Patient Perspectives on Physical Therapy Outcome Measures and Engagement after Stroke

by

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Abstract

Introduction

Outcome measures are highly recommended in stroke physical therapy, however, most of the existing research has been performed from the provider perspective. Patient engagement encourages active participation in the therapy process and requires partnership between patient and therapist. Relational autonomy recognizes that patients may not be able to be fully autonomous at all points of their recovery journey. In relational autonomy, therapists aim to facilitate the level of autonomy that the patient is able and willing to attain. Understanding the patient perspective of outcome measures may help therapists to better support patient engagement and autonomy, particularly during this time of significant change as Alberta Health Services moves to a provincial electronic health record.

Methods

This qualitative case study is based on patient-oriented research principles, with three patient partners embedded in the research team. The case is a stroke physical therapy program in a major rehabilitation hospital in Canada, involving both inpatients and outpatients. Data collection included chart reviews, observations, patient interviews, and therapist interviews. Patient partners participated in all aspects of research, including thematic analysis of the data set.

Results

Ten patients and seven therapists participated in this case study. Patients of both genders, as well as a variety of ages, ethnicities, and ability levels, were recruited. Therapist experience ranged from 3.5 months to 31 years. Analysis of the data revealed the following two themes: 1) tracking progress, and 2) partnership. Tracking progress included the expectations patients had for improvement, the importance of objectively measuring change and the functional improvement observed day by day. Partnership described the relationship between therapist and patient including communication, encouragement and affirmation, the therapist as expert and the gradual shift in autonomy from therapist to patient.

Conclusion

Patients valued the objective results of outcome measures. They had high expectations for treatment and were interested in testing that could show that they were making progress towards their goals. Patients were encouraged by observable changes in their ability to perform everyday activities. Patients and therapists found that simple measures that showed progress in these day-by-day activities were most meaningful.

The partnership between patient and therapist seemed to provide a foundation for effective therapy. Patients placed a high degree of trust in their therapists and looked to them for expertise and encouragement. Effective communication helped patients to better understand the results of the outcome measures and facilitated patient decision making, particularly as therapy came to an end. Patients expressed that they are interested in accessing results of physical therapy outcome measures through an electronic patient portal. Maximizing the use of physical therapy outcome measures may improve patient engagement and support relational autonomy.

Preface

This thesis is an original work by Alyson Kwok. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Maximizing Patient Engagement through Collaborative Outcome Measure Selection and Tracking: Patients' Perceptions of the Use of Physical Therapy Outcome Measures Post-Stroke", No. Pro00101757, October 12, 2020.

Dedication

I would like to dedicate this thesis to my two children, Julie and Ethan, who missed out on a few evenings of playtime with Mom while I finished my work. I would also like to dedicate this work to my husband, Andrew, who spent endless hours engaged in theoretical discussions in the kitchen as I sorted through all of my thoughts.

Acknowledgment

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Introduction

“Why do I have to do this again?” a patient asked while performing a standardized balance assessment. He had suffered a stroke a few weeks ago and I was proceeding through his assessment, including our typical selection of outcome measures. I had been going through the motions with no real thought as to why I was using these outcome measures for this patient. The patient’s question was a common one and I started to wonder if this routine task could present an opportunity to actively engage patients.

Over 400,000 people live with the effects of stroke in Canada, many of whom access physical therapy at some point. Physical therapists, like myself, are guided by the Canadian Stroke Best Practice Recommendations, which endorse the use of evidence-based outcome measures to monitor progress (Teasell et al., 2020). Involving patients in their care is widely recommended (Teasell et al., 2020; WHO, 2016), but this approach does not appear to be used when selecting or tracking outcome measures. A recent survey of patients found that outcome measures are important to neurologic patients, but many did not receive information about how the outcome measures informed their plan of care (J. L. Moore et al., 2018).

Outcome measures should be a natural extension of goal setting, with recommended outcome measures proposed for each typical category of patient goal (J. L. Moore et al., 2018). However, recommended measures are not consistently used, patients are routinely transferred from provider to provider with different providers choosing different measures and no method to ensure outcome measures are linked to the patient goal. This can lead to patient confusion, especially when many patients experience cognitive or communication problems after stroke. Consistent outcome measures, aligned with patient determined goals, could help patients track progress toward their goal.

My study comes at a unique time, where the increased availability of electronic health care records may further enhance the opportunity to engage patients. Alberta Health Services is currently rolling out a provincial electronic health record that will provide one health record for each patient (AHS, 2020). This health record will allow for both consistent communication during patient transitions and patient access to their health information. Information from my study at this stage will help to support improvements to both the patient portal and the process surrounding outcome measures within Alberta.

A patient-oriented approach is the foundation of healthcare services and health research in Alberta (AHS, 2018; CIHR, 2014), but there is a lack of patient perspectives when it comes to outcome measures. Most research on outcome measures in stroke rehabilitation has been conducted from the provider perspective (J. L. Moore et al., 2018; Teasell et al., 2020; Tyson, Greenhalgh, Long, & Flynn, 2010). If we are to provide patient-centred services that engage patients in monitoring their health, we must start with asking the patients about their experiences and for their suggestions on how to improve.

Literature Review

Definition of terms*.* Terms with interchangeable or ambiguous meanings are used throughout this paper. For clarity, definitions are provided here:

Patient-centred, client-centred, or *person-centred* are terms often used synonymously (Morgan & Yoder, 2012) for care that is respectful, individualized, and empowering (Castro, Van Regenmortel, Vanhaecht, Sermeus, & Van Hecke, 2016). *Patient activation, engagement,* and *empowerment* are states of patient involvement that are closely related. *Patient activation* describes a patient's ability to manage their health conditions (Hibbard, Stockard, Mahoney, &

Tusler, 2004). *Patient engagement* is the active partnership between patients, families, and health care providers (Carman et al., 2013). *Patient empowerment* is the process of improving a patient's ability to influence their lives beyond the interaction with the healthcare provider (Anderson, 1995). These terms describe a process by which patients are supported and encouraged to take an active role in their care (Bravo et al., 2015; Bright, Kayes, Worrall, & McPherson, 2015; Hibbard et al., 2004).

Patient-centred care. Patient-centred conceptual models map out both ethical and practical outcomes. Ethically, patient involvement in their care acknowledges that patients are responsible for their own health most of the time (Anderson, 1995) and deserve a voice in anything that happens to them (Delbanco et al., 2001). Practically, patient-centred approaches lead to patient empowerment (Castro et al., 2016), which in turn, fosters improved patient outcomes (Bravo et al., 2015). Patient-centred approaches have been found to reduce length of stay, improve health outcomes, and improve patient experience (Charmel & Frampton, 2008; A. Coulter & Ellins, 2007; Hibbard & Greene, 2013).

Patient engagement strategies. Patient engagement strategies primarily include methods to support shared decision-making and long-term health management, such as improving health literacy, patient education, motivational interviewing, decision-support aids, health coaching, and self-management/self-monitoring education (Angela Coulter, 2012). Effective communication for shared decision-making and collaborative goal setting has consistently been proposed as an important aspect of patient-centred care in physical therapy (C. L. Moore & Kaplan, 2018; Wijma et al., 2017). Motivational interviewing, patient education, and patient-centred goals may even encourage neuroplasticity in neurological patients by increasing attention and motivation (Danzl, Etter, Andreatta, & Kitzman, 2012). While evidence supporting these strategies remains limited, some studies have demonstrated the effectiveness of a health coaching strategies on physical therapy clinical outcomes (N. M. de Vries et al., 2016; Nienke M. de Vries et al., 2015; Lenze et al., 2012; Skolasky, Maggard, Li, Riley, & Wegener, 2015; Skolasky, Maggard, Wegener, & Riley, 2018).

Patient portals. Patient portals, the patient-facing versions of electronic health records, are relatively new within healthcare. Early information shows that patient portals may have a positive effect on patient outcomes (Kruse, Bolton, & Freriks, 2015). As well, it has been hypothesized that patient portals have the potential to empower patients and improve health outcomes by giving patients access and greater insight into their health information (Otte-Trojel, de Bont, Rundall, & van de Klundert, 2014).

Outcome measures. Outcome measures generally fall into two categories: patient-reported outcome measures (PROMs) and clinician-reported measures. Within neurologic physical therapy, several recommended, clinician-reported measures exist (J. L. Moore et al., 2018). Clinician-reported measures tend to be used primarily by therapists to help with assessment, treatment planning, or discharge planning (Tyson et al., 2010). The use of outcome measures during patient discussions seems to further support the typical hospital hierarchy, where patients' progress or lack thereof is used to reinforce the clinician's message, rather than support shared decision making (Tyson et al., 2010). PROMs are more patient-centred, but current valid tools for stroke rehabilitation are generic (Reeves et al., 2018) and are not likely to align with a specific physical therapy goal. For example, the Patient Reported Outcome Measure Information System collects a wide variety of patient-reported data on function and quality of life (Cella et al., 2007), but is not intended to track progress of any one functional goal over time.

Self-monitoring of physical therapy outcomes has not been studied, however, there is literature to support this method in other populations. Self-monitoring of blood glucose is an effective self-management strategy for patients with type II diabetes (Norris, Engelgau, & Narayan, 2001), and monitoring activity with a wearable activity tracker results in a significant increase in daily step count in the general population (Brickwood, Watson, O'Brien, & Williams, 2019). Perhaps the most encouraging study in this area is one looking at gait speed in stroke rehabilitation. The intervention group was provided with daily reports of the results of a 10 Meter Walk Test. At the end of the large, multi-centred randomized trial, it was found that the intervention group significantly improved their gait speed compared to the control group (Dobkin, Plummer-D'Amato, Elashoff, & Lee, 2010), which was hypothesized to be due to the effect of regular, extrinsic feedback on motor learning (Subramanian, Massie, Malcolm, & Levin, 2009).

Decision-making and relational autonomy. Patient-centred care can be problematically interpreted as autonomous, unsupported decision-making (Entwistle, Carter, Cribb, & McCaffery, 2010), causing clinicians to become frustrated when patients have unrealistic expectations (Morera-Balaguer, Botella-Rico, Martinez-Gonzalez, Medina-Mirapeix, & Rodriguez-Nogueira, 2018). Patients often adopt a passive role, fearing that asking questions will cause their clinician to label them as “difficult” (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012; Joseph-Williams, Elwyn, & Edwards, 2014). Clinicians may not recognize that their patients want to participate in shared decision making (Dierckx, Deveugele, Roosen, & Devisch, 2013) or may abandon shared decision making, assuming that they can better understand all factors involved, such as the level of function required for inpatient discharge and hospital resources available to support attainment of those goals (Plant & Tyson, 2018; Trede, 2012). This hierarchical view reinforces power imbalances, further limiting the potential for shared decision-making (Ters & Yima, 2014).

The challenge of using the most appropriate outcome measure to track progress toward a goal may be impossible for many patients without adequate support. The concept of relational autonomy helps to address this challenge. Relational autonomy recognizes the interplay of the social environment and autonomy (Christman, 2004). Clinicians who practice relational autonomy recognize the nuances of each patient situation, providing support for decision-making when needed (Ells, Hunt Matthew, and Chambers-Evans, 2011). Relational autonomy also recognizes institutional limitations to autonomy and encourages dialogue to help patients understand what is within their control (Ells et al., 2011). In the case of outcome measures, relational autonomy would encourage the clinician to provide education and decision support during the process of selecting the appropriate measure.

Therapeutic Relationship. The therapeutic relationship is characterized by partnership, connection, personalized therapy, and open communication (Babatunde, MacDermid, & MacIntyre, 2017; Besley, Kayes, & McPherson, 2011). A positive therapeutic alliance has been associated with decreased pain, decreased disability, improved physical and mental health, and improved satisfaction with treatment (Hall, Ferreira, Maher, Latimer, & Ferreira, 2010). Elements of a strong therapeutic relationship overlap with concepts of patient engagement and relational autonomy. While a positive therapeutic alliance may be a key method to improve patient autonomy and shared decision-making, therapeutic relationships are often embedded in a power structure (Cummins, Payne, & Kayes, 2021). Patients are less willing to participate in open communication when therapists display a judgmental attitude, so therapists need to be selfreflective to foster a healthy relationship and shared decision-making (Morera-Balaguer et al., 2019).

Rationale, Purpose, and Research Question

Performing outcome measure assessments was a daily occurrence during my work as a physical therapist, repeated so often I had the standard tests memorized. I have experienced the pressure to maximize efficiency and outcomes within our healthcare system. In conjunction with my research team, I designed this study to explore how we might maximize the time spent on outcome measures. We were curious to understand the patient perspective regarding outcome measures and how these measures might be used to provide the patient with information to better understand their own health. To ensure the research would resonate with patients, we followed patient-oriented principles at all stages, including patient partners to guide the process. The purpose of this patient-oriented, qualitative research was to explore adult patients' perceptions of the use and monitoring of outcome measures in physical therapy post-stroke in Alberta to inform changes that will lead to better engagement and improved outcomes. The research questions are as follows: 1) What are patients' perceptions regarding outcome measures in physical therapy post-stroke? 2) How do outcome measures relate to concepts of patient engagement and relational autonomy? 3) How might outcome measures be used to maximize patient engagement, particularly with the roll-out of the new electronic health record?

Research Design

Locating the Research. This research is embedded in a critical theory paradigm, which embraces multiple truths and views the construction of these truths as shaped by power imbalances (Ponterotto, 2005). Critical social theory, based on the work of Jurgen Habermas, provides a critique on society with an emancipatory agenda (Scott, 1978). We also drew on the writing of Paulo Freire, whose work helped to shape participatory action research (Freire, 1993). As a frontline physical therapist, I have first-hand knowledge of the power imbalances present in the typical healthcare system. Patients, even if they are doctors themselves, may find it difficult to speak up when receiving care (Ters & Yima, 2014), which highlights just how ingrained the medical hierarchy is in our society. In this research, we explored these power imbalances and aimed to facilitate action through the dissemination of patient-identified recommendations.

Theoretical Framework. The overall theoretical frameworks guiding this research are patient engagement theory and relational autonomy. The Multidimensional Framework for Patient and Family Engagement in Health and Healthcare (Carman et al., 2013) states that engagement is a continuum, where the goal is not always shared partnership, but rather understanding how to optimize patient engagement in each situation. The framework lays out barriers to engagement such as patient education and organizational policies, which helped to shape the specific interview questions. Relational autonomy recognizes the importance of social relationships in shaping autonomy and encourages healthcare providers to assess the individual needs of a patient to support their autonomy (Ells et al., 2011).

We used the Strategy for Patient-Oriented Research Patient Engagement Framework, and the International Association for Public Participation Spectrum of Engagement (IAP2, n.d.) to help situate the research in patient-oriented principles. ‘Empower’ is the highest level of engagement on the IAP2 spectrum, where the public would lead all aspects of a project. My study achieved ‘collaboration’– a step below ‘empowerment’ – by including and supporting patient advisors on the research team. As the research purpose was already developed prior to recruiting patient partners, we were not able to achieve an ‘empower’ level of collaboration.

Methodology. We chose to use case study methodology to explore practices and patient perceptions within a specific rehabilitation stroke program. Case study is a form of qualitative research that focuses on a single, bounded case (Merriam, 1998). Case studies provide a concrete and contextual situation for the reader, which allows them to better generalize to their own experience (Flyvbjerg, 2006; Stake, 2006). The case in question is the physical therapy stroke department of a large rehabilitation hospital. The hospital provides both inpatient and outpatient rehabilitation. Case study methodology provided a thorough exploration of current and potential processes surrounding tracking outcome measures.

Within this case study, we used principles of participatory action research and patient-oriented research to guide authentic inclusion and lay the ground for subsequent action. In true participatory action research, the community on whom the research is conducted is also part of the research team (Reason & Bradbury, 2008). The community forms the question, leads the research, and disseminates the findings. Change is a primary goal, so participatory action research embraces 'action' as a key element within the research (Reason & Bradbury, 2008). Participatory action research in healthcare focuses on similar elements of participation and praxis (reflection and action) (Baum, MacDougall, & Smith, 2006; Cargo & Mercer, 2008). Although different from participatory action research, patient-oriented research has developed over the last decade as a practical and ethical approach to research in healthcare (Frank et al., 2015; Manafo, Petermann, Mason-Lai, & Vandall-Walker, 2018) and shares the element of patient inclusion with participatory action research. We followed the principles for engaging patient partners as laid out by the Canadian Institutes of Health Research (CIHR, 2014). We were also guided by the strong philosophical underpinnings of participatory action research, which helped us to avoid the tokenistic patient input sometimes apparent in health research.

Methods. The Strategy for Patient-Oriented Research advocates for patient engagement in governance and decision-making during healthcare research (CIHR, 2014). We recruited three patient partners to join the research team and guide the project. Although this is not true participatory research, in that the research question is not emerging from the patients, the patient partners ensured that the research remained patient-centred and relevant. The patient partners had each experienced a severe stroke requiring rehabilitation in the last ten years. They were left with a range of physical, cognitive, and language impairments. While the partners are somewhat representative of the population of interest, they are younger than the stroke population average and are all exceptionally motivated.

Recruitment. Recruitment occurred with the help of physical therapists working in the facility. I communicated with the clinicians bi-weekly to discuss potential candidates. After determining if the patient was appropriate, the clinician approached the patient. Consent to be contacted was obtained verbally or in written form. I followed up personally with interested patients to explain the study in detail and obtain written consent.

All physical therapists working in the area were invited to participate in separate interviews through a general email. Interested therapists contacted me directly.

Sampling. The Multidimensional Framework for Patient and Family Involvement in Health and Healthcare (Carman et al., 2013) suggests that engagement is a continuum, with some patients content to be consulted only, while others are interested in sharing power. We aimed to find representation from both ends of the spectrum. After the patient consented to participate, the primary therapist completed the Hopkins Engagement Rating Scale (HERS) to confirm the patient's level of engagement (Kortte, Falk, Castillo, Johnson-Greene, & Wegener, 2007). A score of more than 25 on this scale indicates that the patient is fully engaged, 20-25 is indicative of a moderately engaged patient and less than 20 may indicate risk of absenteeism. We were unable to recruit any patients who had poor levels of engagement, although fewer of these patients may be admitted to the specialized rehabilitation program.

Patients seem to feel that their engagement is somewhat dependent on the physical therapist (Wijma et al., 2017), so I ensured that patients had been treated by different physical therapists. Additionally, I was interested in ensuring that I had a range of patients represented – inpatient and outpatients, as well as different genders, ethnicities, language abilities. Purposive recruitment (Creswell & Creswell, 2018) continued until the research team felt we had attained acceptable variation.

Sampling was not applied to physical therapist participants. All physical therapists working in the stroke program were invited to participate in the interview process.

Inclusion/exclusion criteria. We kept the inclusion as broad as possible to fulfill the sampling criteria listed above. Since the case study was an adult program, all participants were over 18 years of age. I administered the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC) (Jeste et al., 2007) with all participants to confirm they were cognitively able to provide consent. Any participants who were unwilling or unable to provide consent would have been excluded, however, all patients were able to provide consent. Although it was an extra step and uncomfortable to administer at times, the tool proved to be a valuable addition. There were several times when I identified that participants did not fully understand the study and I was able to re-word the explanation until I was confident that they understood what they were consenting to.

Data Collection. A case study relies on multiple methods to fully understand the case, typically including observation, document review, and interviews (Merriam, 1998). As I have spent time as a clinician in this program, I drew on that experience using reflexivity throughout the data collection and analysis (Maton, 2003). Reflexivity, defined as "thoughtful, conscious self-awareness" (Finlay, 2002), helped me to inject my own experiences carefully into data collection and analysis.

Specific methods of data collection for this case study included observation, chart reviews, and interviews. Observations of therapist-patient interaction in which outcome measures were administered were used to better understand the culture of the organization, including typical interactions and language used. Charts were reviewed for each patient interviewed. The chart review provided information about basic demographics, goals documented, the outcome measures selected, and any documentation of patient involvement. In-depth semi-structured interviews were conducted with patients and with physical therapists. As our primary interest was the effect of current practices on patient engagement, the interviews allowed me to thoroughly explore the topic with each participant (Hesse-Biber, 2017). I was able to interview inpatients in person, following full hospital infection control protocols such as donning personal protective equipment and maintaining two metres of distance. Outpatient interviews were conducted over Zoom, over the phone, and, in one case, through email. All therapist interviews were conducted over Zoom.

Data Analysis. Thematic analysis as described by Braun and Clarke (Braun & Clarke, 2006) was used for data analysis. The theoretical frameworks guiding my research helped to search for concepts of patient engagement and explore potential power imbalances. Field notes written after all observation and interview sessions helped to shape preliminary codes. The patient partners each read two of the interviews prior to discussing their early impressions as a group. My supervisor and I then used this information, along with information from the chart reviews, observations, and field notes to proceed with coding and theming the data. The patient partners divided the remaining transcripts, each reading a portion of the data. Once I felt that I had quotes grouped into appropriate themes, I presented the grouped quotes to the patient partners without titles. The patient partners discussed and confirmed the groupings, then titled each theme.

Rigour and Quality Criteria

To ensure quality throughout this study, we used the eight "Big Tent" criteria for excellent quality research: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical and meaningful contribution (Tracy, 2010). The multiple data sources – chart reviews, patient interviews, and therapist interviews – and the addition of patient partners on the research team, are sources of credibility and trustworthiness. The case study approach, with its detailed description of a single bound case, enhances resonance. Reflexivity, used throughout, bolsters sincerity and credibility.

Ethical considerations

Procedural ethics were obtained through the University of Alberta, Health Research Ethics Board. Practical ethics were addressed through reflexive journaling and regular discussion with the research team. Establishing a reflexive practice helped me to address situations with ethical questions appropriately (Phelan & Kinsella, 2013). For example, early interviews revealed that some questions seemed to make patients feel defensive about their therapists. The patient partners helped to reshape the interview questions and process to minimize this response.

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Patient Perspectives on Physical Therapy Outcome Measures and Engagement after Stroke

Introduction

To achieve care that is both ethical and effective, post-stroke physical therapy aims to interweave concepts of patient-centred and evidence-based care. Evidence-based practice requires the application of research to practice, with subsequent evaluation of the results of that application (Dawes et al., 2005). The Canadian Stroke Best Practice Guidelines recommend the use of valid, standardized outcome measures (Teasell et al., 2020), and several outcome measures have been recommended for use in neurological physical therapy (J. L. Moore et al., 2018). Patient-centred care requires a biopsychosocial perspective, where power is shared between patient and provider (Mead & Bower, 2000). Standardized outcome measures are well-accepted adjuncts to providing evidence-based care however there has been very little published on patients' perceptions of these measures and how they might support patient-centred care.

Patient engagement and relational autonomy are concepts related to patient-centred care. Patient engagement involves patients, families, and healthcare providers working in active partnership (Carman et al., 2013). Strategies for engaging patients in physical therapy include building rapport and sharing decision-making (C. L. Moore & Kaplan, 2018). Benefits of engaging patients include improved patient outcomes, improved patient safety, and reduced health care costs (Coulter & Ellins, 2007). Relational autonomy is a nuanced concept, where autonomy is situational and will depend on the environment and the patient’s readiness (Ells, Hunt Matthew, & Chambers-Evans, 2011). Healthcare providers who practice relational autonomy recognize the unique needs of the patient and ensure choices are offered with explanation and support (Entwistle, Carter, Cribb, & McCaffery, 2010).

This study was conducted during the roll-out of a large, provincial electronic healthcare system that will provide patients access to their health records through a patient portal. Patient portals may improve patient health outcomes by increasing the information available to the patient (Kruse, Bolton, & Freriks, 2015; Otte-Trojel, de Bont, Rundall, & van de Klundert, 2014), however, factors like health literacy and usability of the system may impact patient engagement with an electronic health record (Irizarry, DeVito Dabbs, & Curran, 2015). At present, there is little research exploring how physical therapy outcome measures might be shared with patients effectively through a patient portal.

The purpose of this study was to explore patient perspectives on outcome measures used post-stroke. The research questions are as follows: 1) What are patients' perceptions regarding outcome measures in physical therapy post-stroke? 2) How do outcome measures relate to concepts of patient engagement and relational autonomy? 3) How might outcome measures be used to maximize patient engagement, particularly with the roll-out of the new electronic health record?

Methods

Locating the research. This study is embedded in a critical theory paradigm, which centers around the concept of societal power imbalance (Ponterotto, 2005). A critical theory lens requires emancipatory interest and careful reflection upon established practices (Trede, 2012).

Design. Case study design, which focuses on a single bounded case (Merriam, 1998), was used for this research. Methods for this case study included document review, observations, and interviews (Figure 1). The physical therapy stroke program of a large rehabilitation hospital serving both inpatients and outpatients was the focus of the study. The program has approximately eight full-time equivalent physical therapy staff, treating over 300 inpatients each year. The outpatient program serves a mixed population and sees over 900 patients each year, a large portion of which have a stroke diagnosis. Ethics approval was obtained through the University of Alberta Health Research Ethics Board (approval number Pro00101757). Operational approval to conduct the research in the rehabilitation hospital was granted through the Northern Alberta Clinical Trials and Research Centre.

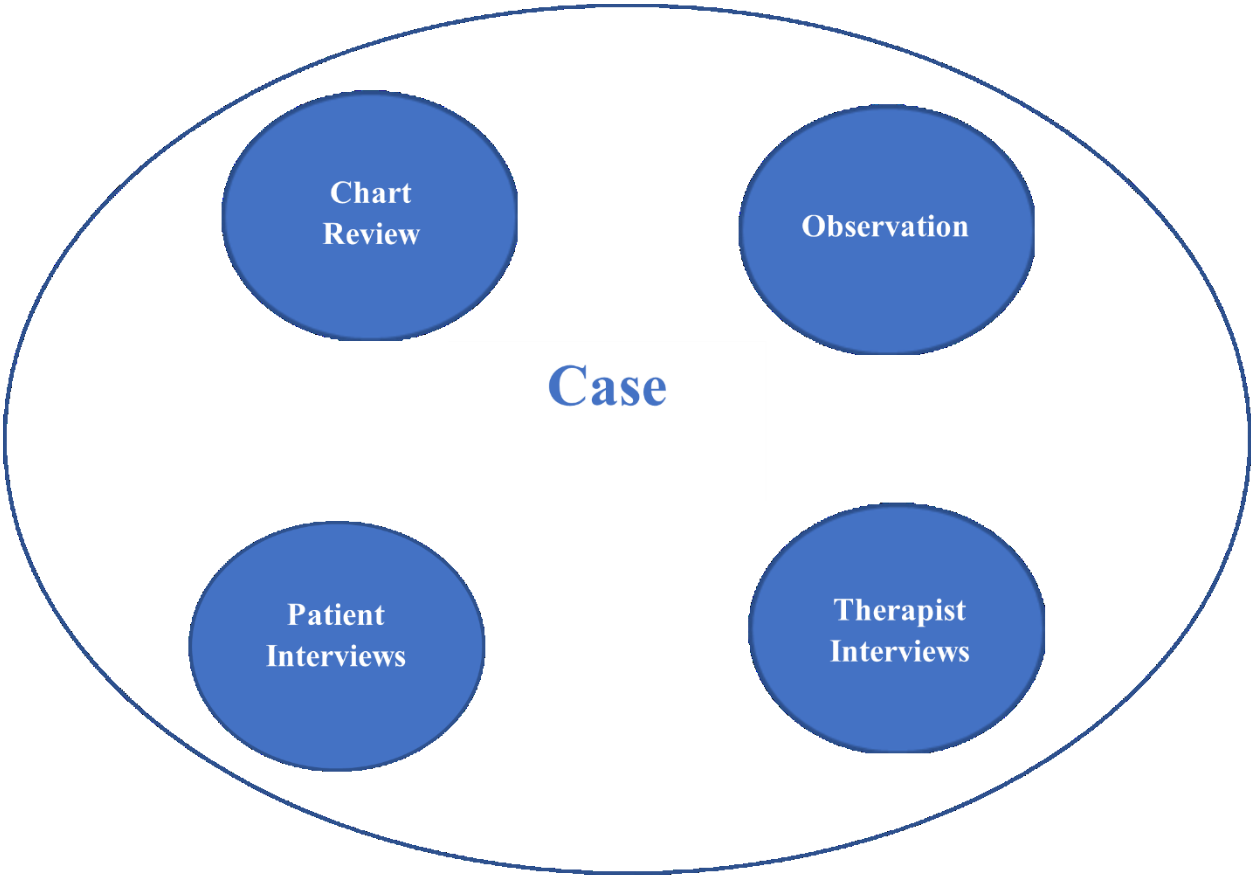

Figure 1. Representation of case study methodology and methods used.

Patient-oriented research principles guided every step of the research (CIHR, 2014). Three patient partners with lived experience were recruited. The patient partners (DK, ML, EM) were paid members of the research team and were involved in guiding the development of the interview questions and process, as well as the subsequent data analysis. Each partner had experienced a severe stroke, ranging from two to ten years prior to the start of the research, with a variety of stroke consequences, including motor weakness and aphasia.

Participants. Participants included both patient and therapist participants. Eligible patient participants were identified by treating therapists, who liaised frequently with the research team to ensure maximum diversity. Patients were included if they had or were receiving physical therapy treatment after a stroke and had the capacity to consent, as determined by the University of California, San Diego Brief Assessment of Capacity to Consent (Jeste et al., 2007). An aphasia-friendly consent form was used if a patient presented with communication impairment. Therapist participants were recruited via email, with interested participants self-identifying for the study.

Procedures. Data collection was obtained through chart reviews, observation of outcome measure administration, patient interviews, and therapist interviews. To determine patient level of engagement, primary treating therapists were asked to complete the Hopkins Rehabilitation Engagement Rating Scale (HRERS) (Kortte, Falk, Castillo, Johnson-Greene, & Wegener, 2007). Patients scoring more than 25 on this scale are considered in the ‘normal’ range for engagement. Information gathered from chart reviews included basic demographic information, type of stroke, medical comorbidities, physical therapy goals, physical therapy outcome measures, functional status at the time of chart review, and any documentation of patient participation in outcome measure selection and tracking. Observations were arranged whenever it was possible to observe a session where outcome measures were used. Field notes were taken to record observation sessions.

Interviews were conducted with both patient and therapist participants. The patient partners and a volunteer therapist helped to pilot the interview process, determining that one-hour sessions would be sufficient. Patient interviews were conducted in person or virtually, using Zoom or telephone. One patient was interviewed via email due to multiple technical complications. All therapist interviews were conducted using Zoom. Similar questions for therapists and patients guided the semi-structured interviews, which were adapted slightly throughout the process based on initial results and feedback from the patient partners (Table 1). Interviews were audio, or, in the case of communication impairment, video recorded, and transcribed verbatim. AK, who had previously worked as a physical therapist in this stroke program, conducted all observation sessions and interviews.

Table 1. Semi-structured interview guide.

Research Question	Patient Interview Question	Therapist Interview Question
What are patients' perceptions regarding physical therapy outcome measures post-stroke?	What does the term outcome measure mean to you?	How do you use outcome measures in your practice?
	Tell me about the outcome measures your physical therapist has used during your rehabilitation. What do you think these measures are used for?	Which outcome measures do you typically use? Why?
	How do you feel about these measures?	What is your opinion regarding these measures? What do your patients think of these measures?
	How were the outcome measures and your goals related?	How do patients' goals typically relate to the outcome measures?
How do outcome measures relate to the concepts of	Tell me about what patient engagement means to you?	Tell me about what patient engagement means to you?

patient engagement and relational autonomy?	What parts of therapy feel most meaningful to you?	How do you encourage patient engagement?
	Do outcome measures play a role in making your therapy meaningful?	Do you involve your patients in selecting or tracking outcome measures?
	Which tests were most meaningful to you?	
	How would you choose an outcome measure if there were a selection of different tests that measured similar things?	How do you encourage patient autonomy?
How might outcome measures be used to maximize patient engagement, particularly with the roll-out of the new electronic health record?	How might outcome measures be used to help you in your physical therapy? (After initial response, Figure 3 provided as an example graph for feedback)	How might outcome measures be used to help patients in their physical therapy? (After initial response, Figure 3 provided as an example graph for feedback)
	With the new electronic health record, would you appreciate it if a therapist could show you your progress on a computer?	How might an electronic medical record be used to support this?
	Would you like to access this information on your own device?	What if patients could access this information on their own devices? Would they use it? Would this be helpful?

Data Analysis. All transcripts from field notes and interviews were reviewed by AK and TM to develop initial codes and overarching themes (Braun & Clarke, 2006). Using NVivo software, quotes were grouped into themes and presented to the patient partners. The patient partners, who had each reviewed a portion of the interview transcripts, further shaped the themes based on their interpretation of the data and provided the final labels for each theme. Rigour and quality for this qualitative research were guided by the eight “Big Tent” criteria (Tracy, 2010). Multiple data sources and the inclusion of patient partners enhance rigour and trustworthiness of the data. In addition, extensive notes and a reflexive journal were kept throughout the study to enhance resonance, sincerity, and credibility.

Results

Ten patients and seven physical therapists participated in this study. One patient refused to be interviewed and so was only observed (Patient 3). Two patients were only interviewed because they had recently been discharged from physical therapy and observation sessions could not be arranged (Patient 2 and Patient 7). The rest of the participants participated in both an observation session and an interview. The patient participants included five males and five females (Table 2). Five were participating in an inpatient program, two had been very recently discharged from inpatient rehabilitation and three were attending outpatient therapy. Chart reviews revealed that the patient participants presented with a range of impairments including weakness, sensory loss, visual impairment, perceptual impairment, aphasia, spasticity, and ataxia. Each patient had outcome measures documented on the chart. Specific measures used included the 10 Meter Walk Test, the Berg Balance Scale, the Clinical Outcomes Variables Scale, the Chedoke McMaster Impairment Inventory, the 30 Second Sit-to-Stand Test, the 2 Meter Walk Test and the 6-Minute Walk Test. In addition, each patient had several impairment-based assessments, such as the Modified Ashworth Scale and Manual Muscle Testing. None of the patients had any record of the degree to which they were involved in or educated about the measure. All but one of the participants was in the “normal range” for engagement. Therapist participants included four inpatient and three outpatient therapists. Years of experience ranged from 3.5 months to 31 years (Table 3).

Table 2. Characteristics of patient participants.

Patient	Age	Gender	Inpatient or Outpatient	Diagnosis	HRERS*	Gait Speed (m/s)**
Patient 1	63	Male	Inpatient	Multi-territory stroke	26	0.22
Patient 2	58	Male	Inpatient	Right lacunar stroke	30	0.6
Patient 3	72	Male	Outpatient	Right lacunar stroke	30	0.59
Patient 4	65	Female	Inpatient	Right frontoparietal ICH	29	0.2
Patient 5	64	Female	Inpatient	Right MCA stroke	24	0.1
Patient 6	58	Female	Inpatient	Right parietal ICH	29	0.15
Patient 7	42	Male	Inpatient	Multi-territorial left hemispheric and right posterior internal capsule infarcts	28	1.2
Patient 8	46	Female	Outpatient	Left lateral medullary stroke	30	1.8
Patient 9	70	Male	Inpatient	Left thalamic intracerebral hemorrhage	28	0.55
Patient 10	41	Female	Outpatient	Left MCA stroke	27	1.57

*Hopkins Rehabilitation Engagement Rating Scale. “Normal” range >25, “at risk”, 20-25, “requiring clinical intervention <20. **Normal gait speed is 1.2-1.4 m/s (Lerner-Frankiel, Vargas, Brown, Krusell, & Schoneberger, 1986)

Table 3. Characteristics of therapist participants.

	Years of Experience	Primary area of treatment
Therapist 1	31	Inpatient
Therapist 2	15	Outpatient
Therapist 3	25	Outpatient
Therapist 4	5	Inpatient
Therapist 5	3.5 months	Inpatient
Therapist 6	21	Outpatient
Therapist 7	16	Inpatient

After detailed review of the transcripts and field notes by the researchers in conjunction with the patient partners, two primary themes emerged: 1) Tracking progress and 2) Partnerships (Figure 2). These themes are further divided into subthemes, listed below. While much of the data was focused on measuring progress, the participants also talked about partnership and its impact on their care. The therapeutic partnership appeared to provide the foundation for meaningful physical therapy sessions. If partnership was established, tracking progress could be fully utilized.

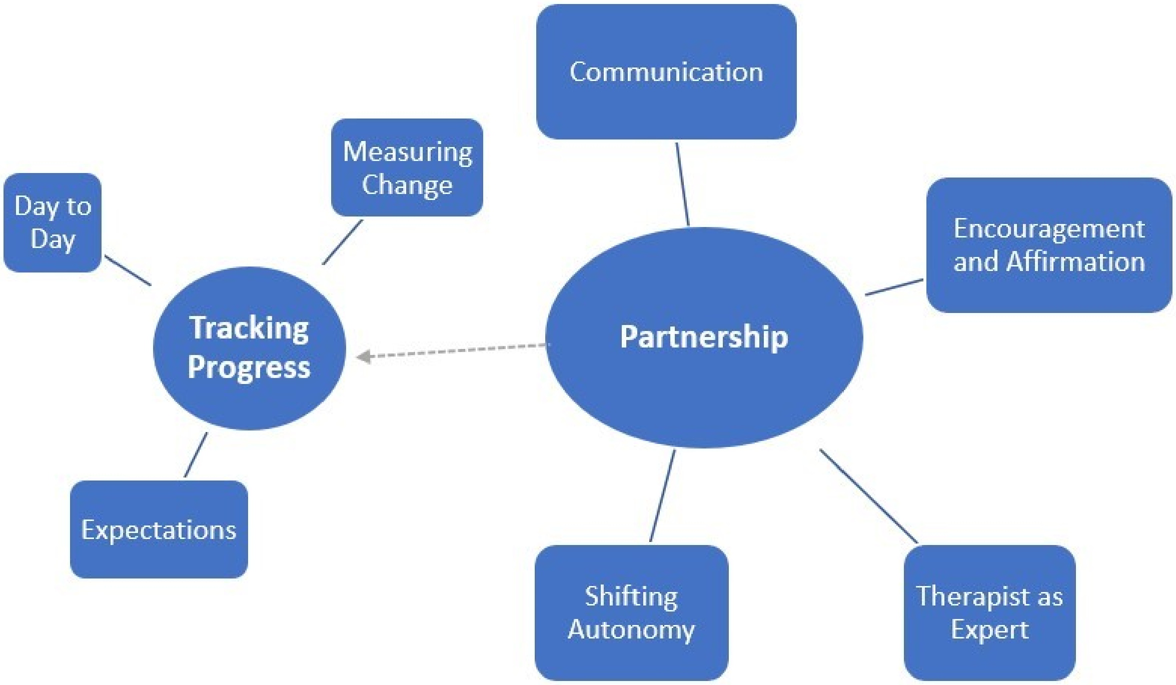

Figure 2. Depiction of the primary themes and associated subthemes. Tracking progress appears to require a foundational therapeutic partnership.

Theme 1: Tracking Progress

Outcome measures function to diagnose, inform prognosis or evaluate the effectiveness of treatment (Potter, Sullivan, Fulk, & Salem, 2011). In this study, tracking progress over time emerged as a primary theme, indicating that using outcome measures to evaluate treatment was the most important function to patients and therapists. The other purposes of outcome measures were rarely mentioned. Tracking progress involved the expectation of the result of therapy, measuring change objectively, and observing day-by-day improvements in functional activities.

Expectations. Expectations appeared to shape both the patients' goals and their interest in tracking improvement. Several patients talked about returning to normal and felt that improvement in outcome measures supported this expectation. Patient 7 described this as, "Going back to normal" and felt it showed that "…I'm going to get better – to get back to work." Another patient stated:

> "…when she did the test, she would tell me the, you know, the number that would total up to and then she would explain that, yes, you're going upwards. So, it's working. The physio is working for you." (Patient 4)

Progress in outcome measures provided a source of motivation, helping patients to believe that their expectations were possible, and their goals could be achieved. Tracking objective progress was, "kind of like a yardstick" (Patient 2) to measure progress toward a final goal.

> "It's motivation. Like it would give one a reason to want to strive and achieve whatever one can, knowing that there is no limitation or that there is a goal ahead that you're aiming at getting to that you can reach." (Patient 5)

Therapists used outcome measures to help determine if a patient's expectations were reasonable.

> "I think also if we're goal-setting and someone says, 'well, my goal is to get rid of my walking aids' and their Berg is like a 22, I can say, 'well, okay, but we've got a lot of work to do if that's even possible.' And so it can help give some reality check." (Therapist 6)

Measuring Change. Patients generally liked the idea of objective measurement of change and found it motivating to see test scores improving and measures of gait distance or speed increasing. They appreciated when the therapist talked to them about their progress over time.

Patient 1 said, “It’s nice to see that you are improving, you know? Not going in the opposite direction kind of. Or, you’re not staying the same. You are gradually improving.” Another stated, “I do appreciate all the tests because that gave me the confidence or assurance, which I can do, which I still improve…Those are measurements, like just the kind of way the science doesn’t lie, right?” (Patient 2). Therapists also found that objective measures could help to quantify improvements for patients who were not able to remember their progress over time and provided an objective target to reach for.

> “…one of the things that I really like about the outcome measures is, it gives an, obviously, an objective view of progress or change over time. I find it really helpful for patients who aren’t seeing progress in some more functional areas… and then you can say, ‘well, like look at the actual scores and the numbers.’” (Therapist 5)

Sometimes patients were confused about what was being done to measure change. Therapists talked about how they did not always explain outcome measures to patients, particularly if they thought it would make the patient frustrated, overwhelmed, confused or anxious.

> “…some people are anxious when they’re tested. And sometimes you don’t even want to tell them that you’re doing an assessment. You just start to kind of do it because you know if you tell it’s a test, then they’re going to be so anxious that they’re going to do worse.” (Therapist 7)

There were differing opinions regarding how these measurements would be best provided. Some patients preferred to see the scores only and others liked the idea of a graph to visually track change (Figure 3). Patients talked about how they wanted to be able to have a record of their progress over time. One patient said that at discharge, he would have liked a "report card" (Patient 2). Patients were strongly divided on whether they wanted to be compared to other people or not. Some patients felt the comparison would be "detrimental and discouraging" (Patient 6), while others expressed interest in knowing what "people my age, or women my age, what their averages are" (Patient 10).

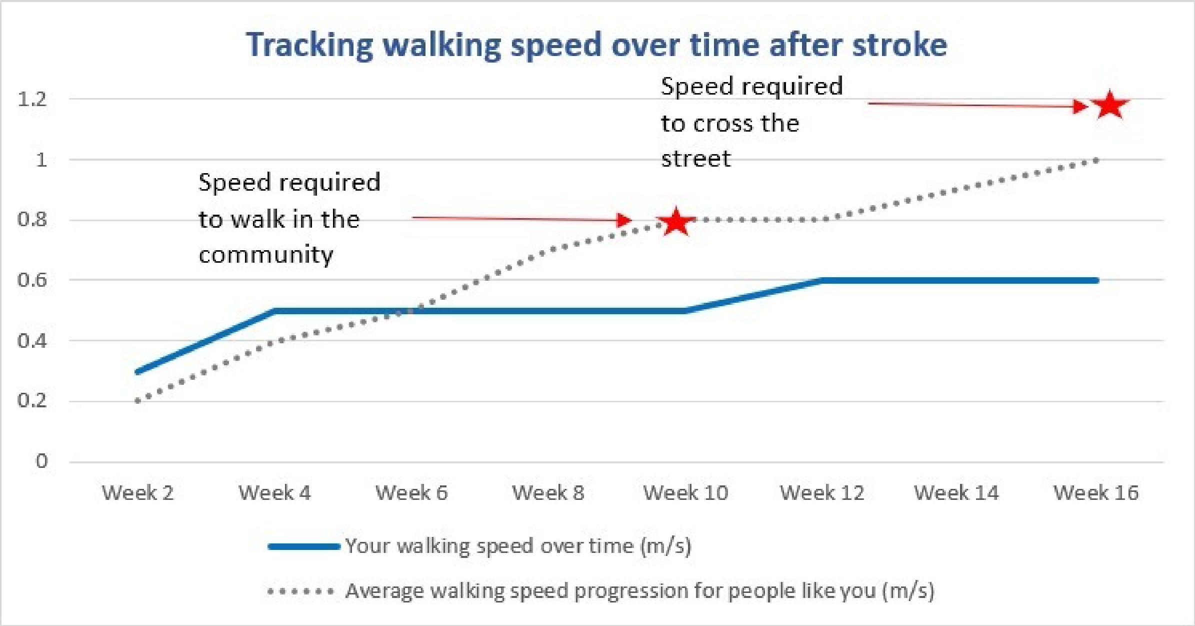

Figure 3. Example graph with mock-up data provided during interviews.

Day by day. Patients spoke extensively about noticing functional changes, showing they were "improving day by day" (Patient 7). Functional milestones, such as being able to climb the stairs or walk without a gait aid, were very meaningful to patients and helped them to appreciate day-by-day changes.

> "And then one day, she tried me on the stairs and it took three of them to hoist me up there. And then, after the second time, about two weeks after, she tried me again and I climbed the stairs." (Patient 4)

> "The improvement I experienced by walking with a cane, 2-wheeled walker and 4-wheeled walker and finally without walking devices. I am now at home, managing independently." (Patient 6)

Patients and therapists recognized that not all outcome measures were equally important from a patient perspective. Outcome measures that aligned with everyday life or easily showed progress over time were most meaningful. Timed walking tests, such as the 6-minute Walk Test or the 10 Meter Walk Test, the Clinical Outcomes Variables Scale (COVS), and the Berg Balance Scale are examples of outcome measures that were frequently regarded as valuable tests. The Chedoke-McMaster Impairment Inventory is an example of a test that felt abstract and irrelevant to patients. For some patients, "it doesn't make sense for many reasons" (Therapist 1) such as poor cognition, language problems, or orthopedic issues.

> "I think the COVS I find is more meaningful for the majority of my patients because its things that, generally speaking, activities that they're going to do every day. So I think the more functional it is, the more meaningfully they interpret the results." (Therapist 4)

> "The one outcome measure…I find myself doing a little bit more frequently is like a walk, a timed walk distance. I build that into the program because I think it's, it's just one number that the client has to keep in mind. And they actually seem to do quite well, even if there's a minor cognitive issue, they can remember how far they walked last week." (Therapist 6)

Theme 2: Partnership

Partnership was foundational for patients in this study. A strong partnership with the therapist gave the patients trust and confidence to engage fully in therapy. In the early stages of therapy, patients appeared to rely on the therapist as the expert and a source of encouragement and affirmation. As therapy progressed, they started to make more decisions for themselves, representing a shift in autonomy. Effective communication was a cornerstone supporting this partnership.

Communication. Patients valued communication with their therapist. They looked to their therapist to provide context for the test scores and further detail about what was observed during the test. "Some stuff I don't even notice, that they just point out… they understand the situation, and they try to improve with the knowledge and then they remind me what to do" (Patient 2). Patients appreciate when therapists explain "why you're doing it" (Patient 4) and provide the explanations in "layman term" (Patient 2). Patient 5 said,

> "…he takes the time to explain why he's doing whatever he's doing. And he will give me, I will say, the physics of it. The basics of the explanation to say we're doing this because this is what we want you to be able to do and that kind of thing."

Some patients expressed that they would have liked even more detail in communication so that they could better understand their level of function and use that information to make decisions in the future.

> "…telling me like as we're stretching, telling me why this would be helpful and what exactly we are stretching. So I remember it, so I, so I can do it on my own. And like the walking, if she tells me the results, kind of like, 'Oh, these are your results. And that's about average.' Right? 'That's where you are, that's average. But if you're going to walk, [you would probably need to] walk faster, probably at this speed." (Patient 10)

Therapists try to explain not just outcome scores, but also “how they're doing things” (Therapist 2) and to “give some sort of context to what this assessment might mean” (Therapist 6).

> “I always think it’s weird if I’m going to do a bunch of outcome measures and I just spent like 20 minutes doing it and then I don’t say anything to the person about what that was all about. Like, I’m just doing it, right? That just seems odd. So, then you have to take the time to sort of say, ‘so we did this and this is what this means.’ So, it’s sort of not just time to do it, but time to give some meaning to the patient.” (Therapist 6)

Therapists often reported adjusting how they communicated a lack of progress. Many spoke about protecting their patient’s feelings. Therapist 2 reported, “…but if they do not so well, I still try to spin it and be like, okay, you know, you can, you can do 2, but obviously, that's something we need to work on”.

All patients interviewed were interested in having access to their information through an electronic patient portal, even if they weren’t sure how they would use the information. Patient 2 said, “If I can assess my result in electronic form, on a secure server, I will appreciate it.”

Encouragement and affirmation. Patients felt close to their therapists. “You end up getting a bond with them” (Patient 4). They valued encouragement and wanted their therapist to let them know when they had been successful. Patients, particularly in the inpatient program, seemed to rely on this affirmation as a source of motivation. Patient 5 said, “I feel, I feel happy. And they’re very supportive. That’s the thing about them. Both of them are really very supportive and encouraging.” Patient 9 stated, “…they never tear me down. You know, that’s why I have incentive to go my therapy because they really want me to, to get better.” Therapists recognized that their role was to "…keep him engaged and enthusiastic and wanting to work hard, even though he's probably not going to walk independently." (Therapist 1)

Therapist as expert. Several patients talked about putting their trust in the therapist because they "are professionals" (Patient 1). Most people did not expect to direct their therapy sessions or choose which standardized tests to use. In fact, some patients seemed to find this idea humorous (Patient 7) and one therapist recounted how a patient "burst out laughing" (Therapist 6) when she asked her what she wanted to do in the session. However, other patients felt that "if they can explain to me beforehand" (Patient 10), they could participate in choosing an outcome measure. Within the therapy session, patients seem to feel that the therapists are the experts, and they were comfortable with most of the choices the therapists made. Patient 7 stated, "The trust, commitment, especially have to deal with this staff every day. And then they're gonna get me better." Patient 2 articulated his thoughts on why he felt therapists should direct the session:

> "With my experience, I am very satisfied. But the thing is, it is not 50/50. It shouldn't be 50/50. It should be therapist is, maybe at least 75 to 80. And that the patient input is going to be 20 to 25."

Therapists also spoke of the limitations of outcome measures, which fell short of providing a complete picture of a patient's progress. They used their expertise to elaborate on the outcome measure score, helping the patient to make sense of the findings. Therapists also relied on their observation and experience, rather than outcome measure results, when making clinical decisions.

> "And then I do like to be able to make little notes on the sides of my assessments, though, because sometimes, well, all too often, they won't change in their actual assessment score, but I can say, much less leaning backward or much less, you know. So where the observational, where the objective side of the scoring doesn't show a change, it doesn't mean there hasn't been a change." (Therapist 3)

> "…I would weigh observation and intuition and what I'm seeing and how they're responding to treatments a lot more heavily than I'm worrying about a Berg score or a COVS score because I think there are a lot of different aspects that say, a Berg or a COVS can't really grasp that, right?" (Therapist 4)

Shifting autonomy. While in the hospital, most people waited for direction from their therapy team before attempting a new physical task. Once they were home, people started to make more decisions about their movement, such as when and where to walk by themselves or when they were ready to try a new activity. While therapists clearly aim to be patient-centred during sessions and recognize that "they still have to want to do it for themselves" (Therapist 7), patients consistently deferred to them in the observation sessions. Some patients were content to cede their autonomy during the therapy sessions, putting their trust in the therapist. Others, particularly those at or close to going home, wanted more information to help support decision-making. Therapists did not typically provide patients with education on how to observe or track changes in function to make decisions about independent movement in the future. Patient 1 was satisfied with his time as an inpatient, but felt, "You basically want to do what they tell you to do." Patient 4 referred to the vulnerability of an inpatient hospital stay, "When you've been five months in the hospital, you want to get out" and felt, "physios make the goal, you know, to make you well again, able to go home." The comments from Patient 9 showed how patients may internalize the hierarchy of the hospital system:

> "My job in this team is, I am willing to do whatever he tells me that I can do it. Not frustrate them that, you know, they're willing to help me and I'm not going to help myself and I feel proud of myself to do that. To make them feel good."

Once they were back in their home setting (after inpatient discharge or during their time in outpatients), many patients started to make more decisions for themselves, sometimes veering from the therapist's instructions or even questioning the value of ongoing therapy.

> "If I'm not getting any better, I would just say, 'I think this is as good as it gets for me and … what do you think the advantage of me continuing physiotherapy and staff like that?' Like, I don't want to waste anybody's time either." (Patient 10)

Patient 8 talked about how she, "… followed their guide, but not always rely on them. I just practice different things as home also."

There appeared to be differences in patient autonomy based on age and ethnicity. Younger patients seemed to push for greater control over decisions, while other patients, such as those who were born outside of Canada, seemed more likely to be passive, compliant patients.

Although therapists did not always know how to best support patients to become engaged and autonomous, they recognized the value in these behaviours.

> "I want them to be, you know, asking me what exercises they can do within the room when they're not in physio. You know, talking to me about what they see [to be] challenging or what they see are problems for going home." (Therapist 5)

Discussion

This paper describes the merits and challenges of outcome measures from the patient's perspective. Outcome measures may serve to engage patients in tracking their own progress, provide affirmation of their improvement, and set them up for increased autonomy after discharge. Maximizing the use of outcome measures must be supported by a solid therapeutic partnership, where effective communication and a trusting relationship enable the patient to make best use of the information they receive through these measures. Patients appear to value objective testing and find tracking progress to be motivating. Therapists may undervalue the importance of taking the time to communicate these findings with patients. Based on the information collected during this research, as well as subsequent conversations with patient partners, several recommendations were developed.

Therapists should select a few measures that relate to everyday life and easily show change over time, rather than tracking many different tests. The recommendation to use outcome measures directly relevant to everyday life aligns closely with the core set of outcome measures recommended by Moore and colleagues, which includes the Berg Balance Scale, the Functional Gait Assessment, the Activities-specific Balance Confidence, the 10 Meter Walk Test, the 6-Minute Walk Test and the 5 Times Sit-to-Stand (J. L. Moore et al., 2018). Therapists and patients described how certain tests felt more meaningful than others. These were typically tests that were easy to understand and closely related to therapy goals. Potter, Sullivan, and colleagues have previously outlined a selection process that ensures outcome measures are specifically targeted to the patient and their presentation (Potter et al., 2011; Sullivan, Andrews, Lanzino, Perron, & Potter, 2011). The Core Set of Outcome Measures for Adults with Neurologic Conditions Undergoing Rehabilitation (J. L. Moore et al., 2018), is comprised of measures that closely relate to day-to-day activities and specifically states that each should be used only if the patient has a goal to improve what the measure is testing. This streamlined approach is patient-centred and ensures that therapy time can be dedicated to therapy, rather than testing. Furthermore, selecting measures that align with a patient's goal, rather than a therapist's or facility's standard practice, could provide consistency as the patient moves through the healthcare system.

Therapists and patients should take some time to discuss standardized testing, including the testing process, what the scores mean, and how the patient is changing over time. Communication is foundational to the therapeutic relationship (Besley, Kayes, & McPherson, 2011). Moore and colleagues have laid out a process for sharing decision making (C. L. Moore & Kaplan, 2018), which could be applied to outcome measure selection and tracking. Surprisingly, only a few patients in our study had an interest in participating in selecting specific outcome measures. Instead, they were interested in discussing how the measures were conducted. Therapists sometimes chose to covertly conduct a test to minimize anxiety or confusion for the patient. Some patients agreed with this approach and acknowledged that the testing process could feel stressful, but preferred it to be a joint, rather than a unilateral decision.

Therapist elaboration was also important, both in helping to understand the scores and the relevance of the score to the patient's goal. Patients liked when a therapist explained, for example, how far or fast they would need to walk to get around the community. They also appreciated when a therapist explained what they could practice to improve their performance. Therapists may not realize how important tracking change is to patients and may not take adequate time to report progress. Davoody and colleagues found that post-stroke, patients felt they did not receive enough information about tracking the rehabilitation process (Davoody, Koch, Krakau, & Hägglund, 2016). Therapists sometimes struggled when a patient showed a lack of progress, often opting to skip reporting the test scores or reframe the result. This is counter to the idea that honesty and transparency are important elements in the therapeutic relationship (Miciak, Mayan, Brown, Joyce, & Gross, 2018). Therapists worried about taking away a patient's hope, but in doing so may have missed an opportunity to ground the patient in realistic hope (Soundy et al., 2010). Repeatedly reporting results of a simple standardized test has also been found to improve patient outcomes for that test (Dobkin, Plummer-D'Amato, Elashoff, & Lee, 2010).

Whenever possible, therapists should use technology, like a patient portal, to share progress with patients, illustrating with graphs or tracking progress to milestones. All the patients who participated in our study expressed an interest in accessing their medical records through a patient portal, despite their demographic differences. This is counter to previous studies that have found that engagement with patient portals remains low (Crameri, Maher, Van Dam, & Prior, 2020), however, it is possible that the patients in our study, who had spent a considerable amount of time with healthcare providers after their stroke, had increased confidence in accessing the system. A Swedish study found that stroke patients were interested in accessing their rehabilitation plan and progress through an electronic health system (Davoody et al., 2016). Our study did not evaluate actual patient portal use, only the patient's interest in accessing their information.

Most patients and therapists liked the idea of visually tracking their health information with targets or milestones marked along the way but were divided regarding whether they wanted to see their results compared to other people like them. Comparing to similar people is a concept suggested by Kittelson and colleagues (Kittelson, Hoogeboom, Schenkman, Stevens-

Lapsley, & van Meeteren, 2019). If possible, it would be best to have comparison data as an optional presentation. A patient portal with data that is easy to access and understand may have positive effects on patient engagement and patient outcomes (Otte-Trojel et al., 2014).

Therapists should show patients how the results from the outcome measures help to make decisions. Over time, decision-making can shift from therapist to patient, especially regarding day-to-day activities. During the observation sessions, we saw a tendency for patients to be deferential. Particularly as inpatients, most patients felt their decisions were driven by the healthcare team. For example, the patientst interviewed felt they needed their therapist's approval before walking independently because they would otherwise risk a catastrophic fall. Within therapy sessions, patients seemed to prefer to be directed by the therapist expert. As outpatients, participants appeared to make decisions about independent mobility based on what they felt they could do rather than discussing these choices with therapists or basing the decision on something objective, like an outcome measure. Previous literature suggests these types of behaviours are based in the hierarchical nature of our healthcare system. Patients may avoid bringing up concerns for fear of being labeled, 'difficult' (Frosch, May, Rendle, Tietbohl, & Elwyn, 2012) and strive to be a good, passive patient (Joseph-Williams, Elwyn, & Edwards, 2014). However well-intentioned the therapist, the therapeutic relationship is often still based in a power strategy and therapists, who must answer to supervisors and funders, may unwillingly contribute to this power imbalance (Cummins, Payne, & Kayes, 2021). Part of the struggle is a focus on patient independence, while embedded in a system that inherently restricts a patient's independence (Jones, Mandy, & Partridge, 2000).

Instead, we might consider moving towards relational autonomy, where patients are provided the information they need to make choices they are capable of (Entwistle et al., 2010) and we recognize that most people in society are interdependent, not independent (McClure & Leah, 2021). Patients may resist the transfer of power and will need to be supported by a strong therapeutic relationship and appropriate education. Collaboratively tracking simple, functional outcome measures may play a role in giving patients the information they need to start making decisions that are increasingly autonomous and may help patients start to take responsibility for their own health. Use of a patient portal could enhance two-way communication between patient and therapist after discharge, providing opportunities for check-ins to avoid an abrupt withdrawal of decision-support. Further study is required to explore to what degree patient involvement in outcome tracking might support autonomous decision making.

Strengths and weaknesses. Overall, this study was conducted with rigour and used multiple sources of information to fully explore outcome measure use in one stroke rehabilitation program. This research significantly benefitted from the addition of three patient partners, who contributed hours to ensuring this work reflects the patient experience. We acknowledge that although these partners were crucial, the fact that they were willing to contribute so much time and effort is because they are exceptionally motivated individuals and may not reflect the average patient. To balance this, we sought to recruit a diverse group of patient participants.

During patient recruitment, we felt we were successful in recruiting a wide range of ages and ethnicities, except for a notable gap. We were unable to recruit any Indigenous people into our study. Upon questioning the therapists, we found that in the study timeframe, very few Indigenous people were admitted to the stroke program and those who were stayed for a very brief time. This is concerning given that the prevalence of stroke among First Nations, Inuit, and Metis people is similar to or greater than other populations in Canada (Atzema et al., 2015; Hu, Singh, Kenny, & Chan, 2019; Kapral et al., 2020).

A primary consideration for this research was the level of patient engagement, as determined by the Hopkins Rehabilitation Engagement Rating Scale (HRERS). This tool is a valid and reliable measure (Kortte et al., 2007), however, after extensive reflection and review of the reflexive journal, it appeared that the scores did not always correlate with our definition of engagement. According to Bright and colleagues, "Engagement is a co-constructed process and state. It incorporates a process of gradually connecting with each other and/or a therapeutic program, which enables the individual to become and active, committed and invested collaborator in healthcare" Pg. 650 (Bright, Kayes, Worrall, & McPherson, 2015). In contrast, adherence commonly describes the degree to which patients follow the directions they have been given (Bissonnette, 2008). All but one patient in our study was rated 'highly engaged' by their therapist, however, this appeared to reflect a patient's level of adherence, rather than their level of engagement. Based on the observation and interviews, we feel we were able to obtain a sample of patients that represent moderate to highly engaged patients and that the HRERS did not fully capture the range. Since the study occurred in a highly specialized stroke program, patient triaging may have screened out patients with very low levels of engagement.

Conclusion

This research is an important step in understanding outcome measures from the patient perspective. Patients valued outcome measures as a means to track progress, particularly when there was a strong therapeutic partnership in place to help them interpret and use the information provided. Outcome measures could help to engage patients more actively in their therapy and might provide them with helpful information that could assist in decision-making after discharge from therapy. Using outcome measures that align with patient goals and clearly communicating progress, through a patient portal and/or through visual tracking are methods that may support active patient engagement. The addition of patient partners, as well as data collection from multiple sources, provides a comprehensive picture of how outcome measures might be used to maximize patient engagement during therapy and empower self-management beyond therapy. The lived experience of the research team as both therapists and patients, as well as suggestions extracted from the transcripts, informed the development of recommendations to guide therapists in the future.

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Conclusion

The purpose of this research was to explore patient perceptions of outcome measures used in physical therapy after stroke. A qualitative case study design was used to robustly explore one rehabilitation stroke program. Case study is a pragmatic approach, providing the reader with practical and contextual information through the description of a single case (Flyvbjerg, 2006). I have previously worked as a clinician in this very stroke program, so in many ways, this work was the culmination of not only my graduate studies to date but also the 15 years I worked as a physical therapist before beginning the program. The final research product was the result of observations, chart reviews, and interviews with participants, as well as discussions with patient partners and extensive self-reflection. Beyond simply answering the research questions, the learnings derived in the process of conducting the research are contributions to knowledge themselves. Therefore, I will summarize each of the following in turn: 1) the process of conducting patient-oriented research in the context of both a major healthcare pandemic and the roll-out of a provincial electronic healthcare record, 2) key findings that answered the research questions, including clinical implications and dissemination, and 3) next steps for analysis, publication, and research.

Research Process

***Process of conducting patient-oriented research*.** The Canadian Institutes of Health Research supports patient-oriented research as a priority and has developed the Strategy for Patient Oriented Research (SPOR) to support this aim. The Patient Engagement Framework states that patient-oriented research should feature inclusiveness, support, mutual respect, and be co-built (CIHR, 2014). Additional support for researchers and patient partners can be found in Alberta at the Alberta SPOR Support Unit. Despite endorsement, it has been found that very little research engages patients throughout the research lifecycle (Manafo, Petermann, Mason-Lai, & Vandall-Walker, 2018). We sought to create research that followed the patient-oriented research principles as closely as possible.

Under the guidance of the Alberta SPOR Support Unit, we recruited three patient partners through previous contacts and word of mouth. Each patient partner had experienced a severe stroke in the last 10 years. While not representative of the average person with stroke – they were each involved in volunteer work and were all under the average age of stroke – they tried to imagine other patients' perspectives. Through some trial and error, we found processes that worked for this diverse group of individuals. We managed to secure an honorarium payment for each partner to ensure that they were compensated for their work and mutually established a contract, so the expectations were clear. In the end, they went above and beyond the expectations of the contract, but we reminded them at each meeting that they were free to leave whenever they chose.

Meetings were loosely structured with agenda items or anything to prepare sent in advance. This met the needs of both the partner with aphasia and the other two, who generated ideas best when not confined to a structure. The patient partners provided guidance on the interviews, helping to pilot, adjust and problem solve. They also contributed to the final analysis. Since the data collection phase had produced an overwhelming amount of transcript pages, we opted to begin the coding process prior to presenting it to the patient partners. They divided the interview transcripts between the three of them, so they each understood a portion of the data and were advised to take their personal experience into account. We then clustered quotes into what we thought were key themes and presented them to the patient partners. They reviewed the unlabeled groupings and help to brainstorm the final themes for the paper. Documentation of our processes will contribute to knowledge about methods of conducting patient-oriented research, particularly when involving patient partners who might have experienced effects of their illness/injury that limit their ability to participate in research. The experience of conducting research with patient partners will continue to shape my work in the future.

Conducting research in a pandemic. Patient partners were recruited in the summer of 2020, with data collection occurring from January to May of 2021, placing this research squarely in the middle of the largest healthcare pandemic of our lifetime. Due to COVID-19, several of our original plans needed to be adjusted. All meetings with patient partners were conducted over Zoom. There were benefits and challenges to this process. As the meeting facilitator, the online format made it easy to share documents that I wanted to talk about. It was easy to plan meetings because I did not have to secure a meeting room and we did not have to compensate the partners for the cost of parking or travel. The partners were well-versed in the use of Zoom and found the online meetings easier to fit into their schedules. Facilitating discussions was challenging over Zoom, particularly with the one partner with aphasia. While the other partners tried to make space for his opinions in the discussion, sometimes the dual task of trying to come up with the right words and then interject himself into a rapid discussion was too difficult. To ensure his opinion was still included, I often followed up over email and he would provide additional thoughts in written format.

Recruiting and interviewing patients also came with additional hurdles in the pandemic. As an employee of the hospital where the research was conducted, I was able to come and go freely to talk with inpatients, provided I was wearing full personal protective equipment. Outpatient recruitment and data collection was a far greater challenge. Many outpatient services had been canceled to redeploy staff to cover other areas of the hospital. With significantly fewer patients coming through the outpatient area, it took much longer to recruit an adequately diverse sample. Research interviews were set up remotely, but some of the patients struggled with Zoom. Interviews were shifted to phone interviews where necessary. One patient was not able to access Zoom and, due to financial struggles, did not have a working phone. She was able to periodically access email, so she completed the interview in written format. Working within this incredibly challenging time helped me to explore alternate avenues and to not hold too tightly to an established protocol.

Conducting research during the roll-out of an electronic health record. The province of Alberta has elected to implement a province-wide electronic health record. This massive undertaking has required a multi-staged roll-out where analysts from both the province and the vendor work together to ensure the system is working the way it needs to. In the future, the analysts for the vendor will withdraw and fewer modifications will be possible in the system. At the time of data collection, the hospital in which the case study was conducted was functioning in a hybrid state. Outpatient care had fully converted to the electronic health record, but inpatients had not yet started the process. The hybrid state presented benefits and challenges. When receiving operational approval, some requirements were not well-known and it took several extra months to receive final approval since we needed to be able to access both the electronic system and the paper-based system. A primary benefit has been that I have been able to take part in provincial discussions where I can informally share feedback from patients before the conclusion of the study. I hope that this research will play a small part in shaping the electronic health system so that it is more accessible and useable for patients.

Answering the research questions

***What are patients' perceptions of outcome measures post-stroke*?** There was no a priori hypothesis for this qualitative case study. However, as an experienced clinician, I entered with assumptions about patient's perceptions, some of which proved incorrect. The first theme from the research was regarding measuring progress over time. I was surprised by how consistently patients of all ages and backgrounds expressed that they appreciated objective testing. During my time as a clinician, I didn't think that most patients cared very much about standardized testing. After listening to many of the patients and observing other therapists, I reflected on the process of conducting standardized tests. I realized that, like the clinicians I had observed, I was often moving through the testing quickly and skimming through explanations for the patients. This research showed that patients are interested in data, but they need the details explained so they can understand the application to their own life. Many stated unequivocally that seeing numbers improve on a test was highly motivating and reassuring. I was not surprised to hear that most patients measured progress primarily through the activities of daily living that they could or could not do. Discussions about this with the patient partners led us to recommend that outcome measures reflect this. We encourage therapists to select tests that primarily measure tangible, functional changes. This means that the patient can easily see the application to their own life.

We might also look to work that is emerging from the Academy of Neurologic Physical Therapy. This group is re-imagining physical therapy assessment and has proposed a framework for movement analysis to be used in conjunction with appropriate outcome measures (Quinn et al., 2021). The framework revolves around analysis of core tasks: sitting, sit to stand, standing, walking, stepping, and reaching/grasping/manipulating. Use and communication of a movement framework in conjunction with functional outcome measures may further help patients to better understand their own capabilities.

How do outcome measures relate to concepts of patient engagement and relational autonomy?

The second primary theme that emerged from the research was one of partnership. This endorses our accepted definition that engagement is a co-created state (Bright, Kayes, Worrall, & McPherson, 2015; Carman et al., 2013). The importance patients placed on the partnership between patient and therapist provides further support to the concept of the therapeutic relationship, which has been well studied (Babatunde, MacDermid, & MacIntyre, 2017; Besley, Kayes, & McPherson, 2011; Hall, Ferreira, Maher, Latimer, & Ferreira, 2010; Miciak, Mayan, Brown, Joyce, & Gross, 2018; Morera-Balaguer et al., 2021). Patients appreciated clear communication, trusted their therapist as the expert, and found motivation in the encouragement and affirmation provided by their therapist. This appeared to be the platform from which patients could become more engaged.

An undercurrent throughout the interview transcripts was the question of autonomy. Patients initially seemed to view their time in therapy as temporary. They trusted that if they followed their therapist's guidance, they would 'get better'. As a patient's time in therapy progressed, particularly once they were back at home, they seemed to take back some of their own decision-making. Our patient partners confirmed that their idea of what the rehabilitation journey would look like shifted over time. Unfortunately, autonomous decision-making appeared to be a somewhat binary state. Patients were either doing what their therapist asked them to do or they were making their own decisions to the best of their ability. Embracing the concept of relationship autonomy (Ells, Hunt Matthew, & Chambers-Evans, 2011) would help therapists to support the patient as needed, gradually shifting decision-making to the patient and family as discharge approaches. Effective communication around progress through rehabilitation may provide patients with the tools they require to begin to make independent decisions. If possible, therapist support could continue to be available through electronic means after discharge.

How might outcome measures be used to maximize engagement? Outcome measures and how they are presented may serve to maximize engagement both by providing encouragement and by improving a patient's knowledge of their capabilities. Patients in this study reported that seeing objective improvement on a standardized test was very encouraging. Danzl and colleagues suggest that therapists may use motivational strategies to build confidence and self-efficacy, thereby increasing engagement (Danzl, Etter, Andreatta, & Kitzman, 2012). Over the longer term, patients will be responsible for the management of their own condition and they will be better prepared to take an active role if they have knowledge of their condition and abilities (Anderson, 1995). The results from this study indicate that patients would like accessible outcome results. Many liked the idea of a graph to show progress over time and all wanted to be able to access their results through a patient portal. Information that is easy to understand is a principle of health literacy (Koh, Brach, Harris, & Parchman, 2013) and patients are interested in accessing data on their progress and rehabilitation even after discharge (Davoody, Koch, Krakau, & Hägglund, 2016).

Clinical Implications

This research has the potential to impact both patient-therapist interactions and outcome measure use at the system level. Understanding how patients perceive outcome measures may encourage therapists to involve patients in the tracking of outcome measures, both by providing education about the measures selected and by ensuring patients understand the outcomes.

Presenting progress using a variety of formats may improve patient's understanding of the data. This includes graphing progress, indicating which functional milestones are associated with certain scores, marking final goals to target, and comparing progress to similar patients. Based on the information in this study, therapists may choose to limit outcome measures to only those most relevant to the patient.

At a system level, this information may improve length of stay efficiency and inform how patients are able to access results on an electronic patient portal. Patients and therapists have suggested that certain outcome measures are more valuable than others, however, sometimes therapists conduct several tests out of habit or facility expectation. We also know that intensity of treatment is an important factor in motor recovery (Jennifer L et al., 2020; Klassen et al., 2020). If therapists can decrease the number of tests performed to those that are the most universally meaningful, this will increase the amount of time they can spend treating the patient, thereby improving their overall effectiveness and efficiency. Furthermore, as access to electronic patient portals is improved, analysts and technicians can use the information from this study to enhance the type of data provided to patients, such as using visual displays, and showing progress over time.

Dissemination

Dissemination of findings will start with presentations of recommendations to appropriate staff within Alberta Health Services. The patient partners will be invited to co-lead these presentations to ensure the information remains patient-centred. Separate sessions will be offered for therapists and administrators responsible for the roll-out of the electronic health record.

More formal presentations will include poster presentations at relevant research conferences, such as the Alberta Strategy for Patient Oriented Research Unit Virtual Institute. A manuscript of this research, as well as the process of conducting patient-oriented research and secondary analysis of therapist transcripts, will also be submitted to peer-reviewed journals.

Future research

Process of patient-oriented research. I found in the course of this research that there were very few resources available to guide me in engaging patient partners, particularly those who had limitations due to their stroke. I was able to work with three exceptional partners who provided feedback and gave permission for all our meetings to be recorded. I plan to work with the three of them to produce a journal manuscript to discuss our journey and articulate solutions we tested for certain challenges. This manuscript will include information on why we included three partners, how we accommodated a partner with aphasia, strategies I used to guide and facilitate communication, and how the patient partners participated in the data analysis. Data analysis proved to be one of the most difficult components, but through our collaboration with the Alberta Strategy for Patient Oriented Research, we were able to find successful methods.

Clinical decision-making and outcome measures. Upon reviewing the pages of transcripts generated in this study, I realized that there is a second story within the data. Therapist interviews, specifically, had information about clinical decision-making and outcome measures that were beyond the scope of my research questions. I plan to perform a secondary analysis of the data to support another publication. Therapists discussed the challenges of selecting the most appropriate outcome measure and how their choices were sometimes guided not by the patient's goals, but by habit and/or perceived expectations from the department or healthcare team.

Therapists also had varying ideas of how outcome measures supported their clinical decision-making. A reflection I had when conducting these interviews was how clinicians sometimes struggle with prognostication; effectively mapping outcomes over time may assist the therapist as much as the patient.

Patient autonomy within the healthcare system. Observing other therapists and conducting a variety of interviews was interesting with my lens as an experienced physical therapist. I found myself becoming curious about how to practically apply the concept of patient autonomy, as well as the role the healthcare system plays in supporting patient autonomy. I noticed that some systems I had participated in, such as language used or process of limiting patient independence, felt uncomfortable when I watched them unfold as an outsider. Patients were sometimes chastised for their poor choices or told to await 'permission' to do certain tasks independently. I realize that the answer is not handing full responsibility over to the patient because as a young practitioner, I also tried this approach and found it was uniformly unsuccessful. The concept of relational autonomy, introduced to me by an instructor at the university, appears to be an appropriate middle ground. I am interested in further exploring this concept as it relates to stroke physical rehabilitation in future research.

Final Comments

This research represents a valuable contribution to the field at a critical time. Outcome measures are highly recommended, but there is little information available from the patient perspective. This case study showed that patients are interested in outcome measures and value objective tracking over time. At a time when there may be a push to measure everything, patients and therapists have indicated that selecting a smaller number of relevant measures may be more meaningful to patients. Patient interest in information available through a patient portal is timely, as Alberta Health Services is in the middle of a province-wide roll-out of an electronic health record that comes equipped with a patient portal. Analysts are currently making adjustments to the platform based on feedback received. This study may be able to impact the information patients can access within the patient portal. The themes uncovered through analysis also provide support for a growing area of research, the therapeutic relationship. Despite the fact the interview revolved around outcome measures, patients took the time to communicate how valuable partnership with their therapist is to them. Finally, the process of conducting research with three patient partners contributes to the growing body of literature in which patients are an active part of the research team.

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Appendices

Appendix A - Consent to be Contacted

CONSENT TO CONTACT FOR RESEARCH PURPOSES

TITLE: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke

INVESTIGATORS:

Research Investigator:	Alyson Kwok	Phone: (780)735-6142
Supervisor:	Dr. Patricia Manns	Phone: (780)492-7274

You are being asked to give consent for Alyson Kwok, or a qualified member of her study team to contact you at some time in the future to tell you more information about a research study.

Are you willing to learn more about the Maximizing patient engagement through collaborative outcome measure selection and tracking study? (Circle one) YES NO

If yes, you will be contacted at a later date. Please include your contact information below.

Name: ____
Phone Number: ____

By signing this form you authorize the disclosure of your name and telephone number to the research team for the purpose of being contacted to learn more about the research study, Maximizing patient engagement through collaborative outcome measure selection and tracking.

Every effort will be made to safeguard your contact information. Although access to this information will be limited, there is a small chance that this information could be inadvertently disclosed or inappropriately accessed.

You have been made aware of the reasons why the contact information is needed and the risks and benefits of consenting or refusing to consent.

This consent is effective immediately. Your consent to be contacted can be revoked by you at any time.

Patient's Signature: ____

Date: ________________

Clinician's Name: ____

Appendix B - Patient Consent

PARTICIPANT CONSENT FORM

Title of Research Study: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: Alyson Kwok Phone: (780)735-6142

Supervisor: Dr. Patricia Manns Phone: (780)492-7274

Why am I being asked to take part in this research study? You are being asked to be in this study because you are experienced a stroke and are currently participating in physical therapy at the Glenrose. After stroke, physical therapists typically perform several tests to monitor how you are doing. These tests are called outcome measures. We are interested in your experience with these measures and your opinions about them. for this study. Before you make a decision one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study? Past research around physical therapy outcome measures after stroke has not included patients' experience and opinions. We would like your opinion on these measures to be able to make recommendations for improvement.

What will I be asked to do? There are 4 parts to this study. You may withdraw at any time.

1) A researcher will look over your medical chart to gather some information about the type of stroke you experienced, the type of physical therapy outcome measures you are using and any other documentation from your physical therapist around outcome measures. At this time, your physical therapist will also complete a questionnaire about you.
2) A researcher will come to some of your physical therapy sessions to watch the conversations you have with your physical therapist. The researcher will take notes about these sessions.
3) You will be invited to participate in an interview with one researcher. In this interview, you will be asked several questions about your experience. The interview will take about 60-90 minutes. It will be video recorded. The interview will be held in a private location that is convenient for you or can be completed remotely. All hospital protocols, such as using a mask and handwashing, will be followed during this interview if it occurs in person.
4) You will be invited to participate in a group interview, called a focus group. In this focus group, other patients participating in the study will join you to talk a little more about physical therapy outcome measures. During this focus group, you will be encouraged to help to come up with and vote on recommendations for changes. This focus group will be held in a location that is most convenient for the group. If the location chosen is not convenient for you, but you would still like to participate, the research team will arrange for you to join using a computer or telephone. The focus group will be video recorded. If the focus group occurs in person, everyone will be asked to wear a mask and to wash their hands before and after the session.

What are the risks and discomforts? There are no known risks associated with this study. Speaking in the interview or focus groups may leave you feeling tired. If you feel tired at any time, you may take or break or stop. In addition, any in-person interactions are currently associated with an increased risk of communicable diseases such as COVID-19. This includes in-person interactions on public transport if this is required to travel to your interview. To minimize your risk, all communication can be conducted virtually. If you are comfortable proceeding with in-person sessions, everyone participating will wear masks and keep 2m apart. Hand sanitizer will be provided before and after every session and all surfaces, such as tables and chairs, will be cleaned before and after use.

What are the benefits to me? By taking part in this study, you will help to develop recommendations for improvements. These improvements may help many patients in the future. You will not receive any direct benefits however many people report that working in this type of project is satisfying.

Do I have to take part in the study? Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the treatment that you receive.

Will I be paid to be in the research? We would like to make it easy for you to attend the interviews and the focus group. If you need to travel, we will pay for you parking ($2.25/hr) or bus tickets. If you have young children who require childcare, we will pay for the cost of childcare ($20/hr).

Will my information be kept private? The investigator or their study staff may need to look at your personal health records or at those kept by other health care providers that you have seen in the past (i.e. your family doctor). Any personal health information that we get from these records will only be what is needed for the study. During research studies it is important that the data we get is accurate. For this reason your health data, including your name, may be looked at by people from the University of Alberta, HREB, Health Canada and/or other foreign regulatory agencies. By signing this consent form you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above.

We will do everything we can to make sure that this data is kept private. In the focus group, any information you share will be heard by the group and we cannot guarantee that others from the focus groups will maintain the confidentiality of what is discussed. No data relating to this study that includes your name or any other identifying information will be released outside of the researcher's office or published by the researchers.

After the study is done, all the information will be kept electronically for a minimum of 5 yrs. Access will be password protected. Only the research team will be able to access this data.

What if I have questions? If you have any questions about the research now or later, please contact Alyson Kwok at 780-735-6142. If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT FORM

Title of Study: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: Alyson Kwok BScPT **Phone Number: (780) 735-6142**

Supervisor: Patricia Manns PhD **Phone Number: (780) 492-7274**

	Yes	No
Do you understand that you have been asked to be in a research study?	×	×
Have you read and received a copy of the attached Information Sheet?	×	×
Do you understand the benefits and risks involved in taking part in this research study?	×	×
Have you had an opportunity to ask questions and discuss this study?	×	×
Do you understand that you are free to leave the study at any time, without having to give a reason and without penalty?	×	×
Has the issue of confidentiality been explained to you?	×	×
Do you understand who will have access to your records, including personally identifiable health information?	×	×
Future Contact		
Do you agree to be contacted for follow-up or to facilitate future research?	×	×

Who explained this study to you?
____

I agree to take part in this study:

Signature of Research Participant
____

(Printed Name)
____

Date:_______________________________

Signature of Witness
____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee _________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A SIGNED COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix C - Physical Therapist Consent

PARTICIPANT CONSENT FORM

Title of Research Study: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: Alyson Kwok Phone: (780)735-6142

Supervisor: Dr. Patricia Manns Phone: (780)492-7274

Why am I being asked to take part in this research study? You are being asked to be in this study because you are experienced a stroke and are currently participating in physical therapy at the Glenrose. After stroke, physical therapists typically perform several tests to monitor how you are doing. These tests are called outcome measures. We are interested in your experience with these measures and your opinions about them. for this study. Before you make a decision one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study? Past research around physical therapy outcome measures after stroke has not included patients' experience and opinions. We would like your opinion on these measures to be able to make recommendations for improvement.

What will I be asked to do? There are 4 parts to this study. You may withdraw at any time.

1) A researcher will look over your medical chart to gather some information about the type of stroke you experienced, the type of physical therapy outcome measures you are using and any other documentation from your physical therapist around outcome measures. At this time, your physical therapist will also complete a questionnaire about you.
2) A researcher will come to some of your physical therapy sessions to watch the conversations you have with your physical therapist. The researcher will take notes about these sessions.
3) You will be invited to participate in an interview with one researcher. In this interview, you will be asked several questions about your experience. The interview will take about 60-90 minutes. It will be video recorded. The interview will be held in a private location that is convenient for you or can be completed remotely. All hospital protocols, such as using a mask and handwashing, will be followed during this interview if it occurs in person.
4) You will be invited to participate in a group interview, called a focus group. In this focus group, other patients participating in the study will join you to talk a little more about physical therapy outcome measures. During this focus group, you will be encouraged to help to come up with and vote on recommendations for changes. This focus group will be held in a location that is most convenient for the group. If the location chosen is not convenient for you, but you would still like to participate, the research team will arrange for you to join using a computer or

telephone. The focus group will be video recorded. If the focus group occurs in person, everyone will be asked to wear a mask and to wash their hands before and after the session.

What are the risks and discomforts? There are no known risks associated with this study. Speaking in the interview or focus groups may leave you feeling tired. If you feel tired at any time, you may take or break or stop. In addition, any in-person interactions are currently associated with an increased risk of communicable diseases such as COVID-19. This includes in-person interactions on public transport if this is required to travel to your interview. To minimize your risk, all communication can be conducted virtually. If you are comfortable proceeding with in-person sessions, everyone participating will wear masks and keep 2m apart. Hand sanitizer will be provided before and after every session and all surfaces, such as tables and chairs, will be cleaned before and after use.

What are the benefits to me? By taking part in this study, you will help to develop recommendations for improvements. These improvements may help many patients in the future. You will not receive any direct benefits however many people report that working in this type of project is satisfying.

Do I have to take part in the study? Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the treatment that you receive.

Will I be paid to be in the research? We would like to make it easy for you to attend the interviews and the focus group. If you need to travel, we will pay for you parking ($2.25/hr) or bus tickets. If you have young children who require childcare, we will pay for the cost of childcare ($20/hr).

Will my information be kept private? The investigator or their study staff may need to look at your personal health records or at those kept by other health care providers that you have seen in the past (i.e. your family doctor). Any personal health information that we get from these records will only be what is needed for the study. During research studies it is important that the data we get is accurate. For this reason your health data, including your name, may be looked at by people from the University of Alberta, HREB, Health Canada and/or other foreign regulatory agencies. By signing this consent form you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above.

We will do everything we can to make sure that this data is kept private. In the focus group, any information you share will be heard by the group and we cannot guarantee that others from the focus groups will maintain the confidentiality of what is discussed. No data relating to this study that includes your name or any other identifying information will be released outside of the researcher's office or published by the researchers.

After the study is done, all the information will be kept electronically for a minimum of 5 yrs. Access will be password protected. Only the research team will be able to access this data.

What if I have questions? If you have any questions about the research now or later, please contact Alyson Kwok at 780-735-6142. If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT FORM

Title of Study: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients’ perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: Alyson Kwok BScPT **Phone Number: (780) 735-6142**

Supervisor: Patricia Manns PhD **Phone Number: (780) 492-7274**

	Yes	No
Do you understand that you have been asked to be in a research study?	×	×
Have you read and received a copy of the attached Information Sheet?	×	×
Do you understand the benefits and risks involved in taking part in this research study?	×	×
Have you had an opportunity to ask questions and discuss this study?	×	×
Do you understand that you are free to leave the study at any time, without having to give a reason and without penalty?	×	×
Has the issue of confidentiality been explained to you?	×	×
Do you understand who will have access to your records, including personally identifiable health information?	×	×
Future Contact		
Do you agree to be contacted for follow-up or to facilitate future research?	×	×

Who explained this study to you?
____

I agree to take part in this study:

Signature of Research Participant
____

(Printed Name)
____

Date:_______________________________

Signature of Witness
____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ___________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A SIGNED COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix D - Physical Therapist Consent – Observation Only

PARTICIPANT CONSENT FORM

Title of Research Study: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: Alyson Kwok Phone: (780)735-6142

Supervisor: Dr. Patricia Manns Phone: (780)492-7274

Why am I being asked to take part in this research study? You are being asked to be in this study because you are the primary physical therapist for a patient in the stroke program at the Glenrose Rehabilitation Hospital who has consented to participate in this study. We would like to observe this patient during physical therapy sessions.

What is the reason for doing the study? This research is primarily focused on gathering patient perceptions of outcome measures post-stroke, which has been identified as a gap in the literature. We are also asking physical therapists for their opinions to ensure we have a complete picture of current processes and suggestions for improvement.

What will I be asked to do? You will be asked to complete a questionnaire about your patient. You will also be observed during some interactions with this patient, particularly when discussing goals and outcome measures.

What are the risks and discomforts? There are no known risks associated with this study. In-person observations may increase your risk of communicable diseases, such as COVID-19. The observer will follow all facility protocols, including maintaining appropriate distance, wearing a mask and handwashing regularly. Some people also feel uncomfortable during observations. If, at any time, you feel uncomfortable, you may choose to end the observation session.

What are the benefits to me? By taking part in this study, you will help to develop recommendations for improvements. These improvements may help many patients in the future. You will not receive any direct benefits however many people report that participating in this type of project is satisfying.

Do I have to take part in the study? Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time.

Will I be paid to be in the research? Participation is voluntary, so you will not receive any payment for participation.

Will my information be kept private? Observations will not be recorded; however the observer will take detailed notes. These notes will be kept in a secure location that can only be accessed by the research team. No data relating to this study that includes your name or any other identifying information will be released outside of the researcher's office or published by the researchers.

After the study is done, all the information will be kept electronically for a minimum of 5 yrs. Access will be password protected. Only the research team will be able to access this data.

What if I have questions? If you have any questions about the research now or later, please contact Alyson Kwok at 780-735-6142. If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT FORM

Title of Study: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: Alyson Kwok BScPT **Phone Number: (780) 735-6142**

Supervisor: Patricia Manns PhD **Phone Number: (780)-492-7274**

	<u>Yes</u>	<u>No</u>
Do you understand that you have been asked to be in a research study?	×	×
Have you read and received a copy of the attached Information Sheet?	×	×
Do you understand the benefits and risks involved in taking part in this research study?	×	×
Have you had an opportunity to ask questions and discuss this study?	×	×
Do you understand that you are free to leave the study at any time, without having to give a reason and without penalty?	×	×
Has the issue of confidentiality been explained to you?	×	×
Do you understand who will have access to your records?	×	×

Who explained this study to you?

____

I agree to take part in this study:

Signature of Research Participant
____

(Printed Name)
____

Date:__________________________

Signature of Witness
____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ____________________________ Date
____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A SIGNED COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix E - Patient Consent – Aphasia Friendly

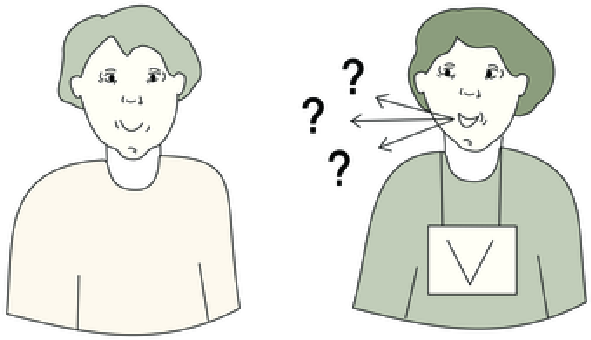
RESEARCH STUDY

Maximizing patient engagement through collaborative outcome measure selection and tracking: perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: **Alyson Kwok, BScPT** **(780)735-6142**

Supervisor: **Patricia Manns, PhD** **(780)492-7274**

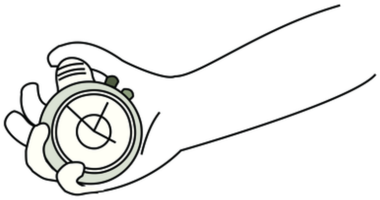
PURPOSE

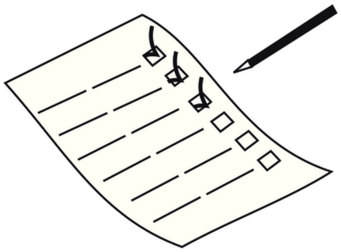


We would like you to tell us what you think

about physical therapy **outcome measures** used after stroke.

Outcome measures are tests used to measure how well you are doing.



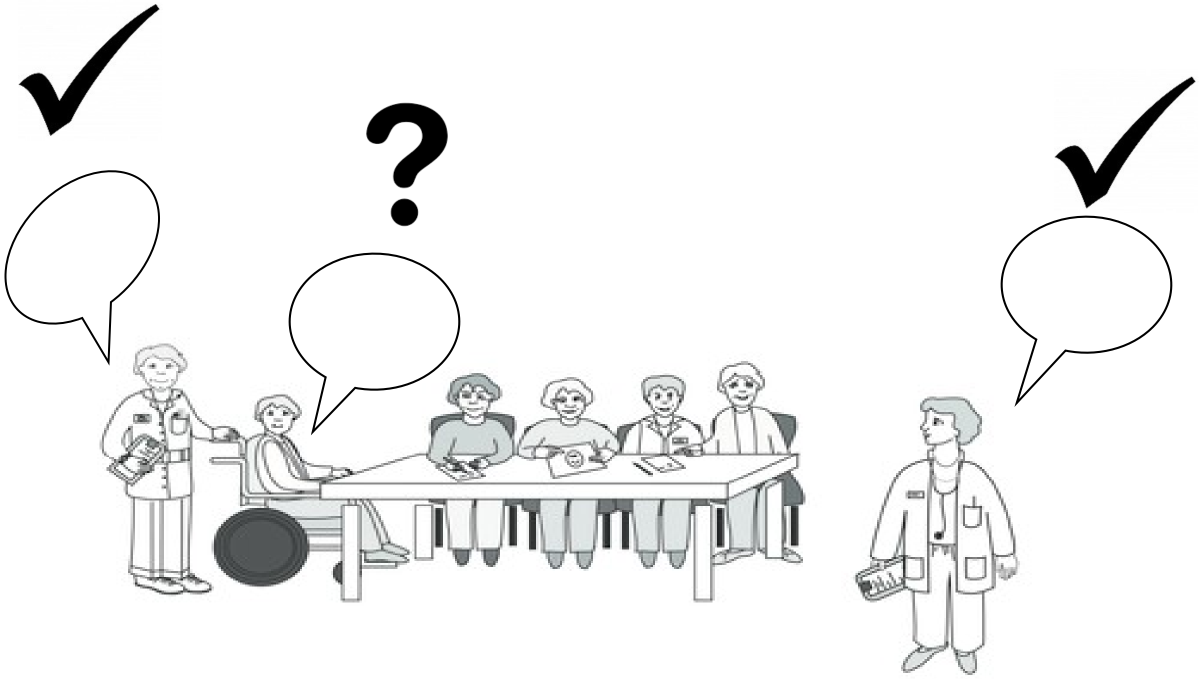


WHY ME?

You are invited to participate because you are receiving **physical therapy** at the **Glenrose** after experiencing a **stroke**.

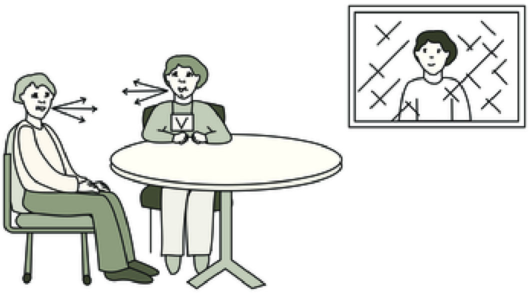
WHAT IS THE REASON FOR THIS STUDY?

We know what physiotherapists think about outcome measures. We want to know what **patients think** of physical therapy outcome measures.

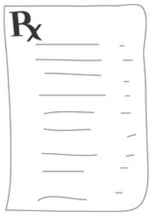


WHAT WILL I DO IN THE STUDY?

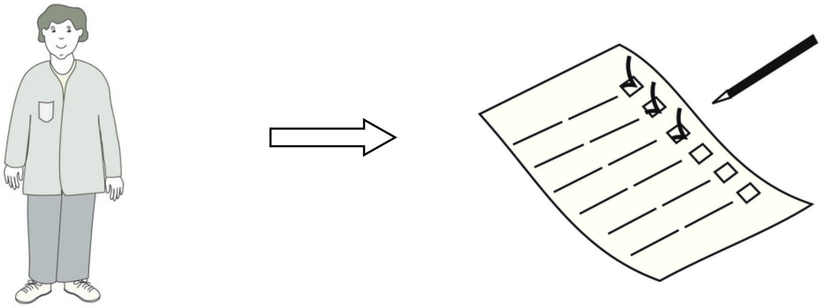
There are **4** parts to this study:



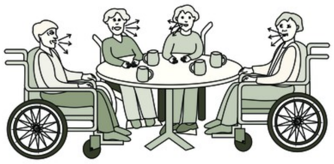
1) A researcher will **watch** some of your conversations with your physical therapist



2) A researcher will **read** your **medical chart and your physical therapist will answer questions about you**



3) You will be **interviewed**



4) You will join a **group interview** to talk about what you liked and didn't like

WHERE?

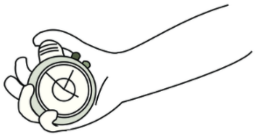
The interviews could happen at the Glenrose or virtually

your

home

zoom

HOW LONG?

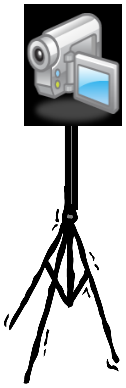
Each interview  will last **60-90** minutes.

We will take **breaks** if you get **tired**

or we can **stop** at any time

Digital Audio/Video Recording

Your interviews will be video recorded

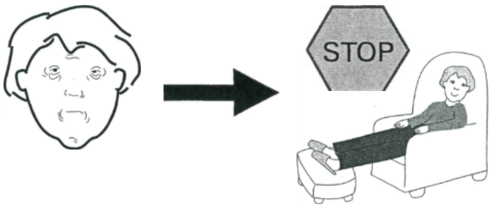


PARTICIPATION IN THE STUDY

Possible Risks

No danger

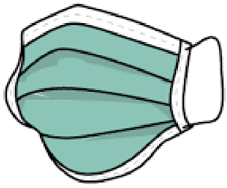
- NO medical procedures and NO known risks
- If you become frustrated or tired you may take a rest break or stop.



- In-person interviews may increase your risk of COVID-19

↑COVID-19 RISK

- We will wear masks and use hand sanitizer



or you can choose to use Zoom
instead

Potential benefits

✓ This *may* help researchers

✓ This *may* help other patients

Right to withdraw

✓ It is your choice

✓ You can stop at any time

✓ It is okay to quit

✓ Withdrawal will not affect your usual care

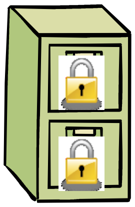
<u>WILL I BE PAID TO BE IN THE RESEARCH?</u>

- You will be reimbursed for parking expenses or be provided with bus tickets.

WILL MY INFORMATION BE KEPT PRIVATE?

Everything is confidential

Personal information, data and video recordings are all kept confidential and are only seen by the researchers working on the study.



This information is kept in locked cabinets behind locked doors and all computer files are kept on a secure server.

No personal information will be mentioned in

any resulting publication or presentation.

QUESTIONS or CONCERNS

1) About this project?
   Please contact:

☎ Alyson Kwok, 780-735-6142, alyson.kwok@ahs.ca ✉

2) About your rights as a research participant?

☎ University of Alberta Health Research Ethics Board

780-492-2615

We would like to acknowledge and thank the Aphasia Institute for some of the pictographs used in this information consent form

CONSENT FORM

Title of Study: Maximizing patient engagement through collaborative outcome measure selection and tracking: patients' perceptions of the use of physical therapy outcome measures post-stroke

Research Investigator: Alyson Kwok BScPT **Phone Number: (780) 735-6142**

Supervisor: Patricia Manns PhD **Phone Number: (780) 492-7274**

	Yes	No
Do you understand that you have been asked to be in a research study?	✗	✗
Have you read and received a copy of the attached Information Sheet?	✗	✗
Do you understand the benefits and risks involved in taking part in this research study?	✗	✗
Have you had an opportunity to ask questions and discuss this study?	✗	✗
Do you understand that you are free to leave the study at any time, without having to give a reason and without penalty?	✗	✗
Has the issue of confidentiality been explained to you?	✗	✗
Do you understand who will have access to your records, including personally identifiable health information?	✗	✗
Future Contact		
Do you agree to be contacted for follow-up or to facilitate future research?	✗	✗

Who explained this study to you?

____

I agree to take part in this study:

Signature of Research Participant

____

(Printed Name)

____

Date:______________________________

Signature of Witness

____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A SIGNED COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix F - Chart Collection Form

Maximizing Patient Engagement through Collaborative Outcome Measure Selection and Tracking

Data Collection Sheet

Participant #:

Primary physical therapist:

Year of birth:

Specific stroke diagnosis:

Date of stroke:

Inpatient or outpatient program:

Data of admission to current program:

Other hospital admissions or therapy programs prior to current program:

Comorbid conditions:

Sex:

Ethnicity:

Details about current residence (rural/urban, home/apartment/assisted living & postal code):

Impairments due to stroke:

Current description of mobility (transfers, ambulation):

Premorbid level of independence:

Physical therapy goals in chart:

Physical therapy outcome measures in chart:

Documentation around patient involvement in outcome measures selection and tracking:

Appendix G - UCSD Capacity to Consent

UCSD Brief Assessment of Capacity to Consent (UBACC)

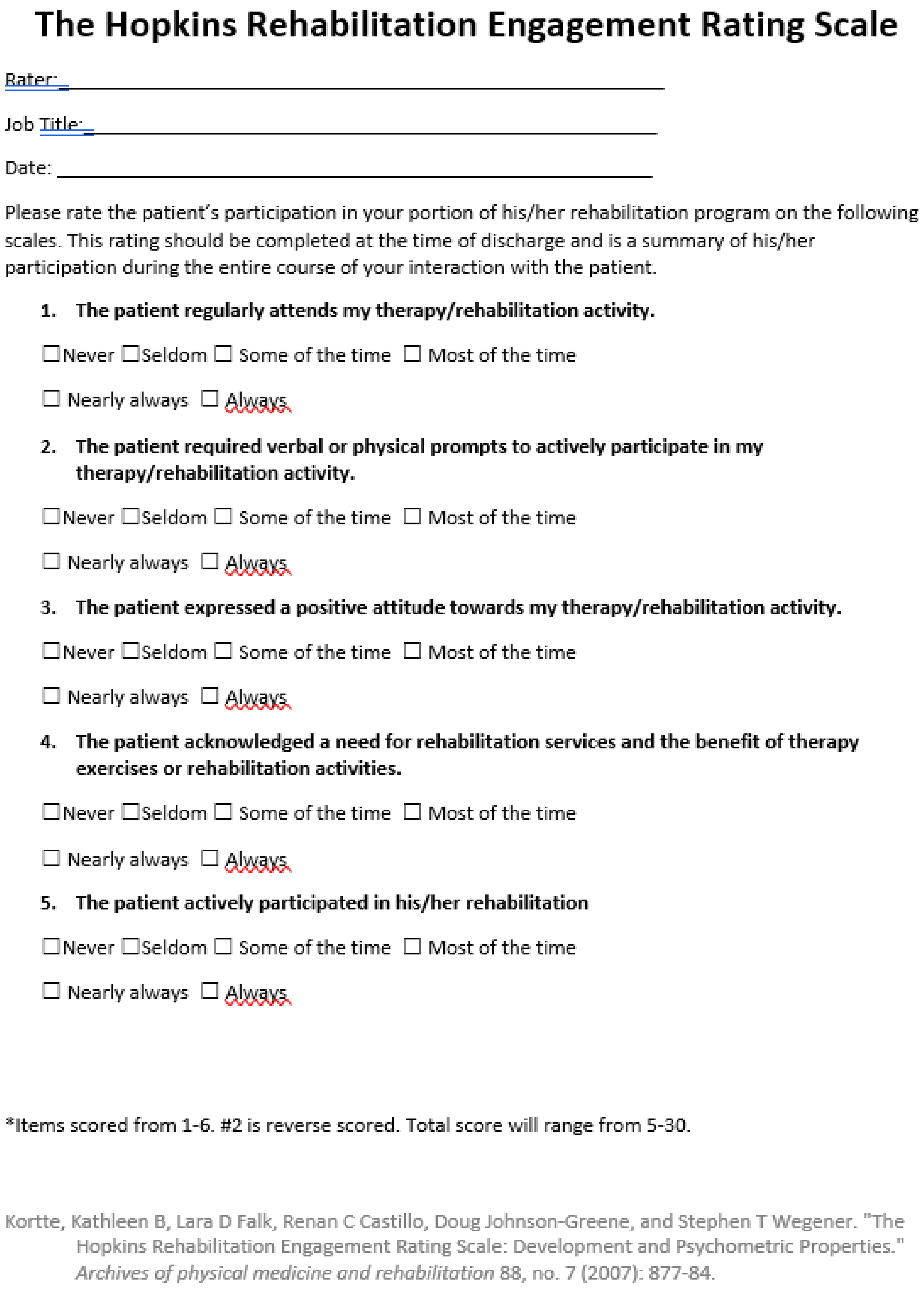
1.What is the purpose of the study that was just described to you?	
Response (2= Tell us what you think about outcome measures after stroke)	Score
	0
	1
	2
2.What makes you want to consider participating in this study?	
Response (2=Help others)	Score
	0
	1
	2
3.Do you believe this is primarily research or primarily treatment?	
Response (2= primarily research)	Score
	0
	1
	2
4.Do you have to be in this study if you do not want to participate?	
Response (2=No)	Score
	0
	1
	2
5.If you withdraw from this study, will you still be able to receive regular treatment?	
Response (2=Yes)	Score
	0
	1
	2
6.If you participate in this study, what are some of the things that you will be asked to do?	
Response (2 = Any 2 of: participate in interviews, participate in a focus group, be observed, allow access to my medical chart)	Score
	0
	1
	2
7.Please describe some of the risks or discomforts that people may experience if they participate in this study?	
Response (2=Frustration or fatigue)	Score
	0
	1
	2
8.Please describe some of the possible benefits of this study.	
Response (2=Help other researchers or patients)	Score
	0
	1
	2
9.Is it possible that being in this study will not have any benefit to you?	
Response (2=Yes)	Score

	0
	1
	2
10.Who will pay for your medical care if you are injured as a direct result of participating in this study?	
NA - #10 will not be asked	

A deviation from the predetermined answer will be scored as 1 or 0. If an answer to a question is ambiguous or uncertain, the subject should be asked follow-up questions to clarify. If a subject does not get a score of 2, the information o the items missed may be repeated and the specific question(s) asked again. This may be done for a total of 3 trials. During the second and third trials, it is important to ensure that the subject does not merely parrot back information but shows clear understanding of the issue.

Jeste, Dilip V., Barton W. Palmer, Paul S. Appelbaum, Shahrokh Golshan, Danielle Glorioso, Laura B. Dunn, Kathleen Kim, Thomas Meeks, and Helena C. Kraemer. "A New Brief Instrument for Assessing Decisional Capacity for Clinical Research." Article. *Archives of general psychiatry*, no. 8 (2007): 966.

Appendix H - The Hopkins Rehabilitation Engagement Rating Scale



The Hopkins Rehabilitation Engagement Rating Scale

Rater: ____

Job Title: ______________________________________

Date: ____

Please rate the patient's participation in your portion of his/her rehabilitation program on the following scales. This rating should be completed at the time of discharge and is a summary of his/her participation during the entire course of your interaction with the patient.

1. **The patient regularly attends my therapy/rehabilitation activity.**

☐Never ☐Seldom ☐ Some of the time ☐ Most of the time

☐ Nearly always ☐ Always

2. **The patient required verbal or physical prompts to actively participate in my therapy/rehabilitation activity.**

☐Never ☐Seldom ☐ Some of the time ☐ Most of the time

☐ Nearly always ☐ Always

3. **The patient expressed a positive attitude towards my therapy/rehabilitation activity.**

☐Never ☐Seldom ☐ Some of the time ☐ Most of the time

☐ Nearly always ☐ Always

4. **The patient acknowledged a need for rehabilitation services and the benefit of therapy exercises or rehabilitation activities.**

☐Never ☐Seldom ☐ Some of the time ☐ Most of the time

☐ Nearly always ☐ Always

5. **The patient actively participated in his/her rehabilitation**

☐Never ☐Seldom ☐ Some of the time ☐ Most of the time

☐ Nearly always ☐ Always

*Items scored from 1-6. #2 is reverse scored. Total score will range from 5-30.

Kortte, Kathleen B, Lara D Falk, Renan C Castillo, Doug Johnson-Greene, and Stephen T Wegener. "The Hopkins Rehabilitation Engagement Rating Scale: Development and Psychometric Properties." *Archives of physical medicine and rehabilitation* 88, no. 7 (2007): 877-84.