# R A T E 🖈

## Considerations for at-home upper-limb rehabilitation technology following stroke: Perspectives of stroke survivors and therapists

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#### Abstract

**Introduction:** This study investigated the needs of stroke survivors and therapists, and how they may contrast, for the design of robots for at-home post stroke rehabilitation therapy, in the Ontario, Canada, context.

**Methods:** Individual interviews were conducted with stroke survivors (n = 10) and therapists (n = 6). The transcripts were coded using thematic analysis inspired by the WHO International Classification of Functioning, Disability, and Health.

**Results:** Design recommendations, potential features, and barriers were identified from the interviews. Stroke survivors and therapists agreed on many of the needs for at-home robotic rehabilitation; however, stroke survivors had more insights into their home environment, barriers, and needs relating to technology, while therapists had more insights into therapy methodology and patient safety and interaction. Both groups felt a one-size-fits-all approach to rehabilitation robot design is inappropriate. Designs could address a broader range of impairments by incorporating household items and breaking activities down into their component motions. Designs should incorporate hand and wrist supports and activities. Designs should monitor trunk and shoulder motion and consider incorporating group activities.

**Conclusion:** While therapists can provide insight in the early stages of design of rehabilitation technology, stroke survivors' perspectives are crucial to designing for the home environment.

#### Keywords

Robot-assisted rehabilitation, design requirements, stroke rehabilitation, rehabilitation devices, telehealth

#### Introduction

Stroke is the third most common cause of disability worldwide<sup>1</sup> and the number of stroke survivors is expected to increase as the global population ages.<sup>2,3</sup> It is more urgent than ever to develop technologies to improve access to post-stroke rehabilitation therapy. Stroke is a medical condition where the brain is deprived of blood flow due to a blockage or rupture of a blood vessel, resulting in brain damage.<sup>4</sup> The brain damage caused by a stroke can result in a variety of physical and mental impairments, with upper limb motor impairment occurring in approximately 77% of stroke

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survivors.<sup>5</sup> The nature and degree of recovery after stroke is dependent in part of on the spontaneous processes after brain injury, but also on the person's experience following the acute onset of stroke.<sup>6</sup> Recovery is optimized through repetitive task oriented practice involving the more impaired limb.<sup>7,8</sup>

The post-stroke timeline of a stroke survivor can be divided into several periods according to the biological processes involved in recovery.<sup>9</sup> The acute phase is the time period immediately following the stroke, and lasting up to a week, when the initial damage to the stroke survivor's brain occurs and the brain experiences inflammation and scarring. The subacute phase follows the acute phase and lasts roughly 6 months. Stroke survivors generally experience the greatest improvement in function in the first 3 months, with slower gains happening in the later months until the chronic phase. The chronic phase is the time period following the subacute phase (longer than 6 months post-stroke) where motor function recovery is expected to plateau.<sup>9</sup> However, there is evidence that stroke survivors can still experience recovery in the chronic phase.

A stroke survivor's recovery process is determined by the health system of their country and region. In Ontario, Canada, following acute care where the stroke itself is treated, patients are discharged to a variety of destinations based in large part on their post-stroke functional status as well as their social situation.<sup>13</sup> Patients who are considered moderately or severely disabled are admitted to inpatient rehabilitation where they participate in a recommended minimum of 3 h of therapy per day, although this target is not always achieved.<sup>14</sup> Patients who are considered mildly disabled or those who are not expected to experience further benefits from inpatient rehabilitation are discharged home if it is judged sufficiently safe, where they may attend regular therapy sessions in outpatient clinics or have visits from therapists directly in their homes. Patients, and the broader Ontario healthcare system, would benefit from the improved outcomes<sup>15</sup> and lower costs<sup>16</sup> associated with increased access to well-supported, high quality at-home rehabilitation.

Stroke survivors who live in rural areas or are otherwise distant from outpatient clinics experience barriers to accessing rehabilitation services post-discharge. The COVID-19 pandemic exacerbated these issues by reducing access to in-person therapy activities in general. Stroke survivors could benefit from improved access to rehabilitation therapy through the introduction of athome rehabilitation robots,<sup>17,18</sup> however, stroke survivors' perspectives are too often missing from the early design phase of such devices. In this work, a rehabilitation robot is defined as a machine with actuators and sensors with a computer-controlled feedback loop. Meyer et al.<sup>19</sup> found in the design of wearable robotic devices that target users are often not involved in the design process until the prototyping phase. The past decade has seen some of the first user studies of at-home rehabilitation robots.<sup>20</sup> These studies have evaluated user needs after the designs have already been made. Chen et al.<sup>20</sup> found in a survey of these studies that the most significant challenges in the development of at-home rehabilitation robots are safety, cost, space requirements, and independent ease-of-use.

As rehabilitation robots become more widespread and their potential benefits to patients and therapists increase, there is a need to proactively involve stakeholders in the design of such devices.<sup>21</sup> A proactive approach differs from the more common reactive approach by involving stakeholders at the beginning of the design process, rather than seeking their feedback after a prototype has been designed. When stakeholders have been consulted prior to design prototyping,<sup>22,23</sup> the focus has been on therapists', rather than stroke survivors', perspectives. Other studies have looked at stroke survivors' perspectives for wearable assistive robotic devices,<sup>24</sup> but not devices specifically for therapy activities. A review of home-based stroke rehabilitation technologies by Chen et al.<sup>20</sup> called for more research into the social and technical barriers to introducing these technologies in the home environment.

Sivan et al.<sup>25</sup> conducted a study of user needs, published in 2014, for home-based rehabilitation technology that included both therapists and stroke survivors. They conducted semi-structured interviews with nine stroke survivors with upper limb weakness and six therapists involved in the United Kingdom's National Health Service. They used the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) as a framework for their analysis of the interview data. Sivan et al. concluded that the ICF provided a useful framework and matched well with the concepts derived from the interview data. Although the focus of Sivan et al. was on the suitability of the ICF as a framework for user needs data, they identified several design features from their interview data. Some examples include that designs should have simple user interfaces, monitor users' pain, provide tasks connected to activities of daily life, and fit within a small space. They also found that factors such as stroke survivors' computer skills, perception of technology, and interest in technology could influence the success of any technology introduced into the home environment, and that privacy, such as not being watched by carer's or other people while using the technology, was important to some of the stroke survivors.

In the ICF's biopsychosocial model of disability,<sup>26</sup> a person's function can be understood on multiple, interacting levels: the function and structure of their body, their ability to perform activities, and their ability to participate in life and society. The WHO provides a detailed classification through the ICF Core Sets.<sup>27</sup> The ICF Core sets contain four top-level categories of factors that impact disability; these

categories are: Body Functions, which concerns the physiological and psychological functions of the body; Body Structures, which concerns the anatomy of the body; Activities and Participation, which concerns the performance and capacity of a person in different tasks and their involvement in life situations; and Environmental Factors, which concerns the physical and social environment of a person's life.<sup>26</sup> Personal Factors are not categorized in the core sets, but would include factors such as age, gender, education, and experience.<sup>26</sup> Each top-level category contains more specific (second-level) subcategories, which in turn contain the most specific third-level subcategories. Sivan et al.<sup>25</sup> found the second level was sufficient for their purpose of categorizing and analyzing interview data.

The goal of this study was to gather the perspectives of both therapists and stroke survivors on their needs for athome post-stroke therapy for the upper limb prior to the design of a robotic rehabilitation device. From these perspectives this work aims to draw specific design recommendations and considerations for researchers and designers of these robotic devices. This work is especially timely as the COVID-19 pandemic has disrupted many traditional forms of rehabilitation therapy, and the participants interviewed in this study had first-hand experience with these disruptions. Future pandemics may create similar disruptions and therefore the findings of this work will continue to be relevant. Sivan et al.<sup>25</sup> noted a limitation of their study was the absence of Personal Factors in the analysis, so in this work Personal Factors were addressed indirectly by tying them to the other categories of the ICF. Since the perspectives of stroke survivors are less studied at this stage of development, this study provides a better understanding of how their perspectives align with and differ from that of therapists.

#### Materials and methods

A semi-structured interview approach was chosen to explore each participant's perspective in depth while also allowing different participants' experiences to be compared. Ethics approval for this study was granted by the Queen's University Health Sciences Research Ethics Board (file number 6,028,571), and informed verbal consent was obtained from each participant. Verbal consent was obtained rather than written consent since the study occurred during the COVID-19 pandemic when in-person meetings with written consent were not possible.

#### Participants

The interview participants were stroke survivors and stroke rehabilitation therapists living in the province of Ontario, Canada. All participating stroke survivors were required to be 18 years of age or older, have upper limb weakness or hemiplegia, and have participated in upper limb rehabilitation. Another requirement for participating stroke survivors was that they be able to speak, however one participant whose verbal communication was impaired had his caregiver assist him in the interview. Exclusion criteria included participants with upper limb impairments unrelated to stroke and participants who would be unable to understand speech. All therapists were required to have experience in providing post-stroke rehabilitation therapy for the upper limb.

Participants were recruited through word of mouth and through calls for participants in the electronic newsletters of professional organizations and stroke survivor support groups. Interview participants were offered a small honorarium to incentivise participation.

A total of 16 participants were recruited for the study; 10 stroke survivors and six therapists. The interviews were conducted between March 2020 and January 2021. Recruitment continued while the interviews were ongoing until saturation was reached in the responses. The participant demographics are presented in Tables 1 and 2. Of the stroke survivor participants, 30% were women and 70% were men. Eight out of the 10 stroke survivors were 60 years of age or older, while one was in his forties and one did not share his age. Nine of the stroke survivors were in the chronic phase; one was in the subacute phase. Eight had participated in a therapy session in the 4 weeks leading up to the interview. Seven of the stroke survivors responded to a follow-up questionnaire that implemented the QuickDASH,<sup>28</sup> a selfreport outcome measure for people with upper-limb disorders. The QuickDASH Disability/Symptom score produces a result between 0 and 100, with higher scores representing a greater experience of disability. The questionnaire included the QuickDASH Work Module as well, however, none of the participants who responded were working. All of the stroke survivors who responded to the QuickDASH questionnaire experienced some amount of upper-limb-related disability; the scores ranged from 32 to 73. All but one stroke survivor had participated in therapy in an inpatient setting, and six had participated in at-home therapy. Of the therapist participants, five were physiotherapists, one was an occupational therapist, and half had over 30 years of experience.

#### Procedure

Interviews were carried out over the phone or through video call both to protect participants during the COVID-19 pandemic and to allow the interviewer to cover a wider geographical area. The interviews were conducted over a 30 min period and the audio was recorded to allow later analysis of the interview content. Interviewees were notified when the 30 min time limit was reached, and interviews were allowed to continue if the interviewee wished. The

	<b>A</b>		<b></b> .	Time in a last damas		Therapy types (Inpatient, outpatient, home-based)	
ID	Age group (years)	Gender	Time since stroke	Time since last therapy session (weeks)	QuickDASH Disability/ Symptom score	Physiotherapy	Occupational
SI	80–89	Man	3 months	1.5	_	I,H	I
S2	60–69	Woman	8 months	4		I,H	I
S3	70–79	Woman	8 months	3	43	I,O	I,O,H
S4	—	Man	II months	0		I,O	I,O
S5	70–79	Man	17 months	6	43	I,O	I,O
S6	70–79	Man	20 months	4	73	I,O,H	I,O,H
S7	4049	Man	2 years	3	55	I,H	I,H
S8	70–79	Man	9 years	4	52	0	0
S9	60–69	Man	10 years	2	32	I,O	I,O
S10	60–69	Woman	-	>52	34	I,H	Н

**Table 1.** Demographic information of the stroke survivor interview participants. The participants are listed in increasing length of time since they experienced a stroke. The QuickDASH<sup>28</sup> is a self-report outcome measure for people with upper-limb disorders on a 100 point scale, with higher numbers representing a greater experience of disability.

**Table 2.** Demographic information of the therapist interview participants. The participants are listed in increasing years of experience.

ID	Therapy Discipline	Years of experience
тι	Physiotherapy	4
Т2	Physiotherapy	10
Т3	Physiotherapy	24
T4	Physiotherapy	30
Т5	Physiotherapy	36
T6	Occupational therapy	36

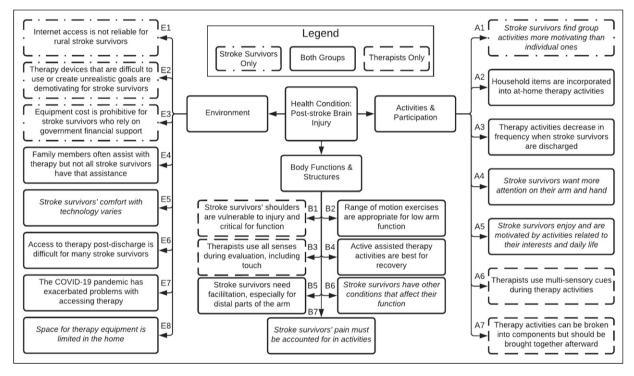
average interview length was 31 min. The interviewer (author S.F.) followed an interview guide with a set of openended discussion questions listed in Table 3. The questions were designed to encourage introspection on the therapy process, as well as to determine the needs not being met in the home, without biasing the interviewees toward a specific type of robotic system. These questions served as starting points to allow the interviewees to initiate a conversation about their needs and ideas. The questions were designed to provoke ideas from a negative direction (i.e. "what prevents you from...?") and a positive direction (i.e. "what could help you...?" or "how would you like to be helped...?"). The interviewer asked follow-up questions related to the ideas brought up by each interviewee. The interviewees were not provided with an introduction to or description of existing rehabilitation robot designs to avoid biasing them towards certain solutions, or focusing on the form of the solution rather than articulating their needs.

The interview recordings were transcribed and themes were identified from the transcripts. The second category levels of the ICF were used to group statements from the interview data, similar to Sivan et al.<sup>25</sup> Personal Factors were not coded directly because the ICF core sets do not provide a strict set of categories for those factors. For example, computer skills or knowledge is a personal factor that would be classified under Environmental Factors because it connects how a person relates to the technology in their environment. Authors M.L. and S.F. identified the themes from the coded statements through deductive analysis.

#### Results

The themes identified from the interview data were categorized according to the top-level categories of the ICF. Major themes identified in each category are summarized in Figure 1. The themes identified in the Body Function and Body Structure categories had sufficient overlap that these categories were collapsed into a single category in Figure 1 and the following subsections. Twenty-two separate themes were identified in total: seven in Body Functions & Structures, seven in Activities & Participation, and eight in Environment. Each theme on the figure is identified by a letter and number code. Seven out of the 22 themes were also identified in Sivan et al.<sup>25</sup> and are highlighted with italicized text. The overlapping themes were: in the Environment category, themes E5 (comfort with technology) and E8 (limited space); in the Body Functions & Structures category, themes B6 (stroke survivors' other conditions) and B7 (pain monitoring); and in Activities and Participation, themes A1 (group activities), A4 (more attention on arm and hand), and A5 (therapy activities related to interests and daily life). Theme A1 (group activities) was also identified by Sivan et al., but they found that there was some disagreement among the participants as to whether group activities were helpful or Table 3. Open-ended discussion questions provided in the interview guide.

For stroke survivors	For therapists
What sort of exercises have you performed for your impaired arm?	What sort of equipment do you recommend to help patients perform upper limb therapy exercises at home?
What exercises or parts of exercises have you enjoyed, or not enjoyed?	What aspects of home-based therapy delivery are particularly challenging?
Is there anything that prevents you from performing your exercises at home?	Are there any upper limb exercises or therapies that you would like to use in home settings, but are unable to? What prevents your use of those?
If there was a machine that helped you exercise your arm, how would you like it to help you?	If there was a machine that made home-based upper limb therapy delivery easier, what would you want it to be capable of?
What concerns would you have for operating and interacting with a rehabilitation robot in your home?	What concerns would you have for a rehabilitation robot interacting with a stroke survivor in their home?



**Figure I.** Major themes identified in the analysis of the interview data, grouped according to the top-level categories of the WHO International Classification of Functioning, Disability, and Health (ICF). Themes with italicized text were also identified in previous work by Sivan et al.<sup>25</sup>

not. Some stroke survivors disliked stroke clubs and resource centers, especially if there were "able-bodied" people watching or participating. This dislike was not noted by the interviewees in this study.

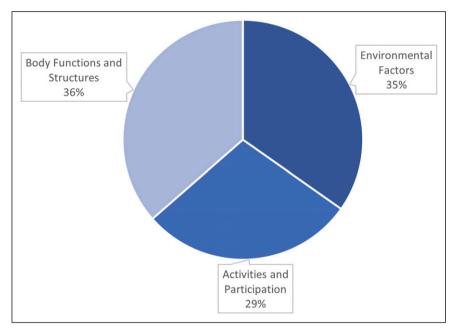
The total number of references coded to each top-level category are presented in Table 4, and the proportions of each category are shown in Figure 2. Each top-level category is nearly evenly represented, with 35% of references made to Environmental Factors, 29% made to Activities & Participation, and 36% made to Body Functions & Structures combined. Figures 1 and 2 together show that the interview discussions evenly covered the top-level

categories of the ICF both in the number of unique themes identified and the total number of references to each category.

Figure 3 shows the difference in the proportion of statements made by each group of participants, coded to each category of the ICF. The figure shows that the stroke survivors and therapists made an equal proportion of statements relating to Environmental Factors, while the stroke survivors had more to say about Activities and Participation and less to say about Body Functions and Structures. This differs from the proportion of themes identified from the statements made by each group, shown

**Table 4.** Number of statements coded to each category of the WHO International classification of functioning, disability, and health (ICF) (environmental factors, activities & participation, body functions, and body structures), by participant type and in total for all participants.

	Env Factors	Activ And Particip	Body Func	Body Struct
Stroke survivors	89	85	65	17
Therapists	56	35	47	23
Total	145	120	112	40



**Figure 2.** Proportion of statements coded to each category of the WHO International Classification of Functioning, Disability, and Health (ICF) for all interview participants.

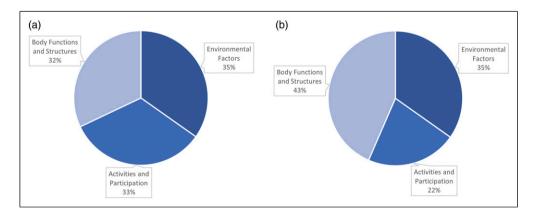


Figure 3. Proportion of statements coded to each top-level category of the ICF for (a) stroke survivors and (b) therapists.

in Figure 1. A greater number of themes in Environmental Factors were identified from the stroke survivors' statements even though they made the same proportion of statements within that category as the therapists. Also although the stroke survivors had a greater proportion of statements classified in the Activities and Participation category than the therapists, the number of themes identified from both groups in that category was similar. This illustrates how each group provides a different breadth of information for each category.

In the following subsections, quotes are attributed to the participants according to the participant IDs listed in Tables 1 and 2. The prefix 'S' indicates a stroke survivor, while the prefix 'T' indicates a therapist.

#### Body functions and structures

Stroke survivors and therapists both emphasized the variability and variety of impairments experienced by stroke survivors. In addition to the primary stroke related impairments (e.g. weakness of arm and hand), some stroke survivors interviewed reported other comorbid impairments including shoulder pain (1 participant), rotator cuff tear (1 participant), and fractured hip (2 participants), and other stroke related impairments such as aphasia (1 participant). They emphasized that each stroke survivor is different in function and needs. Cognitive impairments in particular could make operation of technology more difficult for some stroke survivors. As one stroke survivor noted: "We've had something happen to our brains. So, our brain functions differently." (S10) Additionally, one therapist indicated that in her experience patient function can vary even within a short time period:

I even think of the people that I work with now and depending on the day even, it might depend how much assistance they might need. Maybe they have a particular day where they're having lots of spasms and really finding range and movement difficult. (T1)

Another therapist (T5) recommended that an at-home robotic rehabilitation system would be most suited to patients with good posture and shoulder control who need to focus on their wrist and hand activity.

All of the stroke survivor participants described needing some arm support or facilitation from their therapist to perform therapy activities either now or early in their recovery. This is especially true for distal anatomy, as control over the wrist, hand and fingers tends to be lower than for proximal anatomy like the elbow and shoulder. Two stroke survivors specifically dealt with having tone in their hand that prevented them from doing some exercises. "When I first had my stroke my hand was in the clenching mode where my nails were digging into my hands.. I still have For those stroke survivors with low arm function, their primary concern was to have help moving their arm during exercises to relax their arm muscles and improve circulation (2 participants). When asked how a robot might help him with his therapy activities, one stroke survivor suggested "I think just moving the arm so the muscles don't tighten up. And just getting things moving again. Circulation helps the muscles." (S7) One therapist indicated that passive activities, such as range of motion exercises, were appropriate for stroke survivors with little to no functional movement in their arm and hand: "...[If] they have no active movement it might start with more passive range of motion and having them try their best to move the limb as much as they can." (T1) Such exercises can help maintain muscle length and joint range of motion.

Stroke survivors who have some arm function emphasized the importance of feeling engaged in their exercises and actively using their muscles during those exercises to promote recovery (3 participants). One therapist described patients having trouble achieving the necessary number of repetitions without assistance after they leave inpatient therapy:

With us coming in for an hour, or three times a week, they either have to be able to be motivated enough to do what you want them to do or, with the FES [Functional Electrical Stimulation] system, if they're able to, with a family member, work with the equipment then you'd be able to have more repetitions than you could do in a normal single session. (T3)

All therapists emphasized the importance of active assisted therapy when possible, with one saying:

Active assisted is what we'd want to do more, so you're helping them engage those muscles and work on that activity. If they can only get halfway, you assist them with the rest. Or if they can partially open their hand, then you can assist with opening the rest. (T2)

Five stroke survivors described feeling pain in their shoulder and other joints. In one stroke survivor's case (S7), the pain was so intense that it caused him to lose consciousness during an activity. This outcome is rare but illustrative of how important it is to monitor pain during therapy activities. One therapist we spoke to explained that pain cannot always be avoided and must be monitored during therapy. "We will often use either a rate of perceived exertion or even a pain level to determine whether or not we should increase the intensity [of the activity]." (T1)

Two areas of importance were identified only by the therapists. These included the importance of the shoulder and trunk to upper limb function, and the importance of physical interaction between the patient and therapist. All interviewed therapists agreed that the trunk and shoulder must be monitored during therapy exercises and activities and cueing should be provided to encourage appropriate postures and movement during activities. Any system that could add weight to the arm would make fine movement harder and potentially exacerbate or cause injury, particularly at the shoulder or wrist (1 participant). Physical interaction between the patient and therapist is important to evaluate function and structure of the patient during therapy. All the therapists indicated that physical interaction (e.g. hands-on contact) between the patient and therapist is important to allow continuous evaluation of patient engagement, characteristics and restrictions of movement, and risk for injury.

#### Activities and participation

Both groups emphasized that stroke survivors prefer to participate in therapy activities related to their activities of daily life and interests. Many stroke survivors mentioned enjoying activities related to their interests such as art, paddling (S7), writing, knitting (S2), and golf (S8). Two participants (S7, S8) mentioned that they and their therapists would design therapy activities and goals around their interests. The therapists explained that this was a key advantage of in-home therapy: daily activities and interests can be incorporated into therapy much more easily at home (3 participants). "They want to see something or do something that they think will actually cross over into their everyday life." (T1) This helps link therapy goals to the interests of the patient and ensures that they are achievable, an approach in-line with best practices for stroke rehabilitation.

One therapist described incorporating household items into functional therapy activities at home. "Usually [we] try to use what you've got at home. Maybe a deck of cards or kitchen utensils, that type of thing." (T5) Additionally, simple exercise kits with tools such as the GRASP program, an at-home arm and hand exercise program for stroke survivors,<sup>29,30</sup> can enable more diverse activities for therapy in the home (2 participants).

The stroke survivors found that group activities were motivating for their therapy. Two stroke survivors mentioned that participating in therapy with peers, both in person and remotely, was very motivating for them. The caregiver of one of the stroke survivors described his experience:

He was hesitant on the start of going to the [therapy] group but once he got there he realized everyone there was in the same boat, some much worse off than he was. He felt good then and really enjoyed going to that group. (S6) Another stroke survivor (S5) described his experience with an online group:

I joined [a local online therapy group] and 3 times a week they come on with instructions and I do therapy with them for an hour and 15 minutes. [We do] stretching exercises, making your muscles work. They do a very good job of "don't overdo it, if you can't do it just do what you can do". [...] On Wednesday's we do mind games and we socialize, we all know each other and we talk. It's always nice to talk to other people.

The encouragement, feedback, and progress tracking that stroke survivors experience in these settings are very important to help maintain their motivation.

Both groups emphasized that therapy activities tend to decrease in frequency when stroke survivors go home. One stroke survivor mentioned "I am not doing [therapy] enough, often enough, to get really exhausted. That is one aspect that definitely was better when the physiotherapist was supervising." (S1) Another stroke survivor (S4) and his family hired a private therapist to help maintain regular therapy after being discharged from inpatient rehabilitation. One therapist agreed that they generally saw a decrease in therapy frequency when their patients moved to a home setting:

In the home environment, you're limited versus a facility where all eyes are on all the time. Repetitions of lots of things happen throughout the day, versus the home environment where daily life is going on and therapy comes in as it can. (T3)

Both groups mentioned that many stroke survivors want more attention on their arm and hand during therapy and in their therapy goals. One stroke survivor wished that more focus had been put on the arm and hand during inpatient therapy and another regretted their own exclusive focus on recovery of walking and lack of attention to their arm and hand. "I was mesmerized by the fact that I needed to be mobile, I needed to be able to move around." (S4) Although this was his highest priority at the time, now that he had returned home he felt the loss of hand and arm function more acutely. Two of the therapists (T2, T6) mentioned seeing patients long into the chronic phase of post-stroke disability who wanted more use of their hand.

Consistent with comments discussed in the Body Functions and Structures subsection related to the role of physical contact between therapist and patient, the therapists emphasized the importance of therapist cues during activities to instruct and provide feedback to patients. Two therapists (T4, T5) explained that instructing a patient in using a complicated device in the home could be difficult especially if the patient has any cognitive impairments or neglect. One of those therapists (T4) mentioned that verbal instructions alone are less effective or efficient than using physical cueing as well. "Sometimes it's hard to relay verbally what normally I would just go up and position them and touch them and put them in that position right? It takes a bit longer but it's not impossible." (T4) The therapists emphasized that any device used in home therapy would need to convey feedback to the patient either automatically during therapy or by relaying information from a therapist. This feedback is important both during the therapy activity and afterward.

When asked about the possible activities that a robotic device could be used for, one therapist suggested that activities in therapy can be broken into components, but these components must be brought back together into a meaningful activity according to the patient's needs.

If you think about reaching forward to pick up something, that involves a number of different movements. So sometimes we'll just break those down and work on the individual components and then try and put them together as part of the motor learning piece of that. (T1)

#### Environment

Both stroke survivors and therapists discussed the importance of having family or other types of assistance available in the home environment. Two of the stroke survivors had their family members helping them with their therapy activities. This was something that four of the therapists saw in their work as well, often recruiting family members to help them during at-home therapy sessions. "Right now, we don't have physiotherapy assistants working with us so if it requires more than one person to assist with whatever we're doing it's either OT/PT joining together or sometimes family members are a part of that." (T3) Family members would be recruited to help set up exercise equipment. However, one therapist (T1) emphasized that family members and other sources of assistance such as Personal Support Workers cannot be expected to provide all the assistance that a stroke survivor might need. One stroke survivor (S7) spoke of being concerned about using a device or being able to set up a device without having someone to help him. Another (S2) expressed concerns about being able to move a heavy device within her home.

The stroke survivors had varying levels of comfort with technology and personal electronic devices. Several of the stroke survivors (S2, S7, S8, S10) described themselves as comfortable using computers and tablets in their daily life for communication purposes, music, and exploring the internet. Two of the stroke survivors (S5, S6) had also used video chat technology for online group exercise sessions. One stroke survivor (S6) described how he had been comfortable using technology like tablets in the past but aphasia had made interaction them more difficult. His If [the device] would talk to him so he would be sure that he was pushing the right [button.] If he pushed a button, which is the way the iPad works, it would tell him what to do next or how it would work. (S6)

This reflected what we heard from therapists. One therapist explained that her patients had mixed levels of comfort with computers and technology. "There are definitely some people who feel more comfortable with computers than others, even when their brains are completely intact, so that's something to keep in mind." (T5) Four therapists mentioned that the COVID-19 pandemic has promoted the use of virtual and remote interaction with patients. One therapist described finding audio-only feedback insufficient for remote therapy: "I don't find that actually works as well as being able to see the person, I think particularly with this you want to actually see how they're positioned and see how they're using it." (T4)

The stroke survivors and therapists agreed that a major concern for bringing any device into the home is space constraints. While one stroke survivor (S7) mentioned having a lot of room in his house, he did suggest that many others would have limited space in apartments. Another stroke survivor (S10) who lived in an apartment expressed the same concern. A related issue raised by one of the therapists (T3) was that keeping equipment secure when not in use can be challenging in the home environment when the patient has little private space.

Both stroke survivors and therapists agreed that, while many stroke survivors want additional therapy postdischarge, it could be difficult to access such therapy. The stroke survivors stated that they wanted to have longer access to therapy post discharge with a greater proportion of that therapy devoted to their arm. While some regions within Ontario have publicly funded community stroke rehabilitation programs which feature high frequency home visits,<sup>15</sup> not all stroke survivors have access to those programs. Additionally, one therapist with experience in athome rehabilitation described the struggle some therapists face in reaching all of their patients:

We do have some therapists that travel extensively. I know they have difficulty with a stroke survivor referral, three times per week, they struggle to put that into their full day when they're travelling three to four hundred kilometres to see patients. (T3)

The COVID-19 pandemic has exacerbated the issue of access to post-discharge therapy. Six of the stroke survivors described having reduced access to in-home therapy or difficulty attending outpatient clinics for therapy. The same trend was observed by one of the therapists (T1) who was concerned that patients were not participating in therapy at the recommended frequency.

Some issues that the stroke survivors raised which were not brought up by the therapists were difficulties accessing remote therapy and affording necessary medical equipment. One stroke survivor described the low-quality internet available in his rural community:

I'm pretty rural, so even access to internet, some places or people don't have that. We've noticed out here now, with the kids doing online school, the internet slows right down. (S7)

Even cellular phone service connections were unreliable in his community. One stroke survivor relied on government support to fund her health and rehabilitation. She described how difficult it can be to purchase regular health-related equipment:

There's people out there who have insurance, who can pay for it. Then people like myself, who are on ODSP [Ontario Disability Support Program]; a thousand dollars is my whole cheque. So, you've got the extremes: you've got the ones that can afford it, and you have the ones that have to rely on ODSP and can only get a new brace every two years or so. That's one thing to take into consideration. (S10)

One stroke survivor (S4) had tried several interactive therapy devices, including the FitMi<sup>31</sup> and MusicGlove,<sup>32</sup> and had some insights to share on his experience with their design. He had abandoned several devices that were difficult to use because he decided they were not worth the effort he had to put in to using them. He also found that the design of the therapy activities for these devices often left him feeling demotivated. He specifically mentioned that the pass-fail or win-lose framework that some of these games used, where your performance is evaluated as a success or failure rather than a score that can be improved, was very discouraging. He preferred games or activities that gave a score or some indication of improvement or development.

When asked about tools that they might like to have in the at-home therapy context, one therapist (T3) mentioned her greatest need was to have a stable work surface for performing therapy activities with her patients.

Finally, another therapist raised the issue of liability and patient safety for remote therapy devices:

From a therapists perspective, one thing is how [an autonomous rehabilitation robot] might work in terms of liability. If something were to go wrong and you were remote you can't [intervene]. We're responsible as therapists to make sure that the exercise equipment that we use in our gyms are maintained. [...] From a therapists perspective, how you would figure that

out [remotely]? [...] Certainly we have shifted, especially in private practice setting, to doing more teletherapy and telehealth. But you're talking about a piece of equipment so I think that's a little different than just guiding someone through an exercise. (T1)

#### Discussion

While the statements from the stroke survivors and therapists tended to be broadly similar, there were some differences in the content expressed by the two groups. Therapists spoke about the importance of posture and protecting the trunk and shoulder, physical touch and interacting with their patients, and details of therapy like cueing and how activities can be broken down into components. Stroke survivors were more interested in what motivates them, the conditions of their environment, their access to resources, and their experience with technology. Although the total proportion of statements coded to Environmental Factors was the same for each group, as shown in Figure 3, the stroke survivors had more unique statements on the topic, as shown in Figure 1. These results are reasonable given that we would expect stroke survivors to be more knowledgeable of, and therefore have more to say about, their life experience and environment, while therapists would have more detailed knowledge about the body and how it is involved in therapy activities.

Figures 1 and 3 can also show how bias from only including therapists' perspectives can be difficult to detect without having stroke survivors' perspectives available to compare. For example, consider Figure 1 with the stroke survivors' perspectives (the dash-dot boxes) removed. All the categories would be evenly represented: five themes in Environment, seven themes in Body Functions & Structures, and six themes in Activities & Participation. Figure 3(b), which is based on the therapists' responses, shows that more statements were made about Body Functions and Structures in total, but does not indicate any major gap in the topics discussed. Therefore, only consulting therapists could give the mistaken impression that the topics around at-home robotic rehabilitation are well and evenly covered with their input alone. Furthermore, the themes from stroke survivors that would be missed all touch on issues of engagement and usability at home: poor internet access, difficulty of use and demotivation, lack of financial resources, and a desire for connection with other stroke survivors. In other words, all the themes that would be missed by not including stroke survivors could determine the success or failure of a robotic rehabilitation device in the home environment, but the resulting gap is not visible.

As a result, stroke survivors must be included in discussions of design requirements because the information they share is different from therapists and critical to the long-term success of any at-home rehabilitation device. Therapists can describe the basic motions and actions that are involved in therapy activities, as well as therapy methodology and potential pitfalls. However, designers must speak with stroke survivors to determine how a robot can fit into their lives and environments, so that the device not only performs a therapy task but is useful to stroke survivors. Since it can be easier to access therapists, and therapists are often seen as the decision makers regarding the prescription of rehabilitation equipment to their patients, designers may be tempted to exclusively rely on their knowledge, especially in the early phase of designing their first prototype. By leaving stroke survivors' perspectives for later in the design process, or by not including them at all, stroke survivors' needs are inherently given lower priority than those of therapists'. This risks creating devices that work in theory, but are abandoned in practice because stroke survivors cannot fit them into their homes and their lives. This is already happening, as evidenced by one of our participants who had abandoned several devices that failed to meet his needs. Previous research has identified that assistive technologies for stroke survivors may be abandoned when the technology does not align with the needs or goals of the user, particularly when those goals connect to their interests and ability to participate in their community.<sup>33</sup>

#### Stakeholder needs

Many of the statements from the participants can be interpreted as descriptions of their needs for at-home poststroke upper limb rehabilitation. Both groups described the struggle many patients experience to participate in rehabilitation once they are discharged from the hospital or inpatient care. The stroke survivors emphasized their desire to improve their arm function, especially wrist and hand function, which suggests that a focus on creating devices for that anatomy is warranted. A lack of distal interaction has been identified by stroke survivors and therapists in evaluations of existing clinical rehabilitation robot systems.<sup>34</sup> The therapists who were familiar with participating in athome therapy also indicated that the long travel times between patients create a barrier to more efficient use of therapist resources, which suggests that a system that could reduce the frequency of in-person visits while maintaining a similar level of therapist interaction would be beneficial. Increasing therapy frequency without increasing in-person visits is also beneficial for protecting patients during emergencies such as the COVID-19 pandemic. In-person visits cannot and should not be eliminated entirely, since the social nature of visits for patients and the necessity of maintaining and educating users on the devices cannot be ignored. Additionally, some benefit of the reduced in-person visits may be reduced by the up-front cost of purchasing and installing this technology.

Since technology for telerehabilitation without physical interaction between the patient and therapist, or assistance for the patient, already exists in the form of video games and video conferencing,<sup>20,35</sup> both groups were interested in a system that could provide facilitation and assistance to the patient similar to how a therapist would in-person. Both groups were interested in a system that could facilitate range of motion activities and active-assisted, task-based activities.

While the participants noted many conditions experienced by stroke survivors that are relevant to the design of at-home rehabilitation robots, some conditions were not discussed in the interviews. Many stroke survivors experience visual impairments and other sensory issues<sup>5</sup> that would affect their ability to use a graphical user interface. Some specific manifestations of upper limb impairment were not discussed, such as: neglect, sensitivity, apraxia, and coordination problems. Similarly, while cognitive impairment was discussed in a general sense, specific types of cognitive impairment will have different impacts on design.<sup>36</sup>

#### Design recommendations

The most general design recommendation from the participants' perspectives was to account for the variability of stroke survivors' body functions and support systems (such as caregivers and financial resources). This suggests that a one-size-fits-all approach is unlikely to succeed.<sup>24</sup> Labelling novel robotic rehabilitation devices as being "for stroke survivors" is a misleading practice that should be reexamined. Describing the application of a robotic rehabilitation device in terms of the specific impairments it targets could be a better approach. For example, 'a robotic system for people who require facilitation for wrist movements'. This aligns with existing research findings that therapists wanted a better understanding of what rehabilitation goals would be facilitated by a given rehabilitation robot.<sup>34</sup>

One approach to broadening the applicability of a robotic rehabilitation device to a diverse group of users is suggested by existing therapy practice. The therapists described breaking activities down into components to target specific issues the patient might be experiencing, then bringing these components back together into the complete activity. A somewhat similar approach in robotic rehabilitation was tested by Rosenthal et al.,<sup>37</sup> where they used an algorithm to detect the parts of an activity that patients had the most trouble with and practiced those components more. They found that there was a significant improvement in the Fugl-Meyer Assessment for the patients that practiced the movements they had more difficulty with versus the patients that practiced all the movements equally. It may be beneficial to bring this strategy into future designs in both the

software and hardware design. A modular design for a robotic rehabilitation device could allow the device to only include parts that target the specific problems that a patient is experiencing in their rehabilitation activities, then assist in or simply monitor the patient's performance during the complete activity. The PLUTO robot<sup>38</sup> is an example of a modular approach to rehabilitation robot design.

Another insight from the therapists for potential design approaches is in the use of household objects during conventional at-home therapy. Robotic rehabilitation devices could also incorporate household objects or simple physical objects in their design to improve realism and similarity to activities of daily living. For example, a task used in the GRASP program<sup>29,30</sup> involves moving an empty cup across a tabletop. A mixed-reality robotic rehabilitation system<sup>39,40</sup> could have the patient grasp a real cup and add or remove virtual inertia to make it seem as if it is full of water, increasing the difficulty and realism of the task without risking the potential mess of a patient dropping a cup full of water. It also could allow patients with more limited function practice the whole task of grasping, lifting, and moving a cup of varied loads with assistance from the robotic system. Some work in mixed-reality for rehabilitation has been done in virtual reality,<sup>41</sup> and mixed reality has been used in medical training simulators.<sup>42</sup>

Design features. The participants also suggested specific features that should be considered in future device designs. One important feature emphasized by therapists is the ability to monitor their patients' shoulder and trunk position during therapy activities to detect unhealthy compensation. In general, designs could protect the shoulder with appropriate shoulder and arm supports, however this may be overly restrictive. A study of remote rehabilitation therapy found a major challenge experienced by the therapists was difficulty seeing their patients' bodies due to limited camera views,<sup>35</sup> and another study found that therapists considered clear visual feedback between therapist and patient to be the most useful potential feature of robot-augmented telepresence.<sup>23</sup> Some success in identifying compensatory movements has been achieved using a combination of video and depth sensing.<sup>43,44</sup> A review of computer vision-based approaches to rehabilitation assessment<sup>45</sup> found that most approaches require both video and depth information, such as that provided by the Microsoft Kinect sensor; however, as deep learning methods improve it may become possible to achieve reasonable accuracy from video alone. It should be noted that requiring that a camera always be on when a patient is using their rehabilitation robot is less respectful of patient privacy. Researchers and designers should consider ways of monitoring and detecting compensation that do not require video, or at least do not require the video to be permanently stored, and can provide summary reports for therapists to easily review at the start of a therapy session with their patients. Some work on camera-free methods of compensation detection has already been done.<sup>46</sup>

Both groups suggested that pain should be monitored, but not in a binary approach that only considers the presence or absence of pain. The stroke survivors and therapists described pain as a condition stroke survivors often experience during therapy and as something to be monitored and managed rather than an immediate indication that something is wrong. This suggests that having a simple stop button alone is not sufficient to ensure safety. Designers should consider adding regular check-ins during autonomous therapy sessions to encourage the user to reflect on their level of pain and decide if they need to stop or slow down, similar to what a therapist might do during an inperson session.

The stroke survivors participants found it motivating to connect with other stroke survivors in group therapy and support groups. A study of an online group rehabilitation program during the COVID-19 pandemic also found that participants found the group setting to be positive and motivating.<sup>35</sup> Researchers and designers should consider how social features could be added to future designs. This will require significant future research to navigate the potential privacy issues, as well as how to create social interactions that encourage users rather than creating negative or unhealthy competitive behaviour. Mace et al.<sup>47</sup> have investigated collaborative gaming as a way to improve engagement and reduce slacking by having users work together to accomplish a collaborative task.

Finally, physical touch and cueing were described as an important part of in-person therapy activities by the therapists, a theme identified in another study of therapists' perspectives on rehabilitation robotics.<sup>23</sup> Bringing that sense of touch between patients and therapists into remote therapy would give the therapists additional tools to communicate with their patients in a way that is already familiar to both groups. This is an opportunity for researchers in haptics and robotics to investigate the specific kinds of touch that are involved in therapist and patient interactions and develop technologies that enable remote haptic interaction in this context.

#### **Barriers**

Several of the statements made by the patients and therapists suggest barriers they experience to participating in at-home therapy that cannot be entirely addressed by the design of a device. Some problems described by patients include a lack of financial means to access technologies for their rehabilitation, poor internet access in their homes, lack of space in their homes, and a lack of family members or caregivers to assist them in their therapy. Some of these problems can be partially addressed by the design of a device itself: designing less expensive devices, creating more stable and efficient control algorithms that can perform well at low bandwidths and long delays, and creating designs that are lightweight or wearable and can be set up one-handed. However, the ability of the design of the device itself to mitigate these problems is limited. For example, one of the stroke survivors was dependent on government assistance which she already found insufficient for her needs. In her case, it may not be possible to design a device inexpensive enough to purchase or even rent. It is worth considering how researchers, designers, and users can contribute to policy conversations around access to health-related technology and equipment, financial support for individuals with disability, government spending on rural infrastructure, and inclusion of robotics and other emerging technologies in existing or new government healthcare programs.

#### Limitations

This study involved a small number of stroke survivors and therapists from a small region within Canada. The limited number of participants and length of the interviews mean that while the results indicate different potential blind spots or focuses between the two groups, these results are not guaranteed for all research involving these groups. It may be possible to account for these discrepancies between the groups by asking different questions. For example, many of the questions asked to therapists in this study centered on their needs (i.e. "what prevents your use of rehabilitation technologies"), however, questions that asked therapists to anticipate their patients' needs would likely produce a different result. Nonetheless, stroke survivors can still provide more direct examples of their needs in this context while therapists would be expected to speak more generally so as not to single out any of their patients. While many of the themes and ideas identified may be common to other regions and stakeholders, there may be other issues that were not discovered.

It is notable that the gender demographics of the participants are not in line with the expected demographics for Canada: 53% of stroke survivors in Canada are women,<sup>48</sup> while only 30% of the stroke survivors in this study were women. Although this is not statistically concerning given the small sample size, it still could mean that women's perspectives are underrepresented in this study. Additionally only one occupational therapist participated in the study, which could bias the results towards physiotherapists' perspectives.

The participants in this study were mostly in the chronic phase (nine out of 10), with only one stroke survivor in the subacute phase. Therefore, the results primarily represent the perspectives of those in the chronic phase. This is not unexpected since there are far more total survivors of stroke than new stroke survivors in a given year,<sup>3</sup> and stroke

survivors in the chronic phase could be more likely to participate in studies since their condition is more stable.

The COVID-19 pandemic likely affected the responses of the study participants, however it should be noted that the majority of the stroke survivor participants experienced a stroke prior to the pandemic and therefore had experience in therapy both before and after the pandemic. Similarly, most of the therapists had decades of experience prior to the pandemic. This experience both pre- and post-pandemic could limit the amount to which the pandemic affects the conclusions of this study.

#### Future direction

Many further opportunities remain for discovering and clarifying stakeholder needs in the context of rehabilitation robots. While this study focused on the two stakeholder groups who are expected to have the most direct interaction with any rehabilitation device, many other stakeholders should be considered, including caregivers and family members of stroke survivors, personal support workers, the designers and maintainers of existing rehabilitation technology, and public and private insurance groups that determine funding for rehabilitation devices. The results of this study can be further expanded upon by investigating if the identified themes hold true for a larger sample of therapists and stroke survivors.

The authors intend to use the identified themes as a foundation for the design of a novel rehabilitation robot.

#### Conclusion

Consulting therapists alone when designing stroke rehabilitation robotics is insufficient to capture details about stroke survivors' needs in the home environment. In this study, stroke survivors had more information to contribute about the needs in their homes, their access to different support systems, and their understanding of technology. In other areas, therapists and stroke survivors were largely in agreement about the different challenges and needs for athome rehabilitation. While many of the issues raised in this study are already being explored in a limited extent, there is a clear need for further research, including remotely enabling physical interaction between the patient and therapist using haptic technology, monitoring stroke survivors' trunk and shoulder movement during autonomous therapy, and bringing stroke survivors into collaboration with each other during therapy.

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#### Contributorship

SF researched literature and conceived the study. SF, TCD, VD, EM, and KHZ were involved in protocol development and gaining ethical approval. SF, VD, and EM were involved in participant recruitment. SF conducted the participant interviews. SF, ML, TCD, and KHZ were involved in data analysis. SF wrote the first draft of the manuscript, with the Materials and Methods section contributed by ML. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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