



Immigrants' Experience of Inpatient Rehabilitation

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Abstract

Background: In recent years, the United States has experienced profound changes in the diversity of its population. An increase in the number of immigrants to this country has contributed to these changing demographics. Healthcare providers are faced with the challenge of meeting the unique needs of these individuals and groups. However, there is limited research investigating the experiences of immigrant patients in an inpatient rehabilitation program.

Objective: This study aims to describe the experiences and perspectives of immigrants admitted to an inpatient rehabilitation program.

Design: A qualitative phenomenological study was conducted to examine the experiences of immigrant patients in an inpatient rehabilitation program.

Methods: A purposive sampling process was used to recruit 10 patients who were immigrants to the United States with a native or primary language other than English. Semi-structured interviews were conducted with all individuals. Data analysis included reviewing all transcripts for intra- and inter-case content.

Findings: Two themes emerged: Understanding the language and life of rehabilitation, and Trust and decision-making in the rehabilitation experience.

Conclusion: The immigrant participants were able to understand and take part in the rehabilitation program. English language skills for several participants presented difficulties in the care process but did not detract from the participants' experience, affect their recovery, or delay their discharge and return to home. Decision-making regarding the course of care was largely determined by healthcare providers, with participants trusting in and accepting the caregivers' expertise to provide appropriate and effective care.

Keywords: Immigrants, inpatient rehabilitation, healthcare, literacy, decision-making

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We all have dreams.

But in order to make dreams come into reality,
it takes an awful lot of determination, dedication, self-discipline, and effort.

Jesse Owens

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Immigrants' Experience of Inpatient Rehabilitation

Immigrants and Healthcare in the United States

The changing face of the United States can be readily seen in the increase in the number of foreign-born individuals in the US from 19.7 million, or 7.9 percent of the total population in 1990, to approximately 40 million, or 13 percent in 2010 (Morse & Cui, 2013). These trends are expected to continue with immigrants contributing up to 82% of the growth in the United States population in the coming decades. As a result of this influx of immigrants, by 2050 nearly one in five Americans (19%) will be foreign-born. In addition, the nation's ethnic and racial mix is expected to change. Non-Hispanic whites, who made up 67% of the population as of 2008, are expected to decrease to 47% of the population in 2050. In contrast, the Latino population is expected to rise from 14% to 29% and the Asian population will grow from 5% to 9% during the same period, with the Black population remaining at the same percentage (13%) as it is currently (Passel & Cohn, 2008).

Health Disparities among Immigrant Populations

Immigrants to the United States experience a wide array of changes as they adapt to life in this country, affecting virtually every aspect of their lives. At the same time, the social and economic systems of the United States face the task of responding effectively to the diverse needs of these individuals. A critical concern is immigrants' access to and use of health care in this country. The disparities in health status and access to health care between native- and foreign-born individuals have been shown to exist in the United States. Prus et al. (2010) found that 33.4% of foreign-born non-White individuals in the United States, aged 45–64 years, reported poor health while less than 13% of native-born White Americans of the same age reported similar conditions. Access to care is also significantly lower for the foreign-born non-

Whites as 24.2% of this group indicated they did not have a regular doctor and 16.5% reported that they had unmet health needs. In contrast, 12.7% of native-born Whites lacked a regular doctor and 10.4% noted unmet health needs. Moreover, these disadvantages were found to exist regardless of a person's socio-economic status, lifestyle, and access to health insurance (Prus et al., 2010).

Several factors contribute to health disparities among immigrants including the length of time an individual has lived in the United States, their level of English proficiency, and their income (Lasser et al., 2006; Lee & Choi, 2009). The cultural values and practices of immigrants can also influence how they utilize health care services (Shaw et al., 2008). Culture, language, health literacy, and socio-economic factors that many immigrants encounter can limit their ability to manage health care needs effectively (Garces et al., 2008; Lee, et al., 2010). The increase in immigrant populations has led to a growing need for health care providers to have the skills and tools to address the unique cultural, language, and social needs and practices of these individuals (Dressler & Pils, 2009; Omu & Reynolds, 2012). Together, these factors present significant challenges to providing interventions to meet the health care needs of immigrants (Zou & Parry, 2012). Understanding immigrants' experiences and perspectives of the health services they receive is essential for healthcare providers to devise strategies and tools that are culturally sensitive and appropriate for the populations they serve.

Cultural Influences on Immigrant Health

An essential concept to explore when discussing immigrants and health care is the impact of an individual's cultural background on their ability to take care of their health effectively. Several studies illustrate ways that culture can affect an immigrant's beliefs about and ability to respond to health care needs. Garces et al. (2008) and Lee et al. (2010) found that cultural values

and practices, language and health literacy skills, and socio-economic status encountered by many immigrants can limit their ability to manage their health successfully. Morris et al. (2009) found that “culture directly affected refugees’ concept of prevention services, independence, expectations of care and stigma around health conditions - all of which influenced their health care choices” (p.535). Immigrant populations may define health and illness differently than those found in mainstream Western models. Kiesser et al. (2006), and Martin (2009) discussed how immigrant groups may have a more holistic perspective of health and illness, one which seeks to address not only injury or illness, but rather a balance of spiritual, natural, physical, emotional, and moral conditions within a person. These groups often rely more readily on traditional, complementary, and alternative medicine (TCAM) as remedies to illness in place of or before resorting to healthcare services typically found in the United States as well. Lee et al. (2010) found similar results in Asian American populations.

Immigrants’ cultural beliefs about health and health care can also shape their decisions in seeking health care. Kiesser et al. (2006) found that Mexican immigrants utilized home remedies not only due to the accessibility and familiarity of these choices but also as a result of their beliefs that issues of health management are best addressed at home rather than in a doctor’s office. The authors found that immigrants viewed the conventional medical setting in the United States as a foreign and, at times, frightening, environment. The medical jargon, complexity, and impersonality of the health care system they encountered when in these settings compounded the discomfort they experienced. Participants in Kimbrough’s (2007) study also reported that they would rather rely on herbal or home remedies because they were not used to going to doctors for their care.

Language, Literacy, and Immigrant Health

An immigrant's culture, as well as their English language skills, may affect their ability to effectively participate in and manage their health. Individuals receiving medical care must have adequate proficiency in reading and/or oral communication to understand the care they are receiving and to communicate their medical needs. Several researchers have demonstrated how literacy, and health literacy, in particular, can negatively impact immigrants in this respect. Dressler and Pils (2009) described barriers healthcare providers encountered when working with migrant and ethnic minorities. The clinicians in this study reported how language and cross-cultural issues affected many aspects of inpatient rehabilitation care. Dressler and Pils noted that language barriers hindered the patients' participation in treatment because the clinicians were unable to "convey the importance of and/or objectives of therapies and of rehabilitation to them" (p. 1186). Clinicians in this study also felt the rehabilitation process was hampered when tests and evaluations could not be completed due to language barriers, and that their program had limited resources to overcome these obstacles. Jirwe et al. (2010) reported that student nurses experienced difficulties in communicating with patients when they did not share a common language with them. These barriers negatively affected their ability to interact with and to form therapeutic relations with patients.

The language skills of immigrants can also be a significant factor in the health behaviors of these individuals. Proficiency in verbal, written, or visual communication in English is essential for immigrants to access healthcare services. Twenty percent of the respondents in a study of Latino immigrants in southeast Michigan by Harari et al. (2008) identified language barriers as the primary obstacle to health care access. In this study, 82% of respondents stated they had difficulty communicating with their doctor during their last visit, and 8% reported

traveling as far as 35 miles to seek health care at a clinic with Spanish-speaking staff. These findings are similar to those noted by Morris et al. (2009) who noted that “Every participant perceived language to be a major, if not the most major barrier to refugee health care access” (p.533). Over half of the study’s participants used healthcare services only when very ill, or not at all, as a result of language barriers.

Suurmond et al. (2011) found that immigrant patients reported negative health care events as a result of insufficient information or ineffective communication and from differences in expectations about medical procedures due to language differences between them and care providers. These findings are similar to the examination of Hispanic immigrants by Garces et al. (2008) in Midwest rural communities. The authors of this study stated that:

Participants with no or limited English proficiency mentioned that their limited skills speaking and understanding English seem to have a negative impact on their ability to seek and access health care services, to get information about local health care services available to them, and to understand their own health problems and treatments. (p. 641).

Easton et al. (2013) found that low literacy had a significant impact on verbal communication and on understanding written information. They found that individuals with low literacy frequently concealed their lack of understanding from healthcare providers by feigning understanding of conversations or not asking questions about their care, even though they were unsure of the information they received.

The Patient Protection and Affordable Care Act of 2010 defines health literacy as “the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions” (Centers for Disease Control and Prevention, Health Literacy, para 1). However, Zou and Parry (2012) found that

“immigrants often lack the basic knowledge and skills to navigate western healthcare systems” (p. 484) and found that some immigrant populations have limited basic medical knowledge and understanding of health maintenance and disease prevention. Immigrant focus groups in Kimbrough’s study (2007) reported one of their biggest challenges was understanding medication instructions and labels, as well as acquiring the knowledge they needed for continuing medications to manage chronic health conditions such as diabetes. These difficulties increased when healthcare providers did not appreciate the degree to which their patients did not understand their medical condition and prescribed treatments. Individuals with little or no skills in English encounter these obstacles as well. Lee et al. (2010) found that Asians with “...a relatively good command of the English language have difficulty in describing symptoms, understanding the physician’s explanation and treatment, and reading prescriptions” (p. 26).

Immigrant Patients and Healthcare Providers

Culture and language may also combine to affect an immigrant's abilities to establish effective working relationships with caregivers. As a result, immigrants may anticipate a different type of care or participate in treatment in ways that are not consistent with expectations found in a more Western-based model of care. Healthcare providers, who are aware of and able to address the unique needs and customs of immigrants, can have a significant effect on their care and overall health. Omu and Reynolds (2012) investigated the perceptions of healthcare providers in a rehabilitation program in Kuwait. The clinicians reported that patients’ cultural beliefs and practices had an impact on patients’ participation in treatment, including their ability to set meaningful therapy goals. The clinicians, who used a Western model of stroke care, found their approaches were often different from the beliefs and practices of their patients, who held more traditional views of their role, and of their families’ involvement, in rehabilitation. Omu

and Reynolds also reported that the level of education about stroke and rehabilitation within Kuwaiti society limited the patient's and family's expectations about stroke recovery.

The development of a relationship enabling healthcare providers to get to know immigrants as persons, not merely as sick or injured individuals, was found to be a critical element in influencing immigrants' choices in medical care. Participants in studies by Lee et al. (2010), Markova et al. (2007), Marshall et al. (2010), and Morris et al. (2009), expressed a preference for healthcare providers who spoke their language and were of the same gender and ethnic background. The immigrant participants in these studies expressed that these factors were necessary for healthcare providers to understand their specific cultural needs and that they established a trusting relationship and a greater degree of satisfaction with the healthcare providers who shared their backgrounds. Ascertaining the patient's perspective of their health care experience is an indispensable element of developing appropriate treatment interventions. Kimbrough (2007) used focus groups to investigate immigrants' identified health care needs. The immigrants in the focus groups identified essential needs, such as increasing the cultural awareness of healthcare providers and making culturally and linguistically appropriate patient education and information available to immigrants to help them maintain their health and manage illness successfully. Participants stated that trained interpreters were essential to address communication barriers they encountered.

Gill et al. (2014) used focus groups to describe the experiences, needs, and preferences of English-speaking inpatients of a rehabilitation program and those of their families as well. The participants reported that the timing and quality of their communication with staff, including non-verbal communication, had a significant impact on their rehabilitation experience. Patients and families also indicated they needed different types of information at different stages of their

rehabilitation, and that using techniques such as audio-visual presentations could help them understand and retain the information they received. Participants pointed out that although communication between staff and patients was important, communication among clinicians about coordinating and delivering care was critical to their recovery as well (Gill et al., 2014). Meeting and communicating with staff also helped establish effective relationships during the immigrants' admission and fostered better care.

Currently, there is little research that examined the perspectives of immigrants to the US who receive care in an Inpatient Rehabilitation Facility (IRF). There is a growing need to develop treatment approaches to meet the unique needs of the increasingly diverse population of the United States. These needs are especially acute in inpatient rehabilitation due to shorter lengths of stay, the intensity of services, and the importance of consistency in patient care (Dressler & Pils, 2009). Collaboration between health care recipients and the professionals providing health care services will be necessary to address the needs of immigrants.

The first step in this process is understanding immigrants' perspectives of health care. In their review of immigration statistics and reports on literacy, Zou and Parry (2010) recommended that strategies should be developed for technological and educational approaches suited to immigrants' needs, especially language skills. In addition, they advocated for the formation of partnerships with healthcare professionals, and more importantly, with immigrant communities, to improve health care services for patients of these communities. Graces et al. (2008), Valenzuela et al. (2013) and Vincent et al. (2006) described how the concerns and practices of ethnic and immigrant populations could be addressed by examining their perspectives and experiences of health care service using focus groups and community needs assessments.

Over the past several decades, the influx of immigrants into the US has contributed to profound changes in the ethnic and cultural diversity of the US. Immigrants face many challenges of adapting to the new social customs and economic systems of the US, including health care services (Prus et al., 2010). Improving access to and use of health care is essential to address their needs. Several factors influence immigrants' use of health services effectively. These include cultural beliefs and practices, English proficiency, and health literacy (Dressler & Pils, 2009; Garces et al., 2008; Lee et al., 2010). Healthcare providers must establish interventions to address the unique needs of these diverse populations. Understanding immigrants' views of their experiences is necessary to create and implement these interventions (Graces et al., 2008; Valenzuela et al., 2013; Vincent et al., 2006). An interpretive phenomenological approach was used to examine the meaning that immigrant patients attribute to being in an IRF. The purpose of this study was to gain a better understanding of the experiences of immigrants in an IRF. Additionally, the study further aimed at exploring the factors that assist or hinder immigrants' recovery and return home. The insights gained can be utilized to develop interventions to improve patient care and outcomes in rehabilitation settings.

Methods

Interpretative phenomenological analysis (IPA) was used in this study to examine the lived experiences of immigrants in an IRF. As defined by Smith, Flowers, and Larkin (2009), IPA is a qualitative research approach that aims to capture and explore the meaning that research participants assign to their experiences. Data in the study was collected through in-person interviews, which "invite participants to offer a rich, detailed account of their experiences" (p. 57). Data analysis with an IPA approach is an iterative and inductive process that is employed to

identify superordinate themes that reflect the lived experience of the participants (Smith et al., 2009).

Recruitment

I used a purposive sampling process to select ten patients from the inpatient rehabilitation program at the Alexian Rehabilitation Hospital (ARH). I identified potential participants by reviewing patient demographic information provided by the admissions office and from referrals by therapists whose patients were in the rehabilitation program. I met with the therapy team to identify patients who met the inclusion criteria. When immigrant patients meeting the inclusion criteria were within 4 to 10 days of their discharge, I invited them to learn about the study by scheduling an in person meeting with each potential participant to present information and answer questions about the study. Individuals recruited for the study were no more than 1–3 days from their anticipated discharge from the IRF and were scheduled for continued therapy services in the day rehabilitation (DR), outpatient (OP) therapy or home health (HH) programs through ARH after their discharge.

Participants

Participants were immigrants to the United States, at least 18 years old, with a native or primary language other than English. They were able to communicate in English or through an interpreter and had the cognitive ability to understand and respond to questions in a 30-minute interview as indicated by a Functional Independence Measure (FIM) rating of 5 or greater for the social interaction, problem-solving, and memory components of the FIM. Ten patients from the IRF agreed to take part in the study. The participants were migrants from nine different countries who had immigrated to the United States between 26 and 60 years before their hospitalization at ARH. Their ages ranged from 52 to 80 years (average age 66.2 years). Five of the participants

were admitted following a stroke and the remaining five had were admitted for such musculoskeletal diagnoses as hip fracture and total knee replacement (Appendix B).

Study Design

Data Collection Procedures

I met with each individual and reviewed the informed consent document, answering all questions. Interpreter services were used if requested or needed by the participant, to translate the information on the consent form and assist in answering any questions asked by the participant. Translated versions of the consent form in five languages most commonly spoken by the patient population at ARH were also made available. Individuals who agreed to participate in the study were asked to sign the consent form (Appendix C).

Before initiating the interview, I reviewed the study procedures and timeline to ensure that the participants were still interested in taking part in the study. Interpreter services were offered to all participants in the study. The interpreter service was available in person, or by phone/internet using ARH's interpreter services, depending on availability of the services and preference of the participant at the time of the interview. One participant requested an interpreter for the interview to ensure the participant understood the purpose and format of the study. The IRF's online service, using an iPad, was used to access an interpreter for this interview.

I implemented data collection procedures similar to those described by Martin (2009). I obtained data through a single face-to-face interview using a semi-structured interview guide. The interview guide included close-ended questions to collect demographic information and open-ended questions, including probes, to elicit a comprehensive description of the experience of each participant (Appendix A). Open-ended questions enabled participants to describe ideas and experiences in their own words rather than respond to preconceived concepts of the

researcher. A second researcher reviewed the interview guide to ensure appropriateness and clarity of the interview questions before the use of the guide for a pilot study. Four individuals who met the inclusion criteria were interviewed to provide feedback about the clarity and suitability of the questions on the interview guide before the start of the study. I modified the guide based on additional insights gained through this process. Data collected from these patients was not analyzed or used in the study.

I completed the interviews at the IRF dates and times convenient for the participants. The participants were interviewed at a location in the facility that was free from distractions and excessive noise. Nine of the ten interviews were conducted in English, and one was conducted through an interpreter accessed with the iPad at the request of the participant. The interview conducted with the iPad service was transcribed verbatim into English by a certified interpreter to ensure that the translation was consistent and correct. All of the interviews were audio-recorded and lasted for between 18 and 34 minutes, with an average length of 25 minutes. I took field notes during the interviews to document additional comments or observations during interviews.

Informed consent forms, recordings of the interviews, and transcripts were stored electronically in password-protected files on the primary researcher's computer. Field notes were stored in a locked file cabinet in the primary researcher's office until transcribed. The transcribed field notes were stored electronically in password-protected files on the primary researcher's computer. The participants' identities were protected by substituting their names and other identifiers with alphanumeric codes. The electronic files and hard copies of information will be destroyed three years after the conclusion of the study.

Researcher's Role

As an occupational therapist, with more than 30 years of experience in a variety of adult physical rehabilitation settings, I was employed at the study site for over 17 years. Therefore, I am familiar with many aspects of patient care in an IRF. Consequently, I am familiar with medical and therapy interventions as well as educational methods and materials used at ARH for educating patients and their families. As a native born, English-speaking individual, however, I do not share an immigrant's experience and perspective.

I used the hermeneutic perspective of IPA to interpret the participants' experiences through the participants' own descriptions of those experiences (Smith, et al., 2009). In this study, I was both an insider, because of my clinical training and experience, and an outsider because of the lack of immigrant self-experience. As a result of this my background as a clinician could have contributed to preconceived ideas and expectations of patients' experiences in an IRF. I used reflexivity throughout the study to be aware of my own biases and expectations about the participating patients' experiences in rehabilitation. I journaled my personal reactions about participants' comments and experiences recorded during the interviews, reviewing information during the data analysis process to ensure that I remained focused on the participants' experiences as they were stated.

Internal Review Board and Confidentiality

This study was approved and completed in accordance with the procedures reviewed and approved by the Institutional Review Board of Board (IRB) at Alexian Brothers Medical Center and the University of Indianapolis.

Data Analysis

I read and re-read the interview transcripts while listening to the recordings. I provided the participants with copies of the transcripts so they could read the interview text without my presence or potential influence. Follow-up meetings were offered to the participants to ensure accuracy of the transcripts, to clarify words or phrases that could not be identified during transcription, and to provide an opportunity for participants to offer feedback and ask questions. When face-to-face meetings were not possible, copies of transcripts were mailed to participants with requesting them to provide feedback in person, by phone, or in writing. At least two follow-up phone calls were made to the participants who did not return the transcripts within two weeks. I spoke face to face with four participants and by phone to an additional two participants. Four participants neither returned the transcripts nor could be reached by phone.

After receiving feedback on the transcripts, I reviewed the transcripts repeatedly to develop preliminary codes describing the participants' experiences. A three-column grid, as described in Saldaña, (2010, p. 17), was used to establish preliminary codes based on the participants' comments. I grouped similar codes and supporting data into themes for each participant. The resulting themes were organized to allow a comparison and analysis of each participant's themes and supporting comments. To examine the participants' words to identify commonalities and differences in their experiences to develop final thematic ideas, I used a cross-case analysis process using a conceptually clustered matrix as described in Miles et al. (2014, p.173-178). Participants' quotes that were identified for each theme during the cross-case analysis provided support for the resulting themes. A second researcher with expertise in qualitative analysis independently reviewed the codes and themes to enhance the credibility and dependability of the resulting themes. The two researchers discussed the themes and reached a

consensus on the final themes. An audit trail documenting the research and analysis process was maintained throughout the study to ensure the rigor of the study and reduce bias in it.

Trustworthiness

To establish the trustworthiness of the study, I engaged in reflexivity by keeping a journal of experiences and feelings during the study as a way of separating them from those of the participants. This step minimized the potential of personal experiences and biases to distort the meanings of the participant's experiences of the phenomenon (Cresswell, 2013; Henderson & Rheault, 2004). All participants reviewed written transcripts of their interview and offered corrections and revisions to their content as needed when participants came to ARH for their scheduled DR or OP appointments (Henderson & Rheault, 2004; Martin, 2009). If participants were not able to take part in a feedback session in person, I attempted to do so by phone, at a time of the participant's choosing.

Transparency for the study was increased by establishing an external audit trail for examining participants' interview transcripts. Further, another researcher with a background in qualitative research provided peer review to confirm or refute my findings from this study. The iterative approach used in the study helped reduce bias by presenting opportunities to review the findings repeatedly to gain a better understanding of the participants' responses and to bracket the researcher's reactions more thoroughly. Dependability was addressed by describing the research process, presenting relevant aspects of this process including participants' quotes and concepts that supported the themes that were identified. Participants' demographic information and the inclusion criteria imparted transferability to the study.

Findings

The purpose of this study was to examine and describe the experiences and perspectives of immigrants to the US as they completed their episode of healthcare at an IRF. Two themes emerged from my review and analysis of the participants' responses during their interviews. The first theme, *Understanding the Language and Life of Rehabilitation* was derived from participants' remarks that reflected their understanding of the daily routine on the IRF. These remarks focused on their day-to-day schedule, medical care, and therapy sessions. Participants also shared their views about the care they received and interventions they felt were most effective and useful in their recovery. The second theme, *Trust and Decision-making in the Rehabilitation Experience*, was developed from the participants' responses about their interactions with healthcare providers and their families as they completed their rehabilitation. The participants conveyed their sense of trust and confidence in healthcare providers' expertise in directing the course of their rehabilitation and facilitating their recovery. They also expressed feelings and concerns about their impending discharge, including thoughts about the support and assistance of their families when they returned home.

Theme 1: Understanding the Language and Life of Rehabilitation

The participants' responses about their experiences during their admission reflected their level of understanding about the medical care, therapy sessions, and the day-to-day routine of the IRF. The participants varied in their ability to describe a typical daily schedule. Some respondents provided a more general overview of their day. For example, one participant (Female, 60) stated,

Oh, so my routine activities here and plus ever, whatever I'm doing it or only activities here? First thing I can tell like in this rehab center, since I came I get up 7 o'clock, 7 to 3

my schedule is so tight, I cannot do here that, that's for sure. They keep me busy all the time. No matter what. And meantime, they careful for that too I get enough breaks. So, from the time when they start the schedule. How do you call that? It's in sequence.

Another participant (Male, 65) made similar remarks, "Oh, wake up, get part of your medications, mostly in my case, get your pain medication, and soon after it, get your food, breakfast. Have your breakfast, and then starts the rehabilitation service."

Others offered more specific descriptions of the routine they experienced as one (Female, 70) explained,

So, from the time when they start the schedule. How do you call that? It's in sequence like 8 o'clock for OT, then PT 9 o'clock or 9:30, and then the speech sometimes is in the afternoon, but also everything's in the morning and so by 12 o'clock you're done.

Although most participants' comments were focused on their therapy schedule, several commented on physician and nursing care as well.

The routine is they come, check on the person, how he's feeling, they take the temperature, blood sugar, then they do the medications, they're supposed to have the medicine, they give you the medication, that's the nurse now and get the housekeeping come to look what I need in the room (Male, 68).

Even though most participants were able to present their perspective of the daily routine in the IRF, several individuals had difficulty describing therapy and medical services they experienced during rehabilitation. For example, one participant (Female, 80) stated "Uh, I don't know what they're called. I don't remember what they're called, like you know, all the therapy I got from them it's the ones that I needed what, but I don't remember the names."

Many participants indicated they preferred an active, hands-on approach to therapy, and especially therapy sessions associated with mobility or self-care and stated, “Walking. Standing. Maybe, like kitchen, getting out of bed, trying out different chairs” (Male, 55), “... the most I will say is that they have been teaching me how to walk, how to go to the bathroom” (Female, 68), and “Practice and how to walk how to walk with a walker, how to go stairs... The best was the practice.” (Male, 75).

The participants demonstrated their understanding of the goals of the various types of therapy they received by describing the differences in the services they received. One (Male, 65) participant remarked,

Occupational therapy teaches you how to do [*sic*] in cases that you have to do something at home... The other is physical therapy, where it teaches you strength that you need to perform a certain task and, in a way, in a lot of ways, both are the same.

Another (Female, 60) offered her perspective about the differences between PT and OT and the benefits of those activities in her recovery by stating,

First impression was that I needed my legs not OT, I was thinking OT means upper body exercising, but then... when I, when they took me in the kitchen, and then they told me do this, do that. Like I to get stuff from the fridge, and put it on the dining table and then I realized it's necessary too [*laughs*]. It's not only PT.

The participants' understanding of the purpose of therapy was also noted in their comments about the importance of the direct interactions they experienced with clinicians. Participants described how the instruction and feedback they received from therapists enabled them to understand the objectives and outcomes of treatment activities more readily such as:

Most effective think [*sic*] is when they show you what to do, a certain movement, and tell you why you have to do it. What does it do to your body, or to your well-being, which is what you need in the end result... When the therapists, takes their time to explain everything to you, because just “Oh, you see this movement, just do it 15 times”. Yeah, but I’d like to know what the end result will be for me (Male, 65).

Participants not only recognized the benefits and efficacy of the training they received through direct practice and repetition but they also expressed awareness that their relationship with clinicians helped them in the recovery needed for going home. One participant (Male, 68) noted “The trainers I think they’re doing marvelous job, we get enough time, one hour is more than enough to work with the person”. Another (Male, 52) stated “I mean learning how to proceed and dealing with my injury... that’s the goal, and that’s what everybody [referring to therapy staff] here is been doing”. The participants reported similar perspectives about their relationship with the medical care staff. For example, one participant (Female, 69) said, “I know the doctors and nurses were very nice for me they teach me, like, if sugar is low, I have to go drink or eat because to morning would be no good with that goes very low”. Moreover, participants acknowledged their role in furthering their recovery by completing activities outside of therapy sessions, as indicated by (Female, 70) “It’s to follow the instructions they give me to do when I am in the gym. When I go back to my room to have simple exercises that they ask me to do”.

Despite the preference for a more active, movement-oriented approach to therapy, the participants acknowledged the value of other forms of instruction, such as printed materials, for carrying over training outside of treatment sessions with one participant (Male, 55) commenting:

Not harder no, maybe the one paper I got, yeah, that's very helpful because you go home and it's like forgetting, you're getting everything of your own stuff, but if you get paper, the ones you give me, I should get some more stuff, the paper from the therapist. And it gives you more resources.

Another participant (male, 68) had similar observations about materials he received from SP stating,

They give me the papers and I have to answer it, and then they to check how I'm doing. They don't let me know immediately, they will wait until the next day to give me the same work but a higher level and look what you didn't do yesterday, but now you do it. So, it's like you improve yourself by answering.

The majority of participants expressed their preferences for the treatment techniques used in their rehabilitation. One individual (Male, 65) was more assertive in expressing his likes and dislikes about the care he received stating his preference for one to one therapy, stating "What I personally don't like when it's mat therapy. A group of two, three, four or five people have to do everything with the same trainer". He had similar remarks about aspects of nursing care he did not agree with, commenting "Oh, some of the things, they baby you. In my opinion, the nurses and their assistants plain and simple baby you". This individual's remarks are distinct from all other participants who expressed satisfaction with their care such as (Male, 68) "They're complete helpful, especially this, the trainers, they know what to do, and they do it from the beginning slowly."

Just as some participants had difficulties in describing the daily routine of rehabilitation, several individuals also commented on the challenges they encountered in understanding the instructions they received during their therapy sessions. One participant (Female, 68) stated,

“Well, I think that it [using an interpreter service via iPad during therapy] is something good because, in other ways, we wouldn’t be able to do the therapy”. Another (Male, 68) stressed the need for demonstration by therapists and repetition to facilitate learning the skills in the PT that he had experienced, commenting,

Sometimes I can miss communication [*sic*]... Like okay, now we’re going to do step up, step down. I get confused, what you do want me to step up where or you know, so no, it’s like I show you, one step up, one step down, like you walk, like don’t drag your feet, ... it’s like I couldn’t understand exactly maybe, because she thinks I know it, but I have to more, to more explanation [*sic*].

A participant (Female, 69), who stated that she typically spent up to six months of the year in her home country of Poland, shared the following about her speech therapy activities, “She tell me story, she have to ask me about the story, yeah, I have to remember, but I remember, but sometimes was problems with the English language because I talked to her”.

Theme 2: Trust and Decision-making in the Rehabilitation Experience

The participants’ responses throughout this study illustrated their trust in the judgment, efforts, and recommendations of the healthcare providers at ARH. They articulated their beliefs that their caregivers were knowledgeable and attentive to their needs and ascribed much of the progress they made during their admission to the staff’s care. The participants expressed this trust and confidence in their care providers in a number of ways. Several participants used more general terms to express their feelings such as one (Female, 68) who remarked “Well, I think that I will say it’s good because you [therapists, doctors] are ones that know how to do those these things, and if you are here it’s because you know how to do all those things” when describing interventions by various clinicians. Other participants were more explicit about their trust in the

health care provider, as indicated when one participant (Female, 80) remarked “Their dedication. They’re, you know, very dedicated to me, so you know that I can trust the way they are, I feel very, that I trust the doctor”. Another (Male, 75) said “I don’t know with some other people, but the people [therapists] I have experienced, everybody know what to do, and everybody doing right”.

Some participants specifically spoke of their trust in the expertise provided by doctors and nursing staff, one (Female, 60) commenting:

Ahhh, if they both [the doctor and the nurse] doing the same day but I’m more satisfied the doctor see that, or the nurse, you know, doctor is doctor, nurse is nurse. I know that, but still even the nurses say “Oh, you are okay” but still when the doctor say, I feel more comfortable and more trusting kind of. Like a kid does something in cooking and then you say something and mom says, “oh yeah it’s good” and then father says “oh but it’s all great” both of them in a like that kind of confidence.

Others had similar observations about Allied Health staff, with one participant remarking

... I think OT, PT, and SP therapists they know their own field and they, it’s a different form of teaching, the different fields, it’s just different” (Female, 70) and another saying “They’re complete helpful, especially this, the trainers, they know what to do, and they do it from the beginning slowly (Male, 68).

A patient’s ability to take part in decision-making can influence their understanding of the purpose of these activities and ultimately affect their capacity to achieve goals set during their admission. Participants expressed faith in the skills and interventions of healthcare providers at ARH. They acknowledged that clinicians of all disciplines directed their care process, with participants providing limited input to this aspect of their care. Deference to

clinician's judgment and recommendations was reflected when participants repeatedly used the word "they", as stated by one individual (Female, 68) "they [therapists] telling me", "... helping me", "... teaching me" when referring to the training she received. Though occurring less frequently, the participants recounted similar experiences of trust in the care they received from physicians and nurses. As one participant (Female, 60) stated, "Yeah, the doctor teach me how to stretch your legs early morning when you get up before you go to therapy, yeah. He teach me, no doubt about it."

Participants not only expressed their confidence in the skills of clinicians in the rehabilitation program but they also indicated they felt that following instructions of the clinicians was essential to their recovery, as noted by one participant (Male, 52), "You have to be patient, and learn, and cooperate with, with the therapists, and follow what they say, in order for my benefit to be better." Another (Male 68) stated,

Just to listen what the instructor tell me, and do it exactly, because they been doing it to so many patients. I'm not going to come here to not listen, because I want to get me in shape so I can go home. *So anything they tell me, [emphasis added] I'll start giving more attention and don't aggravate them, or something making them upset. The minute that I'm in the train [sic] with that person, I have to keep my ears open...and they know they what to supposed to work with me there's no choice for me to say "No, I don't want to", I have to listen, and okay, and we go through it together.*" [emphasis added].

Although most participants acknowledged that they provided little feedback to the clinicians on the directions they gave during therapy, one individual voiced a contrasting point of view. The participant, (Male, 65), who earlier emphatically expressed his preferences for individual rather than group treatment sessions, also conveyed his perspective about the methods

of instruction he expected from therapists during his sessions, saying: “When the therapists, takes their time to explain everything to you, because just ‘Oh, you see this movement, just do it 15 times’. Yeah, but I’d like to know what the end result will be for me.”

This participant also described why he felt it was important for a patient to be actively involved in the rehabilitation process stating:

In therapy, I think that we have as patients, we have also to give feedback to therapists, what is helping us, what we don’t need what is too difficult, maybe to change the ways, but we have to give feedback because therapists cannot read minds and they won’t be able to help us.

This remark is consistent with other participants who acknowledged they also had responsibilities in their recovery such as:

To me everything, I mean, I keep saying everything, everything is very important because I learn, I learn every day when they come out with something, I learn, and I put it in practice. And I do it because I know it’s all my own benefit. Because that’s going to help me out to get better (Male, 52).

Another (Female, 80) stated:

...the way I’m learning here, it’s really that you know, it’s with patience I’m going to be able to do because I’m, I was always the way I wanted do it, where I, everything that I want to do, and to recuperate from this injury, that’s what I want.

The participants’ perspectives of trust in the inpatient rehabilitation process that they experienced were also reflected in their responses about preparations for discharge from the IRF. The participants revealed a range of feelings and concerns about their level of recovery and independence, from confidence to uncertainty. One (Female, 60) noted the progress she made

during her rehabilitation and how she believed it helped her be ready for home. “I’m ready, I’m prepared, and I feel more like, I’m oh, and I can go home and I can do much better than before.”

Another (Female, 80) remarked “Well, all the exercise, the therapy you know, made the possibility for me to go home because I really, I really am much more better [*sic*] than when I came in.”

Even though the majority of participants acknowledged the improvements they made and conveyed a sense of eagerness to go home, several participants mentioned feelings of uncertainty about their readiness for discharge. Several participants indicated that they believed they had not recovered fully during their admission as one (Female, 70) reported: “I think I’m maybe prepared not 100%”, maybe 85%.” Another (Male, 65) stated, “I am scared of going home and at the same time excited ... *I hope that I will be 100% prepared but it will never happen, because it never works out the way you want to.*” [emphasis added].

Participants also voiced faith in their families’ willingness and abilities to assist them at home following their discharge home. One participant (Male, 68) stated,

They’re excited. [Laughs]. They’re excited. And they know it’s a challenge to make it safe for me in there, they know the house is big, and a lot of stairs, maybe slippery floor. They were already talking about having everything ready for that... So, they’re all willing to give the extra hand. Somebody be at home with me, somebody, hour I need help with anything in there ...

However, just as some participants conveyed a sense of apprehension about their readiness to go home, some also expressed uncertainty about their families’ preparedness. One participant (Female, 68) related ... “I just hope that my family is going to be able to take care of me and they are going to do as much as they can as well, so I can be well”. Another participant

(Male, 65) voiced similar concerns stating “My wife is excited, and she is kind of nervous about me coming home but, it’s her job. If you can say that about the wife”.

Most participants also recognized their own role for continued success in recovery by acknowledging they had a personal responsibility following discharge. One participant stated, “I know I have to be busy and not sitting back and thinking” (Female, 69). Another (Male, 68) reported, “they told me you going to go home, you did a marvelous job, but remember, if you stop of [*sic*] training at home or if you start eating salt food [*sic*] or getting your sugars up, you can come back”. Another participant acknowledged:

Well, they are explaining me all the things that we’ve been doing, that’s to protect me, and to keep me safe, and then all those things I’ve been learning here, I put in practice at home. Even though if myself, but I know I have my wife at home and that she will help me 100%. So, whatever they are telling me, it’s is just to get well and to get strong and trying to get me back to what I was (Male 52).

In contrast, other participants appeared to be more willing to depend on the assistance of their families following discharge home. One participant (Female, 80) commented “Happy, they’re [referring to her family] happy you know, they’re willing to help, as a matter fact today they got a little experience to be, you know, the way to act when I’m home.” Another participant (Male, 55) said, “My mother do everything for her little boy. My father, the same thing, even things that are not 100% like walking.”

Summary of Findings

The participants’ responses regarding their time in the IRF revealed differences in how they perceived and understood their experience. They expressed clear preferences for treatment that incorporated physical activities and indicated their readiness to follow the directions of the

healthcare professionals they encountered. Several participants described difficulties understanding information presented in English, although this did not appear to negatively impact their perspective of or participation in care. The participants' understanding and perspectives of their care also reflected the trust and collaboration they developed with their healthcare providers. This demonstrated their belief that the healthcare providers' interventions helped them in their recovery and prepared them for discharge from the rehabilitation program. The trust they experienced may also have been a factor in the participants' limited role in the decision-making process for their care, as they described deferring to the expertise and directions of their caregivers in selecting care and treatment activities. Although several participants voiced a degree of uncertainty about their abilities and readiness to go home, the participants expressed appreciation for the training they received in preparation for discharge and of the assistance and support from their families at home.

Discussion

Theme 1: Understanding the Language and Life of Rehabilitation

The first theme, *Understanding the Language and Life of Rehabilitation* can be explained by two primary concepts. The first of these concepts is based on the participants' understanding of daily routine in the IRF and experiences with the care they received during their admission. The participants differed in their ability to describe a typical day in the rehabilitation program. Some were able to identify specific aspects and offer a detailed account of their routine, while others were unable to do so or could provide only a vague description of their schedule. There are no studies exploring patients' understanding of the overall expectations and format of an IRF. However, as an occupational therapist with extensive experience in inpatient rehabilitation, I have encountered instances in which patients, regardless of their background, have difficulty

appreciating the purpose of their admission to an IRF and understanding the different roles and responsibilities of healthcare providers in the program. Several factors can affect an individual's perception of different aspects of their admission to an IRF. For example, an IRF has requirements for admission that are different from many other levels of care. These include regular participation in three hours of therapy, as well as the need to follow a structured schedule for many activities, from meals to therapy sessions. In addition, patients may be engaging with healthcare providers whose functions are unfamiliar to the patients, such as occupational and speech therapy.

Although all aspects of a rehabilitation program are important in a patient's recovery, therapy interventions to improve a patient's functional status are a primary reason for an individual's admission to an IRF. The participants' responses about therapy intervention during their admission revealed that they considered regaining mobility or upper extremity (UE) function a focus of their rehabilitation. Many of the participants viewed improved mobility, in particular, as a primary indicator of their recovery and as a skill essential for achieving their goal of returning home. This phenomenon is not unique among the experiences of the immigrant participants in this study. Native-born patients of in- and out-patient rehabilitation programs also identified physical activity, and especially those that focused on body functions, such as walking and balance, and improving motor skills, such as arm and leg control, as the most important aspects of their rehabilitation (Galvin et al., 2009; Gustafsson & McLaughlin, 2009; Jäppinen et al., 2017; Luker et al., 2015).

Although the participants in the current study commented more frequently on the activities for improving overall motor abilities, they also acknowledged the benefits of therapy that addressed functional skills. Several participants noted that by engaging in treatment

activities, such as homemaking, they gained a greater appreciation of their limitations and how these interventions would facilitate their return to home. Researchers also found that when patients worked on meaningful and functional tasks that they encountered at home, it helped them regain their previous level of activity (Gustafsson & McLaughlin, 2009; Luker et al., 2015). In contrast to responses about the benefits they perceived with functional interventions, several participants voiced dissatisfaction with rote activities such as tabletop UE exercises during therapy sessions. However, the participants stated they gained a better understanding of the rationale for these exercises when therapists took time to explain the role these activities played in their recovery. These findings are similar to those found in Luker, which reported that efforts by therapists to communicate the role of seemingly menial and repetitive exercises in the recovery process assisted in patients understanding the value of these activities (Luker et al., 2015).

The participants in the current study not only articulated an understanding of various types of therapy they received, they also expressed their preferences for how training should be provided during their sessions with allied health clinicians. The participants preferred individual versus group therapy, with activities gradually upgraded to be more challenging and intensive as they progressed. The participants believed one-to-one therapy sessions provided a better opportunity to understand the purpose of activities because the interventions were more individualized. Moreover, they felt therapists were more attentive to their needs and provided demonstration, repetition, and feedback more easily during one-to-one sessions. Davenport et al. (2019) also reported that patients were most receptive to demonstration, practicing tasks while being observed by clinicians, and treatment that was progressed over time. Tholin and Forsberg (2014) found that native-born patients in a rehabilitation program were most satisfied when “the

rehabilitation was intense, specific, varied, gradually increasing in intensity and was conducted by professional staff” as well (p.825).

The participants of this study not only expressed their preferences for individualized, daily therapy sessions, several participants also stated that completing activities outside of their regularly scheduled treatment, or “homework”, from therapists helped them carry over training from therapy. Galvin et al (2009) and Luker et al. (2015) found that patients believed they could have benefited from more intensive and frequent physiotherapy than they normally received and that being able to do so would have hastened their recovery. In addition to having activity outside of therapy sessions, participants also acknowledged the benefits of receiving printed materials from staff. The participants believed these helped them recall and complete treatment activities when staff were not present and that it would help continue their recovery after discharge home. Jappinen et al. (2017) support this finding, noting that native-born post-surgical patients found printed materials to be beneficial in carrying over training following therapy. Therefore, it may be assumed that this preference was not unique to an immigrant in an IRF.

Most of the participants commented on the value of therapy activities in the gym like strengthening or walking, and functional tasks like homemaking. However, few participants remarked about their experiences completing Activities of Daily Living (ADL) even though this part of therapy interventions comprised a primary emphasis of OT in the IRF. Although there is little research about patients’ perspectives of OT in rehabilitation, Jappinen et al. (2017) reported that patients might not mention the importance of practicing ADL skills due to their limited interaction with OT during their admission. Jappinen contended that this was due to a decreased emphasis on addressing daily living skills for these patients during their admission. The findings in Jappinen contrast with the experiences of participants in the current study who engaged in

regularly scheduled ADL sessions with OT throughout their stay in the IRF and still did not mention ADL as a significant experience during their admission. It is my experience that many patients do not fully understand the purpose of OT in a rehabilitation program, especially as it relates to interventions like ADL. I have observed that patients often view ADL sessions with OT as an extension of nursing care to help them get ready in the morning, rather than skilled interventions to assist them in regaining functional independence in self-care. These misperceptions persist even though patients participate in extensive ADL sessions with OT throughout their admission. Further research could aid in identifying factors that contribute to patients' limited appreciation of the role of OT in facilitating their independence in performing the ADLs in a rehabilitation setting, regardless of whether the patient is native-born or an immigrant.

The participants also mentioned interactions with nursing and medical care less often than participating in therapy sessions. Overall, the participants' responses showed a greater awareness of the purpose of therapy activities compared to their understanding of nursing or medical care. The limited descriptions about the involvement of nurses and doctors in their care may have resulted from participants spending consistent, scheduled time with therapy staff, increasing their familiarity with clinicians and therapy's role in the rehabilitation process. The participants were typically scheduled for a daily routine of three hours of therapy, which were usually completed with the same clinician every day. In contrast, contact with medical staff and participants was often unscheduled and fleeting, which may have impacted their appreciation of the tasks these healthcare staff provide in the IRF.

Tyrell et al. (2012) reported that native-born patients in inpatient rehabilitation often express a decreased appreciation of nursing even though they understand the day-to-day nursing

activities. Patients acknowledged that the nurses provided assistance or supervision and also encouraged the patients to complete their routine tasks independently (Tyrell et al., 2012). The participants in the current study voiced similar thoughts about the support they received from nursing staff during their recovery, demonstrating their understanding of the role of nursing in an IRF may not be different from patients who are native-born.

The immigrant participants not only expressed their understanding of and preferences in their care while in the rehabilitation program but also described the therapeutic relationships with healthcare providers they experienced. Although one participant voiced dissatisfaction with participating in group therapy sessions and that he felt nursing staff “babied him”, the participants generally expressed satisfaction with all aspects of the therapy and medical care they received. The participants stated that therapists wanted them to get well, that the doctors were “nice”, and that they “couldn’t expect more than that” from the program. Patients in IRF often believe they are actively involved in their care and valued as individuals when they can express their concerns, understand their condition and treatment options and feel they are understood by the care providers. Their interaction and connection with healthcare providers also influence how engaged they are in their care and how much responsibility in the rehabilitation process they assume (Jäppinen et al., 2017; Luker et al., 2015; Peiris et al., 2012; Siouta et al., 2016; Tholin & Forsberg 2014; Tyrell et al. 2012).

The participants attributed their progress in rehabilitation to the relationships they experienced with staff as well as the effectiveness of treatment approaches they experienced, recognizing how clinicians’ skills and feedback helped their recovery. Davenport et al. (2019) described similar findings, noting that “Therapists who offered patience, praise, encouragement, belief, feedback and motivation were highly regarded” by patients (p.1971). Jäppinen et al.

(2017) and Tholin and Forsberg (2014) also reported that patients believed feedback about their progress was essential to recovery. In addition, they expected therapists to assist them with overcoming uncertainty about completing exercises and provide guidance and adequate time to learn the exercises.

The second concept that emerged from immigrant participants' responses illustrated the impact of communication and language skills on their experiences. I anticipated that the participants' language skills would exert some degree of influence on their ability to communicate with the IRF staff in English and anticipated that several participants might need interpreters for the interviews. However, this did not happen. Only one participant in this study requested for an interpreter for the interview. However, several participants did need to have questions rephrased or re-stated to facilitate their responses. This may indicate that some participants experienced limitations in understanding and using English, especially for verbal communication. However, the lack of language skills did not prevent participants from answering questions or expressing their thoughts during the interviews when these steps were taken.

Although the participants' language skills did not prevent them from expressing themselves during the interviews, several participants expressed difficulty understanding directions given during therapy sessions. This may be a reflection on the participants' literacy or lack of fluency in English because most instructions would have been provided verbally as they engaged in treatment activities in the therapy gym. There is no research examining the impact of limited English fluency on patients' experiences. However, Easton et al. (2013) found that even for patients whose primary language was English, and who could communicate with the health

providers in English, low health literacy was an obstacle in their interactions with healthcare providers.

Easton et al (2013) also found that patients with low literacy were sometimes deterred from asking questions or would at times feign understanding of care-related information for the fear of disclosing their lack of understanding. I have observed instances in which patients in the IRF responded similarly, indicating an understanding of a task or instructions, while their subsequent performance of the, yet their subsequent action or behavior was not necessarily accurate or complete. The participants of this study did not report concerns about understanding their care or being unable to request healthcare providers to clarify training. On the contrary, the participants said they felt able to ask for and received additional instruction and demonstration from staff whenever it was needed. The participants noted the healthcare providers made specific efforts to demonstrate or clarify instructions that enabled them to comprehend more fully the instructions they received.

Theme 2: Trust and Decision-making in the Rehabilitation Experience

The immigrant participants' perspectives about interaction and collaboration with healthcare providers and family during their stay, and in preparation for their discharge home, were the focus of the second theme of this study, *Trust and Decision-making in the Rehabilitation Experience*. Based on the findings of this study, immigrants in the IRF placed a considerable amount of trust in their healthcare providers. All the participants in the current study expressed the confidence they had in the ARH healthcare providers' ability to provide effective therapy and medical interventions. Although there is limited research about the role of trust in facilitating patient care, the immigrant participants' trust in the efforts of healthcare providers at the IRF is supported by several studies. Patients use trust to evaluate the quality of

the services they receive (Berhardson et al., 2017; Nygårdh et al., 2011; Taylor et al., 2019). Patients in a study by Berg et al. (2012) reported gaining a sense of security because “they could get advice and speak to professionals who understood their condition” (p.212). Nygårdh et al. (2011) and Peek (2009) noted that confidence in the skills and decision-making of clinicians was essential to building a patient’s sense of ability and independence because they were confident they were receiving the best care possible.

Some participants expressed that they had difficulty understanding therapy instructions. Nonetheless, all participants expressed a sense of carrying on a dialogue with clinicians during treatment and being respected by staff. The collaboration formed with healthcare providers during their rehabilitation also increased their involvement and motivation. Peek et al. (2009) also reported that clinicians’ interpersonal skills are important in “creating an environment where patients feel comfortable expressing their concerns, being honest about adherence, and playing a more active role in health-care decisions” (p.1138). Patients have expressed that consistency in care from staff helped them get to know the healthcare providers as individuals and to gain a better sense of their clinical skills. As a result, these patients felt there was no need to question the knowledge and decisions of staff. This provided them with a greater sense of security in how their care was handled (Jäppinen et al., 2017; Nygårdh et al., 2011; Siouta et al., 2016; Taylor et al., 2019).

The immigrant participants’ remarks about decision-making during their rehabilitation emerged clearly in the findings. The participants’ statements indicated they deferred to healthcare providers in the IRF when determining goals for home or when identifying treatment activities to attain those goals. These findings are in contrast with current perspectives concerning patient participation in decision-making. Client-centered care requires that clinicians

share decision-making to ensure that the healthcare provider, patient, and family members “make a healthcare decision that is best for the patient. The optimal decision takes into account evidence-based information about available options, the clinician’s knowledge and experience, and the patient’s values and preferences” (Agency for Healthcare Research and Quality, 2014, The SHARE Approach). The recommendations of the SHARE Approach are supported by Luker et al. (2015) who reported that establishing a partnership among clinicians, patients, and their families enabled treatment goals and interventions to be tailored to an individual’s unique needs and capabilities. This also contributes to patients experiencing greater engagement in treatment because they helped determine their treatment goals (Lindahl et al., 2013; Nygårdh et al., 2011; & Taylor et al., 2019).

Most participants expressed a perspective that staff “knew best” about selecting and directing interventions. The trust participants had in healthcare providers and their skills may have facilitated a willingness on their part to forgo offering input, having confidence that the clinicians’ judgment and expertise would assure that appropriate interventions were carried out. This is consistent with my experiences as an occupational therapist in inpatient rehabilitation. Patients in these instances deferred to therapists in determining goals and treatment activities based on their perception of a therapist’s clinical knowledge and experience in providing treatment interventions. Researchers have reported that while some patients want to be actively involved in decision making, others prefer to leave decisions to the therapist because clinicians were viewed as “experts”, with patients deferring decision-making to care providers’ expertise (Berhardsson et al., 2017; Käringen et al., 2011; Tholin & Fosberg, 2014).

Although the participants’ statements indicated a limited role in decision-making, they described the interaction and communication they experienced with clinicians as effective in

meeting their needs. Facilitating participation in decision-making requires that healthcare providers make relevant information available to patients to create an environment in which a patient feels able and willing to assume responsibility to take part in making choices about their care (Käringen et al., 2011). Patients often report that the timing and quality of communication from healthcare providers in a way they readily understand is essential for them to participate in the decision-making process. This communication offers a way for clinicians to confirm the level and accuracy of a patient's knowledge about their condition, and if it is adequate to make informed choices (Gill et al., 2014; Ibrahim et al., 2019; Lamontagne et al., 2019; Lindberg et al., 2013; Peek et al., 2009). The participants in the current study did not report participating in decision-making in the IRF in this manner. However, their remarks demonstrate the participants' belief in the staff's efforts to ensure that they understood the care and training they received.

Barriers to patient involvement in decision-making can result from organizational or clinician-based approaches to interventions they provide (Elwyn et al., 2012; Levack et al., 2011; van Seben et al., 2019). Patients' participation in their care can also be affected when they do not fully understand the information that is provided. Native-born patients report feeling disempowered or dissatisfied with their care more frequently due to difficulties comprehending and processing information from clinicians, especially when it is given verbally. As a result, these patients report greater confusion and uncertainty about their care and feel unprepared to make healthcare decisions (Ibrahim, et al., 2018; Nygårdh et al., 2011; Peek et al., 2009). In contrast, the immigrant participants in the current study did not report that their care was negatively affected by difficulties they encountered in communicating with the IRF staff. Several participants did note that they experienced problems in following instructions in therapy, especially when these were given verbally. However, these participants also described the steps

healthcare providers took to provide increased time, demonstration, and practice in therapy to overcome any problems the participants experienced in understanding their care.

The participants' comments revealed not only their thoughts about the training they and their families received in preparation for going home. Their remarks also illustrated the anticipation, confidence, and in some instances, uncertainty they felt as their discharge approached. Differences in the perspectives about expectations of patients' recovery by healthcare providers on the one hand, and patients and their family caregivers on the other, can arise as discharge from an IRF nears. Patients and family caregivers may focus on "getting better", with the expectation they will remain in the IRF until they fully recover. On the other hand, healthcare providers may establish goals aimed at hastening the patients' return to a community level setting or to enable patients to meet organizational and financial constraints (Levack et al., 2011; van Seben et al., 2019). These differences present challenges to the patients and their family members who are then faced with addressing residual limitations as well as the need for more assistance or modifications at home (Lutz et al., 2011). Patients want to become independent in self-care to go home as soon as possible and anticipate they will not be discharged until they regain the skills needed to be self-sufficient (van Seben et al., 2019). Several participants in the current study had similar perspectives. These participants stated that they had hoped to recover functionally more than they had before being discharged. They also expressed the view that remaining in the rehabilitation program for additional time could help regain their prior level of function. Others voiced concerns that their residual limitations in day-to-day activities would place a greater burden of care on their family.

Addressing these concerns requires presenting opportunities for patients and their families/caregivers to practice tasks with the therapist prior to discharge. Participants in the

current study commented that their training in the IRF was beneficial and prepared them to manage themselves safely at home. Jäppinen et al. (2017) also reported that native-born patients felt they gained confidence in mobility they needed to be independent as a result of the PT they received. These patients believed that therapy enabled them to move and complete tasks, such as negotiating stairs at home, more safely and with less effort. Lamontagne et al. (2019) reported patients were satisfied with the training and information they received, and that it helped them get ready for the next phase in their rehabilitation.

Several participants recognized they would need at least some level of assistance from their family initially due to residual limitations in their functional abilities. Some participants expressed uncertainty about their family's overall readiness. However, all of the participants appreciated their family's willingness and dedication to helping them when they returned home. They stated that the training they and their families received in preparation for their discharge was useful because it enabled them and their families to have a better sense of each other's capabilities and responsibilities in the home. Research into education processes that facilitate patients' discharge is limited. Even though many patients regain independence in some aspects of their lives, there are instances in which patients continue to need assistance in some form when they are discharged from an IRF. Tholin and Fosberg (2014) also found that patients felt that family and others were essential for social support and assistance with day-to-day tasks after they went home.

Strengths and Limitations

This study has several strengths including the qualitative research approach used in it examines the participants' experiences and points of view. Interpretative phenomenological analysis (IPA) is an approach that examines how people try to make sense of significant life

experiences. IPA endeavors to do this by exploring the meaning of those events as defined and described by the individuals experiencing them. (Smith et al., 2009). The use of IPA was effective in bringing forward the immigrant participants' experiences in the IRF and the meaning each one of them placed on those experiences. IPA also enabled me to incorporate my knowledge as an OT about interventions and care commonly used in a rehabilitation program to facilitate interpreting the participants' responses. This clinical expertise enabled me to establish insights into the immigrant participants' experiences of the rehabilitation process for at the IRF and how these might compare with native-born patients. Trustworthiness and credibility of the findings was assured by utilizing reflexivity, verbatim quotes to establish detailed participant descriptions of their experiences, member checking, and peer review of interviews and analysis during the study. The diversity of the participants is also a strength of the study, as it made it possible to explore a wider range of views and experiences, offering a richer perspective of those experiences for the study. At the same time, interviewing individuals from a single program contributed to establishing an understanding of differences and similarities in the participants' experiences. The description of the participants and the analysis techniques used in the study also helped to establish findings that are transferable to similar studies.

There were also limitations to this study. The diversity of the participant group, while offering the strengths noted above, limited how well the study's findings might be applied to specific or larger populations, as does the fact that the participants were selected from a single rehabilitation program. The number of years the participants resided in the U. S. (39.7 years on average) may have diminished the impact of being an immigrant, as the participants would have had more time to assimilate American social and cultural practices compared to more recent immigrants. The length of time that the participants have spent in the US may have also enabled

them to gain a higher level of proficiency in English. As a result, their language skills may lessen the study's applicability to immigrant populations whose proficiency in English, especially related to healthcare, is more limited. Finally, while the researcher's background as a clinician may have facilitated understanding of the rehabilitation process and patient experiences, the participants' knowledge of the researcher's clinical role in the program may have affected their responses in the interview process.

Conclusion

The perspectives of immigrant patients in an IRF were examined in this study to gain a better understanding of their rehabilitation experiences. Two primary themes emerged in this study: understanding the language and life of rehabilitation, and trust and decision-making in the rehabilitation experience. Most of the participants understood the routine of the IRF as well as the training and care they received. This enabled them to participate effectively in their care, which contributed to their satisfaction with the rehabilitation experience.

Several participants described difficulties they encountered in understanding some aspects of their care, and especially when receiving verbal instructions during therapy sessions. These situations illustrated the impact that language skills can produce during rehabilitation. However, the participants also conveyed their perspectives that the communication and collaboration with clinicians helped them to overcome these obstacles as and when they arose. This suggests that even though language and communication presented challenges in some instances, it did not detract from the participants' experience on the IRF, limit their recovery or delay their discharge home.

The participants did not state whether they were encouraged to take part in determining goals and activities for their care in the IRF. The participants did express trust in the expertise

and judgment of the staff to provide effective interventions in the IRF. As a result, the participants may have been more willing to defer to healthcare providers in decision-making and directing care during their admission. This sense of trust also extended to their feelings about the training they completed in preparation for their discharge from the IRF.

The findings of this study indicate that being an immigrant did not have a significant impact on the participants' understanding of and ability to take part in the rehabilitation program. However, challenges in communication and the limited role in decision-making that the participants experienced point to potential areas for improvement in patient care. It is critical to recognize the impact of a patient's fluency or mastery of the English language when considering their participation in the decision-making process. For example, if therapists have a good understanding of their patients' capabilities, they can provide the appropriate level of assistance or instruction. Incorporating language and literacy assessments, such as the Basic English Skills Test (BEST), Rapid Estimate of Adult Literacy in Medicine (REALM) or the Test of Functional Health Literacy in Adults (TOFHLA) into the evaluation process could help identify individuals with limited fluency or literacy in English. These measures can then aid in the development of techniques and strategies to mitigate the impact of limited language skills in patient care.

Increasing patient participation in decision-making is an important element of patient-centered care. A greater understanding of patients' experiences can facilitate implementing measures to insure patients are able to take a more active role in decision-making regarding the care they receive. Clinicians can incorporate measures to understand factors that influence the decision-making process, such as recognizing the impact of patients' culture and language. Clinicians can also take steps to increase patients' understanding of the objectives of an admission to an IRF as well as the importance of a patient's participation in determining goals

and activities during their stay. The model proposed by Elwyn et al. (2012) or assessments such as the Canadian Occupational Performance Measure (COPM) may offer ways to put shared decision-making into practice on a more systematic basis by healthcare providers and patients, and ultimately, ensure a more consistent and higher level of care to these patients in all settings.

Future studies could establish a better understanding of the impact of language and communication by modifying the inclusion criteria to focus on individuals who have lived in the US for a shorter period, for example, five years or less, or those for whom English is not their primary or preferred language. This may produce markedly different responses than were found in the current study, as individuals who are more recent immigrants have less time to become assimilated, to establish a functional level of proficiency in English, and have less exposure to and familiarity with the US healthcare system, all of which could impact their experience of receiving rehabilitation services. A study that includes matched groups of native-born and immigrant patients could provide another means of determining the impact if any that language or cultural backgrounds might have on the experiences of individuals in an IRF.

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Appendix A

Interview Guide

Name/ID of interviewee:

Interviewee age:

Interviewee gender:

Location of interview:

Date of interview:

May I ask about your education?

Do you work?

Do you live with family?

When did you come to the United States?

1. How would you describe a typical day in the rehab program to a friend?
2. What kind of teaching are you receiving from the doctors and nurses?
3. What therapy are you receiving? (Discuss each therapy named by the patient).

Tell me about your experience in _____therapy.

4. What types of teaching/instruction are you getting from them (hands on, written, verbal)?
5. What things make it easier, or make it harder, for you to understand the care you receive?

Can you tell me more about them?

6. Is there anything you feel could be changed for your care?

Can you tell me more about it?

7. Tell me more about going home. What are your expectations when you get home?

How well prepared do you feel you are to leave the hospital?

Describe things the doctors/nurses/therapists are doing to help you get ready for home.

Appendix B

Participant Demographics

Interview/ Gender	Nationality	Age	Years in US	Age at arrival in the US	Preferred Language	Diagnosis	Length of Stay
1 (F)	Mexican	68	26	42	Spanish	Stroke	15 days
2 (M)	Palestinian	68	46	22	English	Stroke	8 days
3 (F)	Filipino	70	45	25	English	Stroke	16 days
4 (F)	Polish	69	36	33	English	Stroke	24 days
5 (F)	Italian	80	60	21	English	Hip fracture	16 days
6 (M)	Columbian	55	30	25	English	Pelvic fracture	23 days
7 (M)	Hungarian	52	30	22	English	Multiple Trauma	8 days
8 (M)	Ukrainian	65	37	28	English	R foot Trans- metatarsal amputation	33 days
9 (F)	Indian	60	33	28	English	R TKA	16 days
10 (M)	Polish	75	54	21	English	Stroke	20 days
		66.2 Avg.	39.7 Avg.	26.7 Avg.			

*Note Median age is 33

Appendix C

ALEXIAN BROTHERS HEALTH NETWORK

Alexian Rehabilitation Hospital

Consent Form and HIPAA Authorization to Participate in Research

Title: Immigrant Patient Care Experiences during Rehabilitation

Principal investigator(s): John M. Dudzik, MHS, OTR/L

Funding Source: None

Introduction: You are being asked to take part in a research study. This document has important information about the reason for the study, what you will do if you choose to be in this study, and the way we would like to use information about you and your stay on the rehabilitation unit.

What is the study about?

The purpose of this study is gather information about the healthcare experience of patients in the rehabilitation program at Alexian Rehabilitation Hospital. The aim will be achieved by completing interviews from recent patients of the program.

Why are you asking me?

You are being asked to participate because you are currently a patient in the rehabilitation program and are about to be discharged home.

What will you have to do if you agree to be in the study?

If you consent to participate, you will be interviewed in person by the researcher, John M. Dudzik, before you are discharged from the rehabilitation program. The interview may take up to thirty (30) minutes and John M. Dudzik will ask you questions about your experiences as a patient.

After the interview, a typed word-for-word transcript of the interview will be provided to you in a printed form, and you will be asked to check the transcript for accuracy, or to clarify or expand on discussed topics as appropriate. An additional meeting with the researcher, John M. Dudzik, will be scheduled and you will be asked to provide your feedback on the interview transcript. The review may take up to thirty minutes.

If you are unable to participate in a face-to-face meeting to review the transcript, a copy of the transcript will be mailed to you. You are asked to provide feedback by phone or in writing. The total time requirement for participation in the research study will be approximately two to three hours.

Is there any audio or video recording?

This research project will include an audio recording of the interview. The recording will be transcribed by a paid transcriptionist. A transcript of the interview will be provided to an additional researcher who is an expert consultant in qualitative research. This additional researcher will review the transcripts to assist with data analysis of the interviews

No personal information will be asked for on the recording in order to guard your privacy. The recording will be downloaded from the recorder(s) to a dedicated computer and stored in a password-protected file identifiable only by number. The recording will be stored on the computer until the end of the study and deleted after that time. The primary researcher and the transcriptionist are the only individuals who will have access to the recording of the interview. Because your voice will be potentially identifiable by anyone who hears the recording, confidentiality for things you say on the recording cannot be guaranteed, although the researcher will limit access to the audio files using the safeguards described in this paragraph.

What are the dangers to me?

The risk of loss of confidentiality is minimal. All information obtained in this study is strictly confidential unless disclosure is required by law. The IRB and regulatory agencies may review research records. Prior to commencing the interview, you will be assigned an identification number for use throughout the study. This number, instead of your name, will be used to label all information related to your interview. Electronic files will be labeled by number and will be password protected. The informed consent document will be stored in a locked file cabinet in the researcher's worksite.

The risk of time loss is minimal. Participation in the study should require approximately two to three hours. For your convenience, the interview will be scheduled at a time of your choosing. Additional communication will be conducted via electronic mail or telephone.

The risk of discomfort in answering questions is minimal. The interview location will be in an office to insure privacy and increase comfort with the environment during the interview process. You may take a break or stop at any time. You have the right to refuse to answer any question posed and to terminate the interview at any time.

Are there any benefits for taking part in this research study?

You are not likely to have any direct benefits from participating in this study.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you, or payments made for participating in this study.

Who may I contact if I have questions or concerns about this study?

If you have any questions about the research study, your research rights, or have a research-related injury please contact John M. Dudzik, MHS, OTR/L at

847-437-5500, X7286 or X7273.

If you have any questions about your privacy rights, you may contact Shivi Stanley, Manager, AMITA Health Institutional Review Board at 847-506-4479 or the Corporate Responsibility Officer for ABHN at (847)-385-7510.

How will you keep my information private?

The transcription will not include personal information that could be linked to you. The electronic files of the recorded interviews will be password protected and destroyed at the conclusion of the study. Informed consent forms and other hard copy materials will be destroyed with a shredder at the completion of the study. All information is strictly confidential unless disclosure is required by law. The research records may be reviewed by John M. Dudzik.

What are my rights as a research subject?

If you choose to participate in this study, you have the right to be treated with respect, including respect for your decision whether or not you wish to continue with being in the study.

Choosing not to be in this study or to stop being in this study will result in no penalty or loss of benefits to which you are entitled. Choosing not to be in this study will not affect your rights to any present or future medical treatment.

What if I do not want to participate or I want to leave the study?

Participation in this study is voluntary. You have the right to leave this study at any time or to refuse to participate without penalty. If you choose to withdraw, any information collected about you **before** the date you leave the study will be kept in the research records until the conclusion of the study, but you may request in writing that the data not be utilized in the study.

Other Considerations:

If significant new information related to the study becomes available which may impact your willingness to continue to participate, this information will be provided to you by the

investigator.

Voluntary Consent by Participant:

By signing below, you indicate that:

- this study has been explained to you
- you have read this document, or it has been read to you
- your questions about this research study have been answered
- you have been told that you may ask the researchers any study-related questions in the future or contact them in the event of a research-related injury
- you are entitled to a copy of this form after you have read and signed it
- you voluntarily agree to participate in the study entitled:

Participant's Signature: _____ Date: _____

Participant's Name: _____ Date: _____

Name of person obtaining consent: _____

Signature of Person Obtaining Consent: _____ Date: _____