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INTRODUCTION

Negative consequences of stroke for relatives have been acknowledged for more than 3 decades (1). Recent reviews reaffirm the negative impact of stroke on relatives' participation (2) and quality of life (3) while admitting that it can be a

positive experience (4). Relatives' needs for information (5), education (6) and support (7, 8) are also well documented. Internationally, stroke best practices recommend including relatives throughout the continuum of stroke care (9–12) as there is increasing evidence of effective interventions such as counselling program or vocational training specifically targeting relatives and resulting in positive outcomes (13, 14).

However, we know little about what relatives actually receive in terms of services. In a Canadian cross-sectional telephone survey using 3 case studies describing typical patients with stroke, only one-third of clinicians (including physical therapists, occupational therapists and speech language pathologists) identified a family problem when there was one and offered a related intervention (15). It makes common sense that offering services to all relatives post-stroke should be systematic and monitored by all members of the interdisciplinary team and not solely by the 3 rehabilitation disciplines surveyed. As such, stroke best practices do recommend offering support and education to families at all stages across the continuum of stroke care (16).

Purpose of study

The purpose of this study was to explore actual services received by relatives and to contrast it to desired ideal services (i.e. services wished for relatives by participants) in acute care and post-stroke rehabilitation from 3 perspectives: relatives, stroke clients and health professionals.

METHOD

Design of study

A two-phase qualitative design was used. Phase 1 consisted of in-depth interviews (17) anchored in a phenomenological perspective (18) with relatives and stroke clients in order to document their perceptions of actual and ideal services received by relatives in both acute care (T1) and in-patient or out-patient rehabilitation (T2). Only those who actually received formal rehabilitation services were interviewed at both times, more than 6 weeks after discharge, allowing patients to resume their normal activities and have the hindsight needed to comment on actual and ideal services. Phase 2 consisted of 3 focus groups (19), in which results from Phase 1 were discussed with other relatives, stroke clients, and health professionals.

Participants' selection and recruitment

Three populations were targeted by the study: 1) relatives, defined as individuals who had spent time with the patient since the stroke, 2) individuals who had had a first stroke (stroke clients), and 3) health professionals working with stroke clients. Although we did recruit some dyads (relative-patient), this was not an inclusion criterion. Those who could not communicate in French were excluded. Diversity was sought to maximize the scope of lived experiences through age, stroke severity and discharge destination for stroke client, and through discipline and work environment for health professionals.

Participants in Phases 1 and 2 were recruited from 3 acute care hospitals and from 2 rehabilitation centers to represent the continuum of care. Potential participants were screened and referred to the research assistant by an on-site nurse not involved in the study. Eight of the 49 potential participants referred for Phase 1 refused to participate mainly because of fatigue or not having time for an interview. There was no refusal for Phase 2 (focus groups). For both phases, eligible individuals were contacted by a research assistant to explain the purpose of the study and schedule an appointment for an interview (Phase 1) or a focus group discussion (Phase 2). The research protocol of the study underwent a provincial multicenter procedure to ensure that the ethics committee of each establishment involved in recruitment approved the study.

Characteristics of participants in Phases 1 and 2

Characteristics of participants in Phase 1 are presented for relatives in Table I and for stroke clients in Table II. Relatives' ($n=25$) mean age was 53.4 years (standard deviation (SD) 12.7). Nine were interviewed at both times (following discharge from T1 and T2) for a total of 34 interviews. Stroke clients' ($n=16$) mean age was 55.7 years (SD 11.2), and 10 participated at T1 and T2 ($n=26$ interviews). Participants in the

focus group (Phase 2) for relatives ($n=5$) were aged between 43 and 66 years, and 3 were women. Participants in the stroke client focus group were mainly men ($n=3/4$), while participants in the health professional focus group were mainly women ($n=4/5$). For the latter, the entire continuum of stroke care (acute care, in-patient rehabilitation, out-patient rehabilitation) was represented by a variety of disciplines, including a nurse, a physiotherapist, a speech language pathologist, a social worker, and a special educator, while the two facilitators were occupational therapists.

Data collection

An interview guide was used in Phase 1 to facilitate the administration of individual interviews while enabling the emergence of spontaneous, unanticipated content. The interview guide was developed following a rigorous process: 1) drafting of initial questions based on a literature review on the needs of relatives post-stroke; 2) review by an interdisciplinary research team; and 3) content validation by 3 groups of experts (relatives, stroke clients, and health professionals; $n=4$ for each group) using Delphi groups. The interview guide included open-ended questions aimed at documenting the perspectives of individuals regarding health services actually received by relatives as well as health services perceived as ideal. Each question was followed by a list of themes to explore. New themes emerging from previous interviews were added to the list. This procedure allowed discussion of themes spontaneously mentioned by participants. Two interviewers (MT and JB) were involved in data collection of Phase 1 while JB and AR co-animated focus groups of Phase 2. Individual interviews lasted less than 1 h while 2 h period was used for each focus group. Discussions of the focus groups in Phase 2 centered on the similarities and differences emerging from the data collected in Phase 1. All discussions were audiotaped and transcribed verbatim.

Table I. *Characteristics of relatives interviewed in phase 1* ($n=25$)

ID	Interviewed at T1 or T2	Age (years)	Gender	Marital status	Schooling	Main occupation	Relationship with stroke client	Perception of stroke severity	Discharge destination
R1 ^a	T1 and T2	60	F	Married	College	Work	Daughter	Severe	Rehab and Residence with services
R2 ^a	T1 and T2	53	F	Married	University	Work	Spouse	Severe	Rehab and home
R3 ^a	T1	72	M	Married	College	Retired	Spouse	Severe	Rehab
R4	T1	39	F	Divorced	University	Work	Daughter	Severe	Rehab
R5	T1	67	F	Married	College	Retired	Spouse	Mild	Home
R6 ^a	T1	69	F	Widowed	High school	Retired	Sister	Moderate	Long term care
R7 ^a	T1	55	F	Married	University	Work	Daughter	Moderate	Rehab
R8 ^a	T1	62	F	Married	College	Retired	Friend	Mild	Temporary residence
R9	T1	57	F	Married	Prof. school	Work	Friend	Moderate	Rehab
R10	T1	37	M	Single	University	Studying	Grandson	Mild	Home
R11 ^a	T1	70	F	Married	High school	Retired	Spouse	Mild	Home
R12 ^a	T1	49	M	Married	College	Work	Child	Moderate	Home
R13	T1	52	F	Married	University	Retired	Daughter	Moderate	Rehab
R14	T1	67	F	Single	University	Retired	Mother	Moderate	Rehab
R15 ^a	T1	64	F	Married	University	Retired	Daughter	Mild	Home
R16	T1	32	F	Married	High school	Work	Daughter-in-law	Mild	Rehab
R17 ^a	T1	61	F	Married	University	Retired	Daughter	Mild	Home
R18 ^a	T1 and T2	65	F	Married	High school	Retired	Spouse	Severe	Rehab and home
R19	T1 and T2	31	F	Single	College	Work	Sister	Moderate	Rehab and home
R20	T1 and T2	42	F	Married	High school	Work	Daughter	Mild	Rehab and home
R21 ^a	T1	59	F	Divorced	University	Work	Spouse	Severe	Rehab
R22 ^a	T1 and T2	43	M	Single	University	Work	Nephew	Moderate	Rehab and home
R23	T1 and T2	33	F	Common law	College	Work	Spouse	Severe	Rehab and home
R24 ^a	T1 and T2	51	F	Married	College	Work	Spouse	Moderate	Rehab and home
R25 ^a	T1 and T2	45	F	Married	Prof. school	Work	Daughter	Mild	Rehab and home

^aParticipant mentioned during interview either being part of the health care system (e.g., him- or herself being a health care provider) or having a trusted relative part of it.

M: male; F: female; R: relative; T1: acute care; T2: in- or out-patient rehabilitation.

Table II. Characteristics of stroke clients interviewed in phase 1 (n = 16)

ID	Interviewed at T1 or T2	Age (years)	Gender	Marital status	Schooling	Main occupation	Relationship with relative	Perception of stroke severity	Discharge destination
S1	T1	Missing	M	Single	University	Studying	Child	Moderate	Missing
S2	T1	39	M	Married	College	Work	Spouse	Moderate	Rehab
S3	T1	56	F	Married	High school	Work	Spouse	Moderate	Home
S4	T1 and T2	58	F	Single	Primary	Work	Parent	Moderate	Rehab and home
S5	T1 and T2	50	M	Married	College	Work	Spouse	Mild	Rehab and home
S6 ^a	T1 and T2	40	M	Single	University	Work	Child	Moderate	Rehab and home
S7	T1 and T2	37	M	Single	University	Work	Brother	Mild	Rehab and home
S8 ^a	T1 and T2	65	F	Widowed	University	Retired	Aunt	Mild	Rehab and home
S9	T1 and T2	76	F	Widowed	Primary	Retired	Parent	Mild	Rehab and home
S10 ^a	T1	55	M	Common law	University	Retired	Spouse	Moderate	Rehab
S11 ^a	T1 and T2	53	M	Common law	University	Work	Spouse	Severe	Rehab and home
S12 ^a	T1 and T2	63	M	Divorced	College	Work	Parent	Mild	Rehab and home
S13	T1 and T2	61	F	Divorced	High school	Work	Parent	Moderate	Rehab and home
S14 ^a	T1 and T2	50	M	Married	University	Work	Spouse	Moderate	Rehab and home
S15 ^a	T1	65	F	Married	College	Home	Parent	Severe	Rehab
S16 ^a	T1	67	F	Divorced	College	Retired	Parent	Moderate	Rehab

^aParticipant mentioned during interview either being part of the health care system (e.g., him or herself being a health care provider) or having a trusted relative part of it.

M: male; F: female; S: stroke client; T1: acute care; T2: in- or out-patient rehabilitation.

Data analysis

QSR NVivo 10 (Doncaster, Australia) was used for data management and analysis. Data analysis was conducted iteratively while data were being collected in order to validate content with subsequent participants. A summary of all interviews and focus groups was made to identify overall meaning (17). Content analysis of the transcriptions was performed concomitantly using a comprehensive coding grid that evolved as new categories linked to the study theme emerged from the data. Half of all content was co-codified by another member of the research team. The coded content was then grouped into categories and discussed with the research team until consensus was reached about essential meanings. Quotes were identified based on the following system: R (relative), S (stroke client), HP (health professional), ID number, T1, T2, FG (focus group).

RESULTS

Actual versus desired ideal services

The main themes emerging from individual interviews were similar between relatives and stroke clients except that in some cases where dyads were interviewed individually, some unmet needs perceived by relatives were not necessarily identified by the stroke client. For example: "I was holding her the best I could. No one said to me: 'So, you're going out? I'll show you something.' No, it was like, you're going out, you are responsible" [R22T2] versus "I said you have to help me, during that time I'll just tell you to come and help me... then we went out." Interviewer: "It was you who showed him how to help you get up?" Participant: "Yes, absolutely. I explained, it's the left side, the right side, and then he helped me and I went out... it was fine" [S8T2]. The main themes emerging from acute care versus rehabilitation phases were also similar except for a few differences which are highlighted below.

Actual services emerged as being quite diversified from one case to the next and 4 main factors (see Table III) were identified as influencing actual services although the actual referring institution did not emerge as a factor in itself. While participants

were recruited mostly from 5 main health care institutions, they referred to more than 10 different institutions when relating individual experience. The vast majority of participants identified a gap between actual services received by relatives and services perceived as ideal. For some, they perceived receiving no services at all: "It was me who supported her, you know"; "we managed" [S10T1] or "I would have liked to understand what a stroke is, what it does, and where we go from here. What it is, what exactly it is that the spouse has to do to help the patient. ... He [stroke client] told me that she'd met her [social worker], she'd asked how I was doing, but no one ever called me..." [R23T2] or "They ran around doing their thing as if the family didn't exist. They looked after my husband but they didn't tell me what they were doing with..." [R24T2]; whereas others were quite satisfied: "The lady who spoke to us was very nice. Afterwards she called quite often, it wasn't just once and then no news for two months. She definitely called 3 or 4 times, 3 or 4 times at least." [R16T1] or "She [doctor] really explained things clearly, we understood it. She explained well. Said what to do. Explained everything really well." [R11T1]. But when asked about an ideal, they would have liked it to be delivered differently (without having to seek): "She didn't tell us, but it's true that we didn't ask her. Perhaps if we had asked her..." [R16T1] or "It was me who had to go ask the question because they were often too busy to answer me." (R4T1) and earlier (from day one): "First, they explain to us, right when we get there, what's really happening, it's... That there was no delay, what's really happening. Then the steps to take with that. What will happen." [R11T1] or "With hindsight, let's say, it's not something serious, and also I might not have been ready to hear it, I mean, too, that someone might sit down and really explain to me, completely, exactly what a stroke is, what the consequences are and all that..." [R14T1].

Relatives' primary role was still to be a source of information and potential caregiver and they were seldom considered

Table III. Factors influencing actual services which emerged from Phase 1 and were further validated through Phase 2

<p>Ability to seek: the more proactive an individual is, the more they will get information, education or support. Some see this as the only way to get services. For others, especially stroke clients, they think that their relatives got what they needed, otherwise they would have asked. Health professionals perceive relatives to be more proactive in acute care but not necessarily receptive or ready to welcome incoming information and less receptive to education to help in assisting stroke clients in their daily activities.</p> <p>R13T1: <i>"But I went looking myself, it doesn't bother me that they don't give it to me, if I need something I ask them."</i></p> <p>R21T1: <i>"They didn't have any choice, with me they didn't have any choice. I stayed there until I got some answers."</i></p> <p>R1T2: <i>"I don't really like them looking after me. [laughs] I'd rather look after others!"</i> [No one asked her if she was able to handle the discharge, as she was present, she thought they assumed that everything was ok. There were no assessments of her needs.]</p> <p>S14T2: <i>"So could she [spouse] have attended a few meetings maybe? Would she have wanted to? Probably, but she was never asked, no one said 'Would you like to attend a meeting?'"</i></p> <p>R2T2: <i>"I realized it was up to me to get my own resources, it's me who will go to look for my resources, no one will give them to me."</i></p> <p>HP, FG: <i>"In the acute phase they are willing to be very proactive, they will be there all the time, almost 24 hours a day, they will see the doctor, they will get information right away, certainly they want information, so the majority of relatives will go ahead and look for it. Another participant: And at the same time we want to see them... It's not too problematic because we need the information they'll give us, therefore on both sides we want to see each other."</i></p> <p>Self or relative being part of the health care system: was perceived by all as a protective factor because it may be reassuring to give your confidence to someone you trust, knowing you can ask them, also being more resourceful to manage complex health care systems, they know better who to ask (more effective seeking), they may facilitate communication with health professionals (as perceived by HP) but they may also be more demanding as they know the constraints of the system and want to access the best for their relative.</p> <p>R15T1: <i>"I think it could help communications with the social worker once they know she is a social worker."</i></p> <p>S13T2: <i>"I said my spouse was a nurse, so maybe that also played in my favour."</i> [To obtain a weekend pass.]</p> <p>S, FG: <i>"She was fortunate because, for example, she works in a hospital and she really understood."</i></p> <p>HP, FG: <i>"If there's someone who is in the health care environment, it's easier for them to understand what's coming, how the system works, what the limitations of the resources are... On the other hand, we realize sometimes that those people are more demanding, they have more definite expectations because they know the strengths but also the weaknesses in the system and they don't want to experience them... But I see it as facilitating discussions with the health care team..."</i></p> <p>Daytime versus evening or weekend availability to visit stroke client: since most of the services for relatives are offered on the fly and are not organized or planned, this emerged as a factor influencing services received. The exception was when there were planned meetings (mainly in rehabilitation phases) where relatives were invited but these occurred mostly in the daytime on weekdays.</p> <p>HP, FG: <i>"If they [relatives] came during the day, they would know but you come in the evening unfortunately, it's a bit like that and I think it's a reality that is still there because it's true that in the evening you are somewhat disconnected, it's a different reality and they have very few interventions with the physiotherapists, occupational therapists, etc., it's true that all that happens during the day ... when in fact people are working and they already feel guilty about not being there and then they come in the evening and are told to get lost because they weren't there during the day."</i></p> <p>Visibility of progress/improvements in stroke client's condition: whenever relatives saw improvements in the stroke client's condition on a daily basis, it was reassuring, gave confidence and helped to decrease perceived needs; therefore, even if the services offered remained the same, as needs were less, the gap between actual and ideal services was perceived as small. Similarly, in the absence of cognitive or communication impairments, the stroke client would act as a liaison between the relative and health professionals.</p> <p>S14T2: <i>"but I didn't feel on the part of the therapists, or on the part of the doctor, the obligation to encourage a meeting with my wife.. I personally didn't feel the need because I saw that what I was doing, in spite of everything, was progress."</i></p> <p>S1T1: <i>"It was all done through me. I knew where things stood so I was able to speak, was able to tell my mother."</i></p> <p>S9T1: <i>"I didn't need him to ask. No. I knew what was happening and I told them what I had and what I was doing."</i></p> <p>R23T2: <i>"It's my husband who told me: 'How was your treatment? It was fine. What did she think about your progress? It's him who told me."</i></p>

R: relative; S: stroke client; HP: health professionals.

a 'true' client. For example, one HP participating in the focus group mentioned: *"They are not clients"* but: *"All the caregivers want to meet with them to know how things worked before..."* Interviewer: *"They are there in part as a source of information? As a potential caregiver?"* HP: *"Exactly, because for us to develop an orientation plan then a discharge plan, we need to know what the family does, what they are willing to do, to what extent they are willing to get involved. To go to rehabilitation, which they ask us, what is the discharge plan afterwards, what is the family willing to do? What are they open to? What are they envisioning? The discharge plan has to be presented at the same time as the rehabilitation request."* Thus services received were mostly on the fly with the exception of team meetings to which relatives were sometimes formally

invited. Also, as one participant pointed out, not all members of the interdisciplinary team perceived themselves as being concerned by relatives: *"In our team, it's the social worker who is the real contact with the relative, but all the rest of the team is right there for the person who had the stroke."* (HP, FG).

Factors emerging as influencing services received

Four main factors emerged from the individual interviews (Phase 1) and were further validated through focus groups in Phase 2 as influencing the amount and quality of services received by relatives, thus helping to reduce or increase the perceived gap between actual and ideal services: ability to seek, self or relative being part of the health care system, daytime versus evening or weekend availability to visit stroke client,

and visibility of progress/improvements in stroke client's condition. Table III summarizes these factors and provides excerpts from the transcript to illustrate how they shape the perception of a gap.

Main differences between acute care and rehabilitation

Although many similarities were found in the perceived gap in services received as compared to an ideal, there were contextual differences mentioned relating to being treated in acute care versus in a rehabilitation facility. One of these was staff turnover, which was perceived to be higher in acute care and helped to increase the challenge of getting services for relatives: "There was a lot of staff turnover so it was difficult to really get the latest news right away." [R10T1] versus "...it's always the same people that we always see again at the same times, it's always the same people. I think there's less staff turnover..." [R18T2]. Another difference between acute care and rehabilitation was the opportunity for relatives to attend a team meeting, which was more frequent in rehabilitation than in acute care: "... they meet to review his case, how things are progressing, then they tell us about it, they give us a report each time." [R18T2] versus "I wondered why they didn't include me. I would have liked that, to say, listen, there's a meeting, we'll talk about your mother, come to the meeting for just ten minutes. I would have liked that to get the whole picture." [R7T1]. Besides those two main contextual differences between acute care and rehabilitation, participants mentioned seeking for information, education and support throughout the continuum of care, especially at some key transition periods such as getting a weekend pass or before discharge, which happens equally when treated in an acute care setting or in a rehabilitation facility. One participant said the following about the positive impact of receiving information and education: "She [HP providing information] relieved our fears because you're less afraid when you know, you learn things, you understand what's happening and you're less fearful." [R, FG].

DISCUSSION

Variations in actual services received and factors perceived as influencing

Results of this study point up a wide variety in the amount and quality of services received by relatives post-stroke. Overall these services were fundamentally characterized by being delivered mostly on the fly and as a result of an effortful search on the part of relatives. Sub-optimal seeking was reported 10 years ago as a key activity for relatives post-stroke in another qualitative study (20). Another factor influencing the perception of the amount of services received was whether the participants him/herself or a family member was part of the health care system which was mentioned as facilitating receiving services. A positive relationship between information provision and health literacy level, assuming that being part of the health care system favours health literacy, has been documented previously (21, 22). Other factors mentioned were

schedule of visits which was previously also identified as an important factor (15), staff turnover and availability of team meetings representing main contextual differences between acute care and rehabilitation phases.

Part of the diversity found in this study in the amount of services received by relatives could mirror varying needs, dependent in part of daily improvements of the stroke-client. Therefore, it is crucial to assess the patient's social environment in order to provide services in accordance with needs. This type of assessment provides an accurate picture of what the social environment might offer and how it can support the stroke client. It also enables the identification of unmet needs to be addressed to prevent the social environment from deteriorating (e.g. burden (23, 24), depression (25, 26) and change in participation (2)) and ensure its long-term viability given the increasing life expectancy after stroke (27).

As interventions should focus on the process of meeting relatives' needs for information, education and support (9, 28), these needs should be the focus of an assessment. Although measures for outcomes such as burden are available (29), these may well be appropriate for research purposes as outcome measures but may not be so for day to day clinical practice as they don't inform specifically on relatives' needs. In this study we learned that participants greatly valued how services were received and open communication with health professionals was appreciated. Therefore, a qualitative approach might be more appropriate and effective to use in a clinical setting than to use a standardized outcome measure which would provide information only about the efficacy of the intervention. An added merit of a qualitative approach would be to allow a dynamic communication to screen, assess and simultaneously meet needs in the social environment, which remains a challenge in an acute care setting (30) where length of hospital stay are short. In support of this suggestion, we found that team meetings were perceived by all actors in this study as an effective way to simultaneously assess and meet relatives' needs for information.

Services wished for as an ideal

Having to seek emerged as the "normal" way to get services (20) but in an ideal world, participants wished for receiving information, education and support without having to seek for it. Furthermore, timing and readiness were found to be an important issue (7). In this study, participants in Phase I strongly insisted on "the earlier the better" while health professionals reported that sometimes their interventions did not take hold until many repetitions because of readiness issues. We know that length of stay has declined significantly in recent years (31) and considering that the majority of stroke clients are discharged home from acute care (32) without accessing a rehabilitation facility, the suggestion of the earlier the better makes sense.

Relatives' and health professionals' roles

Results of this study highlight relatives' primary role perceived by all actors as being a source of information on stroke client's

previous abilities and as a potential caregiver where, in some cases, education or training on how to best assist stroke-client will be provided and has shown some effectiveness (33). However, their role as a potential client, in needs of information and support to help decrease anxiety and prevent depression is not legitimized. In 2006, Rodgers and collaborators (34) commented on consequences of stroke for carers and insisted on considering relatives not only as a source of information but also as legitimate clients and as such formally assess their needs. Some may argue that relatives are not 'true' clients as they are not the ones admitted for a health problem. This argument displays a reluctance to accept a change in practice towards a family-centered approach (35). Relatives are part of the social environment, which may prove to be more dynamic and interactive than the physical environment, but which should be equally considered a key factor (36, 37), potentially impacting on the participation level of stroke clients (38) and as having to deal with the consequences of the stroke modifying relatives' own participation (2). Although health professionals typically assess the physical environment (e.g. stairs, other architectural barriers), they rarely assess needs in the social environment after stroke (15).

Furthermore, while health professionals perceived the social worker as having the specific discipline-related role of interacting with relatives, our results suggest that in actual service delivery, all disciplines were more or less involved with relatives, depending on the stroke client's impairments or contextual factors such as their availability. Ideally, as the social environment is one element of stroke management, all members of the interdisciplinary team should be involved with relatives since their work is complementary and the team approach has proven to be effective in stroke management (39).

Strengths and weaknesses

A major strength of this study is the inclusion of all actors concerned with the provision of services to relatives post-stroke. Another strength was the rigorous two-phase qualitative design in which emerging themes from individual interviews were discussed and validated in 3 separate focus groups. The specific urban context of only one province among several Canadian health care systems could be considered a limitation, as could the representativeness of the participants, although a deliberate attempt was made to achieve a diversity of individual characteristics. As such, proportion of participants of our samples with higher education was greater than in the general population and thus different results could be found with another sample presenting lower educational level.

Clinical message

- Actual services received by relatives were found to be influenced by an individual's characteristics whereas according to practice guidelines all have an equal right to be treated as clients post-stroke.
- A systematic, concerted and proactive team approach including a systematic assessment of patient's social environment is required in order to provide services in accordance with needs.

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