Exploring patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation

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Abstract

Background: Patient participation is recognized as an important element of rehabilitation. However, few studies have used a qualitative lens to specifically examine factors influencing patient participation in stroke rehabilitation.

Aim: The purpose of this study was to investigate patient perspectives of barriers and facilitators to participating in hospital-based stroke rehabilitation.

Methods: Semi-structured interviews were conducted with 11 patients, with confirmed diagnoses of stroke, recruited from three separate rehabilitation settings. Analysis of the interviews was guided by a process of interpretive description to identify key barriers and facilitators to participation in stroke rehabilitation.

Results: Four main themes and corresponding sub-themes were constructed concerning participation in rehabilitation: (i) Environmental Factors, (ii) Components of Therapy, (iii) Physical and Emotional Well-Being, and (iv) Personal Motivators. An exploratory model of personalized rehabilitation emerged, integrating the themes emerging from the data.

Discussion: Personalized rehabilitation can be considered in comparison to person-centred care principles. The barriers and enablers experienced by patients in this study contribute to the existing knowledge of the patient experience of stroke rehabilitation and may be used to inform clinical practices and future research.

Implications for Rehabilitation

- The surrounding environments can facilitate participation in rehabilitation using strategies to reduce noise and disruption and also by encouraging social interactions among patients.
- Increasing the frequency and consistency of communication with patients about rehabilitation goals and progress could enhance participation.
- Designing interventions to include activities that are meaningful and focused on the resumption of valued life roles is key to participation.
- Therapy intensity, time spent sedentary, and the emotional impact of stroke are aspects of rehabilitation patient’s feel are neglected.

Introduction

Hospital-based (inpatient/outpatient) multidisciplinary rehabilitation programs are reported to be the most effective way to minimize disability and enhance community integration after stroke [1,2]; however, the effectiveness of these programs is contingent on participatory efforts from the patient [3]. Moreover, poor participation in inpatient rehabilitation after stroke is associated with significantly lower Functional Independence Measure (FIM) scores and a longer stay [4]. Conversely, greater participation is significantly associated with larger improvement in activities of daily living (measured using the Barthel Index) and mobility (measured using the Rivermead Mobility Index), as well as a shorter length of stay in hospital-based rehabilitation programs [5].

Since level of participation in hospital-based rehabilitation programs after stroke seems related to rehabilitation outcomes, it is important to discern factors that influence participation. However, few studies have examined the factors impacting patient participation in hospital-based stroke rehabilitation programs. Cognitive and affective deficits are common after stroke; both executive function and depressive symptoms have been shown to negatively impact participation among individuals admitted to inpatient stroke rehabilitation [6]. Further, Yang and Kong [7] reported patients with stroke undergoing inpatient rehabilitation who had a lower level of rehabilitation participation, as measured on the Pittsburgh Rehabilitation Participation Scale [4], were more likely to a) be cognitively impaired (measured using the Elderly Cognitive Assessment Questionnaire), b) have poor functional status (measured using the FIM), and c) have higher levels of fatigue (measured using the Fatigue Severity Scale). Thus, quantitative research suggests cognitive impairment, depressive symptoms,
fatigue, and higher levels of disability are barriers to participation in inpatient stroke rehabilitation.

Qualitative research can confirm and expand the findings from quantitative data. With a focus on people’s lives, behaviours, and interactions, qualitative research provides insight into the uniqueness of individuals’ experiences and perspectives [8]. By exploring individuals’ experiences in health care programs, awareness of patient-perceived issues is heightened, and their voice can be a focal point of consideration. To the best of our knowledge, there is only one study that has attempted to identify barriers and facilitators to participation in inpatient stroke rehabilitation [9]. However, these authors noted that they could not find any studies that explicitly sought to explore barriers and facilitators to participation. Rather, they identified factors that may influence engagement in rehabilitation after stroke from studies that explored patient and therapist experiences. Thus, to the best of our knowledge, this is the first study to explicitly explore barriers and facilitators to participating in hospital-based stroke rehabilitation, from first-hand experiences.

MacDonald, Kayes, and Bright [9] conducted a systematic review to identify barriers and facilitators to participation or engagement in stroke rehabilitation and included quantitative and qualitative designs (N = 14/17 qualitative studies). However, due to the absence of studies with the specific aim of exploring influencers of participation/engagement, authors included studies that explored patient and therapist experiences that might provide insight into engagement-related issues. From these studies, seven key themes relating to factors perceived to help or hinder engagement in stroke rehabilitation were constructed from participant experiences: (1) goal setting, (2) therapeutic connection, (3) personalised rehabilitation, (4) paternalism versus independence, (5) patient-centred practice, (6) knowledge is power, and (7) feedback and achievement. While the review by MacDonald et al. begins to shine a light on the topic of participation in stroke rehabilitation, it is important to remember the included studies themselves did not directly explore factors of participation or engagement in stroke rehabilitation. Also, the review does not isolate the perspectives of patients from that of health professionals; nor does it separate the different experiences of hospital-based rehabilitation from community-based rehabilitation. Since the review was published in 2013, others have explored specific aspects of stroke rehabilitation from patients’ perspectives, such as: goal-setting in rehabilitation [10,11]; aerobic exercise during inpatient rehabilitation [12]; physiotherapy [13,14]; music therapy [15]; exposure to an enriched environment [16]; weekend passes during inpatient rehabilitation [17]; tablet technology [18] and other novel interventions [19,20]. However, consistent with the findings reported in the review by McDonald et al., most of these studies focus on a single intervention or component and do not examine barriers or facilitators pertaining to the overall experience of participating and engaging in stroke rehabilitation.

Although rehabilitation science research has recognized the key role participation plays in successful rehabilitation outcomes, no studies have applied a qualitative lens to investigate factors influencing participation in hospital-based stroke rehabilitation programs from patients’ perspectives. Qualitative research is often used to explore problems about which relatively little is known [21] and is useful for producing contextual understandings of a phenomenon through the analysis of rich and detailed personal experiences [22]. Qualitative research focused on patients’ perspectives can be of significant use in healthcare as patients may provide new knowledge and understanding of a phenomenon and assist in shaping quality care. Therefore, the aim of this study was to explore the perspectives and experiences of patients undergoing hospital-based stroke rehabilitation in order to understand barriers and facilitators to participation in rehabilitation and generate knowledge that could inform clinical practice.

Methods

Design

This study was guided by an interpretive description (ID) methodological approach [23]. ID is an inductive form of qualitative analysis used to generate knowledge of a subjective healthcare experience for the purposes of informing clinical care and research [23], and draws on methods from both grounded theory and phenomenology [24]. An ID approach was chosen because the research question was generated from a clinical phenomenon in which little is known from the patient perspective and our study aim is to use generated findings to inform stroke rehabilitation care and research. This study was approved by a university and hospital-based research ethics board (HiREB #2496).

Participants

Recruitment and inclusion/exclusion criteria

Recruitment was open to patients of three distinct rehabilitation programs within a regional integrated stroke network in south central Ontario. The Ontario stroke system is made up of 11 Regional Networks across the province. Each Regional Stroke Network has a regional stroke centre, and many have one or more district stroke centres. These regional networks are collaborative partnerships of health care organizations and providers that facilitate integration of stroke care across a continuum [25]. The three recruitment sites for this study were all part of the same regional network and Integrated Stroke Program. Participants were referred by program therapists who screened patients for eligibility. During the process of recruitment (May-October 2017), all current or recently discharged patients of the three recruitment sites (see below) with a confirmed diagnosis of stroke were considered for eligibility. In addition, participants had to be able to converse in and comprehend English and provide informed consent. Participants were excluded if they were unable to understand questions because of cognitive impairments. The research team had aphasia-friendly documents (consent form, interview guide, and visual aids) available if needed, therefore presenting with aphasia did not exclude participants from this study.

Sampling strategy and sample size

A purposive sampling strategy was employed to attain maximal variability in the sample with respect to diversity in individual characteristics that may impact the experience of, and participation in, rehabilitation after stroke (e.g., stroke severity, presence of post-stroke pain, presence of aphasia, and rehabilitation site).

Setting

The three recruitment sites were part of a regional Integrated Stroke Program.

Inpatient stroke rehabilitation

This designated 28-bed speciality stroke rehabilitation unit [26] admits approximately 325–340 new patients annually. The main goal of this program is to work collaboratively on functional goals with regards to functional limitations. The interdisciplinary team
(physicians, nurses, occupational therapists [OTs], physiotherapists [PTs], speech-language pathologists [SLPs], social workers, dieticians, etc) provides goal-directed rehabilitation to individuals with moderate to severe stroke (AlphaFIM® of 40–80). Individuals are scheduled for one-on-one therapy sessions daily and are also provided with additional opportunities for group therapy (hand therapy, communication groups, therapeutic recreation). From here, individuals are discharged home, to outpatient rehabilitation, or a higher level of care.

**Outpatient rehabilitation**
This neuro-rehab program admits approximately 300 new patients annually, with approximately two thirds being patients discharged from the inpatient stroke rehabilitation program (described above). The main goal of this program is to assist patients to resume meaningful activities and roles and integrating back into their community. Individuals attend the program 1–3 times per week, for an average of 8–10 weeks, and work with OTs, PTs, SLPs, and recreational therapists, based on individual needs.

**Restorative care**
This 44-bed inpatient unit admits approximately 190 new patients annually and is intended for those requiring complex care and who could benefit from an interdisciplinary, low intensity, longer duration rehabilitation program. Individuals who sustained a severe stroke (AlphaFIM® <40) are admitted to this time-limited program and comprise approximately one third of the patients. The restorative care team is similar to that of the inpatient stroke rehabilitation unit (described above). The average length of stay is 45–60 days and from here, individuals are discharged home or to an alternate level of care as required.

**Data collection**
Written, informed consent was obtained prior to data collection. Author TP and pairs of MScOT students conducted 30–60-min semi-structured interviews at the respective rehabilitation sites. The interviewer(s) had no previous relationship with participants and were trained in qualitative research methodology. Families and informal carers were invited to listen and participate in the interviews at the participants’ discretion for the purpose of supporting communication and to provide clarification if necessary; however, all questions were directed to the participants. Informed consent was also obtained from family members/carers who were present during interviewing prior to beginning the interview process. An interview guide was developed from clinical knowledge, previous research [27], and key informant interviews with occupational therapists and occupational therapy assistants from each of the three rehabilitation settings. A detailed interview guide is included as Supplementary Material – this includes questions about participants’ rehabilitation experience and participating in therapy activities. All interviews were audio recorded and transcribed verbatim by NL to allow for increased engagement with the data and greater attentional awareness to the words of participants; Thorne [28] describes transcription as a powerful experience and encourages researchers to take a more active role in the transcription process.

**Analysis**
Data analysis began at completion of data collection. ID requires the researcher to move beyond formulaic approaches, using iterative reasoning, and making informed decisions aligning with the research question [28]. Here, data were analyzed inductively guided by qualitative content analysis [29]; this approach is commonly utilized in ID as it allows for the uncovering of commonalities and patterns across cases within human experiences and is appropriate to use when prior knowledge of what is being explored is limited [30]. Immersion in the data was extended and sustained throughout the analysis process to enhance the credibility of research findings; to ensure that assigned themes, categories, and codes reflected the experience of the participants. Thorne [28] cautions that in interpretive description it is important to avoid excessive precision in early coding. As such, the analytic approach in this study was stepwise: beginning with describing the data and leading to conceptualizing and interpreting meaning within the data.

Initial coding included highlighting key passages, adding memos, and the development and assignment of broad codes. Code definitions were discussed between research team members to establish conceptual consistency before the next cycles of coding began. The transcripts were read several times and assessed each time for the emergence of new codes. As the analytic process continued and our understanding of the data set as a whole evolved, coding became increasingly explicit and codes were refined, condensed and integrated into main themes. After discussing codes, patterns, and emerging themes with members of the research team, the final coding scheme was developed, and the main themes and sub-themes were deemed a proper fit for organizing and interpreting the data. As the review of the themes was conducted, links between themes were constructed as part of the iterative interpretation of findings. Reflexivity was maintained throughout the study process through the critical examination of preconceptions and constant reflection of personal biases, as well as journaling thoughts, feelings, and ideas throughout the analysis process.

**Findings**

**Participant characteristics**
Interviews were conducted with 11 participants (4 women and 7 men; Table 1). Five carers/family members (3 spouses, all female; 2 children, both male and female) were present in four of the interviews and all participated in conversations to varying extents; however, the findings reported here focus on patient perspectives and therefore will only include quotes from family members that directly reflect the patients’ experience or provide clarification on the patients’ behalf. Median age of patient participants was 60 years and the median time since stroke was 4 months. Two participants were currently on an inpatient stroke rehabilitation unit, 5 were on a slow-stream rehabilitation unit, and 4 were currently enrolled (n = 1) or recently discharged from (n = 3) outpatient rehabilitation. Notably, the 4 outpatient participants had completed inpatient rehabilitation on the inpatient stroke rehabilitation unit described in this study.

**Themes**
Four main themes were drawn from the data in relation to the research question of “what are the patient-perceived barriers and facilitators to participating in hospital-based stroke rehabilitation?” The themes and corresponding sub-themes are illustrated in Figure 1 and are described in detail below.
Environmental factors were described as impacting patient participation and experiences in all three rehabilitation settings. Here, the environment is defined broadly as the hospital environment in which rehabilitation took place and encompassing the corresponding environments within the rehabilitation setting (e.g., physical, social) as well as program resources.

**Physical and social environments.** The majority of participants commented on the rehabilitation environment and most commonly described aspects of the physical and social environments within the hospital, as well as the program atmosphere, as influencing their participation in rehabilitation.

Noise and disruptions in the hospital environment were identified as particular concerns by both patients and their family members. Participants described situations where other patients, visitors, and the daily/nightly hospital activity were disruptive to rest and sleep. Further, this was described as negatively affecting performance in therapy, and the healing and recovery process. For example, one participant stated, "…a lot of us don’t sleep well here cause it’s noisy - if you don’t have a good sleep … you’re not going to have a good physio" [Lola].

Peer interaction among patients was another prominent environmental factor identified by participants. Participants often reflected on their experiences in relation to other patients and described situations of making friends and planning social events, such as going for coffee together. Participants specifically described how these interactions contributed to their progress. One participant, for example, recalled a patient he met that was ‘worse off’ than himself and how befriending him had a positive impact on them both: "…I’m helping him and I’m being a friend to him. And apparently since I’ve been doing that - and it’s not easy - he’s been doing a lot better to try to talk and stuff. That helps me" [Ringo].

Indirect peer interaction, or observing other patients, was also described as influential. It was not uncommon for participants to compare their abilities amongst each other. One participant admitted to using the abilities of others to motivate himself in therapy:

> Because it’s large group therapy … seeing other people succeed and being rewarded … suddenly their rollator is taken away from them and they’re given a cane. Suddenly the cane is taken away from them and they’re walking on their own. And you looked over and they worked hard! And then you look at somebody else who is not working very hard - just going through the motion - and they’re still in a wheelchair. That’s a good part … because you can quickly say, ‘I’m not gonna be that person.’ [Cliff]

Family and friends were also described as an important aspect of the social environment. Their role as facilitators for participation in rehabilitation was noted through the encouragement and emotional support they provided as well as their involvement in the patients’ rehabilitation processes and their overall presence. "Well, my family is the reason I’m doing the therapy" [Ringo]. One participant described how support from family allowed him to participate in the inpatient rehabilitation program: "I depend on them, you know, that they have to look after my life outside this place right now" [Pete].

Program atmosphere was another aspect of the environment perceived to impact the participant experience. Typically, participants used words such as “awesome” or “enjoyable,” and the people and their attitudes were characterized as “the friendliest people ever,” “patient,” or “fantastic.”
I think this place was built in heaven... I’d say that ninety-nine percent of everything that goes on here is, is just amazing... like the kitchen staff... they’re fantastic and compassionate and patient and, and those people are well chosen too. [Ringo]

Another participant, who had completed both inpatient and outpatient rehabilitation, cited:

I enjoyed the therapy because I could have fun in there, and if the music was on I could dance... it was a happy place for me... you know, people weren’t glum and down and everything... I mean, overall, not that I wanted to have a stroke, but it wasn’t a bad experience being here [chuckles]. [Sadie]

Resources. Availability of resources was discussed in most participant interviews, with the majority of participants referring to ratio of patients to staff/therapist and having to wait for therapy.

Many participants noted the low patient-to-therapist ratio as a concern and emphasized how this impacted their efforts to participate in rehabilitation. For example, when describing his rehabilitation experience, one participant stated: “...it’s not that the... people there are doing nothing – they’re dealing with another person. So, I think... for the therapist, it’s just too many people to look after” [Rocky]. Other participants further highlighted a lack of therapy and therapy staff on weekends and holidays. Participants expressed frustration because of the impact of this scheduling issue on their progress. For example:

... it was the Family Day weekend I think. And I thought, what do I do now? Well you just lie in bed, you know. And even, like, the Tuesday when I came back, they had nothing scheduled for me. So, to me it was a four-day weekend, you know, and like, they’re saying, ‘oh you’re sort of slow.’ Well, yeah, when you haven’t done anything for four days! [Rocky]

Some participants felt the quantity of therapy received was negatively influenced by a lack of physical resources, which resulted in further delays and wait times and consequently affected participation in rehabilitation. One participant, who was currently undergoing outpatient stroke rehabilitation, illustrated this point:

The only thing, and this is no person’s fault, this is just a matter of there’s so much to do and so little time and so few resources... it’s not unusual for people to have to sit there and wait for a long period of time from one exercise to the next because the next exercise piece is not free yet. [Cliff]

Overall, it was evident the physical and social environments were important factors in the rehabilitation experience. Perceived environmental barriers were a noisy environment and the availability of resources, while peer interactions, support from family and friends, and program atmosphere were mostly described in a positive manner and were identified as motivating.

Components of therapy
Aspects of therapy that were highlighted as influential in the experiences of persons participating in stroke rehabilitation were: a) interactions between patients and therapists, b) the quantity of physio- and occupational therapy, and c) personalized rehabilitation.

Patient-Therapist interactions. Consistently, participants described their relationship with therapists in a positive manner; “We all praise our therapists” [Ringo]. However, further analysis revealed nuances of how interactions between therapists (and other rehabilitation staff) and patients were perceived and seemed to have a significant impact on how patients engaged in the program.

Participants reported they found information shared by their therapists to be infrequent and sometimes unclear. They expressed confusion about what they were being asked to do, why they were being asked to do certain things, and how it would impact their progress. Participants expressed how they wanted the therapists to educate them on the underlying therapeutic value of activities. For example, one person stated:

They wanted me to work with the silly putty stuff there... I found that it hurt me more to use it so I didn’t know whether I was using it right... I tried that a few times but I didn’t find it was doing anything. But if they explained to me what it did, maybe I would do it more. [Ringo]

Another participant described he appreciated how his therapist explained the purpose of the exercises he was performing in relation to performing daily activities, such as putting away groceries.
Participants also valued feedback and validation from the therapists, which helped them to improve performance and gauge progress. One participant expressed one of the best parts of his therapy was the validation he received from his therapists, stating that, "it feels good to know that you are actually doing better" [Cliff]. Conversely, participants described feeling discouraged when therapists told them they would likely be unable to progress to the extent they hoped. For example, one participant tearfully described an interaction with one therapist that impacted her willingness and motivation to continue to participate:

And then someone in therapy told me after practicing walking again with a walker in between the bars, and he says, 'I don't think you're ever going to get out of the wheelchair' … I don't even know why I go because well, what good is it to me? … It was so demeaning, so low – cause I was always taught, you know, you try and you try, 'til you can't try no more. Like you don't give up. And here [the therapist] says you'll never walk again. Well, how do you know?! That just put such a big damper [crying]… [Marie]

Participants acknowledged that communication is two-sided and noted the importance of communicating their own healthcare needs and keeping their therapists and other healthcare providers informed. The following quote is an example of this recognition: “… you have to tell them [the therapists] what you find is working and what you’re worried about, because 9 times out of 10, they’ve got something in place to help you.” [Cliff]

Amount of therapy. The majority of participants who discussed quantity of therapy during rehabilitation felt they did/were not spending enough time actively participating in therapy activities. Participants perceived they were not getting enough therapy because of limited resources (previously mentioned) or they were not being offered enough opportunities for therapy. For example:

Well, it's not much … you figure we’re here 24/7, that we would go twice a day - we only go once a day. I go at 10 in the morning - I’m done by 10:30 … Then at around 2:00, I have arm therapy - that lasts about 25 minutes, not even … There should be more therapy and a lot of patients have been complaining. [Lola]

Personalized rehabilitation. Participants described instances where therapy was enhanced when activities were tailored to individual needs, preferences, and goals. While some participants perceived therapy to be challenging, others criticized the simplicity of activities. If activities or exercises were perceived to be too easy, they appeared to impact desire to participate in rehabilitation for some individuals. Specifically, participants described their stroke as a life-changing event, often resulting in profound loss, leading to emotional adjustments.

Emotional adjustments. Participants frequently described how physical deficits post-stroke created new challenges for them and how these deficits led to difficulties in daily activities (e.g., dressing, toileting, bathing) and mobility. The process of adapting to these new challenges and living with a changed body appeared to trigger an emotional response. This emotional response appeared to impact desire to participate in rehabilitation for some individuals. Specifically, participants described their stroke as a life-changing event, often resulting in profound loss, leading to feelings of sadness, anger, frustration, and depressive symptoms. One participant cited, “You don't control your life, it controls you … it affects everything - your mentality, your willingness to do things…” [Marie]. Similarly, a family member reflected on her husband’s experience and described how the emotional

was a valued pre-stroke activity - and her therapists incorporated it into therapy:

... I had a goal - I wanted to get into my kayak - she brought a kayak into the pool for me to use … I get in the kayak, but they had to literally pull me out of the kayak in the pool. But that was really great, you know … I looked forward to coming [Sadie]

Participants also shared examples of aspects or events that were individually meaningful to them and revealed the impact they had on the patient experience. Some participants described situations specific to the program, such as how family could join in on classes and “see the progress you’ve made” [Lola] or how being able to go home on weekends added a sense of normalcy to the experience and “gives you a boost” [Sadie]. Another participant expressed how meaningful it was that his pet could visit him on hospital grounds: “And my pet is huge therapy to me - that's one of the biggest things I think about all of the time” [Ringo].

Overall, participation in stroke rehabilitation seemed to be supported when there was frequent and clear communication between the patient and therapist, and patients felt informed and educated. In addition, participants appeared to be more motivated to participate in activities when their needs, goals, and preferences were considered in the administration of therapy.

Physical and emotional Well-Being

Tasks such as getting dressed, using a fork, and going to the bathroom/showering were new challenges participants encountered after stroke. While all participants experienced some form of physical deficit, this was not typically described as limiting their participatory efforts. However, post-stroke fatigue was described by some participants as having overwhelming effects on their ambitions to participate. Further, the undercurrent of the emotional impact of having a stroke and all that it entailed was expressed by some participants in this study.

Fatigue. Participants described how being tired and having strength and energy ‘taken away’ from them made participating in activities a challenge. When questioned about what prevented her from being able to engage in therapy, one participant explicitly stated, “fatigue stopped me from doing some stuff” [Sadie]. In addition, participants often appeared astonished by the impact post-stroke fatigue had on their physical capability:

... it's amazing what a stroke takes out of you. Because I thought I was fairly fit before this happened and when I had it they told me the hardest part is yet to come because you've got to go to rehab, I figured Christ, I'm no baby and I can do exercise and get myself up and going in no time … But I'll tell ya, that sucker [the stroke] took every bit of strength I had … it's amazing what it does to ya. [Pete]
impact of stroke influenced his willingness to participate in rehabilitation:

Everything was different.... And it led to a tremendous amount of stress for [Dick] and myself. I had to go back to work and ... leaving him by himself all day and all he'd do is sit there and worry and get more and more depressed. And along with that came a lack of exercise and the lack of therapy and the lack of wanting to do anything to help himself. [Sue, Spouse (P11)]

Overall, post-stroke fatigue and threats to emotional well-being (e.g., depressive symptoms) were described as barriers to participating in stroke rehabilitation, affecting participants’ desire and ability to participate in rehabilitation program activities.

Personal motivators
The findings reported here focus on personal circumstances that appeared to influence participatory efforts in rehabilitation. Both the desire to resume life roles after stroke and persons' attitudes towards rehabilitation are described in relation to participation in therapy.

Resuming life roles. Life roles were additional aspects of participants' personal lives that appeared to influence participation. Participants reflected on their roles and appeared eager to resume their 'regular' roles after stroke. For example, referring to his role as husband and how his wife had to go back to work as a result of his stroke, one participant stated, "with you working ... that's gonna push me" [Dr. Strange]. Motivation to participate in therapy was seemingly driven by the desire to recover and resume life roles and to alleviate the burden of their stroke on others. One participant, however, revealed how his role as son and caregiver impacted his experience participating in inpatient rehabilitation:

Well, there are certain times I don't feel motivated cause I'm under a lot of stress on my end – it's got nothing to do with anybody else. My mother's got Alzheimer's and she, of course, is all by herself, and she wants me to call her every day and I gotta tell her everything over and over again, and that's pretty stressful for me. [Ringo]

Others noted their motivation for participating or 'working hard' was to be able to resume previously valued activities, regain independence, and get back to 'normal.' In response to a comment about his hard work and effort, one participant cited, "I want to get out of here. I don't want this to become... my home ..." [Pete].

Attitude towards rehabilitation. Participants expressed different attitudes towards rehabilitation during the interviews, which appeared to relate to effort and participation in therapy. One participant noted how his attitude towards rehabilitation set him apart from others:

I know that it isn't a closed door at the end of three months but optimal rehab is in the first three months. So I have two months to go, so I need I need to do everything I can to maximize those two months.... So, that's, that's my thinking ... maximize everything. But that's why I'm not like everybody else, or not everybody, cause some of the other people I see in there, when they're told to do ten of these they do it and then they go sit down – I just wait until I'm told to stop – fifteen, twenty, twenty-five, thirty... just keep going. [Cliff]

The importance of a person's attitude, such as "determination," and effort, were seen as an influential aspect of success in rehabilitation. Determination was contrasted by some participants who felt they were not making progress and made inferences of discouragement and lost hope. Talking about the amount of therapy she was receiving, when asked if she had ever wanted to request more, one participant replied, "No, because ... it's not gonna do nothing for me. I'm not gonna get nothing out of it ... I don't think it's helping me" [Marie].

Overall, the desire to resume life roles was mostly perceived as a motivator to participate in rehabilitation. It also appeared optimism and determination were facilitators of participation; however, those who viewed their rehabilitation, or the progress they were making, in a negative manner seemed less motivated to continue participating.

Overarching conceptual framework: personalized rehabilitation

When examining participant perspectives across the four main themes and subthemes identified, a central concept emerged which seemed to reflect participants’ desire for a more personalized rehabilitation approach. This idea of personalized rehabilitation moves conceptually beyond a component of therapy to incorporate patient views of strategies that might be adopted to build on facilitators and overcome barriers to participation in rehabilitation. These findings provide insight into patient perspectives of ‘ideal therapy' and factors that may influence the provision of personalized rehabilitation. Conceptually, the themes can be viewed as key components of personalized rehabilitation constructed from patients' experiences participating (or not) in inpatient stroke rehabilitation activities. We have illustrated this concept as an exploratory framework of personalized rehabilitation in Figure 2. In addition to the key components, two additional components (resources and attitude towards rehabilitation) are presented as modifiers of personalized rehabilitation.

Inherent to the personalized rehabilitation framework described by the participants is recognition of the interrelationship of the key components. For instance, participants described how their physical well-being and their social environment affected their emotional well-being. In addition, participants described how the relevance of different factors varied depending on their unique situations. Put into perspective, an individual who does not have family support may rely more heavily on support from the patient-therapist relationship and the social environment whereas an individual who is well-supported by family may be more concerned with and responsive to other components, such as meaningful activities they can do independently or with family involvement. "There isn't two people that have the same things" [Dick]. Participants’ circumstances (e.g., level of impairment from stroke, overall physical and mental health, financial wellness, hobbies/interests, level of family support) were all so different, and their needs and desires for rehabilitation appear as diverse. In essence, personalized rehabilitation takes into consideration both the physical and social environments, patient-therapist relationships, meaningful activities, as well as both the individual's physical and emotional well-being.

Resources and attitude towards rehabilitation are represented as external to personalized rehabilitation because they were described as indirectly influencing participation in rehabilitation activities. Resource availability was recognized by participants as impacting the extent to which physical and social environments can be adapted as well as the provision of meaningful activities (amount and type) in rehabilitation. For instance, talking about therapy, Rocky shares, "...I kept bugging them saying, 'Can you give me more, can you give me ...?' And they [rehabilitation staff] were saying, 'No. We don't have the funding to give you more,' you know." Lastly, attitude towards rehabilitation was interpreted to potentially be impacted by each of the main components.
because participants’ attitude towards rehabilitation could be influenced (positively or negatively) by their experience of and satisfaction with rehabilitation. Thus, both limited resources and a negative attitude towards rehabilitation can present as a challenge to the provision of personalized rehabilitation.

Discussion

This qualitative study aimed to identify and explore barriers and facilitators to participating in hospital-based stroke rehabilitation from the patients’ perspectives. Indeed, participants described several factors influencing their participation in rehabilitation which generated four key themes: 1) Environmental Factors; 2) Components of Therapy; 3) Physical and Emotional Well-Being; and 4) Personal Motivators. Through the interpretive description process of iterative analysis and reflexivity, we arrived at an exploratory framework of personalized rehabilitation, that incorporates all of the four themes under a conceptual lens. First and foremost, this exploratory framework of personalized rehabilitation recognizes service users as unique individuals with varying needs and perceptions of ‘ideal’ conditions conducive to optimal rehabilitation and maximum recovery, emphasizing the importance of a person-centered approach to care.

The framework presented here is congruent with the prevailing core element of healthcare – person-centered care (PCC; also referred to as patient or client-centered care), which is now largely considered the gold standard for healthcare delivery across many countries [31]. Though there are varying definitions and parameters for delivering PCC, there is general consensus the concept of PCC involves the consideration of individual needs of patients and supports individual choice and autonomy in healthcare decisions [32]. Person centredness in healthcare involves the organization of care around the comprehensive needs of people beyond their medical condition; it gives individuals a voice in the design and delivery of the care they receive, enabling persons the opportunity to be more active in their experience [33,34]. As with PPC, personalized rehabilitation as presented here has, at its center, the preferences, needs, and values of the individual. In addition, both personalized rehabilitation and PCC include key factors that can either facilitate or impede patient outcomes. The perception is, if put into action, PCC will generate positive outcomes, such as greater patient satisfaction [33], improved recovery [35], and reduced rates of unexpected mortality and complications [36]. Based on findings from the present study, we believe the same to be true of personalized rehabilitation. That is, personalized rehabilitation has potential to generate positive outcomes from inpatient stroke rehabilitation.

As previously highlighted, there is not one universal definition or standard, agreed-upon set of parameters for delivering PCC; however, one approach that very closely aligns with the framework presented here is the Picker Principles of Person Centered Care (formally named The Eight Picker Principles of Patient-Centered Care) [37]. Originally developed in 1987, the Picker Principles were identified through research involving a review of the literature as well as multiple and diverse focus groups with patients, physicians and other hospital staff, and family members regarding their healthcare experiences, to determine what matters most to patients [37,38]. The current eight principles include: (1) fast access to reliable health advice; (2) effective treatment delivered by trusted professionals; (3) continuity of care and smooth transitions; (4) involvement and support for family and carers; (5) clear information, communication, and support for self-care; (6) involvement in decisions and respect for preferences; (7) emotional support, empathy, and respect and; (8) attention to physical and environmental needs (Picker Institute, 2019). The Picker Principles are consistent with the presented framework of personalized rehabilitation inspired by patients’ experiences of stroke rehabilitation. Although continuity of care and smooth transitions...
were not explicitly discussed by participants, a case can be made for the concordance of the remaining seven principles to our framework. For example, fast access to reliable health advice and clear information, communication, and support for self-care align with the personalized rehabilitation key component of patient-therapist relationships.

The personalized rehabilitation framework presented here includes some additional insights into the delivery of person-centered care in stroke rehabilitation. Personalized rehabilitation emphasizes the importance of including persons in the development of their own treatment plans but also the inclusion of meaningful activities as therapy and the resumption of life roles as a primary goal of treatment. The framework puts further emphasis on the relationship-building between patient (and family) and therapist (or other health provider). Participants appreciated when therapists took the time to get to know the person, understand their needs, preferences, and goals and provided them with specific (and constant) feedback on progress and performance. Finally, the framework represents the importance of an environment that facilitates family support and involvement in therapy, as well as peer interaction. The framework also is suggestive of indirect relationships between resources and attitude towards rehabilitation and the provision of personalized rehabilitation; these relationships need to be further explored in future research.

Limitations of study

Although the results of this study highlight the patient voice regarding participatory factors in hospital-based stroke rehabilitation, the work is not without limitations. First, recruitment of participants relied on clinician referrals working at the respective rehabilitation sites, thus allowing the potential for bias in the selection of patients. It is also important to consider the potential impact the presence of family members (in 4/11 interviews) may have had on participants’ comfort level and willingness to share information with the interviewers. Though our sample was small, it appeared to be sufficient to capture a range of diverse experiences, provide rich reflections, support data sufficiency for theme development, and identify critical areas for further exploration. The research examined a small sample within a large urban region and therefore the transferability of the findings requires further investigation using different health care settings, and perhaps larger samples. Finally, we did not perform member checks with study participants. While some qualitative researchers advocate for member-checking to test confirmability [39,40], Thorne [28] cautions against this technique as it can lead to false confidence or potentially derail researchers from good analytic interpretations. Instead, we employed other techniques to enhance credibility of findings, such as reiteration during data collection and analyst source-triangulation during the analysis process.

An exploratory framework was formulated based on interpretation of the themes and sub-themes that emerged from the data analyses. This framework is in the initial stage of development and further research to validate is needed, both in stroke rehabilitation, but in other areas of rehabilitation as well.

Clinical implications

Overall, our findings suggest providing personalized rehabilitation includes considering all aspects of the inpatient rehabilitation experience and how they might influence individuals’ ability and/or desire to participate in rehabilitation. Providing personalized stroke rehabilitation involves determining and addressing individually consequential aspects of the environment, occupation, and person that could hinder achievement of individual goals. In addition, service providers can use individual goals as leverage to encourage and/or motivate individuals to participate in inpatient stroke rehabilitation. By conceptualizing participants’ perspectives of barriers and facilitators to participating in inpatient stroke rehabilitation as an ‘ideal stroke rehabilitation program,’ this work presents personalized rehabilitation as an exploratory framework and exposes the dynamic and delicate nature that is the provision of personalized rehabilitation. For instance, if physical well-being is not being properly addressed, an individual’s emotional well-being may be affected, which can negatively influence their attitude towards rehabilitation, further hindering participation in rehabilitation. While factors will have differing levels of relevance depending on individual situations, these perspectives highlight the clinical importance of skill-challenge matching and avoiding a one-size-fits-all approach to inpatient stroke rehabilitation, which is congruent with person-centered care – a core dimension of health quality.

Conclusions

This study has identified several patient-perceived barriers and facilitators related to participating in hospital-based stroke rehabilitation. It highlights the significant influence of the treatment setting and program design, as well as the pivotal role that others (peers, family, rehabilitation staff) play in influencing patient participation. Further, this study adds the unique perspectives of patients to current stroke rehabilitation knowledge and encourages rehabilitation professionals to reflect on the ways and means of incorporating patient perspectives into daily practice. Lastly, we discuss this idea of ideal therapy and present an exploratory framework of personalized rehabilitation relative to person-centered care. It is our hope that this framework can help propose interventions around personalized rehabilitation, recognizing that improvements can be made in an effort to be more person-centered, at both the individual and system level, and by doing so, facilitate patient participation during inpatient stroke rehabilitation.

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No potential conflict of interest was reported by the author(s).

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Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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