

Towards Supporting Data-Driven Practices in Stroke Telerehabilitation Technology

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Telerehabilitation technology has the potential to support the work of patients and clinicians by collecting and displaying patients' data to inform, motivate, and support decision-making. However, few studies have investigated data-driven practices in telerehabilitation. In this qualitative study, we conducted interviews and a focus group with the use of data visualization probes to investigate the experience of stroke survivors and healthcare providers with game-based telerehabilitation involving physical and occupational therapy. We find that study participants saw potential value in the data to support their work. However, they experienced challenges when interpreting data to arrive at meaningful insights and actionable information. Further, patients' personal relationships with their goals and data stand in contrast with clinicians' more matter-of-fact perspectives. Informed by these results, we discuss implications for telerehabilitation technology design.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; **Empirical studies in collaborative and social computing**; • **Applied computing** → *Life and medical sciences*.

Additional Key Words and Phrases: stroke, telerehabilitation, patient-generated data

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1 INTRODUCTION

Designing technologies to support distant work has long been a focus of CSCW research. For decades we have studied remote work and identified its various social and technological factors in contexts such as video conferencing between co-workers [27]. Recently, we have seen the use of this kind of technology to mediate new forms of working relationships. In the medical field, telehealth systems have been introduced to help connect patients and clinicians in different locations. Telehealth is often studied in the form of patient-provider interaction during clinical visits through video calls (e.g., [30]). This alternative to in-person appointments is particularly beneficial

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for those who live in remote areas or have limited access to transportation. This approach to medical care has become particularly important in the current period of social distancing. Telerehabilitation technology, a means to provide rehabilitation through telehealth, also has the potential to address the fact that most patients in the U.S. receive very small doses of therapy compared to what is needed to change brain function in animal models of stroke [48].

Beyond medical visits, we now have other systems that can remotely assist the work of healthcare providers, such as telerehabilitation systems, designed to assist patients to do continuous exercises at home with remote help from clinicians. These systems can support patients' home rehabilitation exercises and provide clinicians with resources to remotely monitor and guide patients [40]. Telerehabilitation systems are often designed in such a way to motivate patients, such as using game-based strategies. However, there exist challenges for designing telerehabilitation systems, as they connect patients and healthcare providers who have different knowledge and perspectives [97]. Systems designed for remote rehabilitation combine characteristics of consumer health technologies and clinical health technologies, as they must, at the same time, assist patients in their self-care work, provide clinicians with a communication channel to monitor patients and manage their treatments, and address questions and concerns that arise during the course of therapy.

Telerehabilitation technology has the ability to collect data on patients' historical exercises and performance automatically. As we move towards data-driven practices and consider patient-generated data in healthcare, there is an opportunity to examine how such systems can be designed to serve the dual function of supporting data-driven practices for both patients and providers. Health data generated by digital technologies can be useful by informing and motivating patients, informing the work of clinicians, and assisting in patient-provider communication [54]. For this reason, these systems must be carefully designed to present information in a way that helps patients to manage the rehabilitation process by providing feedback and maintaining accountability. Past research has studied how individuals and their healthcare providers engage with patient-generated health data in different contexts [15, 29, 61]. However, we do not yet know how best to use patients' digital data in the context of telerehabilitation, such as what kind of insights these different stakeholders seek in a recovery context.

This study investigates how data-driven practices could best be integrated into a telerehabilitation system. In this research, we aimed to understand patients' and providers' expectations of and relationships with patient-generated data through interviews with stroke survivors and a focus group with Physical and Occupational therapists who used a telerehabilitation system for at least 12 weeks.

We found that patients and clinicians have very different perspectives and information needs while engaging with telerehabilitation data. Beyond requiring different data for their respective roles, we find a need for different data framing: while patients seek indications of future progress and showed great investment in their rehabilitation process, clinicians seek information about the patient's current status and had a more objective perspective in their decision-making process. The contrasting perspectives from clinicians and patients towards data-driven practices in telerehabilitation represent a substantial challenge for the design of consumer-facing health technologies. Our findings reveal that expecting patients to perform the role of "managers" of their own rehabilitation would likely be burdensome and ineffective.

Specifically, we contribute:

- Detailed descriptions of patients' and clinicians' perspectives towards data-driven practices in telerehabilitation, including what kind of data-related issues create barriers for data use.
- An understanding of needed insights for data-driven practices, highlighting differences between patients and clinicians, as well as the reasoning behind these differences.

- A discussion about the implications of these findings for designing telerehabilitation technology that support data-driven practices while aligning with the needs of the different stakeholders.

2 BACKGROUND

2.1 Stroke rehabilitation

Recovery or rehabilitation is a process that aims to restore, maintain, or improve skills or abilities caused by an illness, injury, or disability. With the current changes in health and demographic trends (e.g., aging population and prevalence of non-communicable diseases), as described by the World Health Organization, there is an increasing and unmet global need for rehabilitation services [65], which can include physical therapy, occupational therapy, and speech therapy. These treatments help individuals to recover after disruptive experiences of disease.

Several health conditions require patients to go through rehabilitation. For example, rehabilitation might be necessary to recover from an injury [12, 87], a surgery, or to manage progressive illnesses such as Parkinson's and Multiple Sclerosis [67]. Stroke is a health condition that often requires long-term rehabilitation with the goal to regain function through physical therapy and occupational therapy.

Stroke is a leading cause of serious long-term disability in the U.S., affecting approximately 800,000 people each year [8]. Stroke can cause both mental impairments (e.g., cognition, speech, mood) and physical impairments (e.g., limited mobility, balance, or dexterity). Different aspects of stroke recovery require different specialists, such as Physical Therapists for problems with walking and Occupational Therapists for problems with arm function [49].

Stroke involves an acute phase when individuals are hospitalized for approximately a week, followed by a post-acute phase that lasts 6 months. After 6 months, patients enter the chronic phase [9]. Rehabilitation may last from few weeks to years, depending on severity and sequelae [5]. While stroke survivors make most improvements during the post-acute phase, since recovery slows down over time, many reach the chronic phase having only partially recovered. Between 25% and 50% of stroke survivors experience long-term dependence on caregivers in activities of daily living (e.g., cooking, bathing) [34]. Rehabilitation efforts can continue during the chronic phase, as patients can maintain their improvements and regain further motor function during this period [99]. However, access to long-term rehabilitation services is often limited due to financial or health-insurance related constraints [101].

Stroke rehabilitation is a learning process that involves training, demonstration, practice, feedback, and supervision. The frequency and intensity of treatment are tailored to the patients' needs and abilities, including motivation and endurance [34]. Rehabilitation clinicians perform a baseline evaluation to create long-term and short-term goals and treatment plans. Often, patients are asked to do rehabilitation routines at home in addition to their in-person sessions. Clinicians also periodically assess patients to find if they have reached their goals and if they need to adjust the goals or treatment. These assessments are conducted every two weeks in outpatient clinics. Therefore, stroke rehabilitation commonly requires frequent visits to healthcare providers. Similar to the baseline evaluation, periodic assessments measure several aspects of motor function such as movement, sensation, balance, range of motion, and pain by using standardized tests [34, 86]. Clinicians' approaches tend to involve goals focused on motor function, while patients tend to focus on more abstract goals related to their own sense of identity and societal roles [7].

For stroke survivors going through rehabilitation, progress can be hard to observe due to its slow and gradual nature [88]. They tend to measure recovery through comparisons with their abilities prior to the stroke, and experience frustration for not knowing when or if they will return

to their previous selves. Recovering from a stroke involves uncertainties around the future and self-identity [82]. Active participation in rehabilitation, such as awareness of progress, can provide stroke survivors with a sense of control and satisfaction [70, 82]. However, patients are not always ready to assume responsibility, as sometimes it may cause burden and distress [70]. For example, lack of information about realistic recovery expectations can create disappointment but providing it too early can lead to feelings of hopelessness [73], and hope is an essential factor for motivation and coping during recovery [53, 91].

2.2 Rehabilitation technology

Due to these challenges, technology has been increasingly used to support recovery from stroke, becoming one of the most promising research areas to improve outcomes for stroke survivors. Telerehabilitation is one of such technologies, and it can be defined as a branch of telehealth that focuses on providing rehabilitation techniques at a distance through the use of communication and information technologies [43, 71]. Home-based systems for telerehabilitation have the potential to lower costs for both healthcare providers and patients and increase access to rehabilitation, particularly for patients living in rural areas or remote places, by substituting or augmenting in-person occupational or physical therapy [13, 21]; in this way, telerehabilitation can also support larger doses of rehabilitation therapy.

There are several examples of research investigating technology for physical or occupational therapy [74, 80]. For example, SenseCap is a wearable system that collects data about physical therapy exercises [40], while Physio@Home uses visual guidance and feedback to guide users through exercises [90]. Past work has studied rehabilitation technology in the context of the transition from hospital care [76], knee [3, 38, 39] and wrist [92, 93] rehabilitation, Parkinson's disease [6], cardiovascular disease [60], and stroke [57]. Researchers have identified design opportunities for stroke rehabilitation technology, including validating exercise form and guiding patients to move correctly, providing information to clinicians about patient performance, measuring progress in rehabilitation, and increasing motivation [3, 6, 40, 57, 88, 90]. Motivation can also be improved through rewarding feedback [69].

While telerehabilitation can facilitate interactions between patients and healthcare providers by, for example, reducing the number of in-person appointments and the consequent need for transportation, adherence to treatment and exercise routines remains difficult [47, 50]. For this reason, the recent design of rehabilitation technology often involves game-based strategies. Researchers believe that games can improve motivation and adherence among rehabilitation patients [47, 50], as repetitive or tedious exercises can represent a barrier for adherence, limiting patient outcomes. Games have been leveraged for rehabilitation in different contexts, including stroke [84, 96], cerebral palsy [42], and upper limb recovery [22]. It is common to use video game systems such as the Nintendo Wii or Microsoft Kinect for rehabilitation games [23, 77], as they are designed to estimate upper or lower body movements. These off the shelf game systems also have high availability and relatively low cost [50].

2.3 Data-driven practices in stroke rehabilitation technology

The recent availability of self-tracking technologies has made it possible for patients to gather a variety of types of health data outside of clinical settings. These patient-generated health data (PGHD) can provide information about health status, symptoms, treatment results, and patient behaviors. Such information can be used by healthcare providers for diagnosis and treatment decisions and used by patients themselves for learning about their health and lifestyle. When used collaboratively by patients and clinicians, specific challenges might arise due to differences in goals, expectations, data preferences, and time constraints [31]. While such data have been used in the context of varied

health conditions, including to support post-operative care and transitions from hospital to home environments [83], data-driven (e.g., self-tracking) health systems are rarely designed to support rehabilitation. Most commonly, they are designed to support health management goals such as behavior change, awareness of habits, or managing chronic conditions [51, 62, 66, 68, 75]. It is unclear how findings from this literature translate to a rehabilitation context.

Producing and utilizing data are not the primary goals of telerehabilitation systems. Rather, they are designed to facilitate remote rehabilitation practices for patients and clinicians. However, they can produce data on users' activities and performance during use - at times, massive amounts of data. Such data can carry high significance if we consider and design it well to provide additional and efficient support to both clinicians and patients. Research on stroke PGHD has primarily used data to evaluate system effectiveness and reliability [24]. Still, such data has many other potential benefits for stroke survivors, including facilitating communication with clinicians and providing guidance around exercise form [25].

Information about progress is useful for both patients and clinicians, and it can support collaboration and decision-making [17, 50]. PGHD can help clinicians understand behaviors outside of the clinic, such as the use of the impaired limb in everyday activities [74], and progress over time [1]. Performance and progress data are particularly necessary for clinicians whose interactions with patients are mostly or fully remote, since many standardized assessments used in clinical care require in-person interaction. However, rehabilitation data might be difficult for them to interpret [74].

While some studies have approached data use by clinicians, few papers include the use of stroke rehabilitation data by patients [24]. Providing feedback to stroke patients can affect their health outcomes, particularly when it includes new information or leads to insights that were previously unknown [95]. For example, studies have found that when physical therapists provide feedback to patients during a session, patients might perform better and improve their motor learning. Such feedback can be verbal, visual, or auditory, concern either performance (i.e., exercise form), results (i.e., progress), or encouragement, and it is based on the clinicians' observations or measurements during a session [72, 95, 98].

Data collected by telerehabilitation systems have been used to measure and track progress in rehabilitation (e.g., measurements of movement duration, angle [6, 38, 39], or applied force [57]), to guide patients, and to provide information about progress and task scores [24]. However, these are prototype systems that, to the best of our knowledge, have not been implemented in healthcare practice. We also do not yet have an in-depth understanding of how to design feedback mechanisms for technology-mediated stroke rehabilitation, since much of the research on feedback has focused on the clinical context and telerehabilitation feedback can be very different from what in-person therapists provide. For example, game-based telerehabilitation systems can measure performance and progress through game points, while clinicians provide feedback based on direct observation and standardized measurements of motor function.

It is also unclear how common challenges of PGHD (e.g., aligning the goals of patients and providers, data quality, data interpretation, and taking action based on those insights [97]) will play in a telerehabilitation context, where form and adherence are entangled (i.e., adherence without correct form hinders recovery) and fundamental to progress, but are hard to evaluate and correct at a distance.

In this project, we address these research gaps by studying data-driven practices of users of a telerehabilitation system that does not have data use as a primary goal. In addition, the process of designing to incorporate data-driven resources to augment an existing system is also relevant for other health technologies, such as general telehealth platforms. There is a need to better understand



(a) System in use, a patient plays whack-a-mole during a video call with a clinician. (b) Four game examples: driving simulator, duck hunt, coin drop, and duck shoot.

Fig. 1. The stroke telerehabilitation system used this study

the information needs of healthcare providers and patients as users of telehealth technology that collects patient data [32].

3 GAME-BASED TELEREHABILITATION SYSTEM FOR STROKE SURVIVORS

In this project, we studied patients and healthcare providers who used the Stroke telerehabilitation system (TR). This system was created by a team of physicians, physical therapists, occupational therapists, a computer programmer, a gaming expert, and a motivation psychologist to study the effectiveness of telerehabilitation on patient outcomes. The TR system provides physical therapy and occupational therapy exercises for stroke patients through games and videos. Figure 1 displays the system. The games are intended to make the exercises more engaging and to provide motivation to users. The games are designed in such a way that users perform physical therapy and occupational therapy exercises by playing, as the controllers and games afford specific movements. The system also has video guided exercises for users and it supports video calls with clinicians, performs simple assessments (of movement or self-reported factors using a Likert scale), and provides 5 minutes/day of stroke prevention education. A previous randomized trial found that this TR system is as effective as traditional as in-clinic rehabilitation [21].

The TR system in its current configuration consists of a table with a monitor and several controllers including buttons, joystick, pressure sensors, Nintendo Wii, Playstation Move, mouse trackpad, driving wheel, foot pedals, and a foot camera for augmented reality games. There are more than 20 games that can be played. Figure 1(b) shows four examples. Each controller was chosen, and each game was designed, to replicate physical and occupational therapy exercises.

Although it was not designed specifically to support data-driven practices, the TR system generates data that can be useful for both patients and therapists (e.g., usage statistics, and performance statistics in the form of game scores). The data could help providers to monitor patients and thereby inform adjustments to the assigned rehabilitation therapy, and it also could be used by patients for motivation or to observe measurements of their rehabilitation progress. The full data set had one line per game session, with information such as a timestamp, name of the game, difficulty level, session length, points, and what controller was used.

While both patients and providers have access to TR data, their access is limited. Patients are shown their score at the end of a game session, along with a list of their high scores for that particular game (Figure 2). For them, that is the only form of feedback available through the system. The high scores are ordered from highest to lowest, and only the top 6 will appear on the



Fig. 2. High score screen, shown at the end of a game session. The left section shows the most recent score, while the right section shows a list of high scores for that game (Piano).

screen. Physical therapists and occupational therapists had access to extensive detailed data in a spreadsheet format and a long dashboard with bar graphs, but had limited ability to manipulate the data or the visualizations to find useful insights.

The TR system had many important features for rehabilitation, such as a diverse set of configurable games and exercises to fit patients' needs. Still, conversation with the clinical research team revealed that the data produced in the system should be carefully considered for its potential to offer insights for patients and clinicians. For patients, the data have the potential to provide feedback and motivation. For healthcare providers, the data have the potential to support their work and decision-making. The limitations in data access were not purposeful design choices, but rather they were a result of limited research funds and a lack of evidence on how to support data-driven practices in telerehabilitation.

The qualitative study described in this paper aimed to address this issue by investigating how data produced in the system could be repurposed to support the work of patients and clinicians. We set out to study their relationship with these data and understand how we can leverage TR data to support both patients and clinicians in telerehabilitation technology.

4 METHODS

To understand the perspectives of patients and clinicians, we collected data through a focus group, interviews, and talk-aloud exercises using data visualization artifacts. Both patients and clinicians were recruited for the study.

4.1 Research goals

This study was a part of a larger project that primarily sought to understand the clinical effectiveness of the TR system. The system was designed with the primary goal to support at-home physical and occupational therapy among stroke survivors and promote adherence by translating exercises into games. Although data-driven practices were not designed into the system, we observed that both patients and clinicians interacted with the data generated through telerehabilitation sessions.

While the TR system was part of a clinical study [21], this paper focuses specifically on a subsequent qualitative study conducted with patients and clinicians who were part of the trial. In this section, we provide information about the clinical study to explain the context of the qualitative study and its participants.

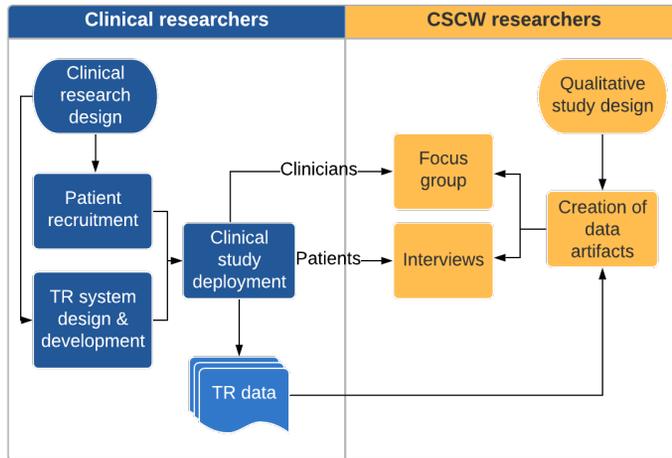


Fig. 3. Simplified representation of the collaborative work of clinical and CSCW researchers. The qualitative study was conducted after the clinical study was concluded.

To investigate the existing practices and information needs of patients and clinicians as telerehabilitation users, we sought to answer the following research questions (RQ):

RQ 1 How does the telerehabilitation system support patients' and clinicians' rehabilitation goals and practices?

RQ 2 What kind of insights do patients and clinicians wish to obtain to support data-driven practices?

Through these questions, we study how a data-driven telerehabilitation system should be designed to support the needs of both patients and clinicians, based on their existing needs, experiences, and challenges.

4.2 The study process

Conducted in collaboration with a team of researchers in the health sciences, this project was a follow-up study with patients and clinicians who were part of a 12-week pilot study of the TR system. Figure 3 illustrates the work conducted by clinical and CSCW researchers for this project.

4.2.1 Clinical trial. The TR system was designed for trials with stroke survivors who used it in their homes. All participants in this qualitative study, both patients and providers, were previously involved in a clinical study of the TR system. Patients used the system to follow a prescribed daily routine of games and exercises for 12 weeks. They also wore a Fitbit during this time. However, the Fitbit data were not visible to patients or clinicians during the trial. The data were collected for research purposes only.

The therapists prescribed activity routines to patients with games and exercises and had video calls with patients every two weeks (Figure 1). These routines were created individually based on patients' abilities and rehabilitation goals, and were updated as needed based on how those changed over time.

This clinical trial affords an opportunity for this kind of study, as it allowed us to understand the experiences of long-term TR users, and their perspectives on data-driven insights that require long-term use (e.g., gradual improvements in motor function).

Therefore, after using the TR system for 12 weeks, patients were asked to voluntarily participate in this interview study. Among the 13 patients in the clinical trial pilot study, 10 agreed to the interview. The project was conducted in a research university in the West Coast of the United States. Both the clinical trial and the qualitative study were approved by the university IRB. All participants were recruited locally following the following criteria:

(1) Key inclusion criteria

- Age ≥ 18 years
- Stroke with onset any time prior to study entry
- Arm motor deficits: arm motor Fugl Meyer score of 28-66 out of 66; if >59 , must also have Box & Blocks score on paretic side that is $>25\%$ lower than on non-paretic side
- Minimal level of arm function remaining: Box & Blocks score with paretic arm is ≥ 3 blocks in 60 seconds

(2) Key exclusion criteria

- A major, active, coexistent neurological or psychiatric disease
- A diagnosis (apart from the index stroke) that substantially affects paretic arm function
- Severe depression, defined as Geriatric Depression Scale Score $>11/15$
- Significant cognitive impairment, defined as Montreal Cognitive Assessment score $< 22/30$
- Deficits in communication that interfere with reasonable study participation

Interviews occurred 8-12 weeks after the subjects completed their 12-week course of telerehabilitation. Due to this time interval, we took measures to prompt participants' memories about the system, such as providing images of the different games during the interviews and asking several questions about their use and experience with the system before the main part of the interview, when we transitioned to discussing data-driven practices. As described below, the main part of the study involved the use of data artifacts that the patients had not seen beforehand.

4.2.3 Data artifacts. Because the current TR system provides limited data-driven feedback to patients, we created visualizations to use as probes to explore patients' perspectives towards their data. In both patient interviews and focus group with clinicians, we used diverse visualizations, such as line graphs, diagrams, and calendars, as tools to prompt discussion about the data and the TR system. Figure 4 shows four examples of these visualizations. The objective of using the artifacts in the study was not to evaluate their design but to prompt discussion and to understand the perspectives of the participants about the data. Because patients had limited access to their data, and because data might be an abstract term to them, these visualizations allowed us to provide a few different examples they could react to and discuss. We sought to use a diverse set of visualizations to investigate in depth different aspects of participants' perspectives.

Participants were shown four different kinds of visualization for their TR data: improvement rates on a body diagram (Figure 4 (a)), a pie chart of time spent per activity in the TR system (Figure 4 (b)), game points over time for individual games or a particular limb or movement (4 (c)), and Fitbit data on a calendar or bar chart (4 (d)). There were also variations for each kind of visualization, such as data from all games involving shoulder exercises in the same line chart, and a slope line indicating an improvement metric (4 (c)). These different kinds of data visualization were created to help understand what kinds of data, insights, and visualizations were useful or

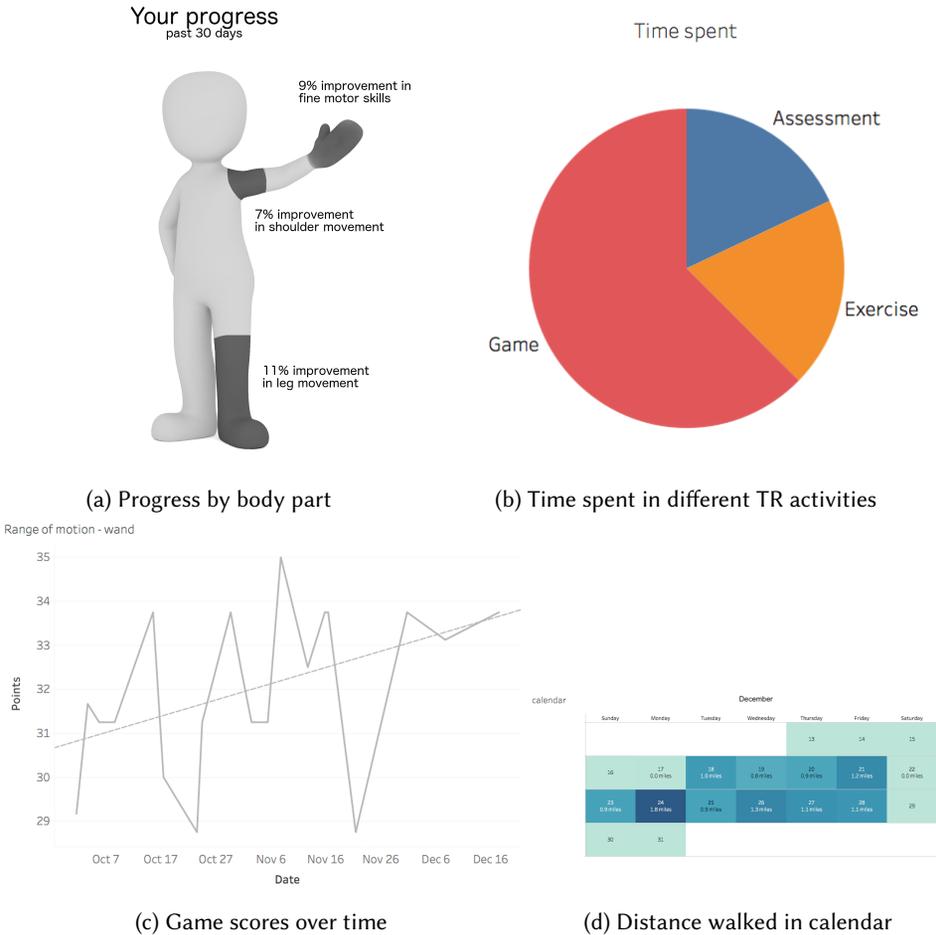


Fig. 4. Data visualization examples

informative to participants. Each of the 10 patients was provided with visualizations of their own data, as shown in Figure 4. Visualizations were created using Tableau and printed on paper to be used in the study sessions.

The visualization artifacts were created through an iterative process with the goal of offering a diverse set of designs, types of insights, and levels of details for the participants. Because they were created using the participants’ data, the designs were limited to what was possible to calculate and display based on the original database. The available data consisted of a log of games and exercises listing points, difficulty level, and metadata (e.g., duration in seconds and a timestamp). We aimed to diversify these artifacts on different levels, including information granularity, insights provided, and chart designs. Different variations allowed us to prompt discussion among participants and understand their perspectives on different information and insights.

Patients did not have access to these data before the interview, except for a list of their highest scores (Figure 2). Beforehand, they were not able to see the history of their game scores and did not have access to their Fitbit data.

4.3 Data collection and analysis

We conducted a 2-hour focus group with 4 physical and occupational therapists and 45-minute interviews with 10 stroke survivors. All sessions were audio-recorded and later transcribed for analysis.

4.3.1 Providers. Two of the healthcare providers were licensed occupational therapists, and two were licensed physical therapists. All four of them were involved in multiple iterations of clinical studies with the TR system wherein patients used the system for 6 or 12 weeks. The providers saw patients in person before and after the clinical trial pilot study to collect demographic data and perform physical assessments, including scoring on the Fugl-Meyer scale [86]. They also created individual treatment plan routines using the system and had video calls with the patients through the TR system periodically throughout the trial. The routines consisted of a list of short (1-3 minute) game sessions for each patient, and typically the full list lasted over an hour. Each patient had a specific routine each day, six days per week for 12 weeks.

The focus group consisted of one hour of questions about their past use of the TR system and patient data, and the second hour involved discussing visualizations, how they could use the data for telerehabilitation, and existing limitations. We used a set of diverse visualizations from five different participants in the focus group. They included all visualizations in Figure 4, except for 4 (a).

They were asked about their work and decision-making process, including how they used the patient data that were available to them, how they decided on what games and activities to prescribe, what kinds of questions they needed to be answered, and how they found answers to those questions. During half of the focus group, they discussed the systems they used to see patient data and make decisions. They also discussed what kind of data visualization or information would be useful to support their work. The focus group took place before the patient interviews, and it informed the design of the data visualization artifacts as clinicians provided feedback on early drafts. Based on their feedback, we created a new visualization design (Figure 4 (a)) and added variations to the visualizations, such as grouping data by game difficulty in line charts (Figure 4 (c)).

4.3.2 Patients. We recruited 10 patients to participate in the interview study (Table 1). Most patients were in their 50's and 60's (median = 61.5 years old). Six patients were male, and four were female. All had diverse stroke and recovery experiences. While several participants were close to considering themselves fully recovered, all had enduring physical disabilities (activities limitations). All but one were able to walk unassisted, and only one participant reported requiring help at home for basic daily tasks (e.g., cooking). Eight participants were working or looking for work, one was retired, and one was receiving disability benefits. Only one participant (P3) had had more than one stroke at the time of the qualitative study.

The sessions with the 10 stroke survivors consisted of an interview followed by a talk aloud study. In the interview, they were asked about their experiences with the TR system and in-person stroke rehabilitation. They were asked about their background, their medical history relating to stroke, their overall health management experiences, and their use of technology for health. Overall, sessions with patients lasted between 40 minutes and one hour.

Each person was presented with 8-10 visualizations of their own data and asked questions to prompt reflection about their experiences, and about what they were interested in learning from the data. Each person chose what kinds of data visualization they found useful or interesting, and discussed their reasoning.

P#	Age	Gender	Race/Ethnicity	Days since stroke	Relative performance
P1	78	M	Non-hispanic white	573	0.66
P2	55	F	Non-hispanic African-American	243	0.84
P3	29	F	Asian	121	0.94
P4	62	M	Non-hispanic white	1766	0.88
P5	68	M	Non-hispanic white	566	0.82
P6	61	F	Non-hispanic white	145	0.87
P7	59	F	Asian	912	0.54
P8	66	M	Non-hispanic white	213	0.74
P9	47	M	Non-hispanic white	283	0.75
P10	65	M	Hispanic white	121	0.85

Table 1. List of stroke survivor participants. The last two columns refer to the end of the clinical study. Relative performance is a simplified measure of arm function, calculated as a ratio between affected and non-affected sides in a Box & Blocks test, whereby the number of blocks moved by a single arm from one side of the table to the other is counted over a 60-second period [55]. Values closer to 1 indicate more similar function between the affected and non-affected arm.

4.4 Data analysis

All study sessions were audio-recorded and transcribed. The transcriptions were annotated to indicate which artifacts were shown to participants in order to analyze their responses to the different kinds of visualization.

The data were analyzed using an iterative inductive process based on Grounded Theory [10, 89]. First, one researcher read through each of the transcripts and then conducted an initial coding of the data set using an open coding technique. Using the same method, a second researcher read and coded a subset of the data separately.

An iterative process was used to collaboratively conduct axial coding, write memos about the data, and discuss emerging themes among three researchers. Through several in-person meetings, the three researchers synthesized the themes found to answer each of the research questions.

4.5 Limitations

Because the interview study was conducted after the end of the clinical study, rather than in parallel, the perspectives obtained from participants, while recent, were nonetheless retrospective. Their reflections on the experience and on the data might be different during active use of the system. Additionally, the researchers who conducted the qualitative study did not participate actively in the design of the TR system or in the clinical study.

5 FINDINGS

Both patients and healthcare providers had very practical, goal-oriented perspectives towards the telerehabilitation data. However, their outlooks differed: while patients focused on their desired rehabilitation outcomes such as improved independence, therapists wanted information to allow them to make treatment decisions.

5.1 Healthcare providers' practices and data needs

Physical and occupational therapists expressed interest in information about how each patient is progressing, and about any issues that need solving. This information is useful to determine what games and exercises to prescribe and help to address issues that patients might be facing.

5.1.1 Motor function and difficulty level. In order to define the best treatment, providers need to know patients' current state so they can choose the appropriate set of exercises and games, with the appropriate level of difficulty. Patients had information about their current state based on their own lived experiences, but providers did not. The providers who participated in the study highlighted how the remote nature of TR limited their abilities to observe progress on their own. As a result, they relied primarily on patients' accounts. Overall, healthcare providers used video calls to get answers to these questions by observing patients and talking to them. The excerpt below illustrates how providers obtain information about how patients are doing in the present, and use it to inform the treatment:

T3: "You assess them. You see what their level is, and then you design your treatment plan relative to that."

T4: "So you might ask, show me this. Or ask them what they're doing that's new. Or try to get out of them how they're progressing. And that might be different for every patient, what you're targeting."

T1: "Sometimes you ask, is there anything new that you can do now that you couldn't do before? Like, are they transferring what they're gaining from the system to their daily life."

When prescribing a routine for a patient, providers needed to choose which games or exercises would fit their abilities and needs, including difficulty level, duration, and number of repetitions (for exercises). The right difficulty was important for the game to provide therapeutic benefits without being too tedious or beyond the patient's ability. In the following quote, T2 explained how they estimated the right level of difficulty: *T2: "It is important that they're challenged but not overly challenged to the point of frustration. And usually, you want them to be like 70% successful at least in order to know they're having to work at it, but they can get some level of success."* While discussing a graph that showed a zig-zag pattern of performance over time, the same provider explained that such results alternating high and low scores are actually good for recovery, reinforcing that variation in their performance rates is welcome: *"That's actually optimal for motor learning too. You want variability, variation. [...] You want a trend, but you want this. They are trying. They are trying"* (T2).

Providers used video calls to observe patients' performance and to ask them whether they found the game too easy or too difficult. Although the data had the potential to provide these insights, it was not used by the providers to make decisions.

5.1.2 Adherence and exercise form. Patient adherence and exercise form are fundamental for rehabilitation treatments, and, thus, were very important for providers. Providers monitored adherence and wanted to make sure that patients were moving correctly while using the system. However, providers faced challenges in assessing both aspects of patients' behaviors.

Providers monitored low adherence by noting when patients had not interacted with the system for multiple days. For example, although the system notifies providers when patients do not use it for some days, one provider described how she monitored patients closely to detect issues with adherence early: *"I usually go on there every day and then check who has done it or who has not done it. [...] We get a notification if they haven't complied for three days"* (T4). When detecting low adherence, providers would contact the patient to understand if there was an issue. There were a

number of possible causes of low adherence, such as forgetfulness, software or hardware issues, dissatisfaction with the prescribed routine, and low motivation. After finding the underlying cause, clinicians would take steps to address the issue (e.g., scheduling a visit for technical assistance in the case of a faulty controller).

Although the system had a built-in notification for low adherence, providers still wanted more detailed information. A therapist explained how it was difficult to know how engaged patients were when using the system: *“We know what we assign, but we don’t ever really know what they do. So we could be increasing [his prescribed exercises], but we don’t know if they are keeping up with that [...] The only way we view compliance is if the computer is on”* (T4).

Besides adherence, to gain the intended benefits from using the system, patients must perform the movements correctly. However, because patients use the system on their own and at a distance, providers had limited ability to monitor movement form and make corrections when needed.

To assess movement form, providers used the scheduled video calls with patients. They observed while patients played the games to verify correct movements and provided guidance in case they felt that a change was needed. The video calls were essential to make sure patients were moving correctly since they did not have other means to verify movement form, as a participant explained:

T3: *“We wanted to watch them play the game as it was on so we could sort of see how they’re moving and whether they’re doing it correctly. [...] If we observe them during videoconferencing and it turns out they’ve been doing it all wrong, we don’t have any way of knowing that until a videoconference.”*

In summary, providers relied heavily on video calls to obtain information about how patients were doing. They watched patients while they played and asked questions throughout the session to determine if they needed to make changes to the prescribed routine.

5.1.3 Patients’ experiences and preferences. Patients’ experiences and preferences were also important for providers to prescribe treatments that better fit their needs. Sometimes patients preferred only to do exercises and not play any games. The opposite also happened where patients preferred only to play games. In order to better consider these factors, providers need to have varied options, as explained in the following excerpt: *“Part of it is patient preference. If they hate a game, we don’t assign it. We need a lot of variability. We need a lot of repetition”* (T2). There was also the possibility that patients had an issue with a specific game or exercise, such as pain. In these cases, providers sought to understand the issue by talking with them and revised their prescribed activities to address the issue. In the following quotes, providers explained how they watch for any problems and ask about patients’ preferences. This information is then used when they are creating exercise routines:

T3: *“You always want to find out if they’re having any discomfort or pain or difficulty. Make sure that we’re not making anything worse.”*

T1: *“You always want to discuss if they’re having pain, any problems.” [...]*

Instances in which patients were facing problems were found through conversation with them through video calls. Providers listened to patients’ experiences and preferences and adapted the prescribed routines to align with what patients wanted while still providing physical therapy benefits that suited patients’ needs and rehabilitation goals.

5.1.4 Data use and barriers. Although they had access to telerehabilitation data, including game points and activity history, providers rarely used it to inform their treatment decisions due to challenges in accessing and interpreting the data, or due to data limitations. As mentioned, they relied heavily on video calls to interact with patients and observe their movements. System data was only used to signal low adherence, and in that case, providers also contacted patients to find if

there was an issue they should address. Still, clinicians discussed how data collected by this kind of system had potential to inform their work.

Telerehabilitation data were very labor-intensive to manipulate, interpret, and use in decision-making. The process of interpreting patient data was cognitively difficult because it was missing a frame of reference (e.g., percentage), and because navigating the system was burdensome, as shown in the quotes below:

T3: "I'd like to look at the progress. because I think I should look at those things. But I don't because of the way that the data is presented currently."

T4: "It's not easy, when you're doing the itinerary [daily exercise routine], to look back and forth [between the itinerary and the data screens]."

T1: "It would be great if as you're doing the itinerary for a particular patient, let's say you click on a game [...] and you can see right there on that same page about how they've been scoring.

While these quotes partially reflect critiques of the design of the system itself, they also reflect how the work of clinicians in telerehabilitation could benefit from patient data and how it requires careful and thoughtful design to realistically be part of their workflow. For example, it was not easy for clinicians to determine what a good score was, or what the maximum score was for each game, as the following quote illustrates:

T1: "I think [the points] need to be based on percentage versus a number. We don't know what the number means. You could say, okay, they did this right 25% of the time. And you could look at that meaningful data over time. [...] So both meaningful and historical. It has to be meaningful first."

Due to lacking a frame of reference for interpreting the game scores, clinicians described these data as not meaningful. For example, possible ranges of scores varied between games and could also change depending on the difficulty level. The score data consisted of loose numbers (e.g., 17, 150), and, without a frame of reference, clinicians could not easily determine if the patient did very well or poorly based solely on the score.

Data collected in the system in the form of game scores were also not useful to judge whether patients' movements were correct. Patients might find ways to play a game by overcompensating with a different hand or muscle, achieving high scores despite not moving correctly, as T2 explained: T2: "*People can score high on the games by either cheating or compensating. And so what we don't want to do is foster abnormal movements.*" In this case, the controllers used in the TR system were not able to detect whether the movement form was correct.

Although there were barriers to the effective use of patient data, participants recognized the potential it could have to support their work. For example, beyond motor function, game performance could be an indicator of adherence and engagement. A blank or very low score could indicate that the patient is not playing the game, or that the difficulty level should be adjusted. Clinicians also described a need for different kinds of data reflecting exercise form, and whether the difficulty level prescribed was correct or needed adjustments.

5.2 Patients' practices and data needs

This section describes patients' perspectives towards data-driven practices. The findings are both based on their experiences with the TR system during the clinical trials and also their reflections on the data visualization artifacts we created in the study. As mentioned earlier, the data visualization artifacts were created to solicit patients' opinions about the possible data feedback they could receive from the system, and probe their thoughts about data-driven practices based on the prototypes, as they may not have much prior experience with data driven practices.

Patients were very focused on making improvements. Stroke survivors wanted to be informed about their treatment and progress while focusing on their practical long-term goals. They also wanted actionable information about what they should be doing to improve outcomes. While they primarily discussed their recovery in terms of activities of daily living (ADL) that they could accomplish independently, they still used game-centered TR data. Game points were often interpreted as granular indications of gradual improvement, and as a positive reward for effort. Still, several participants did not trust the data or had difficulty interpreting it.

5.2.1 Making progress and maintenance. Making progress in their recovery process was a priority for patients. They consistently talked about physical therapy games and exercises in a way that highlighted their practical purpose, i.e., how they would benefit from it. The game being fun or not fun was less important and rarely mentioned. For example, P8 explained how he valued the games because they could help to increase his speed and range of motion: *“I was interested in some of the games because I was interested in increasing my speed and agility, because that was more of my focus, but I think of the other stuff and I saw the benefit of it. I also use my range of motions pretty good”* (P8). Participants consistently discussed the impact or benefit in their abilities when asked about their experience with the system. There was more emphasis on liking a game when they noticed that it did make a practical difference for them. Other aspects such as its ability to entertain were less valued.

All participants discussed having made progress and still wanting to make more improvements. Stroke survivors talked about their progress through stories, using ADL (e.g., cooking on their own) or mobility aids (e.g., wheelchair or cane) to describe how their abilities have changed (e.g., *“I couldn’t even move my arm. Now I can at least move it and everything. [...] I did acupuncture. That helped me out a lot. Went from a wheelchair to a walker to a cane”* (P4)). They used these factors to compare their current state with the past and with what they want for the future. When talking about their rehabilitation, they often compared their current abilities with how things were before the stroke. For instance, P8 described how it was difficult to regain the ability to walk unassisted while still highlighting that he was not done: *“For me, it’s still a work in progress, and I’m not satisfied. [...] It was an effort to get back on my feet at all. Walking is still an effort. Hopefully, that is part of why I’m working so hard here, is I’m hoping to reduce that, this feeling, this effort that’s a big thought to walk”* (P8).

At the same time that they wished for more progress, a few participants also expressed concerns about maintaining their abilities. We only observed this concern among people who had a stroke more than two years before the study and had experienced loss in regained abilities in the past. Although losing their progress was a possibility for all participants, only those who had gone through it valued maintenance. For instance, P9 described how physical and occupational therapy are important to prevent decline and maintain a level of ability and independence, highlighting how it takes effort and is part of the rehabilitation process: *“Sometimes it’s very simple for me to fall off the wagon and not do it for a couple of days. After the ablation, I didn’t do anything for two weeks. The consequences were so severe. [...] If I take two weeks off, it takes a month to regain anything I lost. Double down to recover the one I lost”* (P9). In short, those who had experienced a regression in their rehabilitation knew the value of maintaining their current abilities, but they still wanted to see improvements.

Participants believed the data collected by the TR system could provide information on progress by displaying gradual increases in performance. For example, for P3, having confirmation of improvements from the system, either through game points or a different kind of feedback, was important: *“Family could tell me that I was doing better, but I needed to either see it physically or hear from a professional. Not that I didn’t trust family and friends, but it means something a little bit*

different when it's coming from a professional or when you can see it" (P3). This quote suggests that, despite having different ways to notice progress, participants believed that the TR system could be interpreted as an objective measure that was useful for participants.

When shown data visualizations of historical performance and improvement rates, participants responded by focusing on that information as an indication that they would continue to improve in the future. Past performance was not of interest in itself, because it measured past ability, something they already knew well. However, upwards trends of performance were valued as a signal that they would continue to get better. For example, P4 said in response to seeing a calculated improvement rate of 15%: *"Can you imagine if I got 15 percent better per month, if I can walk better? That would be great, wouldn't it?" (P4).*

The progress data, both in the original feedback provided by the system and in the study visualization materials, was not used to understand their habits or how they were doing in the present. These abilities were known to the patients based on their own daily tasks and perceptions. Instead, the information was seen as helpful as an indication of progress in the future.

5.2.2 Encouragement. When reviewing their scores and progress during the study, patients wanted not only to know how they were doing for informational purposes. They wanted confirmation that they were progressing because that was a source of hope, encouragement, and validation.

For example, P8 explained that encouragement through feedback from the system was important to keep patients engaged, and to provide support when they feel discouraged or overwhelmed:

"If you had a way to track that progress and to go back and see what the progress is, it could be a great encouragement. At some point, that's extremely important because this is a very, very tough fight. A lot of people, in my opinion, stop at a certain point. Then next, where are they going to be? They're going to stay there." (P8)

Similarly, P3 also explained the importance of receiving positive news from the system about how they are progressing, since having more visibility of an improvement provides needed encouragement in a psychologically difficult context:

"You always want to know the cause, so you know [...] that what you're doing is getting you somewhere. When I was in the hospital, part of it was mental. I was going crazy because I didn't feel like I was doing any better. [...] If you're learning how to walk again, like I had to or if you're coming back from having different impairments, it's such a huge, huge thing to physically see your progress" - P3

As these quotes show, feedback was, for patients, a form of encouragement and psychological support because of the difficult and personal nature of recovering from a stroke. However, because patients wanted to see improvements continuously, they feared that the data would instead indicate a plateau or regression. They preferred not to see such "negative" data. A few participants *explicitly* said they would prefer not to see negative data. P9 told us he would only want to receive feedback from the system if it showed improvements: *"If you're having failures, it'd probably not be good information for you to share with someone, but improvements are good to have" (P9).*

Other participants showed their concerns about negative data through their tone or by focusing on instances where they had a dip or some kind of trouble with the scores. Lack of improvement in the form of a plateau in the scores could also be interpreted as negative by patients. In the example below, P9 discussed a graph showing a plateau for a game in the TR system:

P9: *"See, I had a great day in November and I'm going down here in December. I thought I had the hang of it here in December, but I disappointed myself because I did not have the hang of it, apparently. That's what it's telling me. I didn't know I did*

so much better in November. That's disappointing, because I really thought I had the hang of it in December."

Interviewer: "It's possible that you're just hitting the maximum score right here. [in November]"

P9: "I'd like it if that were the case."

Because they wanted to see improvements consistently, for P9, a plateau was interpreted as disappointing. Partially due to not having enough frame of reference to interpret the scores, it was not clear in this situation that the data indicated good performance. Instead, the lack of measured improvement over time was seen as a failure.

5.2.3 Striving for better results. Most participants reported making an effort to beat their highest scores by trying to do very well in the game. Their intent was not only to get the satisfaction of doing better, but there was also an underlying belief that working hard at the exercises and games would help them to improve more. P4 was among the participants who tried to do better than their previous high score. He described that this was a constant effort, and it was rewarding to see an improvement: *"It was good for my left arm, moving things. I tried to challenge myself, shoot the gun thing. I used my left arm. [...] I tried to get better every day. I go, yeah, that's my high score. I felt good doing that"* (P4). Similarly, P2 also aimed to get higher scores every time she played by working hard: *"You get the same score some days, so I say, 'I'm just going to have to work a little bit harder.' That's what I was thinking to myself. It was not easy, but the next day, I may score five points higher than the day before that. That's some progress to me"* (P2).

Because they interpreted higher scores as indicators for improvement, participants made an effort during gameplay to improve their chances of getting a higher score. This effort was considered positive not only as a way to confirm that they were making progress but also as a strategy to benefit more from the game.

5.2.4 Data use and barriers. Patients were interested in the system feedback regarding their progress and mostly paid attention to it. However, they also recognized that there were limitations to the points, and sometimes did not trust it as a reliable indicator of ability or performance. While all patients wanted information about improvements, they also wanted the information to be more accurate and easier to interpret. The degree to where they trusted the data from the TR system varied. Participants showed less interest in the data visualizations when they were less trusting of the game point data.

Participants used the system feedback in the form of scores to get an indication of improvement. They compared their last score with the high scores to check if they were getting better. For example, P2 described how she interpreted the game points as indications of increased ability and progress in recovery:

"Some days, if I do the balloon game, it may say the score may be 31. Then I see a score like 50, so I notice the improvement right there. By the end of the week, the score will be a lot higher if I look at them all together. [...] I saw the scores getting bigger, some start off real small, but I improved as it went on and went on. They score you, so I look at the scores, whatever that meant." - P2

Because patients framed their past progress in terms of ADL or mobility aids, it was difficult for them to observe gradual improvements or anticipate future progress without external indicators such as game scores. However, a few participants did not understand or did not trust the game scores. As a result, they did not pay attention to them. They discussed that this lack of trust came from not always understanding what the system was measuring, or what the benefits of a certain game were. For example, P10 did not know how to interpret his TR data: *"Just, how am I doing?"*

There was nobody to tell me how I was doing other than some numbers on a score that didn't make sense to me. [...] Did I lift my arm to a certain level? Does it look at me? I don't know" (P10).

Game points were not the only means through which they observed progress. Patients noticed their improvement by seeing that they were doing better during gameplay. P6 explained that he knew he was improving because he was able to observe a better performance in the game when he was able to shoot all the ducks very quickly. *"The duck hunt [one of the games in the system], my goal always was to get a perfect score, of course. I get them all before the duck leaves the screen. [...] That means I did very well. I'm getting the ducks going back and forth"* (P6). Observing performance during gameplay, as described by P6, was at times more trusted than the game scores as indicators of improvement. Patients noticed that they were better able to play the game (e.g., hitting the target often) in comparison with past experiences.

Participants who did not receive useful feedback from the system emphasized how they still wished for information about their progress. However, they were uncertain about how to interpret the data they could see or how much they could trust it. To interpret the scores, participants needed not only an absolute value but also relative performance in relation to the maximum. However, their relative performance was not clear to them based on the scores, only based on game performance (e.g., hitting all the targets).

Patients were interested in seeing performance over time (i.e., game points), but not interested in activity history. There was little interest in seeing activity logs, such as what exercises and games were done each day, or which were used more often. These data were not useful for them to provide insights on progress. Patients also wanted to know what more they could do to improve beyond what they were already doing. Participants wanted to feel that they were doing as much as they could to keep making improvements and progressing in their recovery. However, since patients did not always know how to interpret their scores due to lacking a frame of reference, sometimes they were not sure if making an effort would matter. Gameplay was also limited in showing progress, particularly when participants felt they reached the best performance the game allowed but not the best one they could reach. For example, for P6, having a game be too easy was frustrating because it meant that it was not challenging and beneficial enough for her recovery. She described how that happened with the duck hunting game, where ducks move on the screen to be shot with a gun controller: *"It got to the point where the ducks were terrible. They wouldn't even get out of the grass and I'd shoot them. They got to speed that up"* (P6).

A few patients expressed a need for clear recommendations from providers or from the system itself on what they should do. While looking at his historic data, P10 talked about how it would have been useful for the feedback to also include advice informed by his performance: *"It would have been nice to have [...] something that says, 'You need to spend more time on the abduction with dowel.' [...] This would've helped then. [...] A recommendation, you should get more steps in"* (P10). Actionable data and recommendations also needed to be timely. Participants expressed how they wanted information in real-time to guide their exercise activity, but looking back on past data was less useful because it was not current and less actionable.

5.2.5 Preference for body-centered data. As described in previous sections, patients often expressed interest in a frame of reference to more easily interpret the game scores and understand the benefits of each game. Participants preferred body-centered rather than game-centered data. In other words, seeing data indicating the progress of a body part was more interesting to them than seeing data about performance in individual games.

All participants showed interest in a simple overview of their ability focused on their limbs, such as the body diagram used in the study (Figure 4 (a)). P6 explained this preference by describing that it was easier to interpret to find meaningful insights about how their abilities were progressing:

“This is a lot better than any lines and numbers. [...] You can visualize it. ‘There we go, nine percent for my hand, my shoulder.’ Then you see it in relation to the body. I like this. You could always visualize a picture compared to writing with sentences and graphs” (P6). This preference was not due to the specific designs used in the study. Rather, it was due to how body-centered data visualization aligned more with the patients’ perspectives. For example, they also tended to prefer line graphs of aggregate data for a body part (e.g. left arm) than line graphs of game score data. They were interested in understanding how their abilities and movements were evolving, such as strength, flexibility, dexterity, and precision, as it can be difficult to translate system data (e.g., game points) into tangible insights related to their goals (e.g., walk better or cook independently).

Game-centered data, such as scores over time, generated mixed responses. Only a few patients were interested in these data. Those that preferred granular game scores either mentioned that they are inherently curious and enjoy detailed data, or they wanted that information to inform their efforts while playing the games. For example, P8 and P9 said that they would like to have access to both detailed game data and body-centered data:

“I liked the graphs. [...] I just think it’s more analytical.” - P8

“‘How am I doing?’ versus did I kill more ducks than I did last time.” - P9

The granular data were still used for the same purposes, understanding progress and estimating improvements. However, it required more effort to translate it from game points to measurements of movements and motor function, which they were primarily interested in knowing. Game data was also seen as less trustworthy and less clear by the participants than body-centered data.

Patients valued games and exercises in the TR system to the extent that they believed each activity was beneficial for their recovery. Consistently across participants, they wanted to understand how each game or exercise would help them to achieve their goals. This perspective was sometimes motivating, when they understood the purpose of a game, or frustrating, when they did not.

For instance, P2 noticed that one of the games, Simon Says, had a positive impact on her left hand. Noticing this benefit made her value and like the game: *“There’s certain games I like, like the Simon Says because it make you just reach out a little bit more. It made me just use [my left hand] more than I realize I was using it”* (P2).

The system did not explain to participants what was the benefit or purpose for any of the games, but participants were able to figure it out most of the time based on the game design, the movements, or the difference they noticed. Not understanding the purpose of a game or why a game or activity was prescribed caused frustration. Participants wanted to know the purpose behind it, how it would benefit them, as described by P3: *“Some of the games are self-explanatory. There was one, the shooting ducks helps with your range of motion. I just like to know, why am I doing this? [...] Why is this going to help me? It’s great that the exercises were explained. It just would be cool to know this works like this sort of muscle, this is the result”* (P3).

Patients understood the purpose and benefits of a game to the extent that they interpreted its design and movements. But when the benefits were difficult to discern, they disliked it and were not sure the game was even helpful at all. Overall, patients found telerehabilitation data potentially valuable, as visualizing past improvement was often interpreted as a sign that of making progress in the present and future. However, they wished to have access to actionable and body-centered data.

5.3 Providers’ and patients’ engagement with rehabilitation data

Patients and clinicians described very different needs around telerehabilitation data. Table 2 illustrates these differences in several dimensions. As shown in previous sections, patients’ and clinicians’ data needs differ because their roles and responsibilities differ.

	Patients	Providers
Type of Feedback Insights needed	Reassuring, positive Progress, what benefits the game or exercise provides	Objective, informational Existing issues, adherence, exercise form, past progress
Temporality	Future (and Present)	Present (and Past)
Actionable insights	How to improve further	What to prescribe next, what problems need solving

Table 2. Patients' and clinicians' information needs in stroke telerehabilitation technology.

Patients had very personal considerations towards the data, as they linked it to their progress and to their ability to reach recovery goals. Their deep investment in the rehabilitation process affected their relationships with the system data, as explained in section 5.2.2. In contrast, healthcare providers displayed a very pragmatic perspective towards understanding patient data. Among providers, the professional perspective towards telerehabilitation data was clear from how they talked about it, differently from how patients discussed their own data. Their decision-making process was very matter of fact, with little hesitation.

Patients sought encouragement from telerehab data and explicitly wished for feedback that *confirmed* that they were making progress. Differently, clinicians needed more objective information describing *whether* the patient was making progress, and at what rate. For example, differently from patients, providers did not show concern about variations in game score data, such as having lower scores at times instead of a steady increasing trend. While patients could see this kind of data as negative, physical therapists viewed that as desirable, as shown in section 5.1.1. Further, while information about progress was of primary interest to patients, providers equally valued information about exercise form and any issues the patient might be facing.

There are also substantial differences regarding what kind of actionable insights each stakeholder wished for, and the time period they focused on. Patients primarily sought indications of their future progress by observing improvement rates. They also discussed how data about the present could be actionable, i.e., if there was anything they could change to benefit their recovery. Clinicians specifically needed data that could inform their treatment plan, including updating difficulty level as needed or helping to address any problems. To that end, they mainly needed information about the present and recent past.

6 DISCUSSION

Stroke survivors can benefit from telerehabilitation technology that provides actionable information about their progress while at the same time promoting hope and encouragement. Meanwhile, clinicians need feedback about their patients to make informed treatment decisions and detect if their patients need additional guidance, such as correcting exercise form. These information needs from both stakeholders demonstrate what kind of data telerehabilitation technology must collect and provide to users to compensate for the limitations created by the lack of in-person interaction.

When interacting with patients in person, rehabilitation clinicians can observe their exercise form, providing guidance and feedback, and notice if they are experiencing pain. In the context of telerehabilitation, clinicians need to obtain that information partially through the system data. Similarly, patients rely primarily on the system for needed feedback, as synchronous interactions with clinicians are limited. Clinicians have limited ability to observe and supervise patients during exercise sessions, both because synchronous interactions are limited, and because videoconferencing provides a much more limited field of vision in comparison with in-person sessions. There are

also limitations around monitoring patients' progress. In-person physical therapy and occupational therapy for stroke survivors involve periodic assessments using standardized tests [86] that must be conducted in person. Without such assessments, clinicians rely on system data (e.g., game performance) and on subjective accounts (e.g., patients' perceptions about the need to change difficulty levels) to inform treatment plans. Similarly, stroke survivors also wish for more information about their progress, and must rely on the telerehabilitation data for feedback. Despite being needed and valued by patients and clinicians, telerehabilitation data was barely used among participants due to the several challenges involved in effectively supporting their data practices.

In the context of telerehabilitation, PGHD practices have very specific characteristics that are not shared by most past research on this topic. The TR system is used by both patients and clinicians, whose interactions are fully remote, and its different functionalities are designed to substitute or adapt elements of an in-person physical therapy session (e.g., providing instructions, supervision, and feedback) for telehealth. Each stakeholder has access to the data from their own interface, data which are byproducts of the rehabilitation tasks. In contrast, most prior work on PGHD has studied contexts where patients purposefully collect data about their health or activities and bring such data into the clinic during in-person visits (e.g., [58]). In this study, we did not observe discussions between patients and providers about the data. Rather, each stakeholder had their own separate data practices, and clinicians used video sessions to ask questions to obtain additional information that was not easily seen in the data they had access to. Thus, it might not be necessary to approach data-driven telerehabilitation design in a way that facilitates collaborative data practices between them [31, 79]. Instead, each stakeholder should have their own interface, designed to address their specific needs.

These findings likely partially apply to other health contexts. We believe that, for rehabilitation clinicians, information needs in a telerehabilitation system are similar when treating patients with different conditions or injuries. Their need to correct exercise form and assess patients' progress to update treatment plans are likely not specific to stroke. However, the experiences of stroke survivors might not be shared by individuals that are in rehabilitation for other reasons, such as an injury or surgery, particularly if their rehabilitation process is shorter. Many of the experiences of stroke survivors are related to the inherent uncertainties involved in stroke rehabilitation: the pursuit of a difficult long-term goal, and the impact of the health condition on a persons' self-identity. These characteristics are present in other chronic conditions and contexts, such as Parkinson's, trying to conceive, and weight loss [4, 31, 59], even if they do not involve rehabilitation.

As our results show, there are several challenges involved in data driven practices for telerehabilitation. In part, these challenges must be addressed through careful data collection and presentation that is able to provide the specific information that users need (e.g., correct exercise form, ideal difficulty level). Primarily, these challenges relate to how the data on rehabilitation *progress* are presented to users. Insights about progress are needed by both patients (for encouragement) and clinicians (for treatment decisions). However, each one of these stakeholders has unique needs regarding data granularity, temporality, and objectivity due to their particular perspectives and engagement with the data. Because these differences in needs are not always compatible, we argue for stakeholder-specific data presentation and feedback.

6.1 Designing telerehabilitation systems to support data-driven practices

Although game points can provide feedback and encouragement to patients, they can face challenges translating data into concrete or actionable information that aligns with their particular goals and perspectives. In other words, patients want to understand the benefits of games and exercises in telerehabilitation. They also need information about the progress they are making towards

their goals. Telerehabilitation systems must be designed to align with patients' primary focus of recovering their abilities to provide understandable and useful information for users.

Stroke survivors approach recovery with the aim to overcome personal or professional challenges associated with their impairments (i.e., restrictions to their participation in social and professional activities) rather than their specific disability (i.e., restrictions in motor or cognitive function) [16, 37]. These challenges affect most stroke survivors, and significantly impact self-identity and quality of life even when accounting for disability [56], including patients who have made a full recovery of physical function [26]. Focusing on physical aspects of disability differs from patients' perspectives, limiting engagement with treatment, and it does not adequately address the needs of this population [16, 26, 37]. Technology for stroke recovery most commonly focuses on motor function, aligning with a medical perspective of stroke recovery (e.g., [57, 74]). However, there are designs that take a more holistic approach, for example, by promoting reflection among stroke survivors around their ambitions and personal narratives [33]. Alternatively, stroke telerehabilitation systems could better align with patients' needs if they communicate to patients how each game or exercise will help them to regain the ability to do a specific ADL or task. For example, activities such as cooking can be broken down into smaller tasks (e.g., turning on the stove, opening a can) and each movement could be linked to a game or exercise. Making these links visible could help to clarify for patients the benefits of each game.

Our results suggest that displaying progress based primarily on body movements and ADL goals, rather than game points, would lead to more meaningful data for patients and providers. For example, telerehabilitation systems could provide feedback showing that patients are 40% closer to the goal of being able to drive. This kind of design would speak more directly to their goals and perspectives. It could also help to encourage patients to try an ADL task when they get close to 90 or 100%. This feature could help to guide patients in deciding when to try new tasks, while at the same time showing incremental progress that is needed for patient encouragement.

While clinicians could also benefit from translating telerehabilitation data into high-level representations such as specific ADL, as a way to provide feedback on progress, this kind of feature is less necessary for them. Their work already involves translating patients' concrete goals (e.g., return to work) and existing impairments (e.g., difficulty typing) into treatment plans targeting the specific motor functions that are necessary to achieve the goal [34]. Granular data that is game-centered can also be useful for their decision-making. For example, game performance can be informative to determine the right level of difficulty that should be prescribed for each patient.

For the telerehabilitation data to be easily interpretable and trusted by both patients and clinicians, data collection tools would require validation when telerehabilitation systems are being designed. For performance data (e.g., game points) to be meaningful in a recovery context, it should measure ability reliably. To that end, it is necessary to translate movements and game performance into measurements of physical ability. These measurements could be calculated based on performance on one game or multiple games. For example, agility could be estimated based on performance on target shooting games and rhythm games.

A standard scale for the data, such as percentage points, could make the tracked data more intuitive, helping users to easily understand what a particular score means. Providing data in different levels of meaning (e.g., game points, movement, body part, or ADL) would help patients and providers to more easily interpret system measurements according to what insights they are looking for. For example, information about specific movements and body parts could be calculated based on performance in games that use them. ADL ability could be quantified based on each movement and limb that it requires (e.g., handwriting could be calculated based on data about hand and wrist movements, grip strength, and fine motor control).

Combining data translation into levels of meaning with reliability would likely require extensive effort and collaboration between technology designers, developers, and health sciences researchers. Still, we argue that this kind of technology could improve the experience of patients and clinicians, better support their work, and potentially impact patient outcomes.

6.2 Aligning temporal concerns with data

The experience of using the TR system involved temporal aspects for both patients and providers, as Table 2 shows. Patients tended to have a long-term perspective and focus primarily on the future (i.e., their future progress). On the other hand, providers had a more short-term perspective and focused on the present (i.e., how patients are doing currently).

Temporality has been discussed in previous research investigating patient-generated health data in other contexts where there is continuous data tracking, such as monitoring chronic conditions to observe symptom progression (e.g., [11, 35]), pursuing gradual goals (e.g., weight loss [94]), or changing behavior (e.g., [2, 68]). In the case of our study, there was a constant expectation of improvement. Patients were invested in what would happen to them in the future, and how their rehabilitation would progress. However, the future was very uncertain for them. They interpreted self-tracked data as an indication of future improvement when it showed a positive trend.

Patients need information about their treatment process, their progress, and actionable insights. For them, providing a clear trajectory or roadmap linking data, treatment, and goals would be useful. A linear historic view that displays progress in terms of specific ADLs would help them to see gradual improvements and estimate what to expect in the future. For example, a progress bar could inform patients that, in the last three months, they progressed from 65% to 80% towards the goal of being able to drive a car. Based on this information, patients would be reassured that they are getting closer to that goal and roughly estimate when they can expect to achieve the goal.

Meanwhile, healthcare providers had a more short-term perspective towards the patients' abilities and progress. They continuously sought to understand how each patient was doing *in the present* to make any needed corrections or updates in the prescribed routines. Providers needed to understand patients' current abilities, limitations, needs, and preferences to decide what should be prescribed. Incremental changes were important for them to inform their decision making, for example, to determine whether they need to increase the repetitions for an exercise or increase game difficulty.

Providers can use telerehabilitation data to monitor patients in a way that is more efficient, effective, and scalable if they have access to an interface designed to support their work. Functionalities that detect and flag issues such as low engagement, low adherence, or a need to update difficulty levels (e.g., if patients' scores are too high or too low) would help providers to make data-driven decisions more easily while reducing burden. For example, the system could flag a potential issue if a patient has performing lower than expected on multiple days. Even if adherent, this information could indicate lower engagement or motivation, discomfort, or even faulty equipment.

As mentioned before, because of their different perspectives, patients and providers seek different insights from the same tracked data. Furthermore, their insights are based on different time scales. Thus, these stakeholders need substantially different interfaces for interacting with telerehabilitation data: while patients would benefit from a design that highlights *long-term* positive trends, providers require more granular information from *the recent past* highlighting potential issues that should be addressed. Patients need long-term information to see how this treatment course will play out in their lives, to know when to expect to return to a stable state where the condition causes little disruption in their lives [19].

6.3 Objective and encouraging feedback

Our findings show that patients wished for feedback that fostered hope and encouragement. They looked primarily for an upwards trend in their tracked data, to see that they were making progress and could expect to see more improvements in the future. This interest in positive tracked data was not only informational, it shows a need for validation, and for feedback that is reassuring. Patients also did not wish to see data that they considered negative, such as indications of a regression or plateau in their rehabilitation.

Rooksby et al. [81] describe how self-tracking is most often prospective rather than retrospective. People use information to “navigate” their lives to pursue a high-level goal. We found that was the case for stroke survivors in this study. They sought from the data some indication that they were still making progress. However, they did not want objective feedback about *whether* they are making progress or not. Because their interest in progress information was primarily related to a need for validation, stroke survivors prefer not to receive feedback that could be interpreted as negative. In contrast, clinicians needed objective data to inform their treatment decisions and address issues such as incorrect exercise form and low adherence. Previous work has described similar challenges in PGHD, as patients’ personal relationships with their health data involve emotional aspects that are not as present among clinicians [20, 36]. However, differently from this work, the specific context of telerehabilitation described here does not involve active collaboration between patients and clinicians to interpret and make decisions based on patient data. As a result, each stakeholder can be provided specific feedback that aligns with their needs.

It is not common to prioritize encouragement over objectivity when displaying data to patients, as technology by default provides users with objective data (e.g., [31, 52]). Still, healthcare technology must support both their illness work and their biographical work (i.e., psychologically coping with illness) [18]. After a stroke, patients go through difficult biographical work to reconstruct interpretations of their self-identity, understandings of boundaries of responsibility among patients, caregivers, and healthcare providers, and reconcile with their new normal [44]. This work is part of their rehabilitation process. Designing tools for this context requires focusing on their practical quality-of-life goals and encouraging them. It is necessary to provide positive and supportive feedback based on self-tracked data by framing such data into information that supports users’ needs, without misleading them.

Balancing objective and encouraging feedback to patients is a complex yet essential issue that warrants further investigation. In the context of telerehabilitation, technology must provide high granularity data to display gradual progress and highlight accomplishments. This information can provide awareness to users of small changes that might not be discernible in their daily lives, reassuring patients that they are continuously making progress. Designs that inform users about how quickly they are progressing towards their practical goals could help users to see and value the progress they are making while being informed and anticipating their future improvements.

Additionally, feedback should be designed to encourage patients even when *little* progress has been made. Showing past progress and highlighting past achievements could help to encourage patients. Past progress can be taken for granted if it is not acknowledged, and it is an alternative to focusing on recent progress. Highlighting past progress could support maintenance, encouraging users to maintain their efforts for rehabilitation even if they are not progressing as quickly as they wish. Further, providing educational resources that teach patients about maintaining motor function could help them to have a more optimistic response when observing data that indicate a plateau.

At the same time, designers of telerehabilitation technology must be careful to avoid creating expectations for progress that might not occur in reality. Seniors, in particular, might experience

declines in health and abilities that can be caused by factors other than the condition they are recovering from. Balancing fostering hope with preventing disappointment is a challenging problem to solve because even when based on reliable data, any predictions involve uncertainty.

6.4 Patients' and clinicians' (separate) data-driven practices

The personal relationship that individuals going through a process of recovery have with their data is very different from the straightforward perspective of healthcare providers. This contrast represents an important and difficult challenge for the design of technologies aiming to empower patients. Different perspectives indicate different needs for feedback design and data framing, meaning that patients and providers should have specific interfaces and data interactions to meet their needs. However, many digital health systems involve little or no guidance from physicians and rely on the patient to take a medical perspective towards their health by collecting and reflecting on their own data.

Consumer health technology aiming to support self-knowledge and making informed decisions for self-management must display data to users in a way that is informative and actionable, while still providing hope and motivation. Combining the pragmatic outlook of providers (i.e., data that supports decision-making) with the more subjective and personal interpretations of patients (i.e., data that is encouraging) can be challenging because the two goals are not always compatible. For example, in a situation where the patient is not making progress as expected, a clinician would evaluate the patient to determine if the rehabilitation goals should be readjusted to be more modest and realistic, or if the patient does not stand to make further progress through rehabilitation. On the other hand, patients might react to the feedback with guilt or hopelessness of reaching their goals of returning "back to normal". In this situation, providing objective feedback to patients and placing responsibility on them to make such decisions can create an undue emotional burden. Instead, the same data should be framed differently for patients to prompt more positive reflection. How information is displayed can influence users' experiences and outcomes. Different kinds of visualization can impact how users interpret the information, the decisions they make as a result, and important internal processes such as self-efficacy [14, 28]. For stroke survivors, empowerment and wellbeing depend as much on the right to make decisions as on the right *not* to make decisions, as they might not be ready to take greater responsibility over their rehabilitation [70]. It might also be beneficial to consider communicating to providers the emotional concerns patients have and what kind of feedback the system is providing, so they know when to comfort and to provide encouragement personally. For example, clinicians could have access to both their interface and the patients', and that can help to inform their synchronous interactions. Further, telerehabilitation systems could monitor patients' psychological wellbeing, tailoring feedback appropriately, and informing clinicians about the patient's state of mind.

Because of patients' close relationship with their data and hesitation to see negative information, receiving more feedback and responsibility could be more burdensome than empowering for them [63]. Researchers have argued for consumer technology that supports patients' work without prioritizing medicalized perspectives, i.e., supporting their medical needs without neglecting their personal and psychosocial needs [41, 64], such as balancing and coordinating their self-care work with other daily activities and coping with an illness. Patients in stroke recovery could benefit from information that is actionable and encouraging. However, it may not be possible to reconcile encouragement with objective information aiming to inform decision-making. This issue reinforces the need for another role in the system besides the patient, either in the form of clinicians or caregivers, who can assist the patient by having a more objective relationship with the data. While the need for clinicians to be actively involved in telerehabilitation leads to limitations in

accessibility and scalability of this technology, they play an essential role as decision-makers that stroke survivors cannot easily undertake. For health technology broadly, active involvement from healthcare providers should be considered as an option to address contexts where interacting with objective personal data might create an emotional burden on users as they are tasked with the responsibility to actively manage different aspects of their health. Delegating tasks to professionals could also help to address the challenges created by technology design that prioritizes medical aspects of health management over patients' other responsibilities and concerns [64].

This tension between encouraging and objective feedback has been described in previous work. Mishra et al. [59] found that at the same time that Parkinson's patients showed avoidance and denial about symptom progression, they still wanted to be able to predict and cope with an inevitable decline with support from PGHD. Overall, patients and clinicians have different expectations towards stroke recovery, as patients hope and anticipate they can recover if they try hard enough, focus on aspirational goals (i.e., lived experience, qualitative), and become demotivated when they lose a rehabilitation game or get a low score. In contrast, clinicians focus on functional goals (i.e., medical, quantitative), know the uncertainty involved in the recovery process, and try to promote motivation to patients without misinforming them [5, 46, 96].

These differences in perspective may cause challenges in communication and collaboration between stroke survivors and clinicians [46], similar to challenges found around PGHD among other populations (e.g., differences in priorities [79, 100]). However, we find that little data-driven collaboration took place between patients and providers in telerehabilitation. PGHD literature studying data use by both patients and clinicians most often focuses on data collected by patients about their behaviors and symptoms and in-person collaboration between them to interpret the data and make decisions (e.g., [61, 85]). This context involves many challenges that are inherent to the collaborative use of data, regarding the work involved in reaching an agreement when making decisions [79], crafting a shared "view" of the data [45, 58], and the need for boundary artifacts [15]. Additionally, the context of telerehabilitation did not include multiple streams of data that need to be interpreted together to find connections, such as in the case of diabetes where patients might need to understand the impact of daily actions on their blood glucose [78]. Still, we found overlapping challenges with prior literature, particularly regarding integrating PGHD into the clinical workflow [45, 97, 100] and identifying meaningful insights [78]. However, while these challenges could negatively impact trust between clinicians and patients when making sense of the data collaboratively, that was not the case for this particular study. Instead, these issues were seen by participants as challenges inherent to the system design.

7 CONCLUSION

In this study, we investigated the experience of stroke survivors and of physical and occupational therapists using a game-based telerehabilitation system. Using qualitative methods, we sought to understand how the system supported the work of these different stakeholders, what challenges they experienced, and their relationship and interaction with patient-generated data. Visualizations of game scores and other rehabilitation data were used to investigate self-tracking in the context of medical recovery among seniors.

The findings show that both patients and healthcare providers have complex needs for telerehabilitation systems. Patients wished for transparency in their treatment and to understand their progress, as they wanted to feel hopeful for the future while still knowing what they can expect. Healthcare providers needed information to support their treatment decisions, including adherence and knowing how the patient is progressing.

The results of this study revealed opportunities to integrating tracking strategies into rehabilitation systems to support both patients' and healthcare providers' data-driven practices. For physical

and occupational therapists, telerehabilitation data could help them to evaluate and monitor the patient and make treatment decisions. For patients, data could help them to understand their progress and achievements, encourage them, and inform them about what to expect in the future.

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