Priorities and needs regarding sexual rehabilitation for individuals in the subacute phase post-stroke

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Abstract

Introduction: It is recommended that sexuality be addressed at all transition points along the continuum in stroke rehabilitation. However, little is known about needs specific to the subacute phase.

Objectives: 1) Explore priorities and needs of individuals who have had a stroke regarding sexuality in the subacute phase of stroke rehabilitation, according to both clients and clinicians; 2) Explore clinicians' perceptions of their professional roles with regard to sexuality rehabilitation after stroke.

Methods: This qualitative study involved a convenience sample composed of five clients and 15 clinicians. Clinicians were asked to implement an interview guide to assess their clients' need to address sexuality during rehabilitation. Following implementation, data was collected through individual interviews (n = 6) and focus groups (n = 3). Verbatim were partially co-coded (15%) and analyzed by two independent assessors through a thematic analyzis.

Results: The mean age of the five clients (3 female, 2 male) was 67.0 years-old (S.D. 4.6) and clinicians included a psychologist and occupational, physical and speech language therapists. Three themes emerged: 1) Sexuality: a secondary priority, 2) Clients' needs: just talk about it!, and 3) professional roles. Clients and clinicians considered sexuality as important, but a secondary priority to be addressed after more basic activities of daily living. Needs varied among clients regarding sexuality and clinicians shared their respective contribution to the issue while emphasizing interdisciplinarity.

Conclusion: This study is among the first to identify priorities and needs related to sexuality for clients in subacute phase of stroke rehabilitation and their clinicians.

Keywords

Sexuality, stroke, rehabilitation, interview, knowledge translation, qualitative methods

Manuscript

Introduction

Stroke may affect sexuality in various ways, such as lack of desire, erectile dysfunction, loss of vaginal lubrication and anorgasmia [1]. Sexuality is part of the individual's social role in the context of the Human Development Model - Disability Creation Process (HDM-DCP) [2, 3] and can be expressed through sexual activities, which have been defined as "engaging in activities that result in sexual satisfaction and/or meet relational or reproductive needs" [4; p. S19]. By anchoring them in the HDM-DCP, sexual difficulties are defined as a disabling situation in which a person's disabilities influence how they engage in a sexual relationship through personal (e.g. sensorimotor impairments, pain) or environmental factors (e.g. accessibility of the bedroom) or other life habits (e.g. support needs for hygiene or dressing). The Canadian Stroke Best Practice Recommendations suggest that sexuality be part of rehabilitation [5], especially in the subacute and chronic phases of recovery [6]. Considering the taboo related to sexuality [7], clinicians should initiate a conversation with stroke clients instead of waiting for them to raise the issue . However, current evidence shows that sexual difficulties are rarely addressed in stroke rehabilitation [7, 8]. Among the factors known to influence the offer of sexual rehabilitation, the scientific literature highlights clinicians' fear of causing harm, lack of knowledge and training, and uncertainty regarding their professional role in sexual rehabilitation and perceptions of clients' needs [9, 10].

In a cross-sectional study which aimed to examine the preferences for counseling related to sexuality among 37 persons who had sustained a stroke, sexuality was indeed among the priorities that participants wanted to address in rehabilitation, and 71% of them wished they would have received sexual counseling within the first year after their stroke [11]. Although this study provided detailed information regarding clients' preferred time to address sexuality issues

and the health professional who should convey relevant information (e.g. written), few data were collected concerning the type of information that the clients sought. To our knowledge, only a study by McGrath and collaborators [6] has addressed this issue. Using a Delphi method, they interviewed persons who had sustained a stroke (n = 30), their partners (n = 18), and clinicians and researchers in stroke rehabilitation (n = 45) to prioritize core concepts to be considered in sexual counseling in stroke rehabilitation. Among these: communication with health professionals, resuming sexual activity after stroke, myths about sexuality and conversations with intimate partners. However, the stroke survivors recruited had sustained their stroke several years prior, with an average time since stroke of 6.1±4.2 years [6], which is more representative of the chronic phase of stroke rehabilitation. It is reasonable to think that clients may have different needs according to the phase of stroke rehabilitation they are in. To our knowledge, no study has addressed clients' needs regarding sexuality as they were taking part in subacute rehabilitation. Exploring the needs specific to this context could help fill a gap in stroke rehabilitation research and contribute to improving interventions related to sexuality after a stroke.

An interdisciplinary approach is recommended in sexual rehabilitation after a stroke [12]. However, it remains unclear what the specific role of each health professional involved should be. Clinicians such as occupational therapists, physical therapists, nurses and physicians would consider sexuality as an important matter for their clients' quality of life, but may not feel sufficiently trained to address this issue [8, 13]. For clinicians, the uncertainty regarding the perception of professional role regarding sexuality and the profession's specific contribution to the topic may also be a barrier to addressing sexuality in clinical practice. To our knowledge,

until now, no study has addressed the perceived professional role, or the contribution of each discipline to sexual rehabilitation among clinicians involved in stroke rehabilitation.

The primary objective of this study was to explore the perceived priorities and needs that individuals in the subacute phase of stroke rehabilitation may have regarding sexuality, according to both clients and clinicians. A secondary objective was to explore clinicians' perceptions of their professional roles with regard to sexuality rehabilitation after stroke.

Methods

Study Design

An exploratory qualitative design was used for this study [14]. It was part of a larger research project regarding the development and implementation of a Sexuality Interview Guide (SIG) in stroke rehabilitation [15]. This study was approved by the Research Ethics Board of the institution with which the first author is affiliated, and all participants were required to provide written informed consent prior to their enrollment in the study.

Members of the research team had a combination of expertise in qualitative research, knowledge translation, sexual rehabilitation and stroke rehabilitation. At the beginning of the study, the first author had a four-year background of clinical practice as an occupational therapist with stroke clients at the rehabilitation hospital where participants' recruitment took place.

Setting

This study was conducted within a Canadian rehabilitation hospital specialized in stroke rehabilitation.

Sample and recruitment procedures

Clients were identified as potential candidates to participate in the study after obtaining a positive result (i.e. interested in addressing sexuality in their rehabilitation) when interviewed by a participating clinician using the SIG. Clients who agreed to meet the first author received information about the study and were recruited if they agreed to participate. To be included in the study, clients had to meet the following criteria: 1- have sustained a stroke, 2- currently receive inpatient or outpatient rehabilitation and 3- have been identified as needing to address sexuality in rehabilitation with the SIG. Clients were excluded from the study if they had severe cognitive deficits and/or severe aphasia based on clinical judgment, as the provision of informed consent could have been affected. Clinicians were recruited during a one-hour conference provided on site by the first author on the topic of sexuality after stroke. Clinicians attended to this conference on a voluntary basis. Other recruitment strategies included 'study follow ups' by the coordinator of the neurology program with his team of clinicians and word-of-mouth referral among clinicians. To be included in the study, clinicians had to work with stroke clients and be willing to interview their clients with the SIG (i.e., ascertain clients' interest in addressing sexuality in their rehabilitation). No exclusion criterion was applied to clinicians. Clinicians were encouraged to use the SIG with all clients so that all would have the same opportunities during their rehabilitation.

Clinicians were encouraged to use the SIG during a 4-month implementation period. During this period, they were invited to participate in ongoing training and supervision offered by the first author regarding sexual rehabilitation.

Data collection

Each participant took part in a one-time data collection exercise, either in an individual interview (clients and coordinator) or in a focus group (clinicians). Individual, 45-minute to 120-minute audio-recorded, semi-structured interviews conducted by the first author took place with stroke clients (n = 5) and one clinician. The latter was later interviewed by the second author. Clients were interviewed a few days before discharge and the coordinator was interviewed after the implementation period. Clinicians (n = 15) took part in one of three 60-minute audio-recorded focus group interviews conducted by the first author with the support of the second or the last author as co-facilitator. Data was collected from clinicians after the 4-month SIG implementation period. Individual interview and focus group guides were developed iteratively with our research team. Interview guides were pre-tested prior to data collection. The final interview guides consisted of four open-ended questions and additional short questions on two broad topics: 1) priorities and needs with regard to sexuality (from clients or as perceived by clinicians) and 2) the nature and extent of the intervention that were realized regarding sexual rehabilitation, including the respective potential contribution of each profession. Sample questions included: "Could you tell me about your needs and expectations regarding sexuality since you had a stroke?'' [stroke clients: needs and expectations related to sexuality]" and "Could you share your opinion with regard to the contribution of your profession to sexuality-related issues during stroke rehabilitation? [clinicians: professional role in sexual rehabilitation]"

Clients' sociodemographic and health data was accessed using medical records (see Table 1). Clinicians completed a sociodemographic form for the purposes of the study (see Table 2).

Data analyzis

Descriptive statistics (i.e. means, standard deviation, frequency and percentage) were used to describe the study sample. A thematic analyzis was performed following verbatim transcription [14] through an inductive process [16]:

1. First, two evaluators (first and second author) read the transcripts several times to gain a better understanding of the content. During this process, they met three times to discuss their respective interpretations and clarify the more complex elements that were raised during the analyzis.
2. Once this phase of analyzis was finalized, the two evaluators met to formulate a summary of the content relevant to this study's objectives. The emerging concepts were used as the first themes to be used in the coding scheme.
3. Using a preliminary coding scheme with the possibility of adding new codes during the data sorting process, approximately 10% of the data was coded independently by the first two authors using QDA Miner Lite 5© software for inter-rater agreement.
4. The first two authors discussed their respective understanding of the coded verbatim, and once consensus was reached regarding every emerging code, the coding scheme was refined. The last author was consulted when consensus could not be reached by the first two authors.
5. Afterwards, the first author coded all of the transcripts.

Horizontal analyzis of the content of the three focus groups and six interviews was followed the method described by Paillé and Mucchielli [14] in order to extract the core elements showing agreements or disparities between the different participants. A logbook was used by the first

author throughout the study to gather his experiences and thoughts to complement the information that would be collected during interviews.

Results

Sample description

Five clients (three female, two male) took part in the study (see Table 1). Two were receiving inpatient rehabilitation, the three others outpatient rehabilitation. Their mean age was 67.0 years (SD = 4.8). Three clients had sustained a right hemispheric stroke and two a left hemispheric stroke, less than 6 months had elapsed since stroke for all of them. In total, 15 clinicians participated in the study (see Table 2).

Table 1: Sociodemographic and health data of clients who participated in the interviews

Client	Age	Sex	Marital Status	Type of Stroke	Time elapsed since stroke (days)*	Inpatient or outpatient follow-up
#1	60	M	Married	Left cerebellar stroke and posterior cerebral artery stroke	144 days	Outpatient
#2	75	F	Single	Right cortical ischemic stroke (middle cerebral artery)	110 days	Inpatient
#3	67	M	Single	Frontal lobe stroke and left occipital stroke	176 days	Outpatient
#4	66	F	Non-married couple	Right temporal lobe infarction and acute frontal right insular lesion	92 days	Inpatient
#5	67	F	Married	Left middle cerebral artery stroke	118 days	Outpatient

*At the time of the individual interview, conducted before discharge from inpatient or outpatient rehabilitation.

Table 2: Sociodemographic and professional data of clinicians (n = 15) and coordinator (n = 1)

Participant	Age	Sex	Profession	Years of Experience	Years of experience with stroke clients
Clin 1	62	M	Psychologist	31	30
Clin 2	30	F	Occupational therapist	7	6
Clin 3	32	F	Speech language pathologist	5	5
Clin 4*	30	F	Physiotherapist	6	6
Clin 5	33	F	Occupational therapist	6	5
Clin 6*	29	F	Occupational therapist	2	1
Clin 7*	35	F	Physiotherapist	13	4
Clin 8*	38	F	Physiotherapist	10	3.5
Clin 9*	55	F	Speech language pathologist	31	31
Clin 10	25	F	Occupational therapist	1.5	1
Clin 11	31	F	Physiotherapist	10	5
Clin 12	31	F	Physiotherapist	4	2.5
Clin 13	29	F	Physiotherapist	2	1
Clin 14	30	F	Speech language pathologist	4	3.5
Clin 15*	38	F	Occupational therapist	18	7
Coordinator	33	M	Coordinator and Occupational therapist	10	7

Clin = Clinician

* These clinicians worked with the outpatient clientele. The others worked with the inpatient clientele.

Three themes were extracted for the primary and secondary objectives: 1) Sexuality: a secondary priority, 2) Clients' needs: just talk about it! and 3) Professional roles. This last theme was separated into two sub-themes: A) intradisciplinarity and B) interdisciplinarity. All quotes included in this article were translated from French to English by a certified translator.

Sexuality: a secondary priority

Basic activities of daily living, such as eating, communicating and walking, were perceived as a greater priority in rehabilitation compared to sexuality for both clients and clinicians: *I don't know, the time I was at* [the rehabilitation hospital] *... you know, I wasn't really tempted to, I wouldn't have been tempted to talk about sexuality there. When you have to learn how to walk again, and learn how to eat again, you know,... I had other things to do there...*'' [Client 1] and ''*So, I was more worried about just learning to eat without having it get everywhere than my sexuality.*'' [Client 2]. Clients were open to addressing the issue of sexuality only once the level of independence required to perform these basic activities had been achieved. Certain consequences of the stroke such as a change in body image, motor impairments and pain were also matters that were more important to address than sexuality, for all participants: *Because, you can't... I couldn't move, as soon as you move your arm a little bit, especially when lying down... when I'm lying down it hurts even more.* [Client 4] *So on those days, when it hurts... if I understand correctly, we don't think about sex*. [Interviewer] *No, that's it.* [Client 4]'' and '' *It* [stroke] *affects you in... actions that you take for granted! Talking is taken for granted for you, for me... doing exercises to straighten my face, you know, it's like more important than sex, I would tell you that sexuality is the least of... of my worries. You know. It really is.*'' [Client 2] and ''*I have another male client* [outpatient setting] *who is also in the process of, with severe hemiplegia, and I think it could have been relevant* [to talk about sexuality] *but* […] *he seemed to*

be somewhere else, he did his exercises in a way, you know he was like in his physical rehabilitation, and then to open the discussion [after the SIG] *he said "I hear you, but I'm not interested* [in sexuality]*, what I want is to get my arm, my leg back", you know, he was like elsewhere.*'' [Clinician 15]. Clinicians, especially for those working in inpatient rehabilitation, considered their clients' priority was to work on everything that would foster their chances of going back home: "*What is your perception of the patients' primary goals? Now, you're all in the inpatient setting here.* [Interviewer] *For the most part, I think it's to go home, whatever the, the house, you know when they get here it's with the goal of being able to... leave.*'' [Clinician 13] and ''*In the sense that, in the inpatient setting, it's really basic stuff that's, like, the priority. It's sure that at home well... it's* [sexuality] *probably more uhm... it's more relevant in the outpatient setting.* [Clinician 4]. Meanwhile, clinicians were also aware that for certain clients, sexuality may also be among their priorities, although it was rarely addressed by them: ''*I think we sometimes say that, this* [sexuality] *is not a priority at the moment... When in fact we have no idea about it* [Clinician 12] *Exactly.* [Clinician 13].

Clients' needs: just talk about it!

In order to give a better account of the clients' range of needs, each of the participants' data is presented in this section. Although not all participants had specific sexual needs, all agreed on the importance of at least talking about it.

The Client 1, who went through inpatient and outpatient rehabilitation, said that he did not have any need related to sexuality at the time of inpatient rehabilitation. In his case, he considered sexuality to be a relevant topic to address in outpatient rehabilitation: ''*For me, the first days* [after the stroke]*, if you came to me with that* [sexuality]*, look… I would have told you ''Don't bother me with that… for now… I am not interested in that''… you know…*'' [Client 1].

He did not have significant needs regarding sexuality that had to be addressed by clinicians, considering that he reported his sexual drive as being at the same level as pre-stroke and that he found himself new positions to compensate for the pain in his left knee. This client mentioned that the pre-stroke pain in the left knee was the aspect that most limited his sexuality, considering that he was scheduled for total knee replacement surgery but the stroke occurred during the waiting period. The stroke affected the right side of his body, including the right leg that was still recovering from his first total knee replacement (the right one), which led the client to overuse his left knee during stroke rehabilitation. ‘’*You know, sometimes certain positions and everything around it… it's harder sometimes.* [Client 1] […] *I understand. And have you figured out by yourself which positions were more comfortable?* [Interviewer] *Yeah, yeah …yeah. We… we manage, you know.*’’ [Client 1].

Client 2 was interested in discussing sexuality with a health professional and participating in the study, but felt no need to specifically address this issue in rehabilitation. ‘’*Do you feel that the follow-up you received here met the needs you had with respect to sexuality?* [Interviewer] *I don't have needs related to it.*’’ [Client 2]. She said that prior to the stroke, she was sexually active with masturbation. However, she didn't have any sexual urge/need since the stroke and was not worried about it: ‘’*Since your stroke, have you tried some individual sexuality* [masturbation]*, like you said earlier?* [Interviewer] *I had no urge so far so… no… during the night I am more in a pain management focus so… no.*’’ [Client 2]. Moreover, she associated sexuality with being in a relationship. Addressing sexuality during rehabilitation appeared irrelevant for her as she was single and expected her chances of meeting a partner to be rather limited since she considered herself old and disabled. “*So you had, as I understand it, no need for sexuality, so you didn't really expect the* [rehabilitation hospital] *staff to intervene at that*

level. [Interviewer] *No. Well if I, if I had been in a couple or in... but I didn't.*'' [Client 2] And ''*For me, in order to have a relationship with someone, I, first of all, need a relationship on an intellectual level. Before, my chances of meeting someone were already low… I am 75 years-old so, considering how I am today* [hemiparesis after a stroke, needing to use a wheelchair]*, it will be even harder to meet someone, let's say, buying groceries* (laughs).'' [Client 2].

Client 3 considered it important to address sexuality in rehabilitation, since he saw it as an important aspect of life, like eating, communicating and walking : ''*Yeah, I would say… that it* [sexuality] *was integrated like… eating… that should be treated by… the nurse, or the doctor… that would be totally included in the rehabilitation.*'' [Client 3]. His main need was information about sexuality after stroke, especially its impact on certain automatic functions such as bodily reactions to orgasm, in which he experienced spasms in his legs. "*Do you feel that your occupational therapist or your physical therapist could have helped you with anything else in respect to sexuality, or did you have any other need?* [Interviewer] *No, I think that informing people… according to me…* [Client 3] *Ok, so the essential for you, in stroke rehabilitation, is to inform and to educate clients* [about sexuality] [Interviewer] *Exactly, and, to not be surprised by… to inform them… about involuntary movements that may occur during sex.*'' [Client 3].

Client 4 experienced a decrease in her sexual drive and on the intensity of her orgasms, although they were still present: "*I feel like it comes less often* [sexual urges]*... it is like if, unconsciously, I was blocking it… because I think to myself that I don't have any way of satisfying them… it is as if I was not able to let myself go ...*[getting to a state of sexual satisfaction]'' [Client 4]. Physical consequences of her stroke affected her participation in sexual activities. She adapted her masturbation practices with her non-dominant hand. Regarding cuddling moments with her partner at home, certain positions were not possible due to shoulder

pain and hemiparesis that limited her ability to be in certain positions, especially lying down and having the weight of a person on her: "*I had so much pain in my shoulder, that I would not have been able to be lying down in a bed with a person on top of me, or me on top of him… movement gives me so much pain, that I don't think it would have been possible. Because of my pain, I feel like it would be almost impossible.* [Client 4] *So, if I get you right, when you are in pain, you don't think about sexuality.* [Interviewer] *Exactly*'' [Client 4]. The lack of privacy in hospital settings was the main aspect that client 4 mentioned as influencing her sexuality during inpatient rehabilitation. In fact, the lack of privacy (e.g. clinicians coming in the room at any moment without warning, sharing a room with other clients) and the fear of disturbing other clients led her to restrain her sexual urges and therefore lower her participation in sexual activities (i.e. masturbating): ''*To not disturb anyone, to not inconvenience, I don't want to … I am not sure, if there was another patient in my room that was masturbating, that I would have liked it. I would prefer that the person be alone to do that. I don't want to inconvenience anyone with that.* [Client 4] And ''*I imagine that, as we make progress in therapy, if it* [sexuality] *comes back gradually, that it is the setting that is lacking… my urges could come back easily if we gave a thought to it* [proper environment]*… it would recover… but I feel like we are putting this aside, as if we were telling ourselves that it is not possible here* [to be sexually active]*… so we keep it down…we don't talk about it in order to avoid awakening anything* [sexual urges] *that we would be stuck with after.*'' [Client 4].

Client 5 considered it relevant to address sexuality in rehabilitation. Her main need was to receive information regarding the impact of the stroke on sexuality, and on a safe way to engage in sexual activities again (e.g. risk of having another stroke during intercourse): "*I'm used to hearing that sometimes people have had another stroke while having sex. So I said okay, I*

would like to have more information to make sure I have the right response [Client 5]. *So that's basically what it was, your needs in terms of sexuality, you wanted more information.* [Interviewer] *Yes.*'' [Client 5]. She appreciated the information she received (official booklet from the Canadian Heart and Stroke Foundation), but there was too little information regarding sexuality /it didn't address her needs: "*I appreciated it* [the booklet] *because it provided lots of information, and it helped me better understand the stroke. It also addressed sexuality, but not in enough detail*'' [Client 5]. Moreover, she said that she had lost the flyer that her physical therapist gave her regarding sexuality after stroke. She wanted to speak with a trained professional to receive information and ask questions (e.g. will sex lead to another stroke?). Therefore, she recommended that the methods used in this study be integrated as a routine clinical procedure for clients, i.e. 1) giving general information with booklets/flyers, 2) identifying the need to further address sexuality in rehabilitation and 3) meeting a trained professional (as we did during the individual interview): "*Yes, I learned a little more* [with the flyer]*... but I don't really remember what was in the flyer because I didn't… read it completely.* [Client 5] *So, if I understand correctly, you had the flyer at some point, but you still needed to speak with a clinician for guidance and suggestions.* [Interviewer] *Yes.* [Client 5] and "*In as a stroke survivor, what would be the ideal way to address sexuality in rehabilitation?* [Interviewer] *Well… the ideal way, for me, would be the way you are doing it right now… just talk about it… to include sexuality in what the rehabilitation will address* [with other treatment objectives]*... you know, to conduct a meeting with stroke patients… this is where it will really help them because, you know, it is not everyone who talks about sexuality…* [Client 5]. She finally said that physical therapy, although not oriented specifically toward sexuality, partly addressed her needs since it improved her functioning in sexual activities: "*Well yes, yes it helped me* [physical

therapy]*, because my right leg did not move well at first. With the exercises that I did here, now, my leg has improved.* [Client 5] *Ok great, and it also helps you in your sexuality?* [Interviewer] *Yes because, in order to have sex, you need your legs… without them, it will be monotonous… it will have no flavor* (laughs).'' [Client 5].

Secondary objective: Professional roles and sexuality

In this section, clinicians' perceptions about their intradisciplinary roles regarding the issue of sexuality is presented. The participants from each profession identified a particular contribution they can make in rehabilitation of sexuality: occupational and speech language therapists have a role as first responders and physical therapists and the psychologist as consultants, when needed. Interdisciplinarity, or an interdisciplinary approach, was perceived as a better way of offering sexuality-related services in stroke rehabilitation.

Intradisciplinarity

Participating **speech language therapists** were confident that they were adequately trained to initiate a discussion on the issue of sexuality and to address the difficulties in communication caused by a stroke, and how those in turn impact intimacy and sexuality. One clinician also said that, as speech language therapists, they are used to addressing more complex and abstract issues, such as financial management, and could therefore also talk about sexuality: "*I think that oral expression, oral comprehension, well, that's where maybe in speech and language therapy, we play a role. And maybe that's where they* [clients] *say it's more important, because, you know, it's more like… sexuality… we work with things that are much more complex, like* [getting a client to understand] *a letter from the notary for example, so you know, if we can sometimes get a mixed aphasic to understand that* [abstract concepts]*, you know, why not*

…[concepts related to sexuality]. *You know, of course, we can easily draw a line, because it's a subject* [sexuality] *we don't usually deal with, but I think that's where we could really talk about it together* [interdisciplinarity]. [Clinician 14].

The **psychologist** who participated in the study confirmed that he could talk about sexuality in his practice, especially if the subject was raised by the client. However, he felt that assessing the need to include sexuality with his clients (using the SIG), which he felt implied imposing the subject in the conversation, did not fit with his current way of working. He described his role with the clients as generally a consultant, which therefore requires him to focus on the major issue that justifies the referral for the few therapy sessions with each client: "*Even if I am alone with the patient, sometimes, I don't even address it* [sexuality] *because, it* [rehabilitation as a whole] *goes too fast. I mean, even if the patient is there two months* [in rehabilitation]*, I will see him maybe once a month… not every day… sometimes it happens that I see them once or twice a week when a lot of things have happened. Let's say,* [we talk about] *the doctor, therapies, worries, a fall… so I am always taking care of what is close to the body first and, then move on to independence and, then it may occur that we talk about social life, family life… we go in every direction so… sometimes we are more on the subject of intimacy in the conjugal relationship so… I do not have a system that leads me to go there* [sexuality] *systematically.*'' [Clinician 1]

Physical therapists expressed confidence that they have sufficient training to address the stroke-related physical limitations that may have an impact on sexuality and to work with the client on certain abilities such as balance, endurance and range of motion. They also considered positioning to be part of their skill set that they could use in addressing sexuality with their clients. Physical therapists did not consider themselves to be the best clinician to initiate a

conversation regarding sexuality: *"In physiotherapy, I would be comfortable if it was something related to a decrease in mobility, a more physical restriction, there for sure, but it hasn't happened… I would be comfortable looking with them at positions, all that. That's it, for me it stops there."* [Clinician 7] And "*You know, in terms of endurance, it* [physical therapy] *can help the patient indirectly, for sure. Of course, if he gets tired walking 10 feet, indirectly...* [Clinician 8] *It's because you still remain in the physical dimensions*. [Interviewer] *Yeah* [Clinician 7]. *Yeah... Physical screening."* [laughing] [Clinician 8].

Occupational therapists participating in the study felt they had the skills to initiate a discussion about sexuality and to provide educational content related to sexuality after a stroke. In their view, sexuality could be addressed just like every other activity of daily living and consequently they could suggest interventions such as positioning, energy conservation, environmental adaptations and safety tips. However, specifically in regard to sexuality, certain clinicians were not comfortable going further than offering interventions relating to positioning: "*Otherwise, for occupational therapy, I think it's a little bit like physiotherapy where you, you rehabilitate the activity whether it's in the positioning of the person or in the layout of the home… do more teaching about energy conservation, how to integrate the activity in your occupational schedule … and I'm thinking about maybe fall prevention strategies.* [Clinician 10] And "*The skills I have, my job is to screen, see the basics, you know, like, I read the little pamphlets* [home-made pamphlets on sexuality after a stroke developed by the first author in conjunction with the rehabilitation hospital] *and make sure the client has a balanced role and a balanced division of household chores with the partner, but in regard to pure sexuality, I don't feel comfortable intervening, you know like, you know the positioning, you know at the very least*

I could do it, you know with a hemiplegic patient, you know, at the level of positioning, but it would really be the maximum that I would do." [Clinician 15].

Interdisciplinarity

There was a consensus among clinicians, who felt that **interdisciplinarity** was likely to lead to better support for the consequences of a stroke that could restrict sexuality. No clinician felt they had all the skills required to address sexual rehabilitation, but that putting all their knowledge together could lead to the management of most stroke-related impairments that could influence sexuality: "*To summarize, if I understood each of you correctly, you all see some contribution of your profession to post-stroke sexuality.* [Interviewer 1] *It's just that that contribution is not the same, depending on your professional identity.* [Interviewer 2] *And we also heard that, in terms of your contribution, there is a risk of not being able to completely address the problem.* [Interviewer 1] *Absolutely* [Clinician 12]. *Did you have the impression that if you acted alone, maybe we would solve a little something, but we couldn't solve the whole, the whole problem, certainly related to sexuality? Is that the impression you have?...* [Sounds of approval from Clinicians 10-11-12-13-14] ... *Hence the interdisciplinarity...* [Interviewer 1] *Yeah*." [Clinician 12]. Clinicians would also have liked to have access to a health professional specialized in sexual rehabilitation to contact when needed, ideally a colleague, easily accessible, working in the same rehabilitation hospital.

Discussion

The primary objective of this study was to explore the perceived priorities and needs regarding sexuality for individuals in the subacute phase of stroke rehabilitation, according to both clients and clinicians. Although every participant considered sexuality to be a relevant issue to address in stroke rehabilitation, both clients and clinicians felt that improving participation in

more basic activities of daily living and recovering body functions such as movement of the affected side of the body (face, arm and leg) were more important. These main priorities, which were related to optimizing function in daily activities and fostering a safe discharge home, are also outlined in the Canadian guidelines for the delivery of inpatient stroke rehabilitation, which include recommendations to promote "optimal recovery and tolerance levels", "ensure a smooth transition from rehabilitation back to the community" and "assess the safety of patient's home" [17; p. 467-468].

Sexuality was therefore considered by most participants as a secondary priority in the subacute phase of stroke recovery, even all believed it was an important issue. Indeed, McGrath and collaborators [6] suggested that it would be better to raise the issue of sexuality three months or more after the stroke. One participant in their study also affirmed that in the first three months after his stroke, he was more focused on communication and movement and less on sexuality [6]. A broad interpretation of the concept of participation includes activities essential to survival (such as eating, communicating and walking), but also activities and roles (such as sexuality) chosen for their meaningfulness to ensure self-fulfilment (Rochette et al. 2006). In another study, walking capacity was the only factor found to be associated with good social participation in 102 participants in the first year after their stroke (Mayo et al. 2002). This concurs with the experiences and observations reported by receivers or providers participating in our study, that sexuality is of secondary importance during stroke rehabilitation. This provides some direction regarding the effort that should be invested in offering sexual rehabilitation services in the subacute phase of stroke rehabilitation. For example, it may be more appropriate for clinicians in inpatient rehabilitation to provide education related to sexuality at the end of follow-up, and then address this issue during outpatient rehabilitation. Our results are interesting because they

suggest that clients and clinicians have similar "first priorities" and that current rehabilitation services, especially as offered in an inpatient setting, meet clients' needs regarding sexuality, although not perfectly.

Needs regarding sexuality were varied among clients who participated in the study, ranging from an absence of needs to a desire for specific suggestions and information on the subject. Those who genuinely needed and wanted to address this issue expected education on sexuality after a stroke (e.g. potential safety issues, influence on the sexual response) and a proper environment to experience their sexuality, especially for inpatient clients. Variability of needs regarding sexuality after a stroke has also been reported in other studies. In their cross-sectional study conducted among 196 persons who sustained a stroke, Korpelainen and collaborators [18] showed that a high proportion of participants experienced impaired erectile function (75%), vaginal lubrication (46%) and orgasms (55%). However, 51% of the participants were still satisfied sexually [18], which suggest that sexual difficulties did not necessarily imply sexual dissatisfaction. Stein and collaborators [11] also showed, in a cross-sectional study of 36 stroke clients, that although 94% reported at least some impact of the stroke on their sexual activities, only 75% actually expressed a need to receive information regarding sexuality after their stroke. Combined with our own results, these studies suggest that a certain proportion of persons who sustain a stroke do not feel a need to address sexuality and/or receive information on this issue during their rehabilitation, regardless of the presence of sexual difficulties related to the stroke. However, given the high proportion of persons who experience sexual difficulties or sexual dissatisfaction after their stroke, and the reality that for most clients sexuality is poorly addressed in rehabilitation [7, 19], every client should at least be offered the opportunity to have a conversation with a clinician about sexuality after a stroke. With such an approach, the clients

could make their own choice about whether or not to address sexuality during rehabilitation, which would respect the Canadian guidelines in stroke rehabilitation [5] and ensure that basic services are offered to those potentially in need of them.

The secondary objective of this study was to explore clinicians' perceptions of their professional roles with regard to sexual rehabilitation after stroke .We found that participating clinicians, all of whom became involved in the project voluntarily, generally felt comfortable initiating a discussion on the issue with clients, providing education regarding sexuality after a stroke and carrying out certain specific interventions related to their discipline. This was especially noted among occupational therapists and speech language therapists, with the psychologist and physical therapists contributing more as consultants, once the need to address sexuality had been assessed by other professionals. Finally, according to clinicians, interdisciplinarity had a greater potential to optimize the outcomes relating to sexual rehabilitation. Clinicians described their role in sexual rehabilitation as a function of their discipline (i.e. psychology, speech language therapy, physical therapy and occupational therapy) in a way that was parallel to the sexological model of intervention called *Permission, Limited Information, Specific Suggestions, Intensive Therapy* (PLISSIT) Model [20], extensively used in this domain until now. In fact, initiating a conversation about sexuality could be related to the *Permission* step, providing education about the consequences of a stroke on sexuality to the *Limited Information* step and carrying out certain interventions such as the training in communication skills or offering tips on positioning to the *Specific Suggestions* step of the PLISSIT model [20]. Therefore, participating clinicians considered that they could address sexuality in a way that related to the three first steps of the PLISSIT model without having received extensive training about it. Interestingly, participating clinicians clearly stated that they

would not go further than certain specific suggestions related to their professional expertise, which is precisely the boundary between the *Specific Suggestions* and *Intensive Therapy* steps of the PLISSIT model, where the latter is dedicated to interventions provided by a specialist such as a sex therapist or medical professionals such as physicians, gynecologists or urologists. The need to have access to specialized resources in sexual rehabilitation was also raised by participants and has been described elsewhere [15]. The fact that participating clinicians only received a one-hour training session regarding the use of the SIG, which is mainly related to the *Permission* step of the PLISSIT model, suggests that they already had sufficient knowledge and skills to provide basic intradisciplinary education (*Limited Information*) and interventions (*Specific* Suggestions) regarding sexuality. Therefore, it could be hypothesized that with only a short training on sexuality after a stroke and on how to initiate a discussion on the subject, rehabilitation clinicians could already apply the *Permission*, *Limited Information* and *Specific Suggestions* of the PLISSIT model, thereby conducting a relevant intervention for stroke clients that would meet Canadian guidelines for their rehabilitation [5]. Participants' consensus on the relevance of an interdisciplinary approach in sexual rehabilitation concurs with suggestions from Moreno and collaborators [12], who described the necessity of combining different expertise and methods to resolve sexual difficulties, in both research and clinical practice. The Sexual Rehabilitation Framework also advocates a multidisciplinary approach, stating that the collaborative work of several professional disciplines is a key component to improve inclusivity of sexuality and fertility-related services in rehabilitation [21]. Our results suggest that clinicians in stroke rehabilitation already have the ability to provide specific suggestions related to their professional disciplines and that they are interested in working in a team to promote the positive outcome of sexual rehabilitation. Therefore, future training initiatives should focus on 1) providing clinicians

with the abilities required to provide *Permission* and *Limited Information* related to sexuality after a stroke, 2) reinforcing professionals' existing knowledge and skills to act on the *Specific Suggestions* that pertain to their discipline and together implement an interdisciplinary approach, and 3) fostering the referral process toward resources for *Intensive Treatment* when needed. However, in order for clinicians to provide gold standard services in sexual rehabilitation, future studies should examine the specific knowledge, practical and interpersonal skills and attitudes that are required by clinicians working in sexual rehabilitation and the best strategies to address these training needs.

Strengths and limitations

This study has many methodological strengths that should be emphasized. First, the fact that it included both clients and clinicians from several professions who were either involved in inpatient or outpatient rehabilitation, offered a variety of perspectives regarding subacute rehabilitation after a stroke, a quality criterion in qualitative research [22]. Second, the sample size (a total of 20 participants) contributed to the diversity of the sample and therefore the relevance of the results. To our knowledge, our study is the first to gather data to document the perspectives of clients in the subacute phase of stroke rehabilitation related to sexual rehabilitation. Therefore, findings from this study fill a gap in stroke rehabilitation research and should be useful to guide health professionals, coordinators and managers who offering services in similar contexts. Moreover, this study was conducted using rigorous methods. In-depth interviews were conducted using a pre-tested interview guide. Focus groups were co-facilitated in order to promote the participation of clinicians and gather as much information as possible. Finally, the verbatim co-coding process and the use of a validated method of thematic analyzis [14] fostered the representativeness and credibility of the data collection process.

This study also presents some limitations. The transferability of our results to other stroke clients must be considered carefully, due to: 1) the small sample of clients, 2) the client inclusion criteria, which required a confirmation of interest and 3) the exclusion of clients' functional status. For example, younger clients may have different priorities and needs regarding sexuality in subacute stroke rehabilitation. The transcripts of the interviews and the analyzis were not validated with participants due to time constraints. However, horizontal analyzis of the data [14] promoted the credibility of our results and is likely to have reduced the impact of not confirming our own understanding of participants' statements with them. Finally, we must also acknowledge a potential selection bias since the recruitment process was conducted by convenience. This recruitment method was selected due to feasibility issues for this study, which was conducted without funding and in the context of the first author master's thesis.

Conclusion

This study showed that clients and clinicians consider addressing sexuality important but of secondary priority in the subacute phase of stroke rehabilitation compared to improving independence in basic ADLs such as eating, communicating and walking. In fact, clients and clinicians that participated in this study identified relatively similar rehabilitation priorities. In inpatient rehabilitation, certain specific aspects related to sexuality, such as safety related to sexuality after a stroke, may be relevant before discharge or during a trial at home. Outpatient follow-up was indicated as the relevant context for thoroughly addressing sexuality with clients in need. Stroke rehabilitation guidelines regarding sexuality should therefore be adapted for each setting in order to better meet the priorities and needs shared by clients and clinicians, which could in turn promote their application by health professionals. Clients' needs related to sexual rehabilitation after a stroke varied but focused on education about the impact of stroke on

sexuality and concrete tips and advice for reintegrating sexual activities. With this deeper understanding of client needs, we can better plan the content of a stroke rehabilitation interventions that address sexuality. The shared perception of participants about the importance of sexuality justifies addressed this subject with each client, in a way adapted to their individual recovery, context and rehabilitation trajectory, even though some will not need services in this area. The perception of professional roles regarding sexual rehabilitation among participating clinicians highlighted great potential to provide basic interventions in accordance with stroke rehabilitation guidelines. Future studies should focus on a younger population, identify strategies to include sexuality in routine care, and develop interdisciplinary clinician training to improve team-based support for the stroke clientele.

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