A Data Visualization Tool for Patients and Healthcare Providers to Communicate during Inpatient Stroke Rehabilitation

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ABSTRACT

Stroke is one of the leading causes of disability worldwide. The efficacy of stroke recovery is determined by various factors, including patient adherence to their rehabilitation program. Effective communication between healthcare providers and patients is crucial for promoting patients' adherence to rehabilitation programs. Aiming to support patient-healthcare provider communication during inpatient stroke rehabilitation, we (1) conducted semi-structured interviews with healthcare providers with expertise in inpatient stroke recovery to extract design requirements for visualizing stroke recovery progress. Using these design requirements, we (2) designed a data visualization tool representing stroke recovery. We (3) sought feedback on the visualization designs from healthcare providers and patients and integrated their feedback into the designs. Informed by the results of our studies, we provided several considerations for designing future visualization tools for patients and providers to communicate during inpatient stroke rehabilitation.

1 INTRODUCTION

In Canada, more than 89,000 strokes occur each year, and this number is predicted to increase due to population growth and aging [40]. Stroke is a debilitating condition; it often requires months of physical and cognitive rehabilitation and is a notable source of stress for patients and their families [62]. The rehabilitation process for patients recovering from stroke is considerable, in terms of cost and the demand it places on the healthcare system [55, 81]. Patients recovering from stroke at inpatient rehabilitation centers receive comprehensive treatment from a multidisciplinary team that assesses the individual needs of patients and develops personalized rehabilitation plans [10]. Adherence to these programs is the key to recovery [14]. However, patients undergoing stroke recovery in inpatient rehabilitation centers often stay in these centers for extended periods. These extended stays can lead to a lack of motivation for goal-directed activities, resulting in reduced engagement and limited benefits from rehabilitation [69] and impending stroke recovery.

Effective communication between healthcare providers and patients is one of the crucial factors for promoting adherence to rehabilitation programs [14,24,67]. This involves monitoring, reviewing, and discussing recovery progress during the patient's inpatient rehabilitation stay [23, 27]. This can provide tangible feedback to motivate patients and reinforce their adherence [29]. However, patients and healthcare providers face difficulties communicating the progress due to the complexity of the recovery progress data collected over weeks or months and the data being scattered at various locations of Electronic Medical Record (EMR) [44, 51]. Visualizing health data is one of the most effective methods for providing insight and facilitating patient-provider communication [12, 19]. This can help better communicate the recovery progress between patients and providers, improve patients' understanding of their health, and encourage positive health behaviors [68].

Several technological and visualization tools were developed to monitor stroke recovery progress, particularly monitoring the patient's upper limb movement during stroke recovery [28, 46, 47]. Stroke recovery is a multifaceted approach that requires a comprehensive overview of various aspects, such as cognition, swallowing, communication, and upper and lower limb recovery, which goes beyond focusing on upper limb rehabilitation [17]. Furthermore, these systems were designed to be used by healthcare providers [46, 47] or caregivers [28] for monitoring patient's recovery progress. They were not developed to be used by healthcare providers and patients for communication during inpatient stroke rehabilitation. Therefore, there is a gap in designing and developing visualizations for use by patients and providers simultaneously to communicate during inpatient rehabilitation stays, providing a comprehensive overview of all aspects of stroke recovery.

In this research, we aimed to design, develop, and evaluate an accessible and intuitive visualization tool representing a patient's rehabilitation progress after a stroke for patients and providers to communicate during inpatient stroke rehabilitation. In our earlier research, we collected data from healthcare providers through email communication to gain insight into how stroke recovery data is gathered in in-patient stroke rehabilitation centers [42]. In this research, adopting a human-centred design [34], we conducted interviews with healthcare providers to gather information on assessments used to evaluate patients' health outcomes, the extent to which patients are informed about their progress results, and the methods used to communicate with patients during stroke recovery. We extracted design requirements for visualizing stroke recovery progress based on the findings. We then designed sketches and developed prototypes to visualize patients' stroke recovery progress. Next, we interviewed healthcare providers and patients to evaluate the prototype and then integrated their feedback into our prototype.

Overall, the results of all our studies indicate that our visualization tool has the potential to motivate patients and can be used by healthcare providers and patients by (i) providing different views for patients and providers, (ii) personalizing views not only for patients but also for providers, and (iii) utilizing lay language in describing visualizations. Our contributions to this paper are as follows:

1. Identified a set of design requirements for representing stroke recovery progress.
2. Designed and developed a medium-fidelity prototype representing patients' recovery progress for use by patients and

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providers simultaneously to communicate during inpatient rehabilitation stays.
3. Provided several considerations for designing future visualization tools for patients and providers to communicate during inpatient stroke rehabilitation.

2 Related Work

In this section, we provide a brief overview of health data visualization applications designed for healthcare providers and patients. We then outline studies and technologies developed to facilitate effective communication between patients and their healthcare providers. Finally, we discuss current technologies and visualization tools designed to visualize patients' recovery progress.

2.1 Health Data Visualizations

Health data is gathered from various sources in healthcare, such as EMR, diagnostic centers, laboratories, pharmaceutical companies, and various Internet of Things devices and remote monitoring devices [37]. However, due to health data's vast quantity and complexity, it can be difficult for healthcare providers and patients to analyze and comprehend the information in a short clinical visit [30, 71]. Visualizing health data has shown promise in organizing and interpreting large data sets to highlight important insights [74]. Visualizing health data has also gained widespread interest because of its usefulness for patients and healthcare providers, such as faster interpretation of data, identifying trends, making data-informed clinical decisions, and informing patients about their care [48, 58].

Researchers have developed various technologies to make health data analysis and navigation easier for healthcare providers. For instance, Lifelines [45] is a visualization system that provides a visual overview and facilitates the navigation and analysis of clinical patient records. Outflow [77] is an interactive visualization that summarizes temporal event data extracted from health data. Another tool called Timespan [33] is designed to provide a better understanding of the temporal aspects of the stroke treatment process. Visualizing health data has also been used to improve medication safety [75], manage intensive care patients [15], promote patient wellness [26], choose treatment protocols [9], and help patients make informed decisions about their healthcare management strategies [13]. However, while these works have made notable contributions to the visualization of patient records, none so far, to our knowledge, have focused on being used by healthcare providers and patients during patient-provider communications.

2.2 Patient-Provider Communication Technologies

Effective communication between patients and healthcare providers plays a crucial role in improving patient care and overall quality of life [24, 67]. However, establishing effective communication can be challenging due to limited time during clinical visits, the use of complex medical terminologies, emotional distress, and information overload [52, 60]. Despite these challenges, research consistently demonstrates the positive impact of effective communication on patient's mental well-being [76], reduction of anxiety [8], control of depression [16], enhancement of mood [25], and the elevation of hope for the future [78].

Various technologies have been developed to enhance patient-provider communication. In a recent study, researchers introduced Talk2Care—a pilot home-based telehealth application system [80] utilizing Large Language Models (LLMs) to support asynchronous communication between older adults and healthcare providers. The system allows older patients to collect health information through a voice-activated interface, while healthcare providers can access a dashboard that summarizes and highlights key information from patient voice-assisted conversations powered by LLMs. Another study presented InvolveMe [59], a digital patient-provider communication intervention designed to improve follow-up care for renal transplant recipients and those with non-functioning pituitary adenomas. BodyDiagrams [22], an online platform, allows patients to annotate pain severity and timing on a visual body representation, helping to communicate pain interpretation between patients and providers. Despite several studies on technology to improve patient-provider communication, there remains a lack of tools to support communication between patients and providers during patient's stay in hospitals or rehabilitation centers.

2.3 Technologies to represent Recovery Progress

Visualizing recovery progress can help better communicate the recovery between patients and providers, improve patients' understanding of their health, and encourage positive health behaviors [68]. AnatOnMe [38] is a handheld device that uses projections to facilitate in-clinic doctor-patient medical information exchange regarding physical therapy. The use of AnatOnMe has led to increased patient engagement in rehabilitation and understanding of medical information. Li et al. [31] utilized visualizations of electromyography biofeedback during physical therapy sessions for patients with acute spinal cord injury. This approach helped increase muscle use and engagement during therapy.

Several visualization systems have been developed for stroke rehabilitation. ArmSleeve [47] is one such system, which includes a sensor to monitor upper limb movement and a dashboard to provide therapists with access to upper limb movement information during stroke rehabilitation. Another study proposed an Avatar-based human digital twin visualization dashboard [28] designed explicitly for informal caregivers in upper-limb stroke rehabilitation. The avatar-based dashboard is designed to communicate complex patient data clearly and provide insights about the patient's progress to informal caregivers in the patient's therapy process. However, the existing tools for monitoring stroke recovery progress focused only on tracking the patient's upper limb movement during stroke recovery. Stroke recovery is a multifaceted process that requires a comprehensive overview of various aspects, such as cognition, swallowing, communication, as well as upper and lower limb recovery [17]. Moreover, the aforementioned systems were designed for either healthcare providers or caregivers and were not developed to be used by both healthcare providers and patients during communication between patients and providers. Hence, there is a notable gap in designing and developing visualizations for use by patients and providers simultaneously to communicate during inpatient rehabilitation stays, providing a comprehensive overview of all aspects of stroke recovery.

3 Study #1: Design Requirements and Prototype

3.1 Study Design, Participants, Data Collection, Analysis

Study design: We conducted a qualitative study to understand how healthcare providers evaluate patient progress, assess health outcomes, and communicate rehabilitation progress to patients over time and to extract design requirements for visualizing stroke recovery progress. We conducted semi-structured interviews, utilizing probing questions to delve deeply into participants' responses. The questions were open-ended, enabling comprehensive insights into the perspectives of healthcare providers. Although both providers and patients are involved in communication, we chose to first interview healthcare providers specifically to extract design requirements. This decision was made because healthcare providers interact with diverse patient populations on a daily basis, allowing them to have an understanding of the patients' needs as a population. They also have extensive experience in communicating with patients and know what information is necessary for patients to know, such as which health assessments are needed and what each assessment means.

Recruitment: We asked managers and physician leads from the local hospital's stroke rehabilitation unit to help facilitate the recruitment of participants. They distributed a research summary

during departmental meetings, and the hospital's communication team placed recruitment posters throughout the facility. Interested individuals contacted us via the provided email address, and we also utilized snowball sampling. Our inclusion criteria aimed to encompass healthcare providers from various specialties with at least a year of experience specializing in stroke recovery within the inpatient stroke rehabilitation unit to ensure a comprehensive perspective on stroke rehabilitation assessment. Following each interview, we inquired if participants could suggest other healthcare providers interested in participating in the study. However, we faced challenges recruiting healthcare providers due to their demanding schedules and potential skepticism regarding the value of new technology research [51]. Additionally, in our city, we have only one inpatient stroke unit with just 10-12 active healthcare providers responsible for stroke rehabilitation care.

Participants: We interviewed four experienced healthcare providers from the local inpatient stroke rehabilitation unit. The participants comprised a Physiatrist (PH) with 30 years of experience, a Physiotherapist (PT) with 11 years of experience, a Speech-Language Pathologist (SLP) with 17 years of experience, and an Occupational Therapist (OT) with 15 years of experience. Even though our sample size is small, we consider our participant group sufficient for this study, given their extensive expertise and potential to provide valuable insights [72].

Data collection: Data collection for this study took place between July 2022 and October 2022. Interviews were conducted via phone or online platforms such as MS Teams or Zoom. The duration of interviews varied, lasting between 30 minutes to one hour, depending on the provider's availability and willingness to share insights. All interviews were recorded and subsequently transcribed. Monetary compensation for healthcare providers' participation was not permitted per the hospital's review board's approval of all study procedures. Participants provided oral informed consent before engaging in audio-recorded interviews. During the interview, the questions mainly focused on three topics: assessments used to evaluate patients' health outcomes, the extent to which patients are informed about their progress results and methods used to communicate with patients during stroke recovery.

Data analysis: We conducted an in-depth analysis of the interview transcripts using an iterative inductive thematic analysis approach [6, 65]. Each transcript was independently analyzed by two researchers to identify emerging themes and patterns within the data. Subsequently, the two researchers met to discuss the identified themes, examining the similarities and differences in the emerging themes. Any disagreements or uncertainties in coding were discussed and resolved during the coding process on a case-by-case basis. The coding process was flexible, allowing themes to naturally evolve from the data without forcing it into pre-existing coding frames or predefined analytical assumptions (See Appendix A for the codebook). Following the thematic analysis, we extracted a set of design requirements for representing stroke recovery progress.

3.2 Findings

Our analysis revealed six themes (T1-T6).

T1: Mediums to communicate health progress to patients

Healthcare providers mentioned that they communicate rehabilitation results and progress to patients in various forms. They document patient information such as level of mobility, transfer abilities and discharge dates on the whiteboards installed in every hospital room. Healthcare providers also communicate patients' progress to them verbally. Additionally, they sometimes share handwritten notes with patients to show their progress.

T2: Types of content communicated to patients

Healthcare providers communicate different types of health information to patients, such as baseline tests, rehabilitation goals, health status scores, discharge summaries, and comparisons between admission and discharge health assessments. "*I always have a folder. . . for all my patients, and I put all the exercises in that so that the first page of the initial assessment is always there. So then, like, they [patients] can go back to it and review it. And then, in the end, when I do the assessment, I summarize all the information again for the patients. And then I put all those two pages together, and I would say, Okay, now you see and compare. . . so then they can see how much progress they made*" – SLP. Each week, the healthcare providers update the patients' functional results and discharge plans, upload them in the EMR, and communicate the results to patients. However, time constraints and the complexity of results can limit the in-depth discussion of all results. Thus, healthcare providers prioritize the most critical results for patient communication.

T3: Weekly progress report information

During weekly meetings, healthcare providers evaluate patients' overall progress by discussing various aspects of their recovery in the team clinical rounds. These meetings cover rehabilitation goals, the patient's initial functional state, and their ongoing progress. Healthcare providers use similar categories from the Functional Independence Measure (FIM) [41] health assessment as a guide using a scale from 1-7 to discuss patients' independence in each rehabilitation area. "*We do have a one-page sheet, which we use to summarize all of the activities of the patient in our rounds, which has the level of function of each patient using, in particular, one weighting system for disability, called the FIM*" – PH. In the weekly progress meetings, PHs address medical conditions that impact rehabilitation. PTs evaluate and assess patients' physical functions, including mobility, lower-limb and upper-limb functions, transfer, walking ability, and balance. SLPs assess patients' cognitive abilities, communication skills, language proficiency, and swallowing abilities. OTs review patients' levels of functioning in daily activities, cognitive-perceptual capacities, and visual-perceptual abilities.

T4: Attempts to increase patient engagement in rehabilitation

Healthcare providers prioritize patient engagement in rehabilitation and strive to empower patients by educating patients about their health. To inform patients about their health progress, healthcare providers communicate patients' test scores to them. Assessment results are often filled with medical jargon that can be difficult for patients to understand. To ensure comprehension, healthcare providers use simple language when communicating results to patients."*The tests you're using are complex, so I use simple language for the patients, then they understand ... [and it is useful] to encourage them to participate*" - PT. Open communication, positive feedback, and a focus on patient goals are key to encouraging patients as they progress in their rehabilitation, as mentioned by the OT: "*I always use open communication. At the end of the session, we usually provide some positive feedback, like, that was really good work today, strong work, I'm happy with the improvements that I've seen [...], And then I also refer back to the goals that we had established during admission [...] and say, you're getting very close to being independent with your self-care, which is what [was] your goal*".

T5: Issues with technology to store/access patient health data

Healthcare providers raised concerns about the available healthcare technology for managing patient health data. Retrieving data from fellow providers becomes challenging when results are improperly submitted or scattered in unconventional EMR locations. The PH underscores the incohesive nature of patient health data within EMR:"*This stuff [patient health data] is buried in the [EMR software], and it sucks. People always complain that it's very hard to find the level of function and care*". Healthcare providers expressed a desire for a standard template for summarising patient health progress. The SLP states *"Actually, I wish I had one [template], but it depends on the patient, you know, not all patients are the same. So then, like, there's no one template that I can use, basically"*. However, the uniqueness of each patient's rehabilitation journey makes it difficult to create an interchangeable template

for healthcare providers to summarize patient health progress, and personalizing each report is necessary.

T6: Inpatient treatment protocol and therapy

The healthcare provider's protocol of care for rehabilitation after a stroke starts with a baseline admission assessment to determine the patient's health upon arrival in the inpatient unit. A team of healthcare providers assesses specific domains, including cognition, swallowing, language, and physical abilities. Rehabilitation goals and treatment plans are then determined based on the patient's current health challenges and the severity of their condition. Below, we detail the specific domain assessment and treatment protocols followed by each provider:

PH: *Assessment:* evaluates the patient's health status and comorbidities affecting rehabilitation, such as hypertension, diabetes, lipids, fever, swelling, and complex regional pain syndrome. They use the Subjective, Objective, Assessment, and Plan (SOAP) method [2] for documenting daily patient notes.

PT: *Assessment:* determines patients' mobility and daily activity abilities, including the social environment, home, and hobbies. *Treatment:* They design individualized physiotherapy plans incorporating assistive devices when necessary. A treatment plan is made depending on the severity of the patient's impairments and typically involves 5 days a week of physiotherapy to work on regaining movement and relearning everyday activities.

SLP: *Assessment:* assesses language, communication, and swallowing abilities and addressing aphasia, dysarthria, and cognitive-linguistic disorders. *Treatment:* They customize design speech-language therapy sessions (2-5 times weekly) with communication devices, speaking activities, exercises for developing speech muscles, and coping strategies.

OT: *Assessment:* evaluates the patient's ability to perform daily tasks and instrumental activities, considering motor control and cognitive function. *Treatment:* They customize design personalized occupational therapy sessions to enhance motor skills and manage post-stroke changes in daily life. A treatment plan is made depending on the severity of the patient's impairment and typically involves 3-5 occupational therapy sessions per week.

3.3 Design Requirements

From the healthcare provider interview data analysis and themes identified, we extracted 5 design requirements (DR1-DR5) to represent stroke recovery progress and help healthcare providers communicate this progress to patients. Although these requirements were specifically extracted for stroke recovery progress visualization, they can also be applied to other types of recovery visualizations. Our design requirements align with several other research studies that have extracted design requirements for recovery, such as post-operative cancer care [4], physical injury [73,82], cognitive rehabilitation [36], and recovery in critical care units [66].

DR1: Include a holistic view of patient's progress

This design requirement is drawn from themes T1, T2, T4, and T5. It was noted to be beneficial to communicate patients' progress from admission to discharge for patients to have a holistic view of how they've been progressing and achieving their goals over time.“*Something written down that compares admission and discharge. For example, minimum assistance, moderate assistance, maximum assistance, so at admission self-care, maximum assistance, for upper body dependent for lower, and then on discharge, minimum assistance for the upper and lower body now, showering.*” - OT. Additionally, healthcare providers emphasized the need for a holistic view of patient's progress to reduce the burden of healthcare providers navigating fragmented data in an EMR system.

DR2: Categorize assessments based on health domains

This requirement is informed by themes T2, T4, and T6. Healthcare providers emphasize the importance of classifying each health assessment based on different health domains. These domains include cognition and perception, language, swallowing, upper body, lower body, total motor recovery, and exercise. “*I think they're all [health assessments] important because they give information on the patient on, you know, their rehab, and where they are at some point and where they can be later*” - PT.

DR3: Include periodic patient health progress

This requirement is drawn from the theme T3. The healthcare providers mentioned that visualizing the patients' health progress periodically, such as from weekly rounds, holds substantial potential. They view it as a valuable tool for facilitating discussions about a patient's status and rehabilitation progress.“*I think that [visualizing weekly rounds] will be amazing. Because then we could show it to people and ourselves. The rounds, they'll become faster and faster*” - PH.

DR4: Use lay language to describe assessment visualization

This design requirement is drawn from themes T2 and T4. Healthcare providers noted that the language used in health assessments can often be complex and challenging for patients to understand. To address this challenge and ensure effective communication of assessment results, healthcare providers utilize simplified language. This approach aims to make sure that patients can easily comprehend the information, “*for example, I would just say 'writing', instead of saying 'executive content'*” - SLP.

DR5: Make cognitively accessible data visualization

This design requirement is drawn from theme T4. Healthcare providers underscored the importance of designing data visualizations to accommodate patients with diverse levels of comprehension and cognitive abilities. They emphasized the importance of using familiar and easily understandable visualizations that can be customized to meet each patient's specific needs,“*we were dealing with clients who cognitively and perceptually may not be able to manage the type of information we're giving them. So it [visualization] would have to be client-centred as well*” - OT.

3.4 Prototype Development - Design Iteration #1

To design the patient health progress visualizations for stroke rehabilitation, we considered requirements (DR1-DR5) from interviews and followed the visualization design guidelines established in the literature [35, 61, 79]. Our process began with low-fidelity sketches using pen and paper that displayed individual health assessments, health domains, and a weekly progress report. We then refined our designs through a collaborative and iterative process and made adjustments as needed. Once we were satisfied with the sketches, we developed mid-fidelity visualizations using Figma software, a web-based application for design and prototyping.

To fulfill DR1, we designed a holistic view of the patients' progress from admission to discharge using line graphs. We opted for line graphs over bar charts as they offer a clearer representation of trends [11, 63] (Figure 1 - a). These graphs indicate inclines or declines in their rehabilitation. The holistic view allows patients to select a health assessment, providing a side-by-side comparison of admission and discharge assessment results for cognition, upper body, swallowing, total motor recovery, lower body, and exercise.

To fulfill DR2, we categorized health assessments according to the specific health domains and then linked these categories to their corresponding body parts on an image of the human body (as depicted in Figure 1 - b). This allows patients to easily access all their health assessment results by selecting buttons associated with the relevant rehabilitation categories.

To fulfill DR3, we introduced the “Weekly progress garden” (Figure 1 - c). In this view, colourful flowers symbolize various functional activities, and their height corresponds to the patient's progress, ranging from level 1 (dependent) to level 7 (independent), aligning with the FIM assessment criteria used by healthcare providers. The garden metaphor offers an intuitive representation of patient progress, indicating gradual improvement in functional

(a) (b) (c) (d) (e)

Figure 1: Design iteration # 1: (a) An integrated overview of patient's rehabilitation progress, (b) Overview of all the categories of health assessments for rehabilitation, signposted to their relevant body parts on an image of a human, (c) Weekly progress view for patients displaying the level of independence in functional activities (coloured flowers) and patient's goals (grey flowers), (d) Weekly progress view for healthcare providers lists the same categories as in the "Weekly progress garden" (e) Lower body health assessments view representing the speed of a patient's progress.

abilities over time. Patients can monitor their weekly progress via the timeline at the top left. Additionally, we designed a separate view for healthcare providers to use during their weekly meetings (Figure 1 - d). This view includes bar charts that the providers are already familiar with. The provider view also lists the same categories as in the "Weekly progress garden".

To fulfill DR4, we used plain language to label and describe the results of each health assessment for patients. For example, we converted "Berg Balance Scale (berg) [32]" to "Balance test" and "Chedoke McMaster Stroke Assessment [57]" to "Motor Recovery test". This approach ensures that patients easily understand the information. In addition, we provided the original name of the test within the health assessment description should the patient decide to share the results with other healthcare providers after discharge.

To fulfill DR5, we adopted the design principle of skeuomorphism [70], which involves replicating real-life objects within a digital context to enhance familiarity and ease of use. For example, using flowers in a weekly progress garden to represent the level of independence, using a speedometer to represent the speed of a patient's progress (Figure 1 - e) and using a real-world balance scale for balance scale tests. We also used commonly recognized graphs and charts that are cognitively accessible. Patients can also customize their experience with dark and light mode options to accommodate different vision abilities. To reduce cognitive load, we present patients with an overview first, followed by zoom and filter, then details-on-demand, following the Visual Information-Seeking Mantra [61]. For example, patients can easily select specific days on the monthly calendar for daily exercise details. They can also choose between weekly and monthly exercise results through a dropdown menu, offering flexibility in the displayed timeframe. Patients can further focus on a specific week's physical exercise progress within the chosen month.

4 Study #2: Evaluating Prototype with Providers

4.1 Study Design, Participants, Data Collection, Analysis

Study design: We conducted interviews with healthcare providers to gather feedback on our mid-fidelity prototype (design iteration #1). We used screen sharing to demo the prototype during the interview.

Recruitment: We invited healthcare providers who had expressed interest in follow-up interviews after our initial round of interviews (study #1) to participate in our second study. *Participants:* The same physician, physiotherapist, and speech-language pathologist from the study #1 returned to evaluate the design.

Data collection: The data collection process occurred between October 2022 and November 2022. Interviews took place virtually over MS Teams or Zoom and ranged from 30 minutes to 1 hour, based on participants' availability and willingness to share. Interviews were audio-recorded and later transcribed. Participants were not monetarily compensated for their time. Providers were instructed to consider a few tasks they would perform while communicating patients' results using our visualization tool. These tasks include selecting health evaluations based on body function, selecting the goals panel, selecting the exercise panel, and interpreting results. We asked healthcare providers to think out loud and tell us about their experiences with the visualization tool.

Figure 2: Design iteration # 2: (a) The overview of the patient's health progress, previously represented in line graphs, has now been replaced with colour-coded "action dots". These dots indicate the patient's rehabilitation progress as progressing, worsening, or remaining the same. (b) The cognitive tests, which previously lacked an explanation of the severity level, now come with severity levels ranging from no deficits to severe deficits. (c) The Berg balance test now has contextual explanations alongside numerical scores. (d) Previously, the weekly progress overview of patients displayed all categories. Now, with a filter option, patients can select and view one category of functional activity at a time. (e) Once a category is selected, it displays the level of independence and goals in functional activities within that category.

Data analysis: Similar to the first round of interviews, we reviewed interview transcripts using an iterative inductive thematic analysis technique for this study [6,65]. The transcriptions were individually analyzed by two researchers, who then convened to discuss commonalities and disparities in challenges and concerns observed in the current designs (See Appendix B for the codebook). We made adjustments to the medium-fidelity prototype designs based on healthcare providers' feedback. One team member then implemented these changes, which were reviewed and discussed by the entire group.

4.2 Findings

During the interviews with healthcare providers, they showed positive reactions to the data visualization tool. They mentioned it has the potential to facilitate communication between healthcare providers and patients during inpatient stroke rehabilitation, especially when dealing with patients experiencing communication barriers such as aphasia. Additionally, they also provided several recommendations.

Categorize and label health assessments: Healthcare providers have recommended several improvements in organizing and categorizing health assessments. They suggest that the results of health assessments should display subdomain categories to help patients understand specific areas where improvement is needed. They have also recommended reorganizing several health assessments into categories that are closely associated with their respective health domains. Furthermore, they suggested that these categories should be associated with relevant body parts within the visualization to aid patients in understanding the purpose of each category. This approach will help patients better understand trends in their rehabilitation progress within each domain. Additionally, it was suggested to include an indicator showing when a patient's rehabilitation results neither improved nor deteriorated. The trends, along with indicators, can provide a more comprehensive view of the patient's status.

Display informative scales: Healthcare providers recommended including the severity levels of scales, which can be informative for patients, providing them with a richer and more detailed representation of their progress. One specific scenario highlighted by the SLP demonstrates the importance of specifying the level of impairment."*If I say you were impaired, and now you're impaired, what's the difference? The difference is that it was severe. Now it's mild. So, it's good to tell them how severe it was*" - SLP.

Provide comprehensive result explanations: Healthcare providers stressed the importance of going beyond displaying numerical scores and instead providing a deeper understanding of what the results mean,"*They'll [healthcare providers] put it together in a bigger picture, they won't just write the report as the results. The results will be ... integrated to say they are independent in their self-care; they are independent in their ability to toilet.*" - PH.

Include a designated place to add notes in assessment visualizations: To facilitate effective communication between healthcare providers and patients, it is recommended that providers and patients have the ability to add freestyle notes within assessment visualizations. These notes can serve as a means for discussion.

Provide customization options: Healthcare providers have suggested providing customization options for both patients and providers. For patients, in the weekly progress garden, instead of showing all categories at once, they should be able to choose and view specific areas of their functioning that are most relevant to

their recovery, such as movement, swallowing, independence in self-care, etc. We reorganized assessments to align with their respective health domains to enhance health assessment categorization of their specific hospital or facility's priorities. This way, they can choose commonly used and relevant assessments to their practice.

4.3 Changes to Prototype - Design Iteration #2

Following feedback from healthcare providers, we implemented several changes to our designs.

Categorize and label health assessments: Healthcare providers recommended reorganizing health assessments into categories. To enhance health assessment categorization, we reorganized assessments to align with their respective health domains. For instance, we moved the 'Assessment of Language-related Functional Activities (ALFA) test' [1] from the language category to the cognition and perception test category, ensuring that assessments align with the appropriate domains, streamlining navigation for both healthcare providers and patients. Furthermore, healthcare providers emphasized the importance of enhancing the existing signposting of each category to its corresponding body part responsible for that function. Initially, the category 'Language and Swallowing' was signposted to the mouth. However, based on provider suggestions, we have now signposted 'Language' to the brain and 'Swallowing' to the throat.

To address healthcare providers' request to include indicators of a patient's rehabilitation progress, we transformed the patient's health progress overview by replacing line graphs with visually intuitive "action dots" that show patients' rehabilitation results as progressing, worsening, or remaining the same. Health progress overview, along with indicators, can provide a more comprehensive view of the patient's status (Figure 2 - a). Action dots in the visualization have shown to be highly effective, providing a simple, quick, and visually accessible representation of information [43]. Thus, we utilized action dots using divergent colour schemes for our colour hues.

Display informative scales: Healthcare providers have recommended adding severity levels to assessment tools to give patients a more detailed representation of their progress. To address this, severity levels were introduced to each scale, providing a detailed assessment of patients' conditions. For example, the scales now include categories such as "No deficits (26-30)", "Mild deficits (18-25)", "Moderate deficits (11-17)", and "Severe deficits (11-17)" for impairments (Figure 2 - b). These numerical ranges correspond to the extent of impairment, offering a quantifiable scale for patients to understand the severity of their condition.

Provide comprehensive results explanations: Healthcare providers have emphasized the importance of providing patients with explanations of their test results. To address this, we provided explanations encompassing the broader meaning of the patients' scores. For example, in the Berg balance test [32], we offer contextual interpretations alongside numerical scores. Instead of solely providing the patient with their numerical scores, we now provide additional information like "At admission, you scored 39/56 on the balance test. This score indicates that you may need some walking assistance like a cane or walker" (Figure 2 - c). These assessments provide detailed descriptions and interpretations of the scores, which can help patients better understand their progress in rehabilitation.

Include a designated place to add notes about assessments: Healthcare providers have suggested that having a place to add freeform notes about health assessment results would be beneficial. For instance, in the swallowing test, notes about food inclusions, exclusions, and swallowing strategies can be very useful in communicating patient results and supporting patients with diet planning. To address this issue, we have added a designated area where healthcare providers can write notes about patient results and provide additional context for specific assessments and areas that need improvement.

Provide customization options: Healthcare providers recommend personalized visualizations that are tailored to each patient's rehabilitation journey. To make the experience more personalized, we have incorporated a filter option. Patients can choose to view one category of functional activity at a time instead of displaying all items within each category on one screen (Figure 1 - c), which can be overwhelming for the patient. In the new design, each category of functional activity is presented within a cloud. The use of clouds was a deliberate design choice to maintain consistency with the nature theme while serving a functional purpose (Figure 2 - d). When a cloud is selected, the corresponding items within that category will be displayed. This will include the patient's level of independence for each activity and goal (Figure 2 - e).

5 Study #3: Evaluating Prototype with Patients

5.1 Study Design, Participants, Data Collection, Analysis

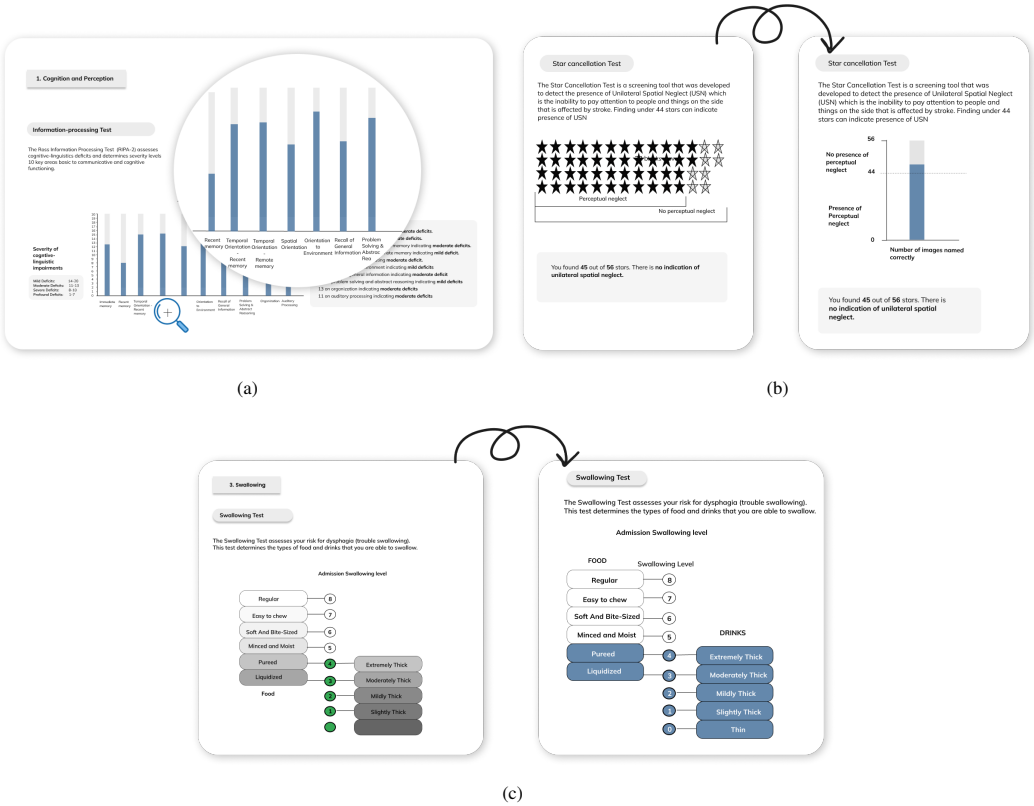
Study Design: We conducted semi-structured interviews with patients to gather feedback on our mid-fidelity prototype. Additionally, we asked them about the challenges they faced during their recovery process, as well as any difficulties they experienced communicating their progress with healthcare providers. During the interviews, we guided patients through the prototype, providing them with an overview of the tool and showcasing various views in the visualization system. To ensure that patients could participate without any technological barriers, a caregiver was present to assist patients with laptop access, guide them through the login process, and address any technical issues.

Recruitment: We asked the physician lead and an SLP from the stroke rehabilitation unit, both of whom had previously participated in the study, to help facilitate the recruitment of patients recovering from stroke. They contacted patients recovering from stroke within the inpatient rehabilitation center, inviting them to participate in the study. When patients expressed their interest in participating, they shared their contact information with the healthcare provider, who subsequently passed this information on to our research team. Next, our researchers contacted the patients via email. Before commencing the study, patients were asked to consent, either orally or in writing. Recruiting patients was challenging, as the focus was on the inpatient stroke rehabilitation unit, which constitutes a vulnerable population. Stroke recovery patients often require specialized care due to their fluctuating health conditions and potential communication barriers such as aphasia. Our recruitment prioritized patient safety, adopting a cautious approach aligned with ethical principles.

Participants: We recruited two patients undergoing stroke recovery at the inpatient stroke rehabilitation unit, both in the final stages of their inpatient stay, preparing to return home. P1 (a 60-year-old male) spent 6 weeks in the inpatient rehabilitation facility with goals focused on increasing swallowing ability, mobility, and walking strength. P2 (a 49-year-old female) spent 9 weeks in the inpatient rehabilitation facility with goals focused on improving cognitive ability, speech, and mobility.

Data collection: The data collection process occurred between May 2023 and June 2023. Interviews were conducted via online platforms such as MS Teams or Zoom. The duration of interviews varied, lasting between 30 minutes to one hour, depending on the patient's availability and willingness to share insights. These interviews were audio-recorded and later transcribed, and participants did not receive monetary compensation.

Data analysis: Similar to the first round of evaluation, we employed an iterative inductive thematic analysis technique [6, 65] to analyze interview transcripts. Two researchers independently analyzed the transcriptions, looking for patients' feedback on the visualization designs, and information about patients' experience with stroke recovery, their current methods of communicating progress and exercise instructions with healthcare providers (See Appendix C for the codebook). Adjustments to design iteration #2, addressing patients' feedback, were implemented by one team member and reviewed by the entire team.



(a) (b)

(c)

Figure 3: Design iteration # 3: The following changes have been implemented: (a) Added a magnifying glass icon to appear on hover, enabling zooming; a sample view is shown for the Cognition test. (b) The Star Cancellation test, previously shown by stars, is now presented as a bar chart. (c) The Swallowing test, previously shown in different shades of gray, is now presented with a blue and white colour scheme, where the blue colour represents the food and drink options that patients can swallow, while white indicates the items they are unable to swallow.

5.2 Findings

Challenges with information retention: Patients have mentioned that they face difficulties remembering the results of the multiple tests they undergo during their rehabilitation journey. They highlighted the complexity of the process and mentioned that they were unsure if they were informed about the tests and how they performed, "*Yeah, I guess that's one of the difficulties is there are so many different tests that you do, and I'm not sure that I can remember if I was told what they were or how I did*" - P2. Despite facing these challenges, both patients expressed feeling encouraged and well-supported by healthcare providers during recovery.

Limited access to recovery progress: Patients mentioned they receive their health assessment results and health instructions through different channels, such as printed instructions, an iPad app with interactive exercise instructions, and verbal discussions with healthcare providers. These methods help them stay informed about their stroke recovery progress and test results. However, they pointed out that the current patient portal does not provide access to all health assessments, which are crucial for a comprehensive understanding of their well-being and recovery journey. This limitation prevents them from gaining a holistic view of their health status and tracking their progress over time.

Feedback on the visualization designs: When discussing data visualization designs, patients mentioned that visualizations with clearly defined goals could be a motivating factor in their recovery process,"*So it [data visualization tool] could be really helpful to some patients who need that motivation to improve. I think that helps to motivate you when you see that you are making progress and to have those goals clearly labelled out, too*" - P2. Patients highlighted the importance of readability in the designs. They suggested using a larger font size than the current 12 pt. font for better legibility of the presented results. This recommendation is especially relevant for older individuals with difficulty reading small fonts. It is worth noting that patients have mentioned they had difficulty viewing the visualizations to their full capacity. This issue could have been due to the screen share setting during the interviews. They were unable to zoom in for a closer look. Additionally, patients suggested designing mobile-friendly layouts to cater to the widespread use of smartphones during hospital or rehabilitation stays. Patients preferred visualizations of their health data in the form of numbers or familiar chart types such as line, donut or bar charts. They found these chart types more helpful in understanding their scores, as more complex visuals can be confusing. Furthermore, patients in our study found visualizations using grayscale colours difficult to comprehend; they couldn't distinguish between different shades of gray.

5.3 Changes to Prototype - Design Iteration #3

Considering patient feedback, we implemented several changes to improve the design. To enhance readability, we made several adjustments, including increasing the font size to 16 pt, the industry standard for website content. We also added a hovering magnifying glass icon that allows people to zoom in on text for a closer look (Figure 3 - a), particularly useful for people with low vision or those who prefer larger text sizes. To address feedback concerning complex charts, we simplified the visualizations for the star cancellation and box and block tests by using bars and donut charts (Figure 3 -

b). We also added numerical scores as data labels to the line graph to offer patients the ability to see their scores easily. Patients mentioned that they found it difficult to differentiate between different shades of gray in the swallowing test. To address this issue, we changed the colour scheme of the test to a combination of blue and white (Figure 3 - c). In this scheme, the blue colour represents the food and drink options that patients can swallow, while white indicates the items they are unable to swallow.

6 Example Workflow

To illustrate how our data visualization tool can be used by healthcare providers and patients to communicate during inpatient stroke rehabilitation, we present an example scenario involving George and Emily. George, a middle-aged man recovering from a stroke, spent six weeks in an inpatient rehabilitation facility with goals aimed at improving swallowing ability, mobility, and walking strength. Emily, a healthcare provider specializing in stroke recovery, has 15 years of experience and works in the same stroke rehabilitation unit.

Today, George met with Emily for their weekly discussion on his recovery progress. They opened George's home dashboard in the visualization tool (Figure 1 - a). In the home dashboard, they could see a summary of his progress for the current week. Emily explained that in the cognition and perception category, there was an increase in rehabilitation progress in the information processing test, trail-making test, and 9 peg hole test, as they are highlighted in green. However, there was a decrease in progress in the cognitive linguistic test, which is highlighted in pink (Figure 2 - a). George asked Emily to explain what the cognitive linguistic test was. Emily selected the health assessment section in the left panel and then chose cognition, which is signposted to the human brain (Figure 1 - b). With the help of the visualization for the cognitive linguistic test, Emily explained the test to George, including the normal and abnormal ranges, and showed his results by comparing them with the given range. Meanwhile, Emily also checked the provider dashboard to see if any other providers had given other free-form notes about George's results with this test (Figure 1 - d). Emily could see that the SLP left a note saying that George showed a decrease in involvement in activities focused on improving his speech and language skills during this week's rehabilitation. With this in mind, Emily and George planned their tasks for the next week to improve George's performance accordingly.

George mentioned that he felt his eating capability had increased since he entered the program. He said that now he could eat with minimal assistance. Then Emily and George selected his weekly progress view from the left panel and chose self-care (Figure 2 - d,e). George quickly identified that his eating colored flower was above halfway and was happy to see that, highlighting it to Emily. He moved the slider from week 1 to week 5 to see how his level of independence had increased and expressed his desire to reach the maximum level of independence soon.

7 Discussion

In this research, we demonstrated the design, development, and evaluation of a visualization tool representing patients' recovery progress after a stroke, which can be used by healthcare providers and patients in patient-provider communication during inpatient stroke rehabilitation. In our studies, we prioritized understanding perspectives at both ends of care provision—those who deliver and receive care. Thus, we involved a multidisciplinary healthcare provider team and patients recovering from stroke within the inpatient rehabilitation center. The feedback from healthcare providers and patients helped us better understand their unique needs and preferences for monitoring and communicating recovery progress data during inpatient rehabilitation stays. Inspired by the results of our three studies with healthcare providers and patients, we offer the following considerations for designing future visualization tools for patients and providers to communicate during inpatient stroke rehabilitation.

Different views for patients and providers: Our studies have revealed that there are distinct requirements for designing visualization systems for patients and healthcare providers. These unique needs arise from the different challenges they face. Patients recovering from a stroke often experience cognitive deficits and memory retention issues. On the other hand, healthcare providers often feel frustrated due to lost time when searching for patient information in EMR software. In terms of design requirements, patients require cognitively accessible visualizations, while healthcare providers need a familiar design to monitor the patient's progress quickly. To cater to these different needs, we designed two different views for patients and providers. For patients, we introduced a weekly progress view that uses the design principle of skeuomorphism. This view includes real-life objects, such as garden view, colourful flowers, and cloud shapes. As patients make progress in their rehabilitation, the flowers grow to show their progress. For providers, we introduced a weekly patient progress view in a bar chart format as they are more familiar with these charts. Previous studies have also emphasized the importance of designing technologies or visualizations that provide patients and providers with alternative ways to interpret data [52]. Thus, when designing a visualization tool for use by patients and providers to communicate during inpatient stroke rehabilitation, one should consider offering different views for patients and providers, particularly for patients with cognitive or language deficits.

Personalized visualizations for both patients and providers: Literature has emphasized the importance of personalization in facilitating patient-provider communication [18, 50]. Previous research has also highlighted the importance of personalized technological or visualization solutions in enhancing patient engagement during physical injury [73, 82] and cognitive rehabilitation [36]. The findings from our study align with these previous findings and extend the focus on stroke rehabilitation. As patients recovering from stroke may experience cognitive or linguistic deficits, our study underscored the importance of personalized designs for individual patients and healthcare providers to enhance healthcare communication in stroke rehabilitation. For example, patients in our study found it challenging to differentiate between various shades of gray. To address this, a personalization option could be to use qualitative colour schemes for categorization, such as using blue and white, instead of using sequential colours, such as shades of gray. This aligns with the literature, which suggests that colourful maps, such as a rainbow, can substantially aid better understanding [53]. Other personalization options for patients include selecting and displaying functional activities and goals that are specifically relevant to their recovery, providing personalized summaries of their progress, and a designated space to view healthcare providers' notes on personalized food inclusions, exclusions, and swallowing strategies. For healthcare providers, customization involves integrating commonly used health assessments specific to their respective hospitals and eliminating irrelevant ones. Different hospitals or rehabilitation centers use various sets of health assessments to evaluate a patient's rehabilitation progress. Thus, visualization designs should be personalized for patients and providers for use by both parties to communicate during inpatient stroke rehabilitation.

Lay language in patient-facing visualizations: Numerous studies recommend using plain language instead of complicated medical terminologies when communicating with patients about their health [20, 21]. Previous literature has also emphasized the importance of incorporating concise and easily understandable textual details in visualizations while visualizing health data to support communication [49, 64]. Our findings from studies also highlight the importance of using lay language in stroke rehabilitation, as patients recovering from a stroke may experience communication difficulties, including aphasia, which affects the patient's ability to communicate [5]. In our visualization design, we prioritized using lay terms to

label health assessments, explain each assessment result, and provide a summary of progress in each assessment as patients recovering from a stroke often struggle to understand their health data due to the complexity and volume of assessments taken during recovery. We also prioritized using bullet points, bolded keywords, headings, and signposting, as recommended in the literature [3, 7, 56] for developing visualizations for people with communication difficulties in our designs. The patients appreciated these design elements in our evaluations, as they found our visualization to be clear, goal-oriented, and motivating. Thus, visualization designs should use lay language in patient-facing visualization tools to facilitate communication during inpatient stroke rehabilitation.

Limitations and Future work: We faced difficulties recruiting participants, resulting in a limited sample size of only four healthcare providers and two patients. Since our city only has one inpatient stroke clinic, it was challenging to secure appointments due to the healthcare providers' busy schedules. The literature also mentions that finding healthcare providers willing to give interview time is a challenge, as they often have busy schedules, or they may be skeptical of the value of new technology research [51]. Additionally, recruiting patients in the inpatient stroke rehabilitation unit was challenging due to their vulnerable state and the requirement of specialized care and attention. Their health conditions are often fragile, and communication barriers such as aphasia made it necessary to approach the recruitment process with caution to prioritize patient safety and well-being. While valuable insights were gained, the small sample size restricts the generalizability of findings, underscoring the need for larger participant numbers in future research. Additionally, due to hospital regulations, patients could not directly interact with the prototype, limiting the usability and user experience evaluation [39]. The colour hues used for action dots in the patient's health progress overview are not colour-blind-safe. We were unable to conduct an evaluation study involving providers and patients to assess how the visualization tool supports real-time patient-provider communication in inpatient stroke rehabilitation facilities.

Future research should focus on conducting a study exploring the impact of this data visualization tool on patient-provider communication during inpatient stroke rehabilitation. Additionally, it should aim to evaluate the usability of our prototype with patients. During our study, we encountered the challenge of determining which health assessments to display for patients. To address this, we followed the guidelines of the Heart and Stroke Foundation's Canadian Stroke Guidelines [54] in addition to the recommendations of our healthcare providers. However, our approach might not fully encompass diverse assessment practices, highlighting the difficulty in customizing visualization designs for different facilities. Further research is needed to explore methods that can facilitate seamless alignment with a variety of clinical practices.

8 Conclusion

Patients recovering from stroke in inpatient rehabilitation centers often stay for extended periods, which can lead to a lack of motivation for goal-directed activities, resulting in reduced engagement and limited benefits from rehabilitation. Effective communication between healthcare providers and patients is one of the crucial factors for promoting adherence to these rehabilitation programs. In this research, we aimed to design, develop, and evaluate an accessible and intuitive visualization tool representing a patient's recovery progress after a stroke for use by patients and providers to communicate during inpatient stroke rehabilitation. At first, we conducted semi-structured interviews with healthcare providers to extract design requirements. We then designed sketches and developed prototypes to visualize patients' stroke recovery progress. Next, we conducted semi-structured interviews with healthcare providers and patients to evaluate the prototype and then integrated their feedback into our prototype. Informed by the results of our studies, we provided several considerations for designing visualization tools for patients and providers to communicate during inpatient stroke rehabilitation.

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