

**An Opportunity for Improving Patient Care:
An Examination of Rehabilitation Patient Experiences
When Their Discharge Date Changed**

**by
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Ethics Statement

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University

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- c. as a co-investigator, collaborator, or research assistant in a research project approved in advance.

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Abstract

Patients requiring rehabilitation have typically experienced a significant change in their abilities from a stroke, amputation, brain injury or other adverse event, which can make them feel as though they have lost control. Having an opportunity to set their own discharge date allows rehabilitation patients to regain some of their autonomy. The purpose of this study was to explore how we can improve patient care by examining the experiences of patients when their discharge date changed. This study used semi-structured interviews with four past patients to qualitatively explore patient experiences at the University Hospital of Northern British Columbia Rehabilitation Unit. Each of the participants shared information regarding their experience determining their discharge date as well as information about their experience in general, which resulted in four themes emerging including: encouragement, relationships, structure and emotional position. This study demonstrates the importance of ensuring patients understand rehabilitation routines and have appropriate communication and supports while working on their recovery.

Keywords: rehabilitation; patient; discharge date; goal setting; social supports; patient involvement

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List of Acronyms

REB	Research Ethics Board
SFU	Simon Fraser University
UHNBC	University Hospital of Northern BC

Glossary

Discharge Date	The month, day and year the patient was discharged from hospital. In this report, discharge date is often referred to as the future date the patient is expected to go home.
Person-centred care	An approach that sees patients and their families as equal partners in planning, developing and monitoring care. Putting people at the centre of decisions and working together with professionals to get the best outcome.
Rehabilitation	As defined by the World Health Organization: a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.
Rehabilitation Unit	A unit at the University Hospital of Northern BC which provides assessment, treatment and rehabilitation for adults following traumatic injury or illness.

Introduction

Patients requiring rehabilitation have typically experienced a significant change in their abilities from a stroke, amputation, brain injury, or other adverse event, which impacts day to day life. They come to the Rehabilitation Unit in the hospital for physical, occupational, and speech therapy to make improvements. A patient's rehabilitation journey is unique and can be lengthy. Patients can feel as though they have lost control. As a Manager of a Rehabilitation Unit for the past two and a half years, I have been in conversations with many patients who experience these changes and perceive them as a stressor in their lives. I have observed patients feel empowered and have a sense of control when they are included in making decisions about their care. A major decision that occurs for all patients during their rehabilitation stay at some point in time is discharge date.

An expected discharge date is a goal. It determines the anticipated length of stay for a patient in the Rehabilitation Unit. The recommendation for rehabilitation patients is to have them involved in the process of goal setting (Plant & Tyson, 2018). Patients may need assistance to understand the process of goal setting and help to articulate their personal goals (Plant & Tyson, 2018). This can require dedicated clinician time and may demonstrate the differences in clinician and patients' perspectives on goal-setting and what participation means (Plant et al., 2016). Patients often focus on hopes and aspirations while clinicians may be influenced by organizational priorities (Plant et al., 2016).

I have observed the process of setting discharge dates in the unit, which does not typically include what I would classify as patient participation. The patient's discharge date is discussed by the team of clinicians, at a meeting called patient rounds, and an expected discharge date is set. Patients are informed of the expected discharge date afterwards and patients and their families can get fixated on their discharge date. This date becomes a clear goal for them to work toward. When patients are discharged prior to the expected discharge date, it can create excitement, however, more often I've observed patients express anxiety, fear, and stress related to feeling unprepared. When the discharge date is moved later, patients often experience disappointment and can feel a

sense of failure. It would be easy to take my observations and make assumptions about what I think works best for patients, but I wish to dig deeper and truly understand how patients experience this process during their stay in rehabilitation.

High quality healthcare is developed through a common understanding of the patients' needs and priorities (Kristensen et al., 2016) and I am passionate about person-centred care and creating a positive experience for patients during a difficult time in their lives. In this project, I explored the specific goal of discharge date to learn from patients' experiences when this date is changed, either with or without the patient's involvement. Nordin et al., (2015) were on target when they stated "the person's narratives about going home should be in focus when preparing for discharge" (p.1105).

Literature Review

As I conducted my literature review, I was discouraged by the absence of studies done regarding patient discharge dates changing and patient involvement in setting discharge dates. To the best of my knowledge, there have not been any studies specific to studying a patient's involvement in determining their discharge date and how this impacts their recovery or their experience. I had to shift my thinking and I began to examine the literature from a different angle. I expanded my search to look for information on goal setting and patient expectations during rehabilitation as well as the importance of social supports to achieve goals of functional recovery. Achieving goals of functional recovery are paramount to getting discharged. If the recovery is slow, it can delay a discharge or result in a patient going home before they are ready.

Importance of Goal Setting

Goal planning or goal setting in patient care and rehabilitation settings is not a new concept. There have been studies on goal setting since before 1979 when Dr. Solomon Cytrynbaum, Professor at Northwestern University, and his colleagues identified that goal setting was being used more frequently and thought to improve outcomes for patients (Cytrynbaum et al., 1979). Their comprehensive review of 91 studies on goal attainment scaling (GAS), which has been used since 1968 in a variety of settings including patient care, education and mental health, demonstrated mixed conclusions, however, their review provided evidence that patient involvement in the goal-setting process enhanced therapeutic success.

In 2006, President of the New Zealand Rehabilitation Association, Dr. William Levack, and his colleagues completed a systematic review of 19 studies on the effectiveness of goal planning in clinical rehabilitation. Their study identified some positive results from goal planning, but there was inconsistent evidence to demonstrate effectiveness across all studies (Levack et al., 2006). More recently yet, Rosewilliam et al., (2011) completed a review of 27 qualitative and quantitative studies looking at the effects and application of patient-centred goal setting in stroke rehabilitation and their findings were similar to those of Levack et al.. These comprehensive studies which

demonstrated inconclusive results identified to me that further research is needed. I chose to focus specifically on the goal of discharge date because I thought I could achieve better results in my study by examining a specific goal, rather than entwining goals altogether.

Patient Involvement in Goal Setting

It is identified as important for patients to be involved in defining their goals (Kristensen et al., 2016; Plant & Tyson, 2018), however, from the studies I examined, nearly all of them indicated patient involvement is limited due to perceived or identified barriers such as communication problems, different perspectives on goal setting, variability of goal setting and conflicting priorities (Rosewilliam et al., 2011; Kristensen et al., 2016; New et al., 2016; Plant et al., 2016; Plant & Tyson, 2018). New et al., (2015) also highlighted communication difficulties regarding discharge date as a barrier, specifically when the discharge date is relayed verbally from clinician to patient so the patient has a limited understanding of the discharge plan, which can contribute to an increased length of stay for patients.

Several articles identified a theme of clinicians as drivers of rehabilitation goals, which does not align with the Northern Health priority of person-centred care focused on shared decision making (Northern Health, 2016). Person-centred care intends to involve the patient and their support network in the decisions and direction for their care. Levack et al., (2011) have been so bold to suggest patient involvement in goal setting is “the primary way of enhancing patient-centredness in rehabilitation contexts” (p. 206). The results of their study found that rehabilitation clinicians were involved in goal setting and although the clinicians perceived they involved patients and families, the data showed that patients and families were seldom involved (Levack et al., 2011). Sarah E. Plant is a researcher at the University of Manchester and in one of her studies, she examined the barriers and facilitators of discharge planning where she stated “patients should be actively involved in the process” (Plant et al., 2016, p. 922) of goal setting, and yet also identified this to be a challenge due to conflicting priorities. The literature identifies a mismatch between the goals of patients, which tend to be long-term and involve hopes

and aspirations, and the goals of clinicians, which tend to be short-term and focus on impairments (Plant et al., 2016). This creates incongruence between clinician and patient understandings and expectations. Due to the differing focuses, often patients and families will defer the decision-making to the clinicians – viewing them as experts (McPhail et al., 2013; Plant et al., 2016; Rosewilliam et al., 2011).

Patients with high expectations may be disappointed with their experience if those expectations are not met. Groeneveld et al., (2018) undertook a study on expectations of stroke patients and found that patient expectations cannot be predicted accurately by clinicians. This further highlights the need to engage patients in conversation regarding their expectations and desired goals. Patients may be unaware of what their rehabilitation journey will entail, and patient education plays an important role in a patient's understanding of rehabilitation as a continuous process (Pryor & O'Connell, 2007). To create an environment for shared decision-making, clinicians need to provide their expert knowledge, while at the same time looking to understand where the patient is coming from.

Social Supports

Ali Yavuz Karahan is an Associate Professor at Usak University Medical School in Turkey who has authored over forty publications in international journals. He and his associates undertook a study which explored the effects of rehabilitation services on anxiety and depression and found that social support is important in the rehabilitation process (Karahan et al., 2014). Social support in this context is defined as “tangible forms of assistance that individuals receive from family, friends and others” (Karahan et al., 2014, p.71). Benefits of social support can include a reduction in mental disorders, a reduction in stress, and positive psychological health benefits. They identified social support as a valuable resource that contribute to an individual's sense of belonging and self worth while positively impacting their health (Karahan et al., 2014). Social supports become an important factor of increased participation in activities when recovering stroke patients have incapacities. They may rely on family and friends to help them get to and from therapies and activities which contribute to their recovery.

Reduced social support has been linked to a risk of slower recovery of functional status post-stroke in a study by Clare et al., (2014) which examined the role of emotion regulation on social participation following stroke. They recommended further investigation into factors that influence social participation as a way to further understand the impacts. They posited that impairments in functional ability could result in stroke recovery patients being less inclined to participate in social activities and interpersonal relationships (Clare et al., 2014). This reduced inclination to participate adds to the risk of slow recovery and without the support and encouragement from social supports, those recovering from stroke may delay their progress by their lack of participation in activities and interactions.

Dr. Sophie Lehnerer, a medical doctor specializing in neurology, and her associates completed a cross-sectional exploratory study of patient needs 2-3 years after stroke and found of the 57 patients included in the study, 30% had not received professional social support (Lehnerer et al., 2019). This is not a unique challenge; the Burden of Stroke in Europe (2017) report also identified a lack of after-stroke social support for stroke recovery in European countries. As further evidence of the importance of social supports, Lehnerer et al., (2019) connected unmet social needs with lower quality of life, poor physical health and higher caregiver burden. With Northern Health's vision of person-centred care, the focus should be on the patient and their social supports being involved in goal setting to ensure the best recovery possible.

After review of the literature and reflection of my own personal experiences and observations in the Rehabilitation Unit where I worked as a Manager, I chose to focus this study to look specifically at the goal of discharge date and the patient's involvement in setting that goal to determine if there are opportunities to improve future patient experiences. Discharge date is a significant event in the patient's journey. My assumption was that it would be memorable and impactful and through reflections on their experiences, past patients would be able to provide ideas and recommendations for improvement.

Methodology

Purpose

The purpose of this research was to explore how patients in the University Hospital of Northern BC (UHNBC) Rehabilitation Unit experienced being involved in determining their discharge date with the aim of identifying areas for improvement of future patient experiences. The research question I asked was: How can we improve patient care at UHNBC Rehabilitation by examining the experiences of patients when their discharge date changed? I chose to use qualitative research as the optimal method to address the research question, which provided an opportunity to examine and gain an in-depth understanding of the patient's experience. As O'Leary (2021) highlights, qualitative research aims to explore the lived experience of an individual.

Process

The study took place in the UHNBC Rehabilitation Unit, which serves an average of 500-600 patients each year. The patient population of the Rehabilitation Unit includes rehabilitation patients as well as patients needing medical services, those recovering from surgeries, and patients awaiting a bed in a long-term care facility. For the purposes of this study I focused on rehabilitation patients, which make up about 300 of the annual patients served. There were challenges with the intended participant recruitment process, which initially was going to be an invitation sent out by mail to patients who had been discharged in the past six months. Privacy legislation limited the study to patients who could be physically presented with a letter of invitation at the time of their discharge. Participants were informed as part of the consent (Appendix B) that I was undertaking this study as a student of Simon Fraser University (SFU), not as an employee of Northern Health. It was disclosed that the results of this study may be shared with UHNBC leaders for consideration of improvement opportunities.

Participants were past patients of the UHNBC Rehabilitation Unit, on the rehabilitation service, who did not have severe cognitive impairment. Starting in January

2022, letters of invitation were presented to patients being discharged inviting them to participate in an interview (Appendix A). A total of 12 potential interview participants including 2 females and 10 males accepted the letter of invitation to be contacted for an interview. Follow up telephone calls were made to all 12 potential participants with the following results: 4 were unreachable after multiple attempts, 4 declined to participate and 4 agreed to do an interview. All 4 who agreed to an interview were male. The interviews took between 30-60 minutes and consisted of open-ended questions (Appendix C). When possible, interviews occurred in person however Microsoft Teams was used upon approval by the participant when in-person was not an option. Interviews were audio recorded with permission from participants and transcribed with the assistance of Otter.ai transcription software. Transcriptions were edited to remove identifying information.

Due to the flexible nature of qualitative analysis, a preliminary semi-structured interview guide was drafted, however, the questions were amended throughout the process based on the conversations with each participant (O’Leary, 2021). Once the data was collected, I systematically reviewed and compared the data, listening for themes. I listened and read through the interviews multiple times to connect the responses back to my research question. I created an inductive analysis by looking for repeated words, repeated phrases, or words and phrases that are different but have similar meanings. I found commonalities and differences in the data to refine relevant data categories and theories. I sorted the data into four themes that presented themselves through analysis, which were: encouragement, relationships, structure and emotional position.

Limitations and delimitations

Qualitative research requires significant time so analyzing a large sample can be unrealistic. The sample size for interviews in this study was n=4. The small sample size created limitations as the data was not as robust as would be achieved with a large sample size and the generalizability of results is restricted. This research was conducted within one specific unit at a hospital so the findings cannot be generalized to other hospitals or

hospital units. Lessons learned from this research are specific to the UHNBC Rehabilitation Unit.

The perceived dual role of the researcher as student of SFU and Manager of the Rehabilitation Unit was a limiting factor. To mitigate any perceived conflict of interest or influence, the researcher clearly identified their role as SFU student during the interviews.

Qualitative analysis requires an open mind of the researcher to allow for themes to emerge based on the data, and not imposed based on researcher beliefs. I had to be aware of my biases and influences on the interpretation of data. I had an expectation that discharge date was a significant event in each patient's journey. Although many questions were focused around discharge date, I had to be sure to provide an opportunity for the interview participants to respond in a way that was meaningful to them. I had to do my best to set aside my experiences and observations as a Manager to learn and understand from the participants what was important and relevant to them.

Ethical Considerations

Ethics approval for this study was obtained from Simon Fraser University Research Ethics Board (REB) and Northern Health's Ethics Committee. Table 1, included below, outlines ethical considerations and measures taken to reduce risks.

Participants may have perceived a conflict of interest due to the role I hold in the Rehabilitation Unit as Manager. At the beginning of each interview, my role was clearly communicated to participants, letting them know I was speaking with them as a student and not the Manager of the unit. This was also included in the consent form (Appendix B) signed by each participant. Involvement was voluntary and no adverse consequences were experienced if participants chose to participate or chose not to participate.

Revisiting a patient experience can trigger psychological stress or trauma. I was particularly sensitive to this occurring as most patients who spend time on the Rehabilitation Unit have experienced significant health changes that may impact both

their mental and physical health. The participants were not required to answer any questions if they posed discomfort and could stop the interview at any time and I had a list of resources available to share with the participants should they be needed. Confidentiality and anonymity was assured and was outlined in the invitation and participant consent (Appendix A and Appendix B).

Time for participation was valued and the participants in the interview process received a \$20 gift card from a local business, whether they completed part of the interview or the entire interview.

Table 1. Ethical Considerations and Measures Taken to Mitigate

Ethical Considerations	Measures Taken
Conflict of interest for role of researcher (also Manager of Rehabilitation Unit)	Voluntary participation
Psychological stress or trauma	Participants not required to answer all questions and could stop interview at any time
Confidentiality / Anonymity	Outlined in participant invitation and consent forms
Payment for participants could be perceived as coercion	Non-monetary remuneration to acknowledge time for participation

Findings

Thirty-three percent of the 12 participants who received an initial invitation agreed to do an interview resulting in a total of four participant interviews. The four participants had varying reasons for rehabilitation as shown in Table 2.

Table 2. Interview Participants: Reason for Rehabilitation

Reason for Rehabilitation	# of Participants
Stroke	2
Car Accident	1
Amputation	1

During the interviews, in addition to experiences with discharge date, participants shared about their overall stay in the Rehabilitation Unit. This unearthed additional themes such as encouragement, relationships, structure, and emotional position.

Discharge Date

As outlined in Table 3, two participants identified their discharge date had changed, one indicated it had remained the same and one was not sure if the date changed or remained the same.

The participants expressed varying degrees of perceived involvement in setting their discharge dates. When Participant 3 was asked how he felt involved in setting his discharge date, he responded with “Well I got asked the question, do you want to go home?”, which demonstrates the different understandings of what involvement can look like. Involvement to this particular participant was sufficient by being asked the question on whether or not he wanted to go home, while that may not feel like involvement to others.

Table 3. Discharge Date Changes

Discharge Date	# of Participants
Discharge Date Changed	2
Discharge Date Remained the Same	1
Patient Unsure if Date Changed	1

Participant 1 felt involved in determining his discharge date and recalled his discharge date was shared with him during a family meeting with his support people in attendance. The date was verbally communicated and from his recollection, the date did not change. He felt comfortable with the process and expressed he had been through something similar with a family member previously, so he knew what to expect.

Participant 2 indicated his discharge date changed multiple times. The date was moved later because he was not gaining his strength back in order to meet the goal of the first discharge date. Discharge dates are generally contingent on the patient reaching their specific goals, for example, climbing up and down stairs, to ensure they can safely return home. The dates can change when patients have not yet achieved these milestones. Participant 2 said he had a conversation with the doctor and physiotherapist about his discharge date and he felt involved in setting the date. He said he felt anxious to get back in his home to be with his pets and anxious about going home because he was not sure how he would manage with the changes he would face with his new functional status. He was discharged two weeks later than first scheduled, but his discharge date was moved later and earlier multiple times. He believed he would have benefitted from a couple more weeks in the rehabilitation program before going home but said he didn't ask for it to be changed again because "I look at doctors and nurses, they know better than I do". Upon reflection of what could help future patients, he recommended the doctors and nurses listen to the patients more. He believed more listening to patients could help improve their experience.

During the time Participant 3 was working towards his goals, but was unaware of when he would be discharged, he expressed feeling vulnerable. There was a specific goal he was working on and he believed when he achieved the goal, he would be able to go home. Upon learning he was going to be discharged within a few days, he felt reassured. Although he did not feel physically ready to leave, he was mentally ready to go home. "There's three authorities that decide when you're gonna go home. You're one authority, the doctors the other authority, and the head nurse, her authority" (Participant 3). Participant 3 felt involved in determining his discharge date because he said, "Well I got

asked the question, do you want to go home?” and he was comfortable to continue his recovery at home.

Participant 4 expressed he was unaware of his discharge date until one day it was posted on his wall in his room. He said he didn't feel involved in setting the date but he felt “successful in the things I did there” and ready to go home. He said he believed the communication was open and if he had questions, he could ask the team.

Table 4. Patient Involvement in Setting Discharge Date

Patient Involvement in Discharge Date	# of Participants
Patient Felt Involved	3
Patient Did Not Feel Involved	1

Of the four interviewees, three expressed feeling involved in determining the date they would be discharged. Participant 1 was directly consulted during a family meeting and Participant 2 had conversations with his care team. Participant 3 expressed feeling involved even though he was unaware of the date during a portion of his stay. While Participant 4 was not consulted in determining the date, he felt involved in the rehabilitation process and felt the lines of communication were open if he had concerns with the date. Table 4 shows a summary of the patient involvement in setting their discharge date.

In addition to the information about discharge date, 4 distinct themes emerged from the information the participants shared about their experiences in general. Each of these themes are represented below and connected back to the patient's experience and their discharge date, where appropriate.

Encouragement

Three of the four participants identified encouragement from the staff in the Rehabilitation Unit as contributing to their experience in a positive way, while one participant did not mention encouragement during their interview. Participant 4 said, “You know, the physiotherapist has given me all this encouragement, you know, it really emotionally affected me that she said, you've got this...” and the participant spoke about

seeing this with other patients on the unit as well and how he believed it impacted their drive to achieve goals. Participant 1 spoke about the positivity of the physio staff and nurses and commented, “They make you really feel very encouraged” and how the staff celebrated achievements and made a “big deal” out of things like standing up. He said, “those were big days” and that he was feeling elated as he started to progress. Participant 2 believed the physiotherapist was proud of him when he achieved a goal they had been working on. He said the physio “liked to push and that was good” because it helped to motivate him.

The three participants all acknowledged this encouragement was around meeting a goal such as standing up, walking for the first time with a walker, or catching a ball. It gave them the desire and drive to continue toward their goals and in the words of Participant 4, “encouragement... sends another layer of hope for the patient.” Encouragement was a significant driving force in goal attainment. Goals are paramount on the Rehabilitation Unit for patients to get home.

Relationships

All participants spoke about the importance of relationships during their stay in the Rehabilitation Unit. “It’s the relationships that starts growing between the patient and the care aide. And pretty soon that makes the patient feel like [they are] not that alone” (Participant 3). One of the participants recalled the personal treatment he received which helped improve his experience and provided examples of activities and meal items he requested and staff were able to accommodate which impacted him positively.

Two participants spoke about meaningful connections they made with other patients in the unit and how these relationships positively impacted their experience. Participant 1 stated “I’d like to think that I helped him” when telling a story of a conversation with another patient and remembered the patient coming to say goodbye when he was leaving. He remembered his last interaction with the patient where he said “It really is up to you if you’re going to get better. It’s up to you and not all the people working here, so I think he came around a bit” (Participant 1). When Participant 4

recounted a story, he referenced “Grumpy Old Men” on the unit and said through a conversation he had, he was able to “pull this guy from being grumpy” and he was “able to talk freely to [his] roommate and look at the change”. Both of these participants identified these positive impacts on relationships as being an important part of their experience and one suggested a male role model would be helpful for future patients.

All four participants identified the importance of support from staff, friends and family during their stay, and when preparing to go home. Participant 4 stated “we need to be very, very gracious” with the support from the staff because it will be different once discharged. Participant 2 said “My experience in rehab was good, I had good people” and credited the success of his discharge to his support system at home. His supports ensured he had required equipment at his home so he could safely be discharged.

Participant 2 spoke about how difficult it was when visitation was restricted due to COVID-19 and he was not able to see or visit with his family. He relied on relationships with the staff because of the absence of visitors. Participant 4 shared his experience being connected to a stroke survivor group and how being able to connect with others who had gone through a similar experience and getting support that way was helpful for him. One of the participants recalled an interaction with one of the nurses just before he went home. He remembered the nurse coming in to see him after she found out his discharge date and the nurse sat down in his room and “we just had a really profound chat, you know, about life. It was really nice” (Participant 4). He was impacted by the time the nurse had given him and he related it back to the importance of relationships and how he was moved by the “profound chat” (Participant 4).

Structure

Each of the four participants identified the importance of structure during their experience. Participant 1 remembered asking the staff “what happens now” and talked about his scheduled therapies and how he was working towards his goals. He knew clearly what his goals were and when he felt strong enough, he asked for more time in the gym so he could achieve them quicker. Participant 2 clearly recalled the goal he was

working toward to be ready for discharge. He was focused on achieving the goal because he believed once he achieved it, he would be going home. Participant 3 remembered the struggle when medication was late and the pain it caused him. He stressed the importance of ensuring the schedule for medication was followed so that patients were not in pain and could do their rehabilitation. He also remembered the goal he was working toward to be ready for discharge.

Participant 4 spent a lot of time during his interview talking about opportunities to improve the patient experience by providing orientation information. None of the 4 participants recall reading through any information at the beginning of their stay that explained what their stay on the Rehabilitation Unit would be like. Participant 4 thought a transition discussion with the patients would be helpful. When this participant was asked if he had recommendations for future patients, he said “I probably would let the patient know to ask exactly what the routines are for the day” (Participant 4). He recalled when the physiotherapists explained the process it was helpful for him and he believed an orientation of process would be helpful for everyone. Participant 4 also spoke about how although the structured routine was helpful when he was in the Rehabilitation Unit, he recalled “it was hard for me to adapt to get out of the hospital because I’m so used to ... those structured routines”.

Emotional Position

Throughout the interviews, there were many feeling words used to describe each participant’s experience. These descriptions have been incorporated into Figure 1 below. The interviewee responses were entered into a wordcloud generator that looked for common words. The most common words are displayed in the largest font.

of their activities, like bars in the bathrooms to hang on to when climbing in and out of the shower. Safety also referred to the functional ability to perform certain tasks like walking up and down stairs if that was required to enter and exit the home.

Participant 4 stated “with the amount of energy that’s in [the Rehabilitation Unit], it made me feel that I got this”. Both Participant 1 and 4 identified a positive attitude as important in helping them to achieve their goals and prepare to be discharged. They also recognized the importance of a positive attitude for other patients, and each shared a story about sharing their positivity with other patients, where they believed they made an impact on those patients and their recovery. One of the stories was about a patient who had been in the Rehabilitation Unit for several months. The patient was feeling quite discouraged and according to the participant was being mean to the staff. Participant 4 had a frank conversation with the patient and explained to him how his hurtful words could impact the staff and reminded him that the staff were doing their best to help and that he would not receive that level of support once he left the hospital. The participant noticed after their conversation that the patient apologized to some of the staff and started speaking to them nicer. The participant said this seemed to change the patient’s outlook and he was more positive after that. It also made the participant feel happy that he was able to change a negative situation.

Discussion

Cyrtrynbaum (1979), Levack (2011), and their associates identified in their research that there can be positive results when patients are involved in goal setting. The participants echoed this when they spoke about the positive impact achieving their goals had on them. The participants expressed how encouragement and support from the staff motivated them to keep moving forward. While this encouragement does not necessarily mean the clinician is driving the goal setting as was highlighted in the literature, it supports the clinician as influencing the patient to achieve the goal.

The main form of communication regarding discharge dates was verbal, with the exception of one participant who recalled the date was written on a board in his room. The literature identified verbal communication of discharge date as a potential barrier for patients understanding the discharge plan. This did not seem to be supported in the responses with three of the four participants having a solid awareness of their discharge date and all four participants indicating they understood the goals they needed to achieve in order to go home. Perceived involvement was shown to be subjective and therefore understanding what each patient expects in terms of communication about their discharge date, and the involvement they desire, could contribute to an improved experience.

The participants spoke about their need to understand the routines. Awareness of the structure during rehabilitation, supported by orientation and resource materials was a recommendation that emerged from the interviews. This lends support to Pryor and O'Connell's (2019) belief that patient education and understanding will support success.

All four participants discussed the importance of relationships, the support they received while on the Rehabilitation Unit, and support when preparing for their discharge, so it is no surprise the importance of support is also reflected in the literature. This further highlights the purpose of Northern Health's person-centred care. The person-centred care approach to patient care intends to involve the individual, and their family or supports, in decision-making. Stories were shared by two participants about the impact they had on another patient's experience, and how the participants hoped they helped in the patient's recovery. Patients on the Rehabilitation Unit are often there for an

extended period of time due to their recovery needs, and it can be discouraging and frustrating for them. Having social support is important to keep spirits up and maintain motivation toward goals to get home on the planned discharge date.

Conclusion

While the interview questions were primarily focused on the patient's experience around their discharge date, there was a lot of beneficial information shared that was not directly related to discharge date. Discharge date remains a significant event in a patient's journey, and this study highlights that the entire patient experience is important. Participants in this study shared varied perceptions of involvement in determining their discharge date, however, none of them indicated they were upset or disappointed in the process of determining their discharge date.

This research provides preliminary opportunities to improve patient care in the UHNBC Rehabilitation Unit. All participants spoke about the positive impact relationships with staff and other patients had on them, and the majority of the participants identified encouragement as pivotal to achieving goals. This highlights the importance of time and effort in developing and sustaining relationships between staff and patients.

In addition, orientation regarding routines on the Rehabilitation Unit and supports for patients like mentors were identified as areas for improvement. If patients received information, they did not recall they had and upon reflection of their experience have identified it would have been helpful from the outset. This information could be verbal or written, but perhaps some combination of both would be most beneficial. A focus group with patients to determine the content of conversations and brochures related to orientation could prove helpful.

I believe there could be benefits found from additional research such as a qualitative study that follows a patient through their journey of rehabilitation and recovery to unearth opportunities to improve patient experiences. I also believe a study that includes the perspectives of staff in the Rehabilitation Unit might demonstrate the differences in experiences and perceptions between patients and staff.

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Appendix A. Letter of Invitation – Interview



Invitation to Participate in a Research Project

An opportunity for improving patient care: an examination of rehabilitation patient experiences when their discharge date changed

January 4, 2022

Greetings, you are being invited by Angela Pontius, a Masters of Education candidate from Simon Fraser University Faculty of Education, to participate in a research project entitled **An opportunity for improving patient care: an examination of rehabilitation patient experiences when their discharge date changed**, which encompasses the following:

Background and Procedures:

The main goal of this research project is to explore how patients have been involved in determining their discharge date in the UHNBC Rehabilitation Unit with the aim of identifying areas for improvement for the patient experience. This project aims to understand patient experiences at UHNBC Rehabilitation through one-on-one interviews with past patients and a focus group with staff.

As part of this project, you are being invited as a patient who has been discharged within the past 12 months from the UHNBC Rehabilitation Unit to participate in an interview. Interviews will take approximately 1 hour of your time. The SFU affiliated research team interacting with participants is fully vaccinated against COVID-19. Your participation will contribute to a deeper understanding of impacts on patients' experiences when their discharge date changes and provide opportunities for future improvement.

In the interview, you will be asked by the researcher about your experience in the UHNBC Rehabilitation Unit. The questions you will be asked during your interview will include, and there may be other questions that emerge from the conversation:

1. Before we begin, can you please tell me a little about yourself?
2. Can you tell me about your understanding of your rehabilitation stay?
3. Were you aware of your discharge date throughout your stay in rehab?
4. Did you feel involved in determining your discharge date?
5. What did you experience when your discharge date changed?

6. Thinking of your own experience and thinking about what others may experience, what recommendations would you have for the rehabilitation unit?
7. What recommendations would you have for other patients?
8. Is there anything else you want to add?

Remuneration: For participating in this study, you will be provided with a \$20 gift card as a gift of appreciation for your time.

To express your interest in participating in a one-on-one interview, please contact the researcher Angela Pontius. The interview will be scheduled at a time and location that is convenient for you.

Thank you for your assistance.

Warm regards,

Angela Pontius

Appendix B. Informed Consent – Interview



Research Project Title: An opportunity for improving patient care: an examination of rehabilitation patient experiences when their discharge date changed.

Study Team

Research Supervisor: Dr. Michelle Pidgeon, SFU Faculty of Education.

Student Lead: Angela Pontius, Masters of Educational Leadership student.

Invitation and Study Purpose

As part of this project, you are being invited as a patient who has been discharged within the past 12 months from the UHNBC Rehabilitation Unit to participate in an interview. Your participation will contribute to a deeper understanding of impacts on patients' experiences when their discharge date changes with or without their involvement and provide opportunities for future improvement.

This main goal of this research project is to explore how patients have been involved in determining their discharge date in the UHNBC Rehabilitation Unit with the aim of identifying areas for improvement for the patient experience. I am interested in exploring your experience as a patient through one-on-one interviews.

Voluntary Participation

Your participation is voluntary. You have the right to refuse to participate in this study. If you decide to participate, you may still choose to withdraw from the study at any time without any negative consequences to the services to which you are entitled or are presently receiving.

Study Procedures

If you choose to participate in the study, we will ask you to participate in an interview. Interviews will take approximately 1 hour of your time. Interviews will be in person at UHNBC, or in a bookable meeting room in a public location such as the Public Library, or on Microsoft Teams if in person is not an option. With your permission, interviews will be recorded. The research team will abide by the latest provincial health guidelines in relation to the COVID-19 pandemic and the SFU affiliated research team interacting with participants is fully vaccinated against COVID-19.

Potential Risks

This is a minimal risk study, however, the researcher understands you may experience emotional or psychological stress from sharing your experience. The researcher has a

responsibility to ensure care and will have a list of available resources should you share you are experiencing emotional or psychological stress. You may end the interview at any time.

Potential Benefits of the Study

We do not think taking part in this study will help you. However, in the future, others may benefit from what we learn in this study.

Payment

We will not pay you for participating in this study. For participating in this study, you will be provided with a \$20 gift card as a token of appreciation for your time. You will receive this at the beginning of the interview if it is in person, or it will be mailed to you. It is not contingent on completing the interview.

Organizational Permission

Permission to conduct this research has been obtained from Northern Health and University Hospital of Northern BC.

Confidentiality and Data Security

Your identity and confidentiality will be respected in final reports, presentations and publications emerging from this research project. Information that discloses your identity will not be released without your consent. Participants will be identified by the use of a pseudonym. Participants will not be identified by name in any reports of the completed study.

With your permission, the audio of the interview will be recorded to assist with data analysis. The use of Otter.ai will be used for transcription and you will be provided with a transcript for your approval prior to inclusion of the data in the report. Any data you provide may be transmitted and stored in countries outside of Canada, as well as in Canada. It is important to remember that privacy laws vary in different countries and may not be the same as in Canada. Once you have approved the transcription, the audio recording will be deleted.

The data will be kept on a memory key or printed hard copy and all data will be stored in a locked filing cabinet in the researcher's office. A master file linking the identity of participants with a pseudonym will be kept and stored securely and separately from the data. Any electronic files will be stored in a password protected folder and destroyed after 7 years.

The student lead is the Manager of the Rehabilitation Unit. To mitigate conflict of interest, the data will be reviewed by both the student lead and the research supervisor.

Future Use of Research Data

This project is being done as part of the requirements for a Masters of Educational Leadership. The results of this project will be presented at the 2022 summer institute at

Simon Fraser University and the College of New Caledonia and may also be shared in other presentations and publications.

Withdrawal

You may withdraw at any time by contacting a study team member listed at the start of this document. If you choose to enter the study and then decide to withdraw prior to the study results being completed, data collected about you during your enrolment in the study will be destroyed.

Study Results and Questions About the Study

To receive a summary of the results or discuss any questions you have about the project contact the researcher, Angela Pontius or research supervisor, Dr. Michelle Pidgeon.

Contact for Complaints

If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you may contact the SFU Office of Research Ethics.

Interview Consent Form

I, _____ (print name),
understand and consent to participate in this study being conducted by Angela Pontius.

I consent to the interview being recorded for transcription.

I understand that I may withdraw from this study at any point during the study
without any negative effect on my relationship with the researcher.

By signing below, I fully understand my rights as a participant in the research
project as outlined in the letter above and consent to participate in this study.

Participant:

{Print name}

{Signature}

{Date}

Witness:

Angela Pontius _____

{Print name}

{Signature}

{Date}

Appendix C. Interview Protocol



Re: Research proposal: An opportunity for improving patient care: an examination of rehabilitation patient experiences when their discharge date changed.

Introduction

Thank you for participating in this interview. I am interviewing you to better understand your experience as a patient in the UHNBC Rehabilitation Unit and how we can improve patient's experiences. I am particularly curious about how your experience was regarding your discharge date. There are no right or wrong answers to any of the questions, I am interested in hearing from you about your experience.

The information gathered will be kept confidential. If you would like, you can choose a pseudonym for yourself. Only me and my supervisor Dr. Michelle Pidgeon will have access to the data. Electronic data will be stored in a password protected file on a USB key and the USB along with all paper records will be secured in a locked filing cabinet.

Your participation is voluntary and you can stop the interview at any time if desired. The interview should take around one hour, depending on how much information you share.

With your permission, I would like to audio record this interview to ensure all of your information is captured. Your responses will be kept confidential and information included in my report will not identify you as a respondent.

Do you have any questions about what I have just reviewed? May I turn on the audio recorder?

This guide represents the main themes to be discussed with the participants and as such, does not include all possible prompts that may be used.

Establishing Rapport:

1. Before we begin, can you please tell me a little about yourself?

Patient Information:

2. Can you tell me about your understanding of your rehabilitation stay?

Prompts: What changes in health did you experience? What care needs did you have? Were you provided resources to help you understand your stay? What went well for you during your stay?

3. Were you aware of your discharge date throughout your stay in rehab?

Prompts: Did your discharge date change? How was it communicated with you? Did you understand the reasons for your discharge date changing?

Patient Experience:

4. Did you feel involved in determining your discharge date?

Prompts: What conversations did you have with care providers about your discharge date? Were you asked for your thoughts regarding your discharge date? What went well for you regarding the plan for your discharge?

5. What did you experience when your discharge date changed?

Prompts: Let's talk about when you found out your date was changing – was it earlier or later than expected? How did it make you feel? Did you feel ready to leave rehab when you were discharged?

Patient Suggestions:

6. Thinking of your own experience and thinking about what others may experience, what recommendations would you have for the rehabilitation unit?

Prompts: What would have helped you during your stay in rehab? What could have been done better?

7. What recommendations would you have for other patients?

Prompts: If you were a patient again, what will be helpful for you now that you have been through the process?

8. Is there anything else you want to add?

Thank you for taking time to have this conversation with me today. I appreciate you and the information you have shared with me. Once the transcription is completed, I will send it to you before finalizing it.