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Exploring the Perspectives of Older Adults and Health Care Providers on Patient Participation in Transitional Care from Hospital to Cardiac Rehabilitation during the COVID-19 Pandemic

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Health and Rehabilitation Sciences

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Abstract

Older adults who transition from hospital to cardiac rehabilitation settings often are vulnerable and at risk of experiencing adverse health care outcomes. Given the complexities of transitional care, it is crucial to engage older adults in the clinical decision-making process and to promote their active participation in their medical care. Older adults have unique ways of understanding their participation in the transitional care process. Gaining an in-depth understanding of their specific needs during this process can help inform clinical practice and interventions aiming to improve care for older adults living with cardiovascular disease. Focused ethnography methodology was used to explore the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation. The study also sought to identify and to gain a better and more in-depth understanding of the challenges and opportunities that shape participation for older adults during transitional care from hospital to cardiac rehabilitation. Semi-structured interviews were conducted with 15 older adults and 6 healthcare providers from cardiac rehabilitation and cardiology units. Additional methods included document analysis and reflexive journaling. Thematic analysis revealed six themes and fifteen subthemes. Themes included: Follow-up from Healthcare Provides, Interactions with Healthcare Providers, Support from Family Members, Information about Medical Care and Rehabilitation, Decision-Making and Participation, and Healthcare Journey during COVID-19. Older adults reported gaps in follow-up and insufficient spaces or opportunities for participation in decision-making. Healthcare provider's support was reported as essential for a smooth transition, particularly nurses' support. The COVID-19 pandemic was mostly reported as a major barrier for participants, especially in terms of delayed medical procedures and difficult hospitalization experiences. Some participants, particularly those who seek social connection, viewed technology and virtual care negatively. However, virtual care delivery also was reported as a fruitful strategy to engage older adults in their care and to overcome transportation barriers. The results of this study can help inform the implementation of strategies that will engage older adults more actively in their care, as they transition from hospital to cardiac rehabilitation settings.

Keywords

Patient participation, older adults, transitional care, cardiac rehabilitation, focused ethnography, decision-making

Summary for Lay Audience

The transition from hospital to cardiac rehabilitation can be a vulnerable time for older adults. It is very important for older adults and their families to engage in their medical care during this complex transition and to promote opportunities for their participation in the decision-making processes. The current study used focused ethnography methodology to explore the perspectives of older adults and health care providers in cardiac rehabilitation and cardiology units on patient participation in transitional care from the hospital to cardiac rehabilitation. The current study also sought to identify challenges and opportunities for the active participation of older adults in their care. Semi-structured interviews were conducted with 15 older adults and 6 healthcare providers in cardiac rehabilitation and cardiology units. Results revealed six themes and fifteen subthemes. Themes included: Follow-up from Healthcare Provides, Interactions with Healthcare Providers, Support from Family Members, Information about Medical Care and Rehabilitation, Decision-Making and Participation, and Healthcare Journey during COVID-19. Older adults reported gaps in follow-up and insufficient spaces or opportunities for participation in decision-making. Healthcare providers' support was reported as important to ensure a smooth transition to cardiac rehabilitation, particularly nurses' support. The COVID-19 pandemic was mostly reported as a major barrier for participants, especially in terms of delayed medical procedures and difficult hospitalization experiences. Some participants, particularly those who seek connection, viewed the use of technology and virtual care negatively. However, virtual care delivery was also reported as a good strategy to engage older adults in their care and to overcome transportation barriers. The results of this study can help inform clinical practice and research aiming to better engage older adults in their care, as they transition from hospital to cardiac rehabilitation settings.

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Finally, thank you to my family and friends for your love and support.

Dedication

This dissertation is dedicated to my grandmother M. Trinidad Valenzuela. Her experiences as a patient inspired the design of this research and she actively contributed to the creation of the interview guide used for this study. She was the most generous, loving and caring person, who always made others happy.

Thank you for everything, grandma. I will miss you until I can hold you again in heaven.

I love you.

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Preface

The desire to explore the patient experience emerged during my doctoral journey. When I started my doctoral degree, I was interested in healthcare teams in the field of aging, particularly the role that interprofessional teams play on the provision of care for older adults. After my candidacy exam, I published two papers on healthcare teams, one was a review with a focus on interprofessional team-based geriatric education and training, and the other paper addressed issues related to healthcare team terminology, including patient-related terminology.

The terminology paper (Flores-Sandoval et al., 2021a) aimed to offer clarity for research and practice by addressing the use of terms such as ‘interprofessional’, ‘interdisciplinary’ and ‘multidisciplinary’. In addition, the paper addresses the use of patient-related terminology, and the use of terms such as ‘patient’, ‘client’, ‘costumer’ and ‘service user’. The review paper (Flores-Sandoval et al., 2021b) examined interprofessional team-based education and training interventions in Canada, focusing on the team component. Interventions included in this review offered healthcare professionals the opportunity to improve their geriatric competencies and the ability to work in interprofessional geriatric teams. Results of this study highlighted the importance of offering more opportunities for education and training to professionals working with older adults, and the relevance of including the team component in such programs.

When completing my papers on interprofessional teams, I realized that the patient experience is sometimes missing and that the perspectives of patients can offer important insight into gaps in the healthcare system and healthcare delivery, particularly for older adults. During my doctoral degree, I also had the opportunity to collaborate with a professor outside of my doctoral committee on a paper on ageism and critical reflexivity (Flores-Sandoval & Kinsella, 2020). It was very interesting to explore the effects of ageism on older adults and how the presence of ageism can potentially impact healthcare for this age group. Even though I planned to work on an integrated article style dissertation, I could not stop thinking about the value of exploring the perspectives of older adults. The present thesis project started as a combination of scientific curiosity and real-life interactions with my own grandmother, and other older adults that I had the pleasure to meet during academic placements and while volunteering at the hospital. This

research aims to highlight the need to address the perspectives and experiences of older adults as they navigate a very difficult and vulnerable transition. I sincerely hope that this research helps researchers and clinicians interested in improving healthcare for older adults.

Preface Reference List

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Chapter 1

1 Introduction

Delivering comprehensive patient and family-centered care is related inevitably to patient and provider experience (Ocloo et al., 2020). Understanding patient experiences and engaging patients in their care can be a forward strategy to improve care quality and service delivery (Kiran et al., 2020). Understanding the patient experience and perspective is necessary to address some of the gaps in their care, especially during transitions from one health care setting to another (Zhao et al., 2019). In line with the necessity for older adults to have more active roles in their health care by participating in decision-making processes, health care providers are encouraged to foster opportunities for dialogue and the participation of older adults according to their preferences and circumstances (Guadagnoli & Ward, 1998). The participation of older adults in health care contexts is necessary because it offers opportunities for them to shape decision-making, increases patient satisfaction with care and facilitates patient adherence to medical treatment and recommendations (Falk et al., 2019). It requires a mutual relationship between the patient and the healthcare provider that involves trust and respect (Castro et al., 2016). Despite the relevance and importance of patient participation in their care, there are several factors that can potentially affect patient participation. For instance, time constraints and providers' excessive workload can hinder communication during the medical encounter (Ha et al., 2010). Patient participation can be also impacted by system-related barriers such as health care providers' skills, training and attitudes towards patients (Hwang et al., 2019), as well as differences in cultural backgrounds, language, religious beliefs and family values (Hawley & Morris, 2017). Patients' unique circumstances, such as health and functional status are important factors that shape participation, often impacting willingness to participate (Falk et al., 2019). Understanding patients' unique circumstances is particularly relevant for older adults who are a vulnerable population with complex needs.

Given that older adults present unique needs that are different from other age groups (e.g. multiple comorbidities, age-related physiological changes, etc.), fostering opportunities for participation can be challenging, especially when older adults underestimate their own knowledge and abilities to make decisions and to be more actively involved in their care (Lyttle

& Ryan, 2010). Age-related changes need to be recognized as important factors that shape participation for older adults in their health care. These include various levels of cognitive functions (Goodwin, 2011), communication skills, hearing and vision changes, slower processing times and difficulties to remember information (Guthrie et al., 2018), plus musculoskeletal changes in strength, balance and flexibility. Older adults' willingness to participate can be also affected by perceived power imbalances as some older adults often see their health care providers as authoritative figures, leading to a passive attitude (Hupcey & Biddle, 2006), and feelings of fear and intimidation (Roberts et al., 2018). The power dynamics can be influenced heavily by patients' identities, including gender, race and sexual orientation (Sharma, 2018), as well as health care access, health disparities and perceived racism (Rhee et al., 2019). The prevalence of ageism in health care contexts can negatively impact the participation of older adults in their care (Dobrowolska et al., 2019). Ageism is a form of discrimination related to myths and stereotypes that associate old age with decline, illness, disability and death (Butler, 1969). Age-related stereotypes shape the way society perceives the roles that older adults assume, and can potentially lead to subtle ageist discourses in a variety of contexts, including the medical encounter (Flores-Sandoval & Kinsella, 2020). The presence of families and other caregivers of older adults is another relevant factor that can potentially impact patient participation because they represent an important source of practical and emotional support (Shin et al., 2013). Nevertheless, when family members or caregivers diminish patients' verbal activity during medical encounters, older adults' personal preferences and concerns might be overlooked (Durocher et al., 2018; Wolff et al., 2015).

Patient participation in decision-making is especially important during the provision of transitional care. Transitional care involves a set of actions to ensure continuity of care for patients across settings (Rochester-Eyeguokan et al., 2016). Transitioning from one health care setting to another creates patient vulnerability that can be aggravated by factors such as miscommunication, lack of coordination among providers, little to no health literacy, and limited understanding of medication management and discharge instructions (Warren et al., 2019). The transitional care processes can be very complex for older adults living with chronic conditions, and there are significant challenges for those with cognitive impairment and dementia (Ashbourne & Stolee, 2015). Additionally, the presence of polypharmacy, pain, anxiety and

fatigue can contribute to a difficult transitional care process for older adults (Lenaghan, 2019). Older adults' use of health care services is very high and acute hospitalizations are common (Zurlo & Zuliani, 2018). After discharge, older adults move to other health care settings, including long-term care (Henkusens et al., 2014) and transition back to their own homes, where they have the opportunity to re-gain independence and to engage in self-management (Georgiadis & Corrigan, 2017), as well as to re-connect with health care professionals (e.g. family physician, nurse practitioner, etc.).

After acute hospitalization, transitions to rehabilitation programs are common for older adults, especially for older adults living with chronic conditions (Lenaghan, 2019). Given that cardiovascular disease is prevalent among older adults and that they are more likely to require post-acute care services after a cardiac event (Dolansky et al., 2011), cardiac rehabilitation is an essential component in the continuum of care for this population (Kumar & Pina, 2020). Cardiovascular diseases include disorders that affect the heart and the blood vessels, and are the first cause of death globally (World Health Organization, 2017). Cardiovascular disease can progress and lead to cardiac surgery (Stoicea et al., 2017). Older adults who have experienced cardiac surgery often transition to cardiac rehabilitation outpatient settings. Cardiac rehabilitation has demonstrated a protective effect against patient mortality and helps reduce rehospitalization (Bush et al., 2020). Cardiovascular disease in older adults can be affected by age-related complexities, such as polypharmacy, multimorbidity and frailty (Schopfer & Forman, 2016). Older adults, different from other age groups, have unique experiences and perspectives in terms of patient participation in rehabilitation settings. In addition, given that older adults are especially vulnerable during transitional care and often encounter difficulties to navigate the health care system, addressing their unique needs can be a forward strategy to ensure comprehensive care for them (Zurlo & Zuliani, 2018).

1.1 Statement of the Problem

Older adults who experience transitional care often are vulnerable and at risk of experiencing adverse events such as lack of treatment follow-up, communication breakdowns and issues related to medication (Ludvigsen & Høy, 2018). It is crucial to engage older adults in decision-

making during their transition from hospital to other health care setting to minimize negative outcomes. Older adults have unique ways of understanding their participation in the transitional care process and some can experience lack of control and feelings of being unsafe (Rustad et al., 2016).

It is very important to identify challenges and opportunities that shape the participation of older adults in decision-making during the transitional care process from hospital to rehabilitation settings. Their participation holds the potential for researchers, clinicians and older adults to gain valuable insights into the specific needs of older adults when they receive transitional care. Given that transitional care is a complex process for older adults and where their participation is sometimes missing (Rustad et al., 2016), incorporating the perspectives of patients and healthcare providers can be helpful to ensure a more patient-centered approach (Toscan et al., 2012). In addition, gaining an in-depth understanding of older adults' specific needs during the transitional care process can help address gaps in the delivery of care from hospital to cardiac rehabilitation. This information has the potential to inform clinical practice and interventions aimed to improve care for older adults. In addition, older adults' perspectives and experiences can highlight current issues related to navigating of the health care system and areas for improvement in the provision of health care services.

1.2 Purpose of the Study

The purpose of this study is to explore the perspectives of older adults and health providers on patient participation in transitional care from the hospital to cardiac rehabilitation. This study also sought to identify challenges and opportunities that shape the participation of older adults experiencing transitional care during the COVID-19 pandemic. The results can potentially highlight the importance of opportunities for meaningful participation among older adults, taking into consideration their preferences, willingness to participate and adopting a respectful approach to their comfort levels when engaging in cardiac rehabilitation settings. A more in-depth understanding of the views and perspectives of both older adults and health care providers that can potentially support the development of initiatives and strategies to improve health care services. In addition, this study sought to provide a better understanding of transitional care and

cardiac rehabilitation services in the context of COVID-19, including the use of virtual care and telemedicine.

1.3 Research Questions

1. What are the perspectives of older adults and health care providers on the participation of older adults in decision-making regarding their care transition from hospital to cardiac rehabilitation?
2. What challenges and opportunities shape the participation of older adults in decision-making regarding their care as they transition from hospital to cardiac rehabilitation?

1.4 Structure of Thesis

Chapter 1 includes a general introduction to the thesis topic and includes the statement of the problem and the research questions. In Chapter 2, an in-depth literature review is presented, encompassing concepts such as: patient participation in healthcare, terminology related to patient participation, barriers and facilitators for patient participation, patient participation and older adults, transitional care, transitional care for older adults, participation of older adults in transitional care, and transitions to cardiac rehabilitation. Chapter 3 includes the study methodology and methods, including a section on Ethnography and Focused Ethnography. In Chapter 3, the conceptual framework used to design the interview guide is presented, as well as the data collection procedures, methods used to triangulate findings and ethical considerations. Chapter 4 includes the results of the study. Demographic information about participants is presented in this chapter, as well as the description of findings, themes and quotes from participants. In Chapter 5, a discussion of the study results is presented. Chapter 6 includes the conclusions of the study, limitations and recommendations for research and clinical practice.

Chapter 2

2 Literature Review

Chapter 2 offers an in-depth literature review on the main concepts related to this study. This chapter includes the concept of patient participation, including terminology uses, barriers and facilitators, and participation among older adults. In addition, the concept of transitional care is presented, in particular, transitional care for older adults, transitions to cardiac rehabilitation, and cardiac rehabilitation services during COVID-19.

2.1 Patient Participation in Healthcare

In healthcare contexts, there has been an effort to involve patients actively in the decision-making process and to respect individuals autonomy (Nanapragasam et al., 2019). Recognizing patients as experts on their own circumstances, bodies and of their symptoms is important to improve the quality of care (Castro et al., 2016). There is a necessity for patients to have a more active role in the medical decision-making. Health care providers are encouraged to foster opportunities for participation according to the patient's readiness, personal preferences, and circumstances, even though some patients might not be ready to participate (Guadagnoli & Ward, 1998). According to Nilsson, From, and Lindwall (2019), patient participation in healthcare is key for the establishment of the patient-provider relationship, and the concept of participation relates to a caring situation, in line with individuals' rights to self-determination. The concept of self-determination relates to the idea that individuals have the ability to make rational decisions, this means that, in healthcare contexts, patients are able to make their own independent choices and they have the right to receive clear information about their care (Nordgren & Fridlund, 2001).

The concept of patient participation was analyzed by Cahill (1996) in the context of nursing practice. According to Cahill, for patient participation to take place in health care contexts, a relationship between the patient and the provider must be in place, as well as an effort to narrow the information, knowledge and competence gaps that might emerge. In addition, surrendering a degree of power is required for providers, as they engage in intellectual or physical activities related to patient care. In this way, participation in health care aims to benefit patients, facilitate decision-making, improve outcomes and ultimately, increase patient satisfaction (Cahill, 1996).

According to Castro and colleagues (2016), participation in decision-making can be defined as: “partaking in decisions related to patients’ condition (through informed consent or a therapy plan) and decisions related to more strategic levels such as service development” (p. 1928).

Patient participation is part of the continuum of patient engagement. Patient engagement can occur at the individual level, program or organization level, and system level (Baker et al., 2016). The concept of patient engagement refers to a broader scope that goes beyond health care delivery and involves families, health care providers, researchers and other professionals working in active partnership across the continuum of direct care, health care services, policy making and research (Carman et al., 2013). In recent years, there is a growing importance of patient engagement in health research, planning and development of health services at the system level (McNeil et al., 2016), as well as remarkable efforts to prioritize patient engagement in quality improvement at the organizational level (Health Quality Ontario, 2016b). However, for the purposes of this study, the focus is patient engagement in direct care, specifically participation in decision-making. Patient engagement at the individual level or direct care involves the active integration of patients’ preferences, experiences, values and perspectives in disease prevention, diagnosis, treatment and management, as well as the decision-making process (Carman et al., 2013). It is important to distinguish between the terminology used in patient engagement at the organizational and system level, and patient engagement in direct care and health care decision-making, especially since some authors discuss the potential lack of clarity in terms of the taxonomy of patient engagement in health research (Manafa et al., 2018).

2.2 Concepts Related to Patient Participation

The concept of patient participation in the literature can be confusing and problematic because it is frequently used interchangeably with other concepts such as patient empowerment (Castro et al., 2016). The concept of patient participation has been considered complex and vague in terms of meaning (Nilsson et al., 2019). Hartford Kvaal and colleagues (2018) conducted a concept analysis of patient participation and outlined the differences in relation with other similar terms. The authors explained that, even though the concepts of patient participation and patient involvement are commonly used as synonyms, these terms are positioned in different places

across the continuum of patient engagement. In this way, the concept of patient participation reflects a higher level of engagement and encompasses a more holistic process than does patient involvement (Hartford Kvaal et al., 2018).

The two concepts that overlap with patient participation are patient empowerment and patient-centered care, however, there are differences among them. Patient empowerment is related to the structural and psychological levels of health care, as it encompasses the social power relations and the individual's independence and control (Opie, 1998). According to Rifkin (2006), there are a variety of perspectives on the degree of power that patients should have in the healthcare system and the contexts for the exercise of this power. However, there are two main views about the role of empowered patients that are 'not mutually exclusive'. The first view establishes that medical compliance can be pursued and better maintained if patients are actively involved in decision-making. The second view refers to an improvement of health not only through medical compliance but also through the transformation of patients' ideas and attitudes about health. Patient-centered care encourages health care providers to treat the patient as a whole person (Stewart et al., 2000). The concept of patient-centered care has a wider scope than patient empowerment and it is considered a biopsychosocial model that aims to deliver health care in a respectful manner, addressing individual preferences (Hartford Kvaal et al., 2018).

The concept of patient participation can be found at the micro, meso and macro levels, from individual care to service development and policy, and it is grounded in a mutual relationship between the patient and the healthcare provider that involves trust and respect (Castro et al., 2016). In line with the importance of the patient-provider relationship, Nilsson and colleagues (2019) included the following features as part of the essential attributes of patient participation: learning, a caring relationship, and reciprocity. A caring relationship between the patient and the health care provider, as well as reciprocity promote a safe environment where freedom and dignity are respected, allowing the patient to feel comfortable, respected and heard. The authors also highlighted the importance of health care providers education and training to be able to foster opportunities for patient participation (Nilsson et al., 2019). In addition, the providers' facial expressions and body language are means to display a caring attitude towards patients, and

combined with the promotion of an emotional connection can facilitate the development of strong and positive relationships between patients and health care providers (Linney, 2001).

2.3 Barriers and Facilitators to Patient Participation

Despite the relevance of patient participation in health care contexts, several challenges and barriers hinder participation. Communication, for instance, is key for patient participation because it enables health care providers to gain a better understanding of their patients' needs, concerns and personal preferences regarding their care, facilitating a more accurate diagnosis (Kee et al., 2018) and promoting respect for patients' autonomy (Ubel et al., 2017). Therefore, health care providers are encouraged to foster opportunities for dialogue, respecting patients' personal preferences and experiences (Hartford Kvaal et al., 2018). Good patient-provider communication benefits patients because it can potentially improve adherence to treatment as well as increase patient satisfaction with care (Street et al., 2007).

There are a number of factors that might affect patient-provider communication during medical encounters, therefore influencing patient participation. For instance, patients might have different perceptions of their provider's communication skills during routine clinical encounters (Kenny et al., 2010). Also, health care providers' excessive workload, lack of time and avoidance behaviour can negatively impact communication with patients (Ha et al., 2010). Given that effective patient-provider communication is an essential component of patient participation in health care contexts, health care providers should be encouraged to address communication gaps in the medical encounter, with emphasis on expressing empathy, while taking into consideration the patients' preferred level of engagement (Jenerette & Mayer, 2016).

Patient participation also can be affected by several system-related barriers such as health care providers' training, skills, knowledge and negative attitudes towards patients (Hwang et al., 2019). Similarly, barriers such as cultural differences and language limitations can affect patient-provider communication, especially if the patient's understanding of information is difficult to assess (Landmark et al., 2017). Diverse cultural backgrounds, including language, religious beliefs, and family values can influence patients' preferred level of engagement in their care

(Hawley & Morris, 2017). Patient-related factors can also affect participation, for instance, patient health and functional status (Falk et al., 2019). Perceived power imbalances between patient and health care providers, as well as individuals' emotional state, knowledge and level of health literacy can influence willingness to participate in care, especially if there is a decision-making process involved (Fisher et al., 2018).

2.4 Patient Participation and Older Adults

As explained above, patient participation in health care contexts can be influenced by a number of factors, including those related to patients and providers individual characteristics, as well as factors linked to particular contexts, for instance, the visit length or the medical specialty (Street et al., 2005). Fostering opportunities for participation can be challenging for all age groups. However, promoting patient participation can be difficult when working with older adults, especially if they underestimate their own knowledge and ability to make decisions and actively participate in their care (Lyttle & Ryan, 2010). Different contexts and circumstances, as well as personal preferences and perceptions of what patient participation entails can potentially affect older patients' willingness to participate. Ekdahl and collaborators (2010) found that some frail older adults expressed their desire to ask questions and receive information during encounters with health care providers. However, older adult did not wish to actively participate in the decision-making process (Ekdahl et al., 2010).

Older adults might see their health care provider as an authority figure and this can impact their willingness to participate and likely cause a passive attitude in some patients due to fear of being regarded as disrespectful (Hupcey & Biddle, 2006). Due to power dynamics, negative stereotyping and the assumption that the physician is the "ultimate medical authority", older adults can be in a position of disadvantage as they navigate relationships with their health care providers (Eliassen, 2016). Power dynamics between patients and providers can be heavily influenced by patients identities, including gender, race and sexual orientation (Sharma, 2018). In addition, some older adults might perceive a culture of dominance in the interactions with their health care providers. On this matter, Aasen and colleagues (2012) explored patient perceptions of participation in a dialysis unit that provided service to older adults with end-stage

renal disease. Patients who had been receiving dialysis reported a sense of powerlessness and considered the unit to be a ‘prison’. Also, participants considered that information about their care was difficult to obtain, dialogue and opportunities for decision-making were missing and participation was challenging as they felt isolated, ignored and perceived themselves as ‘objects’.

Older adults’ age-related barriers such as cognitive ability, functional status and risk of frailty need to be recognized in order to promote patient participation for this age group in health care contexts (Lane et al., 2019). Despite numerous efforts to accommodate patients with limitations to process information and to find ways to promote their active participation in health care settings, achieving participation among older adults with various levels of cognitive impairment can be very difficult (Goodwin, 2011). Additionally, age-related changes in communication skills such as hearing and vision problems, slower information processing times and difficulty remembering information also can impact participation (Bouchard, Ryan, & Butler, 1996).

The relevance of communication for the delivery of health care, the establishment of the patient-provider relationship, the improvement of health care outcomes and facilitation of the decision-making process has been widely recognized in the literature (Leppin et al., 2018; Rentmeester, 2018; Stortenbeker et al., 2018). For older adults specifically, several factors can influence communication, and therefore participation, in the medical encounter. These may include age-related physical and cognitive changes, health care providers’ training and experience caring with older patients, the patient’s feelings of fear or intimidation when interacting with their providers, as well as the belief that ‘doctors knows best’ (Roberts et al., 2018). In this regard, it is essential to understand older adults’ unique needs for the construction and processing of messages during interactions with health care providers, particularly when interacting with patients from varying countries and cultures (Sparks & Nussbaum, 2008).

Factors such as health disparities and perceived racism in health care contexts also play an important role in patient participation and the provision of health care services among older adults (Rhee et al., 2019). Age discrimination, known as ageism, is considered a complex issue that can occur in a variety of contexts, including healthcare (Dobrowolskan et al., 2019). In

addition, the prevalence of age-related negative stereotypes can be also related to lack of knowledge about the human aging processes (Donizzetti, 2019).

As some authors suggest, ageism is experienced almost universally by older adults, and the prejudice against older people among their younger counterparts is an ongoing concern in today's society (Wilson et al., 2019). Ageism exists in a variety of contexts, including healthcare. As health care systems worldwide struggle to provide care for a wide range of populations, terms such as 'bed blockers' shift the blame to older adults for the lack of resources and systemic constraints that affect the provision of comprehensive care for this age group (Senger, 2019). Ageism can affect patient participation because it influences providers' perceptions of older patients, as well as patient-provider communication. For instance, the use of 'elder speak' has been considered detrimental for older adults as it affects their self-esteem and reinforces negative stereotypes that depict older patients as depressed, inflexible and incompetent (Giraudet et al., 2018). On this matter, it is important to recognize older adults as experts about their own needs to avoid patronization and negative assumptions when providing health care for this population (Kane & Jacobs, 2018).

Recognizing the role of families and caregivers in older adults' health care can be a forward strategy to facilitate the provision of more comprehensive care for this age group. On this matter, Dahlke and colleagues (2018) conducted a qualitative study to examine older adults' and their families perceptions of working with interprofessional teams. The participants in this study highlighted the importance of health care providers' attention, especially listening to concerns and answering questions from both patients and family members, as well as timely explanations of medical procedures. Consistency, particularly while receiving care from multiple health care providers, as well as being treated with dignity were considered by the study participants as significant factors that contributed to the delivery of comprehensive care for them, their caregivers and their families. In this regard, an approach that values patients' views as legitimate and important for decision-making is necessary, as well as considering the person as a whole (McCormack, 2003).

Caregivers and family members offer patients both practical and emotional support during their health care (Shin et al., 2013). However, despite the important role that companions might have in communication during the medical encounter (Ishikawa et al., 2006), some challenges for patient participation can emerge from a patient-caregiver dyad because some older adults tend to defer decision-making to their adult children. In this regard, older adults' participation can be potentially influenced by their adult children's willingness to take into consideration their parents' personal preferences, views, beliefs and values (Durocher et al., 2018). For this reason, while family and caregiver engagement is an important component of patient participation, it is essential to distinguish between patients' preferences and those of their caregivers or family members (Garvelink et al., 2016) to avoid situations that might diminish patients' verbal activity during the medical encounter (Wolff et al., 2015).

Older adults have the capacity and autonomy to make decisions independently about their medical care, however, patients often make decisions involving their family members or care partners (Gray et al., 2019). The process of shared decision-making begins with the first conversation between the patient and the provider, frequently with the inclusion of family members or care partners, according to the preferences of the patient (Skolnik & Butler, 2014). Shared decision-making is an important tool to enable patient autonomy, and it has been associated with improved satisfaction and less decisional conflict (Shay & Lafata, 2015). For older adults, engaging in shared decision-making with their providers and their family members or care partners can help them make informed decisions in complex situations (e.g., transitioning from home to long-term care) (Légaré et al., 2014).

Several factors might impact the process of shared decision-making, including level of health literacy, emotional estate, how complex the decision, the time available to make such decision, and the age of the patient (Fisher et al., 2018). For older adults in particular, barriers for shared decision-making might include their ability to understand information (e.g., presence of cognitive decline), poor communication or lack of empathy from providers, and little confidence that they would make a meaningful contribution to the process of shared decision-making (Pel-Littel et al., 2021). For older adults, their relationships with providers and family members or care partners are critical when making decisions, therefore, promoting opportunities to the active

involvement of family members and care partners can be beneficial for older adults (Pusey et al., 2019).

From the health care system perspective, health care providers can encounter challenges when promoting patient participation for older adults, caregivers and families. Some barriers are family dynamics, difficult emotional scenarios and the use of technology to facilitate interaction (Parker Oliver et al., 2005). As reported by Tutton (2005), facilitation style and strategies, such as providing choices or allowing the patient to take the lead, are an important factors to consider when promoting participation for this age group. The author also contends that the foundation for patient participation is the development of relationships based on partnership, trust and respect with older patients. Understanding the patient's personal history, the details of their health condition and the emotions that they might be feeling, can be relevant to create a positive environment where older adults can participate in their care, at any level that makes them feel comfortable (Tutton, 2005).

Understanding how health care providers experience and enact patient participation on a daily basis is essential to obtain a more comprehensive picture of patient participation among older adults, particularly partnering with patients and families to improve quality of care (Gluyas, 2015). Huby and collaborators (2007), interviewed patients and staff in a hospital, with the aim of exploring how dynamics of providers can impact patient participation in an acute care setting. For patients, the term 'participation' held little meaning, while providers reported that achieving patient participation was a difficult task. Patients also perceived a decrease in their physical and cognitive abilities during their hospital stay, leading to an increased reliance on family members, especially their adult children, to make decisions. The authors also found that systemic constraints, including care procedures and structured interactions, often obstructed patient participation and prevented effective communication between older adults and their health care providers.

2.5 Transitional Care

Transitional care, within the context of health care, involves a set of actions to ensure continuity of care for patients across health care settings (Rochester-Eyeguokan et al., 2016), often requiring adequate collaboration among health care professionals and institutions (Coleman & Berenson, 2004). Transitional care also includes ongoing communication and adequate follow-up as fruitful strategies to improve the effectiveness of the process (Callahan & Hartsell, 2015). It is important to distinguish between ‘Transitions’ and ‘Transitional care’. Transitions in care refer to events; that is points where patients move to or return from, for the purposes of receiving health care (World Health Organisation, 2016). Transitions can occur during the patient’s health care journey at different times and places, including referrals to specialists, admission to hospital, and discharge from emergency department or hospital (Health Quality Ontario, 2013). Transitional care on the other hand refers not to events or points in time, but to a process that involves sending and receiving components, as well as components concerning patient and family education, logistics and coordination among health care professionals (Coleman & Boulton, 2003).

In the body of literature on transitional care and health care transitions, authors have used adjectives such as ‘smooth’ (Surburg, 2008) or ‘seamless’ (Misky et al., 2010) to refer to the process of transitional care, post-discharge care or the transition itself from one health care setting to the other. Despite limited conceptual clarity in the literature, these adjectives are often used in relation to a variety of attributes, such as ‘efficiency’ (Health Quality Ontario, 2013), ‘coordination’ (Woods et al., 2006), ‘safety’, ‘consistency’ and ‘care goals’ (Boston-Fleischhauer et al., 2017), ‘improved communication’ and ‘effectiveness’ (Marcotte et al., 2015). According to Noseworthy and colleagues (2014) a smooth transition involves effective communication as a strategy to build trusting relationships, as well as the improvement of community expertise through knowledge sharing.

Appropriate management of transitional care in the health care system supports more comprehensive care for patients, improves health care outcomes, helps prevent acute care readmissions and reduces overall costs for the health care system (Huber et al., 2017). Transitioning from one health care setting to another creates patient vulnerability that can be

aggravated by myriad adverse factors, such as lack of coordination among providers, little to no health literacy, limited understanding of medication management and unclear discharge instructions, and other contextual factors (Warren et al., 2019).

Naylor and colleagues (2017) report that patients in transitional care and their caregivers often encounter several challenges. They identify areas of concern such as lack of patient and caregiver engagement, complex conditions management, patient and caregiver education and well-being, care continuity and accountability. Useful strategies to ensure smooth transitional care also include promoting shared decision-making and incorporating patients' perspectives into the plan of care. Li and Williams (2015) identified other barriers to smooth transitions of care. These included cultural and organizational factors, a rushed or delayed patient discharge process, lack of preoperative meetings with patients due to unexpected admissions to acute care, insufficient or outdated information, and lack of adequate follow-up care and patient education upon discharge (Fuji et al., 2012).

Transitional care involves both receiving patients and sending them along to a number of health care facilities and other locations, including long-term care, hospitals, subacute and post-acute nursing facilities, the patient's home, specialty care and primary care sites (Coleman & Boulton, 2007). Communication with staff at primary care clinics and out-patient settings such as nursing homes and rehabilitation units, is crucial to ensure a successful transition upon discharge from the hospital because it facilitates medication management, adequate patient follow-up and overall adherence with health care plans (Rennke & Ranji, 2015). Adequate and timely discharge follow-up, as well as ensuring communication with providers and staff at primary care settings after discharge from hospitals are considered fruitful strategies to ensure continuity of care for patients in health care transitions (Bricard & Or, 2019). Accurate communication facilitates seamless transitional care because it prevents errors and omissions that might occur in acute care settings due to an increased number of interventions and their complexity (Johnson et al., 2012).

Transitional care also requires coordination of multiple services to prevent poor health care outcomes, especially in high-risk and vulnerable populations (Naylor et al., 2011). Given that older adults are frequently transitioning among a wide variety of services such as hospitals,

primary care and long-term care facilities, appropriate transitional care is essential to ensure older adults' seamless navigation across settings. In addition, transitional care requires the appropriate recognition of the personal preferences of older adults and their families, as well as their individual goals and values (Coleman & Boulton, 2003).

2.6 Transitional Care for Older Adults

Older adults with complex health care needs are at risk of experiencing adverse health care outcomes during the transitional care process, and they are more susceptible to challenges within healthcare systems (Vieira Zamora et al., 2019). Older adults living with multiple chronic conditions who require complex health care are considered to be highly vulnerable during transitions from one health care setting to another (Sheikh et al., 2018). Moreover, the presence of comorbidities, polypharmacy, pain, anxiety and fatigue can contribute to a difficult transitional care process for this vulnerable age group, their caregivers and their families (Lenaghan, 2019). Transitioning from one setting to another is considered as the most vulnerable point within the healthcare system, and has the potential to magnify health disparities for patients with chronic diseases and older adults (Weeks et al., 2020).

Acute care hospitalizations of older adults are frequent and significant events that can result in functional declines, frailty and a higher risk of complications such as sarcopenia, delirium and depression (Zurlo & Zuliani, 2018). Older adults use of health care services is very high and they require support to ensure a successful transition from hospital to a number of settings, including long-term care (Canadian Institute for Health Information, 2017). The proportion of older adults living in long-term care increases as they grow older. In fact, factors such as a dementia diagnosis, mood disorders and the presence of multiple chronic conditions among this age group contribute to an increasing incidence of transitions to long-term care (Garner et al., 2018).

Transitions to long-term care require a significant amount of effort by patients and their families concerning adaptation to a new environment, as well as for health care providers because they need to accommodate patients' specific needs and personal preferences (Henkusens et al., 2014). A high proportion of older adults living in long-term care are at risk of experiencing a transition

to hospitals during their stay, leading to a stressful and vulnerable situation for both patients and caregivers, who often have limited involvement and access to information regarding their transitional care (Toles et al., 2012). Since older adults require multiple types of care in a number of health care settings, ensuring a smooth transitional care process to a new site can be critical for their mental and physical well-being (Health Quality Ontario, 2016a).

In addition to transitions from hospital to long-term care, older adults frequently move from hospitals to home and vice versa, often experiencing a higher risk of functional decline after hospital discharge (Liebzeit et al., 2018). The transition to home from hospital is a vulnerable time for patients that can lead to negative outcomes, such as an adverse drug event (Kripalani, Jackson, et al., 2007) and unplanned acute care readmissions (Zimmerman et al., 2017). During hospital stays, patients are in a medically supervised environment. However, when they go home, they often require self-management knowledge and skills (Keller et al., 2016), as well as appropriate professional specialty specific follow-up, especially among older adults with several chronic conditions (Piraino et al., 2012).

Physical declines, the presence of complex medical conditions, cognitive impairment, polypharmacy and depression, as well as little social support are factors that can contribute to a higher risk of rehospitalization after discharge from the hospital among older adults (Watkins, Hall, & Kring, 2012). Other factors such as socioeconomic background, racial or ethnic characteristics, language barriers, level of health literacy and previous discrimination experiences in health care settings can impact the success of older adults' transitional care from hospital to home (Graham et al., 2009). Foust and colleagues (2012) investigated the multiple perspectives of patients, caregivers and health care providers with the aim of understanding the hospital-to-home transition better among older adults. In their study, clinicians, patients and their caregivers expressed the relevance of timely information about the discharge day and detailed instructions for patients as valuable strategies to ensure a smooth transition. The authors highlighted the importance of detailed discharge information and adequate communication as critical steps to facilitate the provision of care before, during and after the transition, especially if there is home care involved.

For older adults, transitioning from hospital to home involves not only follow-up by home care based service personnel, timely information and discharge instructions, but also the opportunity of (re-)gaining independence and (re-)engaging in self-management (Georgiadis & Corrigan, 2017). This process encompasses all activities of daily life such as walking, shopping, cooking meals, cleaning and interacting with friends and family (Greysen et al., 2009). In this regard, actively engaging older adults, their caregivers and families in the transitional care process, as well as promoting shared decision-making and facilitating participation are critical to ensure that the patient is properly informed and supported during this process (Backman et al., 2018). Hvalvik and Dale (2015) investigated older patients' perspectives and experiences during transitions from hospital to home through a phenomenological-hermeneutic approach, a methodology that aims to understand and interpret meaning of lived experiences based on narrations from the participants. The authors found two main themes, including 1) navigating the health care system and 2) adapting to life conditions. Participants in their study reported feelings of uncertainty, worry, helplessness and vulnerability, unmet needs, experiences of being disregarded by health care professionals, and not receiving sufficient information concerning their care.

After hospitalization and reconnection with their communities, older adults also can transition to primary care. Primary care providers are the first point of contact for patients, facilitating chronic disease prevention and management (Schoen, Osborn, Phuong, & Doty, et al., 2006). Also, primary care services focus on more equitable health care access in populations and reducing inequities (Starfield et al., 2005). The primary care workforce includes a wide variety of practitioners, including family physicians, general internists, geriatricians, general pediatricians, nurse practitioners, physician assistants, pharmacists and health educators (Bodenheimer & Pham, 2010). With a more recent emphasis on interprofessional teams, primary care settings also include community health workers, social workers, nutritionists, dentists, rehabilitation workers, care managers, midwives, traditional healers and other support staff (World Health Organization & United Nations Children's Fund Unicef, 2018).

While hospitals are under pressure to provide comprehensive care and to secure access to acute care for older adults, there is increasing concern regarding the timely transfer of relevant patient

information between hospitals and other healthcare settings, such as primary care (Ludvigsen & Høy, 2018; Scott, 2010). Also, delayed discharge summaries, omissions and incomplete information have the potential to impact patient follow-up and post-acute care, creating a discontinuity in the services the patient receives (Kripalani, et al., 2007). The health care system as a whole plays an important role in ensuring that transitional care is effective for patients. The delivery of comprehensive transitional care requires the seamless, integrated involvement of health care providers and staff from hospitals, long-term care services and community-based services communicating with one another (Golden & Shier, 2013). Focusing on the patient during hospitalization, discharge and follow-up can facilitate patient engagement and contribute to reducing acute care readmissions (Morris & Hawn, 2019).

Systemic factors can affect negatively the delivery of appropriate follow-up care for patients receiving transitional care. These can include providers' lack of availability or competencies, and failure to schedule a patient for a follow-up appointment (Otsuka, et al., 2017). Access to care and suitable patient follow-up are critical factors that can impact the rate of hospital readmissions for patients living with chronic diseases, particularly for those with difficulties acquiring medications or those who encounter barriers for transportation (Farrell et al., 2015; Groesbeck, Whiteman, & Stewart, 2015). Other issues such as lack of language concordance between patient and provider, as well as provision of health care that is congruent with cultural values and norms, can negatively impact transitional care (Rayan et al., 2014). In addition, lack of communication among providers can result in poorly defined providers' roles and responsibilities, leading to a lower quality of care and ultimately affecting the patient (Göbel et al., 2012; Miller, Lin, & Neville, 2019).

2.7 Participation of Older Adults in Transitional Care

In addition to the need for communication between health care providers across settings, involving older adults and their caregivers and families in every step is key to ensure an effective transitional care process (Ludvigsen & Høy, 2018). This can be achieved through a number of strategies, including post-discharge provider follow-up visits (Field et al., 2015), the use of electronic messages (Melby et al., 2015) and telephone calls (Record et al., 2015; Woodend et

al., 2008). Furthermore, it is important to ensure that the patient truly understands relevant information regarding their health care. On this matter, Säfström and colleagues (2018) conducted a study on continuity of care among older adults. They found that 86% of participants received post-discharge written information but only two-thirds knew which health care provider to contact in case of potential health complications.

For patients, (re-) connecting with primary care providers in a timely manner is essential to ensure adequate follow-up after hospital discharge (Balaban & Williams, 2010; Misky et al., 2010). However, barriers such as geographic location, patients economic status, long waiting times and patients previous experiences with providers can interfere with the frequency of follow-up appointments (Wiest et al., 2019). Despite the relevance of follow-up phone calls in primary care practice (Tang et al., 2014), this follow-up strategy can pose a challenge for older patients. In a study by D'Avolio and collaborators (2013) that explored older adults' access to primary care, participants reported difficulties when using the phone. For example, participants reported that dealing with confusing automatic messages and voice messages was difficult, as well as waiting in long phone queues and not getting their calls returned.

Patient participation during the whole process of transitional care is a key factor to promote patient safety, to decrease rehospitalization rates and to ensure timely information sharing (Flink et al., 2012). Older adults are especially vulnerable during transitional care and often encounter difficulties navigating the health care system, especially if they have complex health care conditions, sensory problems and functional limitations (Mann et al., 2001). In addition, the risk of medical complications and the presence of cognitive impairment is higher in this age group (Arbaje et al., 2011). For these reasons, older adults need special attention to their specific needs to ensure a transitional care that addresses fragility assessment, functional status and quality of life (Zurlo & Zuliani, 2018).

Another relevant factor is the need for patient participation measures in instruments used in the discharge process from hospitals to other health care settings, especially addressing the needs of older adults. On this matter, Foss and Askautrud (2010) conducted a critical review of instruments used during the discharge process. The authors found that the majority of

instruments did not cover patient participation in a comprehensive way. Also, considerations for older adults' unique needs were not addressed. Given the vulnerability of older adults during transitional care, the authors highlighted the importance of including their preferences, experiences and perspectives in discharge assessment. In terms of interventions to promote patient participation for older adults, Menichetti, Graffigna, and Steinsbekk (2018) found that educational and behavioural components of interventions, including goal setting and action planning were prioritized over affective ones such as emotional experiences, relaxation exercises and positive thinking. Their study highlighted the importance of addressing the emotional component when working with older adults as an important strategy to promote participation.

Since older adults can have difficulties understanding hospital discharge instructions, health care providers play an important role in implementing a number of strategies that help ensure a smooth transitional care process for this population (Steckbeck, et al., 2018). Doekhie and collaborators (2018) explored patients', caregivers' and providers' perspectives on patient involvement in primary health care settings, focusing on interprofessional teams. The authors found that, despite the importance of acknowledging the patient as part of the health care team, misalignments in expectations regarding specific roles and responsibilities within the team can impact the degree of patient involvement. The authors argued that including patients and caregivers in team meetings was a fruitful strategy to clarify roles and responsibilities, as well as to build trusting relationships. In this regard, focusing on the perspectives of older adults as a strategy to enhance patient participation during transitional care is essential. Despite the different levels of engagement that older adults might prefer, fostering opportunities for participation in transitional care is essential to ensure a smooth transitional care process that addresses the unique needs of this age group.

2.8 Transitions to Cardiac Rehabilitation

After hospitalization, older adults can experience transitions to a variety of settings, including rehabilitation settings. During this process, priorities change and the focus shifts from the immediate demands of acute care to the importance of function and wellness, offering opportunities for the active engagement of patients, families and caregivers (Jeffs et al., 2017).

Rehabilitation settings aim to facilitate the recovery of function among older adults with complex conditions before the reincorporation to their communities (McGilton et al., 2016). For patients with cardiovascular disease, cardiac rehabilitation is an essential component of their healthcare journey. Cardiac rehabilitation is a comprehensive program that aims to support patients maintain their cardiovascular health through risk prevention, patient education, and the promotion of healthy habits such as exercise and proper nutrition (Grace et al., 2011).

Cardiovascular disease is a non-communicable disease that causes more deaths globally, followed by cancer, chronic respiratory diseases and diabetes (World Health Organization, 2020). In Canada, it is the second cause of death and a leading cause of hospitalization (Public Health Agency of Canada, 2018). Cardiovascular diseases refer to multiple disorders that affect the heart and its blood vessels, including: coronary heart disease, cerebrovascular disease, peripheral arterial disease, rheumatic heart disease, congenital heart disease, and deep vein thrombosis and pulmonary embolism (World Health Organization, 2017). The majority of deaths occur due to coronary heart disease and cerebrovascular disease, also known as heart attack and stroke, respectively (D'Andrea et al., 2015). According to the World Health Organization (2020), cardiovascular disease is associated with modifiable risks factors, such as the presence of diabetes, hypertension, and obesity, as well as the harmful use of tobacco and alcohol. Other factors include social determinants, such as income level, access to resources, work-related stress, level of education, access to housing, presence of depression and quality of social interactions (D'Andrea et al., 2015).

With increasing age, the prevalence of cardiovascular disease is higher, often related to structural changes in the heart, such as increased ventricular wall thickness, fibrosis and calcification of the heart valves, stiffness of peripheral and central arteries and higher number of lipid deposition (Saner, 2007). Given the powerful effect of age, older adults are more likely to suffer cardiac events that can lead to hospitalizations, also, they are at a higher risk of major disability and frailty (Forman, 2007). The process of aging goes beyond chronological age and involves individual variability, including several factors like biological differences (e.g. oxidative stress), lifestyle habits (e.g. nutrition), individual risk factors (insulin resistance, hypertension),

comorbidities (anemia, arthritis), psychological factors (coping skills), social factors (e.g. family support), economic resources and culture (Forman et al., 2011).

Cardiac patients who experience an acute event or who are diagnosed with a heart condition have specific needs to help regain function and improve their quality of life, including the adoption of a healthy lifestyle, a medication plan and access to counselling (Piepoli et al., 2010). The promotion of exercise also is an essential part of the recovery process. Exercise recommendations for cardiovascular disease patients started as early as the nineteenth century, and by the mid-twentieth century, exercise programs were expanding rapidly, leading to the emergence of various in-patient and out-patient rehabilitation programs that incorporated all the multidimensional aspects of cardiac rehabilitation (Mathes, 2007). Given that cardiac patients are often older adults with multiple comorbidities, cardiac rehabilitation programs offer a greater focus on the continuum of care, highlighting the importance of self-management and a supportive environment that addresses the complex needs of this age group (Polyzotis et al., 2012). For instance, the consideration of physical frailty as an important characteristic of older patients referred to cardiac rehabilitation programs is acknowledged (Flint et al., 2020), as well as the adoption of a more holistic approach that takes into account the unique needs of older adults beyond medical care, including psychological and social needs (Pedretti et al., 2020).

Despite multiple efforts to maximize enrollment in cardiac rehabilitation programs, some patients might encounter several barriers and challenges to access these programs. Several patient-related gaps include lack of interest, poor motivation, lack of social support and psychological wellbeing, as well as financial difficulties (Piepoli et al., 2016). In addition, other authors who investigated the factors that impact program attendance found that gender, age and culture also have a significant impact on program enrollment (Grace et al., 2009; Rose et al., 2011). Moreover, other researchers have found that discussions and meaningful interactions with health care providers can influence enrollment in cardiac rehabilitation (Pourhabib et al., 2014, 2016). Other investigators reported that the input of family members and friends was a very significant in influencing enrollment in cardiac rehabilitation (McIntosh et al., 2017; Rouleau et al., 2018).

Patient participation in healthcare is associated with positive outcomes for patients with cardiovascular disease, especially when patients and their families are involved in the rehabilitation process (Arnetz et al., 2010; Tuomisto et al., 2018). It should be noted that most of the literature concerning patient participation in cardiac rehabilitation programs focuses on enrollment and utilization of services. In rehabilitation literature, the terms of patient ‘participation’, ‘engagement’ or ‘involvement’ are often used to describe the engagement of patients in research (Harrison & Brooks, 2015), as well as the process and/or rate of enrollment in cardiac rehabilitation programs (Doll et al., 2015). Terms such as ‘participation’ and ‘engagement’ are multidimensional and are sometimes used in various ways within rehabilitation research (Bright et al., 2015). However, for the purposes of this research, ‘patient participation’ will be considered in relation to the interaction between patients and their providers, as well as the decision-making process that acknowledges patients’ preferences, experiences and unique needs, along with medical evidence and clinical judgement (Hartford Kvaal et al., 2018).

2.9 Cardiac Rehabilitation during COVID-19

From the health care system perspective, the COVID-19 pandemic created an opportunity for the modernization of cardiac rehabilitation services and the implementation of virtual models to offer a viable alternative for patients (Besnier et al., 2020; Pecci & Ajmal, 2021). The use of remote telephone-based options in cardiac rehabilitation had been implemented before the pandemic, often to increase program attendance and accessibility for patients who live in remote areas and have to travel a considerable distance (Wakefield et al., 2014). Remote cardiac rehabilitation proved to be a cost-effective model that could be used as a complement to existing services (Maddison et al., 2019).

Given that COVID-19 restrictions made the delivery of traditional, face-to-face cardiac rehabilitation impossible, the use of virtual and telemedicine needed to be upscaled to effectively adapt to the social distancing and shelter in place guidelines (Babu et al., 2020). Multiple resources were utilized to deliver successful cardiac rehabilitation services, including emails, videos, websites, online resources, phone calls, videoconferencing (Charman et al., 2021). The use of this model in lieu of in-person care helped protect both patients and healthcare providers

from disease transmission and offered opportunities to expand services for diverse patient populations. This resulted in virtual care and telemedicine regarded as a ‘must have’ instead of a complementary service (Franki, 2020).

The term ‘telemedicine’ refers to the delivery of health care services using information and communication technologies for the exchange of information for diagnosis, research, evaluation and the continuing education of healthcare providers (Garg et al., 2020). This means that the use of telemedicine helps providers to treat patients remotely, as well as address concerns and give medical advice. ‘Virtual Care’ is related to any remote interaction between patients and providers that uses technology to facilitate the delivery of care, including telephone, videoconferencing, email, text, online platforms and wearable devices (Moulson et al., 2020). These services belong to the broader concept of ‘digital health’, which also encompasses e-health, mobile health and remote patient monitoring (Krishnaswami et al., 2020).

The older adult population greatly benefits from engaging in cardiac rehabilitation, in particular, improvements in strength, mobility and capacity to resume their activities of daily living, as well as promotion of better mental health (Lutz et al., 2020). As the eligible population for cardiac rehabilitation ages, patients become more complex and require different and new approaches to cardiac rehabilitation, specifically programs that address age-related factors such as sarcopenia, polypharmacy, depression, frailty, delirium, social isolation and cognitive impairment (Norekval & Allore, 2020). Incorporating aspects relevant for older adults in cardiac rehabilitation programs, such as the burden of sensory impairment, can potentially help promote a more patient-centered approach in future programs and address the needs of older adults (Cahill et al., 2021).

The present study aimed to address the need for older adults to actively participate in their care during a vulnerable time such as transitional care from hospital to cardiac rehabilitation. The study sought to help researchers and clinicians gain a better understanding of the perspectives of older adults and their healthcare providers on patient participation as older adults engage in cardiac rehabilitation and reconnect with their communities after a cardiac event. A growing body of evidence has revealed that transitional care needs to be more patient-centered, and that

older patients often experience vulnerability and insufficient opportunities for participation during transitions (Olsen et al., 2020). During transitions, older adults are at risk of poor health outcomes, often exacerbated by medical errors and lack of proper follow-up; therefore, implementing patient-centered programs can facilitate the complex process of transitional care (Smith & Fields, 2020).

In addition, few published studies addressed transitional care for older adults during the COVID-19 pandemic. The multiple changes to acute care and public health measures have resulted in a complex environment for older adults to navigate, especially as rehabilitation services rely on digital technologies to deliver service to patients (Nabutovsky et al., 2020). The need of monitoring the quality of the transition for cardiac patients before discharge from hospital is well established in the literature (Ba et al., 2020). However, little is known about the perspectives of older adults who experience this transition. The present study aimed to address that gap and to highlight the importance of offering opportunities for meaningful participation to older adults. Given the medical and social vulnerabilities of older adults, tailored cardiac rehabilitation programs are critical (Norekval & Allore, 2020). The current study sought to contribute to the body of literature addressing the participation needs of older adults who experience transitional care from hospital to cardiac rehabilitation.

2.10 Summary

In this chapter, the main concepts of the thesis were presented. Patient participation is essential for the delivery of quality patient-centered healthcare. The participation of older adults in their care should be promoted taking into consideration their preferred level of engagement, and the various factors associated with older age. Given that transitions are a vulnerable time for older adults, their participation is especially important during the whole journey, from one healthcare setting to the other. Older adults who had a recent hospitalization and were referred to cardiac rehabilitation might potentially experience vulnerability, barriers, communication breakdowns and unclear information about medication, exercise and other relevant next steps in their rehabilitation journey. Promoting the active participation of older adults in their care is essential to deliver quality healthcare to this population and to ensure their specific needs are addressed

across the healthcare continuum. This study aimed to explore the perspectives of older adults and healthcare providers on patient participation in transitional care from hospital to cardiac rehabilitation, and to explore challenges and opportunities that shape participation. Chapter 3 presents the study methodology, it offers an overview of ethnography and focused ethnography, its philosophical underpinnings and data collection methods. Chapter 3 also provides information on participant recruitment, ethical considerations, the conceptual framework used to guide the development of the interview guide, as well as the methods chosen for the triangulation of findings, such as document analysis, member checking and reflexivity.

Chapter 3

3 Methodology

Chapter 3 includes the methodology and methods used in this study. In this chapter, information on the chosen methodology and its philosophical underpinnings is presented. This chapter also includes information on participant selection and the recruitment site, as well as the methodological strategies to achieve rigour, such as triangulation of findings, document analysis and member checking. Ethical considerations and recruitment procedures are also presented in this chapter.

3.1 Introduction

Focused ethnography, a qualitative methodology, was used for this research. Qualitative research in health care contexts allows researchers to explore the perspectives of patients and providers, as well as their experiences and interactions, that can potentially inform future interventions in health care settings (Shaw et al., 2014). Focused ethnography, a form of ethnography, was used to capture older adults' and health care providers perspectives on patient participation. This methodology was chosen to identify challenges and opportunities that shape participation for older adults and to gain an in-depth understanding of how patient participation is enabled by health care providers during transitional care from hospital to cardiac rehabilitation.

3.1.1 Ethnography

The term ethnography was first used by anthropologists during the last quarter of the 19th century to refer to descriptive accounts of local places and people who lived in colonial circumstances. These accounts were considered more comprehensive and accurate way of reporting life in diverse communities (Denzin & Lincoln, 2018). Ethnography aims to understand social life as it unfolds and examines the interaction of structure and agency in the context of everyday life (O'Reilly, 2012). This methodology was exclusively used by anthropologists to study human cultures until the mid-20th century, then it was adopted by a diverse range of disciplines: sociology, marketing research (Kelly & Gibbons, 2008), culture studies, medicine, history, women's studies, business, among others (Van Maanen, 2006).

Ethnography focuses on social interactions, behaviours and perceptions that take place in groups such as communities, teams or organizations; moreover, through the use of this methodology, researchers can gain a rich and holistic insight into individuals' perceptions and actions (Reeves et al., 2013). Ethnography has been considered to be a useful methodology in health care research because it allows for comparison between what individuals say and what they actually do, providing insight into the patient and the clinician worlds, as well as beliefs and behaviours related to health and illness (Savage, 2000). Because ethnography focuses on context, communication, beliefs and perceptions of people in a particular place, allowing for analysis of wider structures (O'Reilly, 2012), it was chosen as the appropriate methodology for this research. More specifically, this study used form of ethnography known as focused ethnography.

3.1.2 Focused Ethnography

Focused ethnography is a form of ethnography that uses short-term field visits, in opposition to complete and permanent immersion in the field (Knoblauch, 2005). Instead of focusing on a whole community or culture, focused ethnography considers a particular setting; for instance, sub-cultures of patients or health care professionals may be studied in the nursing research context (Cruz & Higginbottom, 2013). While ethnographers in previous centuries traveled to distant lands with little to no knowledge of the study setting, researchers using focused ethnography enter the field with some prior knowledge and connection with the setting they are studying (Wall, 2015). In this methodology, research questions are formulated based on prior review of the literature (Bikker et al., 2017).

In opposition to conventional ethnography, focused ethnography is used to gain insight into the small elements of society, focusing in intensity instead of extensity in terms of data collection and analysis (Knoblauch, 2005). Focused ethnography is problem-focused and context-specific and can offer insight into participants' perspectives as it targets a small group of people (Cruz & Higginbottom, 2013). In addition, focused ethnography in health care contexts may offer a more holistic perspective of patients' and health professionals' cultures and sub-cultures, potentially leading to the enhancement of clinical practice (Higginbottom et al., 2013).

For the purposes of this research, focused ethnography was chosen as the appropriate methodology because it permits intensive data collection and analysis in a short period of time, guided by prior specific research questions. Focused ethnography also supports questions such as ‘what’, ‘how’ and ‘why’, and fits with the purpose of exploring perceptions and understandings of participants, their experiences, shared beliefs, practices and meanings (Rashid et al., 2019). In addition, this methodology fits a context where, due to ethical considerations and confidentiality, long-term field immersion is problematic and less feasible.

When using conventional ethnography as a methodology, three main methods are required. These include 1) participant observation, 2) interviews, and 3) the analysis of important documents such as maps, policies, and patients’ records (Cruz & Higginbottom, 2013). According to Higginbottom and colleagues (2013), focused ethnography often requires semi-structured interviews, containing a topic guide relevant to the research questions. Regarding observations, the authors suggest that the observer-as-participant approach permits data collection in settings where active participation is not feasible, such as hospitals or clinics. The researcher can conduct observation during intermittent and purposeful visits, or the observation component may be eliminated.

In addition, a variety of documents can be analyzed, including census data, test results, maps, procedural documents, patient records, photographs, and other relevant documentation. Writing is usually complemented by the use of technology such as recording, video and photo-cameras. This feature gives multiple listeners and viewers access to the data, facilitating analysis and interpretation (Knoblauch, 2005).

3.1.3 Philosophical Underpinnings

The present research study is grounded in the constructivist paradigm. A paradigm is a set of beliefs related to methodological, ontological and epistemological assumptions (Guba & Lincoln, 1994). For constructivism, human action is situated culturally and socially, and there are multiple constructed realities, in opposition to a single reality (Carpenter & Suto, 2008). The

constructivist approach considers reality as constructed in the mind of the participant, instead of external entity; therefore, for meaning to be unveiled, interactive dialogue between the researcher and the participant is essential (Ponterotto, 2005).

In line with Guba and Lincoln's work (1994), a paradigm addresses three fundamental questions: ontological (form and nature of reality), epistemological (refers to knowledge, what can be known) and methodological (how the researcher can find this knowledge). From an ontological perspective, constructivism considers reality as multiple and constructed by individuals, based on experience and social contexts. In terms of epistemology, this paradigm establishes that the researcher and the object of investigation (the participant), are interactively linked and create knowledge together. Methodologically, social constructions can be elicited through researcher-participant interaction, and while consensus is the aim, the research is often open to new interpretations (Guba & Lincoln, 1994).

The constructivist position contends that reality is heavily influenced by particular situations and contexts, including individuals' subjective experiences and perceptions, as well as the social environment and the dynamic interaction that takes place between the researcher and the participant (Ponterotto, 2005). Given that this study focuses on the exploration of participants' perceptions, the constructivist approach is appropriate to guide the philosophical underpinnings of the research.

3.2 Method

3.2.1 Participant Selection

In line with focused ethnography, purposive sampling was used to select participants who can provide relevant and rich data according to the aims of the study. Purposive sampling permits the selection of key informants that act as representatives in interpreting and revealing the culture that is being explored (Moser & Korstjens, 2018).

The participant inclusion criteria were:

- English speaking older adults (65 years and older), able to give consent, with no cognitive impairment, a dementia diagnosis, or a major mental illness diagnosis. Participants were included if they had a recent hospitalization (< 1 year) and were recently referred to cardiac rehabilitation (at least one appointment with the cardiac rehabilitation team)
- English speaking health care providers who care for older adults in cardiac rehabilitation after a hospital discharge.

The participant exclusion criteria were:

- Not an English speaker
- Unable to give consent.
- Older adults with cognitive impairment
- Older adults with a dementia diagnosis
- Older adults with a major mental illness diagnosis
- Severe hearing or speech difficulties that might interfere with interviewing.
- People younger than 65 years old (for the older adult group).
- Health care providers who have never worked with older adults.

3.2.2 Recruitment Site and Procedures

Older adult participants were recruited at a cardiac rehabilitation unit in London, Ontario.

Patients are referred to the cardiac rehabilitation program after hospital discharge. Referrals to the program occur following admission to hospital due to a myocardial infarction. Patients who are referred to the program have undergone percutaneous coronary artery revascularization.

According to Heart and Stroke Canada, a percutaneous coronary intervention refers to a procedure in which a catheter is inserted in the heart to open up blood vessels that are narrowed using a small structure called stent. This procedure helps decrease heart-related chest pain in patients living with cardiovascular disease. Once the cardiac rehabilitation program receives a patient referral, a mail including a western ethics approved 'research opt-out' is sent to the patient. The patient then can choose to be contacted for consideration to participate in research. Since 2018, only 4 of 2799 referrals to date have 'opted out'.

Two cardiologists reviewed the research protocol and collaborated in the planning and logistics of the ethics submission and data collection. The research coordinator of the cardiac rehabilitation program identified patients who met the inclusion criteria and created a list of potential participants. The primary investigator of the current study (CFS) contacted older adult participants via a phone call and invited them to participate (Please see Appendix A). The primary investigator (CFS) informed the participant of the study and asked how they would like to receive the letter of information and consent. A web-based survey tool (Qualtrics) was used to give access to participants to the letter of information and consent.

Letters of information and consent (Please see appendix B) were delivered via email and via regular mail, depending on the participants preferences. For participants who preferred email, the primary investigator (CFS) sent them a private personal Qualtrics link to direct them to the letter of information and consent. Participants were encouraged to contact the research team before signing the consent form. The primary investigator (CFS) answered the participants questions and went through the letter of information and consent with participants. After signing the consent form, participants received the complete letter of information and consent, signed by the primary investigator (CFS) , via Safe File Transfer, using a private password protected Western OneDrive link.

Participants who indicated that they would like to receive the letters of information and consent via regular mail, were asked to give consent to be contacted via regular mail and to have their letters sent to the address they had provided on the intake form. Letters of information and consent were sent using an institutional address to protect the investigator's privacy. Upon receiving the letter of information and consent, participants contacted the student to talk about the study procedures and ask questions. Participants who wished to participate were asked to provide verbal consent. Verbal consent was recorded and documented by the primary investigator (CFS) (Please see appendix C). In addition, for those participants who received the letter of information and consent via email but struggled to sign the form using the electronic signature box on Qualtrics, verbal consent was also recorded.

Healthcare provider participants were recruited at a cardiac rehabilitation unit, as well as at cardiac units in a local hospital. The recruitment process for healthcare providers involved a mass email. The mass email contained the information about the study, as well as the research team contact information. Letters of information and consent for health care providers were delivered via email, using a Qualtrics unique personal link, as well as via regular mail. To protect healthcare providers' privacy, researchers did not have access to their contact information until they contacted the research team first to know more about the study. Participants received the complete letter of information and consent, signed by the primary investigator (CFS), via Secure File Transfer, using a private password protected Western OneDrive link.

3.2.3 Ethical Considerations

This study was approved by Western University and Lawson's Health Research Institute ethics boards (Please see Appendix D and Appendix E). Participants had the right to withdraw from the study at any time. They were encouraged to let the primary investigator (CFS) know if they wished to stop the interview and to leave the study. Incomplete information would not be considered for analysis. However, as per Western Research Ethics Board (WREB) policy, records respecting participation remained, including letters of information and consent, as well as their name in the participant master list.

There were no known risks for participants. However, participants were informed that the use of online technology involves an increased potential for data breach. There were no known inconveniences to daily activities; data collection was done remotely, and no face-to-face contact was required. All interviews were conducted at a time and date convenient for the participant.

All data, including transcripts, source data, audio recordings, and letters of information and consent were stored on Western Institutional Servers. An encrypted password protected folder was used. Only the research team had access to this folder. Working copies of the data were safely kept on the primary investigator's laptop, which was also encrypted using Mac File Vault. All working copies were stored in an encrypted password protected folder.

Written field notes and reflexive journaling were made by the primary investigator (CFS) in a notebook. The notebook was kept by the primary investigator (CFS) to facilitate her immersion in the data and to help her acknowledge her personal biases and assumptions. Notes and information from the notebook were shared only with the research team and no identifiable information of the participants was recorded in it. No source data or personal information was recorded in the reflexive journal.

3.3 Data Collection Method

In line with focused ethnography methodology, the methods used in this research included in-depth interviews, document analysis, and reflexive journaling.

3.3.1 In-depth Interviews

The data collection consisted of in-depth semi-structured interviews. Semi-structured interviews permit more dialogue than structured interviews and allow the researcher to become a knowledge-producing participant rather than adhering to a strict guide (Denzin & Lincoln, 2018). The objective of the interviews was to capture older adults' voices and perspectives regarding their participation in this process. Semi-structured interviews with health care providers were conducted to gain a better understanding of barriers and facilitators, as well as systemic factors that influence older adults' participation in transitional care.

3.3.2 Conceptual Framework

In the literature, there are several conceptual frameworks related to older adults and their active participation in their care. For instance, McCormack's (2003) person-centered practice framework addresses the relationship between nurses and older patients, focusing on values and the context of care. The 'Whole person, Whole journey' framework (Stolee et al., 2021), highlights the need for more integration and coordination, as well as a more person-centered care approach for older adults living with dementia, including special attention to person-centered values, drivers and goals and care partners. Other frameworks addressing frail older adults and a family-centric model, have focused on the context of patient engagement in research, health care decision-making and health policy (Holroyd-Leduc et al., 2016). As for transitional care for older adults with complex health conditions, existing frameworks have included patient involvement

and choice, involvement of caregivers, patient complexity, healthcare coordination, information sharing and documentation, as well as system constraints and relationships (Stolee et al., 2019).

Despite the relevance of the above-mentioned frameworks, a decision was made by the principal investigator (CFS) to develop a conceptual framework instead of using an existing one. The conceptual framework for this research was developed to inform the creation of the interview guide for both older adults and providers (see Appendix F). This framework includes four factors unique to older adults that can impact participation in health care contexts according to the literature. These factors include:

- **Willingness to participate:** this factor relates to how patients prefer to be engaged in their care and in the decision-making process. The concept of willingness to participate recognizes the variability in older adults choice and their desire for participation (Ekdahl et al., 2010), as well as the need for clinicians to pay attention to patients' willingness and ability to participate in their care (van Dongen et al., 2017).
- **Caregiver/family dynamics:** this factor concerns the presence of caregivers and family members as key players in the decision-making process concerning the provision of health care services to older adults (Dahlke et al., 2018). While caregivers, families and friends provide invaluable support for older adults (Robinson-Lane, 2019), every relationship is different and the potential for neglect and abuse of older adults by family members and caregivers should not be disregarded (Lin, 2018).
- **Age-related changes:** this factor involves the cognitive, physical and sensory limitations that older adults might experience that have an impact on participation and decision-making processes (Goodwin, 2011). For instance, the presence of visual impairment (Court et al., 2014), as well as hearing loss and difficulties with speech recognition (Mishra et al., 2014).
- **Ageism:** this factor refers to age-related negative stereotypes and age discrimination experienced by older adults. Ageism can negatively affect the participation of patients in their care and impact the provision of health care services for older adults (Senger, 2019). Ageism is a pressing global problem that leads to negative health outcomes and impacts a number of aspects in the lives of older adults, such as access to health services and

treatments, poor quality of life and wellness, poor social engagement, isolation, and increased mental health issues (Chang, Kanno, Levy, & Wang, et al., 2020).

The conceptual framework guided the development of the interview guide, in line with the study research questions: (1) What are the perspectives of older adults and health care providers on the participation of older adults in decision-making regarding their care transition from hospital to cardiac rehabilitation? (2) What challenges and opportunities shape the participation of older adults in decision-making regarding their care as they transition from hospital to cardiac rehabilitation? The framework was used to guide the development of questions and probes that would address relevant aspects for the participation of older adults during their transition from hospital to cardiac rehabilitation.

3.3.3 Interview Procedures

All interviews were conducted remotely via phone, Zoom/WebEx, depending on participant's preferences. Participants were sent a private Zoom link in advance. All zoom meetings had passwords to protect privacy. Interviews that happened over the phone were conducted by the primary investigator (CFS) in an office at the Canadian Centre for Activity and Aging (CCAA) at Western University. The primary investigator (CFS) ensured complete privacy and silence before conducting the interviews. All interviews had a semi-structured format. Some of the questions in the interview guide varied in some form, depending on several factors such as technical issues with internet or zoom, poor audio during phone calls, interference, or disconnection of the call. Questions might also vary on request from the participant: for instance, if the question was perceived as difficult or if the audio quality was not good, participants sometimes asked the primary investigator (CFS) to rephrase and/or repeat the question or part of the question. Depending on the case, simplified versions of the question were offered, or an explanation was provided, as well as examples to facilitate the understanding of the question and promote a friendly experience during the interview. Interviews were transcribed verbatim by the primary investigator (CFS) shortly after interviews were conducted.

3.3.4 Demographic Information

In addition to the interview, participants were required to fill out a brief demographic information form (Please see Appendix G). All demographic information forms were completed over the phone, via Zoom before the interview, or via Qualtrics private link, depending on participants' preferences. The demographic information form collected the following information:

For older adults:

- Age
- Gender
- Education level
- Marital Status
- Presence of formal caregiver
- Date of most recent hospital discharge
- Length of hospital stay
- Primary language(s)
- Vision problems
- Hearing problems
- Self-reported presence of memory difficulties beyond what is normal for age
- Self-reported presence of depression or any other mental health condition

For healthcare providers:

- Age
- Gender
- Profession
- Specialty
- Years of experience working with older adults

3.4 Triangulation of Findings

Triangulation involves comparing results from different methods of data collection (e.g. observation, interviews and document analysis) with the aim of ensuring a higher level of comprehensiveness in the research (Mays & Pope, 2000). Triangulation aims to produce knowledge on different levels and helps to provide a broader, deeper understanding of the studied phenomena, as well as to enhance rigour and trustworthiness (Denzin & Lincoln, 2018). In this research, methods used for triangulation included: document analysis, reflexive journaling and member checking.

3.4.1 Document Analysis

Document analysis is a method to systematically review or evaluate documents, both printed and electronic material (Bowen, 2009). In qualitative research, document analysis involves the review, examination and interpretation of the data to gain an in-depth understanding of the research phenomenon, and it is often used to triangulate findings from other data sources such as interviews (Gross, 2018). Documents in qualitative research provide background and context and facilitate the verification of findings (Bowen, 2009). Cardiac rehabilitation patient handouts were collected for document analysis. Document analysis was used to triangulate the findings and further refine the understanding of the interview data. Documents were accessed through the program website, and a total of five were selected for analysis:

1. Heart Surgery: A guide for patients, families and caregivers (London Health Sciences Centre)
2. Cardiac Rehabilitation and Secondary Prevention Program Patient Education Guide
3. Cardiac Rehabilitation and Secondary Prevention Program Lifestyle Change and Self-Management Workbook
4. Cardiac Rehabilitation and Secondary Prevention Program Exercise Diary
5. Cardiac Rehabilitation and Secondary Prevention Food Record Instructions

3.4.2 Reflexivity Journaling and Researcher's Positionality

In line with the constructivist approach, the researcher's lived experiences and values cannot be separated from the research process (Ponterotto, 2005), in this regard, it is important to engage in reflexivity. Reflexivity refers to the researcher transparency in terms of the personal, theoretical and epistemological assumptions that might impact their research (Watts, 2011). Researchers are encouraged to be aware of their personal and professional values, as well as their understanding of the study phenomena and how these might affect the process and outcome of the research (Pellatt, 2003). Reflexivity can be presented through the researcher's ideas, experiences and their relationship with participants and the study setting, and can be used by readers to determine their potential impact on the research process (Reeves et al., 2013).

By being reflexive, researchers can explore how their social position (e.g. gender, class) may affect their knowledge claims; therefore, by being reflexive of their social position, researchers can engage in a dialogue about how their interpretive and explanatory claims originated (Lichterman, 2017). Self-reflexivity is an essential aspect of qualitative research because it encourages researchers to be honest about their strengths and shortcomings, this is especially important for ethnography, requiring researchers to report their own voice and to provide explanations for their claim to know what they know (Tracy, 2010).

During the research process, the primary investigator (CFS) created reflexive notes in a hard copy notebook to keep track of her thoughts and biases when collecting and analyzing data. Reflexive notes were taken after each interview and/or interaction with a participant. Thoughts and assumptions regarding the whole research process were also documented in the notebook. No participant identifiable information was included in the reflexive notes.

3.4.3 Reflexive Notes

One of the most important aspects of the research process for me was 'relationship building' with participants. From my perspective, building trust via phone call or via zoom was more difficult than in person. It was challenging to get to know my participants remotely and to show empathy and understanding on the phone or video call. Also, their experiences were sometimes

so difficult that I would feel strong emotions, especially sadness. One positive aspect is that some older adults had a good time during the interview; they shared their experiences and sometimes good humour and laughs. I tried to make them feel acknowledged, and that their stories were valid and important. Writing this thesis was an emotionally charged experience, not only because some older adults shared heartbreaking stories, but because I could see my grandmother in them. The reason I was interested in exploring patient participation in decision-making was because my grandmother had very negative experiences with health care providers, often related to dismissive attitudes, ageism and lack of opportunities to participate in the decision-making process, particularly decisions regarding medication use. My grandmother helped me think about what to include in the conceptual framework for this thesis, and she helped me to develop the interview guide. She was especially interested in questions that would help identify lack of spaces or opportunities for decision-making, as well as ageist remarks. My grandmother passed away before she could see the results of this study. It breaks my heart that she will never get to see that other older adults had similar experiences and that she was not alone in her struggles.

3.4.4 Member Checking

Member checking refers to providing the participants with the preliminary analysis of the data for feedback (Morse, 2015). Member checking is conducted in qualitative research to ensure quality of the research by asking participants whether or not the interpretation of the data is correct. By incorporating member checking in the research process as a collaborative event, researchers can ensure that participants are recognized as owners of their own experiences and experts on the information they have provided (Harvey, 2015). Member checking can potentially enrich the data analysis, can help inform the researcher's understanding and corresponds to an effort to establish a true partnership between the researcher and the participant (Varpio, Ajjawi, Monrouxe, & et al., 2017). A recursive, dialogic member checking has the potential to improve the holistic validity of the research by promoting opportunities for participants to think about the research topic and to recognize the value of their knowledge (Brear, 2019).

A member checking option was included in the consent form on Qualtrics. After the interview, the primary investigator (CFS) explained to the participants what member checking involved and asked them if they would be willing to be contacted to confirm that her interpretation of the data was accurate. Only participants who gave consent were contacted. The 5-step SMC model by Birt and colleagues (2016) was adapted and used to conduct member checking with participants. The model's five steps included the following: 1) preparing of a synthesized lay summary from emerging themes, along with data quotes which represent the themes; 2) checking participants eligibility to receive the report; 3) sending a report with cover letter for the participant to read and return; 4) gathering responses and added data; 5) integration of findings. For the purposes of this research, step 3 of the model was adapted. Given the characteristics of the population, ethical considerations and COVID-19 restrictions, and participants' preferences, all participants were asked to engage in the member checking process via phone call. Six older adult participants agreed to be contacted for member checking. Sessions lasted approximately 10 to 15 minutes. Participants had the opportunity to confirm themes, to expand on ideas, to correct and/or to add information. Some older adults who participated in a member checking session expanded on ideas and added new information related to their situation since the interview.

3.5 Considerations Related to the COVID-19 Pandemic

Due to COVID-19 restrictions, all data collection had to be done remotely. In addition, aspects of focused ethnography methods such as field immersion and participant observation were not possible due to the pandemic. Also, the population of interest was considered highly vulnerable, due to their recent hospitalization, health status and age. To capture the impact of the pandemic on the participation of older adults in the decision-making process, as well as on their journey from hospital to cardiac rehabilitation, two questions were added to the interview guide: a question about the impact of the pandemic, as well as the use of virtual care and telemedicine were added. It should be noted that this research project was conducted during the second and third waves of the COVID-19 pandemic in Canada; therefore, the data obtained from participants is heavily influenced by factors related to the pandemic, including but not limited to: the implementation and use of a virtual care model and telemedicine and the COVID-19 public

health measures in Ontario, such as social distancing, limits on gatherings, use of protective equipment and restrictions to visitors in hospitals and other healthcare settings.

3.6 Quality Criteria

For the purposes of this research, the quality criteria for qualitative research proposed by Tracy (2010) was used. The authors suggested eight criteria:

1. Worthy topic: timely, relevant, significant and interesting topic of research. As the author suggested, a worthy topic emerges from disciplinary proprieties and important current events. This research addresses an important and timely topic related to transitional care, rehabilitation and patient participation and engagement. This research also considers the COVID-19 pandemic as a factor that had a significant impact on healthcare delivery, particularly for older adults who had cardiovascular events and hospitalizations during these difficult times.
2. Rich rigour: the study's theoretical constructs, data and time in the field, sample, contexts, data collection and analysis are sufficient, abundant and appropriate for the research design. In the present study, participant inclusion criteria, methods for data collection and triangulation of findings, number and length of interviews, as well as the use of field notes and reflexivity fits the purpose of the study and offers extensive data.
3. Sincerity: self-reflexivity about the researcher's values, biases and inclinations are included, as well as transparency about the methods and potential challenges. This research started in co-creation with the PhD student's grandmother, who collaborated to design and pilot the interview guide. In addition, the PhD student kept a reflexive journal to document all potential biases, personal experiences and emotions related to this research. Interactions with participants were characterized by friendliness, honesty and transparency.
4. Credibility: the study includes thick description, details, tacit knowledge explanation, triangulation or crystallization, multiple voices and member reflections. The length of interviews and the member checking process allowed for thick description of findings, as well as appropriate triangulation of findings using field notes and reflexivity.

5. Resonance: the research has impact or influences particular readers and a variety of audiences through aesthetic representation, naturalistic generalizations and transferable findings. Participants in this research reported various difficult situations that might be transferable to other populations who also experienced hospitalization and transitional care during COVID-19. Quotes from participants offer depth and emotion, and they are capable of engage readers and promote empathy.
6. Significant contribution: the research contributes theoretically, practically, morally, methodologically, heuristically. The results of this research can potentially impact healthcare providers practice and the delivery of cardiac rehabilitation care for older adults, as well as rehabilitation in other contexts.
7. Ethics: procedural ethics, situational ethics, culturally specific ethics, relational ethics and exiting ethics when leaving the setting are respected. In this research, participants were adequately informed about the research purposes and procedures in a transparent manner.
8. Meaningful coherence: the study achieves its purpose, uses methods that fit the purpose, and connects literature, research questions, finding and interpretation in a meaningful way. This research has a coherent design, data collection process and analysis, in line with the chosen paradigm and methodology.

3.7 Data Analysis

Ongoing deductive and inductive analysis was used for this research. The process of data collection and analysis was simultaneous. The primary investigator (CFS) transcribed and analyzed participant transcripts using NVivo software . Coding was done by hand after each interview or after two interviews, depending on how many interviews were conducted on a given day. After reading the transcripts carefully, the primary investigator (CFS) conducted descriptive hand coding using hard copies of diagrams and a white board. After conducting hand coding, NVivo software was used to code the data and finalized the analysis. Deductive analysis was used to identify codes and themes that had a connection with the conceptual framework. Inductive analysis was used to identify new codes and themes that emerged from the data, that had no connection with the conceptual framework. Data saturation was achieved when the

information emerging from the data and themes began to be redundant. Repetitive information was evident in quotes from several participants that were similar, and the themes emerging from the data were consistent with the existing ones.

All interviews were transcribed verbatim by the primary investigator (CFS). Transcripts contained the participant's numerical code only and participant's names were removed from the final transcript documents to ensure privacy. Transcripts were analyzed using NVivo software. During the initial coding stages, transcripts were read line-by-line and assigned initial codes, then codes were further expanded and elaborated on. Triangulation of findings was facilitated by the incorporation of field notes, document analysis and member checking. Information from document analysis and member checking was aggregated to the results section to contribute to a more in-depth presentation of findings.

3.8 Summary

In chapter 3, the methodology chosen for this study was discussed. Information about Focused Ethnography was presented, as well as the philosophical underpinnings and the rationale for the use of this particular methodology. An explanation of the conceptual framework for the development of the interview guide was also provided, as well as the data collection methods and the recruitment process. This chapter included the methods for triangulation of findings and the quality criteria. Chapter 4 includes the results for this study, including themes, subthemes and quotes from participants.

Chapter 4

4 Results

The findings of the study are presented in this chapter. The first part of the chapter includes characteristics of the participants. The second part includes the themes and subthemes that emerged from the data. Findings are presented in themes and subthemes, along with relevant quotes from participants, data from member checking and information related to document analysis.

Healthcare providers shared experiences related to promoting the active participation for older adults in their care, barriers and facilitators for participation, their own experiences with virtual care and telemedicine, as well as other factors that might impact the healthcare journey of older adults after a cardiovascular event. Older adult participants reported a variety of positive and negative experiences related to their participation during hospitalization and their experiences of cardiac rehabilitation after an acute cardiovascular event. The COVID-19 pandemic greatly impacted the transitional care journey of older adults and their experiences reconnecting with their communities and starting their rehabilitation process.

4.1 Description of Participants

4.1.1 Characteristics of Older Adult Participants

Fifteen interviews ranging in length from 30 to 60 minutes were conducted with older adult participants. Ten male participants and five female participants were interviewed.

The mean age was 72 years old ($M=72.73$, $R= 65$ to 82). In terms of highest level of education, three participants completed secondary school, eleven participants completed a college or university degree, and one participant held a graduate degree. The majority of participants were married and living with their spouse. One participant was a widow. Only one participant received the help of a professional caregiver, a personal support worker (PSW), the rest of the older adult participants did not report having the help of a professional caregiver such as a PSW or private nurse. Four participants reported that their spouses provided support and care when needed.

Hospitalizations occurred between August 2020 and January 2021, with an average stay of 4.6 days. All participants reported English as the language they understand and use every day. Five participants reported knowledge and/or use of an additional language (French, Dutch and Russian). Six participants reported the use of glasses due to vision problems; one participant reported an eye surgery to treat cataracts. Six participants reported hearing problems and the use of hearing aids. As for additional health conditions, one participant reported feeling anxiety and one participant reported feeling depressed. However, when asked, participants reported that they had not been diagnosed by a healthcare professional. No professional help or medical treatments for such conditions were reported. Information about older adult participants can be found in Table 1.

Table 4-1 Demographic information of older adult participants

Gender	
Male (n=10)	67%
Female (n=5)	33%
Age	
65-70 (n=5)	33%
71-76 (n=6)	40%
77-82 (n=4)	27%
Level of Education	
Secondary (n=3)	20%
Post-secondary (n=12)	80%
Length of Hospital Stay	
1 -5 days (n=9)	60%
6 – 14 days (n=4)	27%
Preferred not to share (n=2)	13%

4.1.2 Characteristics of Healthcare Provider Participants

Six interviews, ranging in length from 30 to 60 minutes were conducted with four female and two male healthcare provider participants. The mean age was 39 years old (range= 30 to 62). Disciplines included medicine, nutrition, nursing, psychology and kinesiology. All healthcare providers had at least 5 years of experience working with older adults and expertise related to cardiology, cardiac rehabilitation, chronic diseases management and clinical rehabilitation. Given the small number of healthcare providers who work in cardiology and cardiac rehabilitation, additional demographic information was not requested to protect their privacy and prevent identification of participants.

4.2 Presentation of Findings

The research questions of the present study were: 1) what are the perspectives of older adults and health care providers on the participation of older adults in decision-making regarding their care transition from hospital to cardiac rehabilitation? 2) What challenges and opportunities shape the participation of older adults in decision-making regarding their care as they transition from hospital to cardiac rehabilitation? Interviews with older adults offered a great insight into the transitional care process from hospital to cardiac rehabilitation and how older adults navigate the process with the help of providers and family members, particularly during the COVID-19 pandemic. Interviews with healthcare providers offered information on how they enact participation in their practice and their experiences promoting the active participation of older adults. Document analysis was used to triangulate the findings, as well as member checking sessions with six participants, approximately a month after the interview.

It should be noted that the data collected during the duration of this study is heavily influenced by the COVID-19 pandemic and only a few participants reflected on the 'before' and 'during' the COVID-19 pandemic. All participants in this study gave their consent to use unidentifiable quotes in this study (Please see Appendix B). To protect the privacy of participants, numbers were assigned randomly and the letter at the end indicates the gender of the participant (F for

female, M for male)¹. After each quote, the number of the participant is presented, along with their gender, and their group (older adults/healthcare providers). Results are presented in the following themes and subthemes (Table 2).

Table 4-2 Themes and Subthemes

Themes	Subthemes
1. Follow-up from Healthcare Providers	<ul style="list-style-type: none"> • 1.1 Adequate and Timely Communication • 1.2 Insufficient Communication
2. Interactions with Healthcare Provides	<ul style="list-style-type: none"> • 2.1 Supportive Interactions • 2.2 Suboptimal Interactions
3. Support from Family Members	<ul style="list-style-type: none"> • 3.1 Support for Rehabilitation • 3.2 Emotional Support • 3.3 Active Involvement of Family Members
4. Information about Medical Care and Rehabilitation	<ul style="list-style-type: none"> • 4.1 Timely and Clear Information • 4.2 Difficult and Insufficient Information
5. Decision-Making and Participation	<ul style="list-style-type: none"> • 5.1 Shared Decision-Making • 5.2 Barriers for Decision-Making • 5.3 Age of the Patient as a Factor
6. Healthcare Journey during COVID-19	<ul style="list-style-type: none"> • 6.1 Hospitalization during COVID-19 • 6.2 Transitional Care during COVID-19 • 6.3 Use of Virtual Care and Telemedicine

¹ Please note that all participants in this study identified as female or male. The demographic information form included a question about gender, this included an option for non-binary, neutral and other, as well as the option of 'prefer not to say'.

4.2.1 Theme 1: Follow-Up from Healthcare Providers

The theme of “Follow-up from healthcare providers” refers to the follow-up that older adults receive during their healthcare journey, particularly shortly after hospitalization, and as they transition to cardiac rehabilitation. For some older adult participants, the quality of the follow-up was very satisfactory, and they reported that healthcare providers helped them book appointments, asked relevant questions about their health and explained next steps in a timely manner. However, other older adult participants reported suboptimal, and sometimes nonexistent follow-up. In line with this finding, the theme of Follow-up from Healthcare Providers includes two subthemes: Adequate and Timely Communication and Insufficient Communication. The perspectives of both older adults and healthcare providers are included, as well as additional information from the document analysis and the member checking sessions with participants.

4.2.1.1 Subtheme: Adequate and Timely Communication

From the perspective of the older adult participants, adequate and timely communication from healthcare providers contributed to a smooth transition from hospital to cardiac rehabilitation and promoted opportunities for their participation in their care. Some participants expressed that they were very satisfied with how timely the follow-up was and the quality of the follow-up interactions with the cardiac rehabilitation team and other providers caring for them. It should be noted that the ways in which healthcare providers follow-up with their patients have changed during the COVID-19 pandemic. During the collection of the present data, the use of phone and Zoom calls was the norm, and patients rarely were seen in person.

“They [providers], you know, discussed it with me and asked me if I had any questions, and uh, you know, it’s good having the family doctor backup as well, because if anything to do with the rehab I wasn’t sure on, I can always check with the family doctor, and this group that I have now, as part of this, I’m very pleased with how is going” (P04M – Older adult, 72 years old)

“They [providers] sent me a note to say how I wanted it [appointment], whether it was phone or whether it was by zoom or... and it was all done quickly very efficiently.” (P06M – Older adult, 73 years old)

When discussing follow-up after discharge, a healthcare provider participant explained that the process of booking appointments with the cardiac rehabilitation team is easy for patients and that they make efforts to address the patient needs. For instance, by requesting the help of an interpreter, or booking the person for an in-person appointment.

“She [the administrative assistant] would ask about what their [patients] accessibility options are um, in terms of doing in the computer, doing it on video, or if not, um we have phone-based options for folks. Um, and if we [providers] are really struggling then maybe, phone interpreter options or, we have brought the occasional person in. Um, and, during that dialogue, whichever avenue is appropriate, she will book that type of appointment, and she will explain what they need to know next” (P14F – Healthcare provider)

Some older adult participants perceived comprehensive follow-up and communication with providers as very positive for their healthcare journey, in particular at the start of the rehabilitation process. In the present study, older adult participants who reported adequate communication and follow-up were likely to name a healthcare provider who would be the contact person, often a nurse or their family physician. One older adult participant described the questions that providers asked during the follow-up process after hospitalization. The participant appreciated the interest that healthcare providers showed in his past history.

“We went through a series of questions, and you know, open framed questions and some of them, they were just like you asked... you know, what about depression? What about anxiety? About... this and what about that? And... how much exercise do you do? And, you know, they want your past history, and they want to know where you are at right now, and, how you’re feeling, and how quite open, quite extensive questioning” (P13M – Older adult, 65 years old)

In terms of questioning the patient during the first visit post discharge, one healthcare provider participant explained that first appointments are usually critical to engage patients in their decision-making, particularly after discharge from the hospital. The first appointment is an opportunity to ask the patient questions and offer opportunities for participation, especially after a stressful event such as a heart attack and hospitalization.

“The first appointment is critical I find because whatever happened in the hospital is under very stressful conditions for that patient, and often they’re not really aware of all the things that are happening. We, in the hospital, will adjust medications, we do tests, all these things, and especially in cardiac care, a lot of these things are done very routinely, and the patient is probably not involved in the decision making” (P25M – Healthcare provider)

As participants described, follow-up from healthcare providers is essential for the transition from hospital to cardiac rehabilitation and can potentially facilitate the participation of older adults in their care by promoting spaces for dialogue and by creating opportunities for healthcare providers to get to know their older adult patients better and to make them feel appreciated and heard.

4.2.1.2 Subtheme: Insufficient Communication

Some older adult participants reported insufficient communication and sometimes nonexistent follow-up from healthcare providers during their transition from hospital to cardiac rehabilitation. The lack of follow-up, as perceived by older adult participants, can be related to calls after hospitalization to check on the patient.

“He [provider] gives me a phone call, and uh he...he, he never even follow-up, even when he knew I was in the hospital, I come home and never got a call, no nothing... nothing at all...” (P01M – Older adult, 75 years old)

Some older adults reported feeling alone and not getting help from healthcare providers, especially during the first two months after discharge, as expressed by participant P17F:

“I felt sick all the time, which was awful, and I called the surgeon, but I didn’t really get any help there [...] I think, I think that first two months with no help, I felt quite alone there [...] I just needed more contact the first two months” (P17F – Older adult, 77 years old)

In the member checking session that participant P17F had with the primary investigator (CFS) a month after her interview, she indicated that the transition from hospital to cardiac rehabilitation was very slow paced. The participant reported that she ‘felt abandoned’ during the first two months after discharge. As an area of improvement, the patient indicated that reassuring the patient after discharge and explaining next steps at an early stage might be helpful to understand what to expect from the cardiac rehabilitation process.

Regarding insufficient communication, participant P19F talked about her experience during discharge. She expressed that the nurse at the hospital did not follow-up with her in terms of what had happened during hospitalization. The participant shared that she was taken outside before she could talk to the nurse.

“I think that when I was discharged, I could have... there could have been more explanation by the nurse but what happened there, I think there was an accident. She gave me the discharge papers to review and then this man shows up with the wheelchair and I think that she wanted to have a chat with me and then she realized that I’d been taken away [...] communication with the staff nurse... before I actually left the hospital, yeah, that would have been better” (P19F – Older adult, 74 years old)

In the member checking session that Participant P19F had with the primary investigator (CFS), she indicated that an area of improvement would be to consider the whole patient history and pay

attention to their unique circumstances. She suggested that information tailored to the patient's unique needs and history would be appropriate.

Feelings of 'being alone' and 'on your own' were also expressed by older adult participants. For instance, participant P20M indicated that he felt alone after surgery, and that he had to actively initiate communication with healthcare providers to get information.

"Basically... unless I phone the doctor, you know, which I did with the headaches and stuff, but other than that... you know, there was not, there was nothing. You're on your own" (P02M – Older Adult, 68 years old)

In line with this feeling of 'being alone', participant P20F expressed that she only talked to her surgeon twice, and that she has never met him. Due to COVID-19 restrictions, she talked to him on the phone, but this participant perceived not knowing what the person who was performing the surgery looked like as bothersome.

"The thing that really bothered me going into this heart surgery, I got to talk to the doctor over the phone, I think maybe twice, I've got to talk to them twice, before I went to surgery... but that was all, but... to this date I've never met the man" (P20F – Older Adult, 74 years old)

Older adult participants also reported insufficient follow-up in terms of home care after hospital discharge. For example, participant P04M, who had a very complex health condition and had undergone high-risk surgery, expressed that the hospital did not help coordinate home care, resulting in additional burden for his wife.

"I'm still surprised that, we weren't given a personal care worker or someone like that for me for the first week or two or three. It was all left up to me and my wife to handle it... so that's perhaps one area that could have been improved on" (P04M – Older Adult, 72 years old).

Communication between providers as a factor that affected follow-up was also reported as a concern for older adults. Participant P04M perceived that communication between healthcare providers, including his family doctor and his surgeon, was not very effective.

“I don’t think they... and my family doctor and my surgeon, and uh, were liaising as good as they could. So, when I go for an appointment there and the doctor on charge would say we want you do this, this and this... but I don’t believe my family doctor and the surgeon were made aware of this [...] So, there seem to be a little bit of a gap there where I don’t know whether proper procedure was followed, or it was just miscommunication” (P04M – Older adult, 72 years old).

Participant P20F, who indicated that her family doctor was not aware of medication changes after hospital discharge, also perceived insufficient communication between providers.

“I had an appointment with the two of them [providers], and that... it went well. It was a bit on the scary side because they started sending my medications, from what I was sent home on, and my doctor that I go to all the time didn’t know about this” (P20F – Older adult, 74 years old)

According to healthcare providers, a discharge summary is accessible for other providers. However, as perceived by older adults, there seems to be a gap in the communication between them. Participant P21M explained that a discharge summary is available for the surgeon, the family doctor and other members of the healthcare team.

“I would contribute to... typically to discharge summary and multidisciplinary or interdisciplinary discharge summary, about the patient, if they participated in psychological services. That would get posted on our chart and be accessible to the referring surgeon or consultant, to the family doctor, and really to other members of the surgical care” (P21M – Healthcare provider)

As reported by some older adult participants, insufficient communication with providers and lack of timely follow-up influenced their ability to move forward after cardiac surgery and engaging in activities of daily living. For instance, participant P07M expressed that he did not know if it was safe to engage in activities such as taking out the garbage and shoveling snow.

“I spent a long time waiting to hear from somebody about something, and... even now, I don’t know whether... or not, I can essentially go back to what I was doing before so... taking out the garbage, shoveling snow, um, am I supposed to take it really... really easy?” [...] I spend quite a while with no set appointments, nobody being in touch, and it’s just like... you know, not knowing whether I could return to normal life” (P07M – Older adult, 67 years old)

As for participant P20F, she indicated that she did not have enough communication in terms of her daily diet. Particularly, more clarification was needed about what a ‘Mediterranean diet’ is, how to approach meal planning and how to determine the right amount of food.

“The only thing that I haven’t been able to get done through cardiac rehab is the diet that I’m supposed to be on, and I’d like to know about it [...] I know that they keep saying that I should be on the uh, Mediterranean diet and I say, well, can you give me an idea about Mediterranean diet is about? Seafood, vegetable and fruit. That’s all I get. I’d like to know uh, about... the meal planning part and how much you’re allowed of each thing and that type of thing and I haven’t found that out from anybody” (P20F – Older adult, 74 years old)

As described by older adult participants, follow-up and communication from healthcare providers is critical to facilitate a smooth transition after discharge and a meaningful reintegration to their communities, as well as their active engagement in cardiac rehabilitation. Most older adults expressed the need to receive accurate, timely and comprehensive discharge instructions, as well as information on how to engage in activities of daily living.

4.2.2 Theme 2: Interactions with Healthcare Providers

The theme of “Interactions with healthcare providers” refers to the interactions that older adults had with healthcare providers during their transition from hospital to cardiac rehabilitation. Some older adults reported positive interactions and supportive attitudes from healthcare providers. Nurses in particular were perceived as helpful and supportive, as well as knowledgeable and friendly towards older adults. However, some older adults perceived suboptimal attitudes from healthcare providers, often dismissive. The theme of interactions with Healthcare Providers includes two subthemes: Supportive Attitudes and Suboptimal Attitudes.

4.2.2.1 Subtheme: Supportive Attitudes

The majority of older adult participants reported high levels of satisfaction with the support they received from healthcare providers. Support from healthcare providers was reported as satisfactory from hospitalization to cardiac rehabilitation. These supportive attitudes included providing great care during hospital stay, providing adequate support for rehabilitation, being available for consultation and displaying friendly attitudes. Some older adults shared their positive experiences at the hospital, expressing feelings of ‘being taken care of’ and that someone was there for them.

“The staff, the uh, all of the people, the doctor, everybody were very good and quick in doing their job and it was all done very, very well. And then, I when I was up in the ward, and uh, very efficient at the ward, met me at the bed, talked to me, welcome, and I knew that somebody was there to take care of me.”

(P06M – Older adult, 73 years old)

Positive experiences and interactions with healthcare providers at cardiac rehabilitation were also reported. Some older adults perceived that the attention of different healthcare providers was very satisfactory and that there is a team there to help them ‘heal’.

“But those people, at rehab, are excellent. I’ve talked to, a dietitian [laugh] and hey, is my diet ever changed [laughs] eating all the... uh, she put me in a Mediterranean diet and I, uh, just getting used to it now, really, because I spoke

to her last week and this week, I have an appointment, tomorrow actually, with a kinesiologist. So, they are healing me really good, I really... really like the pace of those people at rehab” (P09M – Older adult, 79 years old)

In the member checking session, a month after the interview, participant P09M reported that his health has improved since the interview and that he received great support from providers at cardiac rehabilitation. He said that he is especially thankful for the medication that providers got for him, which was too expensive for him to purchase.

“I was treated exceptionally well... they looked after me well [...] They were great, uh, they were very understanding, they... were, they asked me questions just like you are doing. They uh, went through my report, I had a complete file given to me from [name of city] and they went through that extensively” (P10M – Older adult, 82 years old)

Healthcare providers being always available for consultation was also related to positive feelings, as perceived by older adults. Having a contact person or someone to talk to was reported as helpful, often contributing to feelings of ‘being supported’ by healthcare providers.

“My exposure has been quite, quite positive [...] [provider’s name] was my contact person, I had her phone number, I was able to reach her, and if I wasn’t able to reach her directly, I was able to leave a message and she usually called back by the end of the day” (P13M – Older adults, 65 years old)

“I have lots of support, lots of support [...] If they [providers] had a problem, they called me, they called me every time. Always! Unbelievable! I had... even if they had the meeting, it’s like you and I, you set up the meeting, and you set the zoom thing, and I had to do is arrive. So that’s fantastic! [...] I have had outstanding support, from the healthcare community, that I have to deal with, no question about it” (P15M – Older adult, 67 years old)

Support provided by nurses was perceived as very positive and older adult participants reported that nurses had a significant impact on their experiences in hospital and at the cardiac rehabilitation program. Nurses were described as knowledgeable and friendly, and the relationships they established with patients were perceived as positive. Sometimes, nurses were perceived as the ones who ‘really’ knew what was happening to the patient or the person who helped older adults in their time of need.

“When I got to cardiac, um, to the rehab program, the nurse... I mentioned this to the nurse practitioner, and she took it by the horns and I... ended up basically going back on two of the medications they remove me from, and it took care of the headaches, so, I’m very grateful to the rehab program for that [...]The, you know, the rehabilitation nurses and the people that are trying to help, they’re very, very good, very good [...] the nursing care was excellent, they really... they really were good, so... yeah, well, all I have to say is that the hospital was amazing” (P02M – Older adult, 68 years old)

Support from nurses to navigate the hospital and to connect with other healthcare providers was reported by some older adults. Helpful and welcoming attitudes from providers were perceived as important factors that made the experience in both hospital and cardiac rehabilitation more enjoyable and friendly.

“They [providers] were, they were really good. They took me in, and the uh, they assessed me; they did all the tests on me. uh, did uh, a small uh, stress test to see what level I was at, uh, I believe if I’m not mistaken, they gave me an echocardiogram at the time, uh, they walked me all through the pages, I had a fantastic nurse” (P10M – Older adult, 82 years old)

Nurses were reported to be the ‘go to’ contact for older adults. Nurses were described as very knowledgeable, pleasant and friendly people. Older adults felt comfortable to ask questions and to request information regarding their rehabilitation activities, such as exercise or diet.

“She [the nurse] helps me, if I have any questions... I call her, and she is good. She is helping me in my exercise stuff and that’s why I see her too.” (P15M – Older adult, 67 years old)

“I guess my first contact would be the intake nurse, so she was very good, we were sharing recipes, so, it felt very personal that way” (P18M – Older adult, 65 years old)

“Nurse practitioner was very, um, knowledgeable and uh, and polite” (P03F – Older adult, 81 years old)

Older adults who reported that they received adequate support from providers described them as ‘helpful’, ‘friendly’, ‘pleasant’, ‘cautious’, ‘respectful’ and ‘knowledgeable’. In addition, older adults reported having a healthcare provider as a contact person was reported as helpful.

4.2.2.2 Subtheme: Suboptimal Attitudes

For some older adult participants, encounters with healthcare providers during their transition from hospital to cardiac rehabilitation were not perceived as very positive. Some older adults reported that healthcare providers’ attitudes were suboptimal. These attitudes included words and behaviours that had a significant impact on the experiences of older adult participants as reflected in the following quotes.

“But he [provider] was kind uh, it was okay, he took the facts, but I had some questions and some things that I wanted to know, and he got uh... kind of edgy, and I got... uh I don’t want to push you anymore [...] oh, I don’t know words sometimes, and the behaviour and body language was telling me that I’m asking questions that were not important or something like... along that line. That I shouldn’t have asked that question, and that was, uh, kind of disturbing for me...” (P01M – Older adult, 75 years old)

Some older adults reported that healthcare providers displayed dismissive attitudes when patients asked for help. Also, some attitudes reflected lack of interest in the patient, as perceived by older adults.

“He [provider] was a retired gentleman up there and I don’t think he was interested in his patients other than the money he was getting” (P10M – Older adult, 82 years old)

“He [provider] wasn’t really interested in me. They took my blood pressure, which was way high; he had no idea what my normal blood pressure was...” (P10M – Older adult, 82 years old)

In terms of healthcare providers’ responsiveness, some older adult participants reported that their health-related concerns were dismissed. These behaviours and attitudes often happened when older adults sought medical advice and medical care due to symptoms of illness or medication side effects, or in some instances, due to an actual cardiovascular event that needed immediate attention.

“My [provider] really didn’t do much for me, other than... he uh, I called him and said look, I think I need, there is something going on with my blood pressure because of the headaches. So, he was saying, you have headaches, better go down to the hospital and get a COVID test, and... all this. He was reluctant to see me. And I thought, that’s stupid, I’m not going to go, in a pandemic, into a hospital, to get a test I know it’s going to be negative” (P02M – Older adult, 68 years old)

“I should have never had that heart attack cause I had booked myself in emerge at [name of hospital] a month prior to my heart attack, with chest pains, pains in my left arm, pains in my left leg and they, two doctors in the uh, triage, the lady doctor said that, uh, there is nothing wrong with me, all I had was a strain muscle [...] So, I knew that there was something wrong, but they said it was a strain muscle... that’s not right” (P10M – Older adult, 82 years old)

Ignoring their patients' wishes was also reported as a concern for older adults. One older adult participant reported that healthcare providers at the hospital did not address important concerns about not wanting to stay in the hospital, and they hospitalized the participant overnight without asking for consent.

“When I went in, they told me I’d be in by 9 and I’d be out by 2. They checked me overnight and I was very upset [...] Apparently by the time I got in there, they had to do things differently than they planned and I end up staying but none of this was really explained... all I knew is I was kept against my will for another day...”

(P07M – Older adult, 67 years old)

Some older adult participants reported lack of emotional support. Feeling valued and supported was perceived as particularly important shortly after hospital discharge, however, some older adults reported that healthcare providers were not responsive or attentive enough to their mental health needs.

“Because you’re not only a doctor to... prescribe pills... but you are also a doctor of emotional welfare, especially in this time. Well, he could have called me and say how are you doing [participant’s name]? What can we do for you? No. nothing [...] So, in other way, the question I had is valuable. And it is put aside, and I feel I was not valued as a... because that question was regarding... about my health and... and how I can go about things.” (P01M – Older adult, 75 years old)

From the perspective of healthcare providers, mental health support is critical for older adults who had a cardiovascular event. Older adults who experience a cardiovascular event are likely to need mental health support to manage conditions such as anxiety, depression and Post Traumatic Stress Disorder (PTSD). Healthcare providers who care for older adults at the cardiac rehabilitation program talked about the importance of mental health care and reported that they do screen for mental health conditions.

“We do screening um, at the beginning for mental health concerns, sort of standardized screening so that we try to pick up on some of that, if it’s happening, because we know that is common in cardiovascular care” (P14F – Healthcare provider)

“Often post heart attack of myocardial infraction, people are quite... can be profoundly depressed, and if you add elderly age, and potentially early dementia to that, it can be quite impactful” (P25M – Healthcare provider)

During the member checking session with the primary investigator (CFS), participant P01M reported that there was a gap in terms of the mental health care he received. He talked about long waits to see a specialist in mental health and that his concerns were not timely addressed, particularly his negative thought, including a very concerning lack of motivation to live. As he expressed, ‘not wanting to live anymore’ was a concern that should have been addressed rapidly by a healthcare provider. The participant reported that now he is feeling better and that he acknowledges that the COVID-19 pandemic and the overloaded healthcare system could have contributed to delays in accessing care. He also talked about how having a heart attack during the COVID-19 pandemic negatively impacted patients’ mental health, particularly what he called ‘body trauma’. The participant suggested that a potential area of improvement would be to ‘help the patient in a more holistic way’. On this matter, a healthcare provider participant explained that despite their efforts to screen patients for mental health conditions, such as anxiety, depression and trauma, sometimes patients might not express clear symptoms right away, especially related to PTSD.

“With trauma, I think that’s sometimes, often more subtle, sometimes a person has been through a cardiac arrest, has gone on a frightening ambulance ride, emergency admission and resuscitation [...]So, sometimes there are clear symptoms, like flashbacks, irritability and aggression, and sleep disturbance and hypervigilance and hyperarousal. Those are the classic symptoms of PTSD, sometimes people have diagnosable PTSD, or just the signs and symptoms of

PTSD, symptoms that meet the criteria [...] but sometimes, is my impression that people may be sort of numbed out, they may be a little disassociated, flatten out emotionally speaking. So, when they come through intake screening in cardiac rehab, they might not score very highly at all, on the screening test, they might sort of fly under the radar” (P21M – Healthcare provider)

Some older adult participants perceived that healthcare providers did not offer enough support, did not answer their questions or were dismissive of their concerns or symptoms. Some older adult participants also reported feeling ignored by providers or feeling dismissed, these feelings were often associated with interactions with providers before and during hospitalization, and shortly after discharge. Some negative feelings were also reported in relation to healthcare providers who did not know about the patient’s history or their specific health conditions.

4.2.3 Theme 3: Support from Family Members

The theme of “Support from family members” relates to the important role that family members have in the transition of their loved ones from hospital to cardiac rehabilitation. Family members provided support from hospitalization to the first appointments with the cardiac rehabilitation team. It should be noted that only one participant had a personal support worker that would help around the house. Most older adult participants reported that it was often their spouses or partners who offered practical and emotional support. Other family members, such as adult children, offered support for older adult participants mainly after discharge. The theme of Support from Family Members includes three subthemes: Support for Rehabilitation, Emotional Support and Involvement of Family Members.

4.2.3.1 Subtheme: Support for Rehabilitation

In terms of engaging in rehabilitation activities, family members offered invaluable support, particularly to motivate the patient to exercise and engage in other rehabilitation activities. As reported by older adult participants, family members helped facilitate their rehabilitation by motivating them to engage in exercise and lifestyle changes.

“My husband has been really good. Like, he’s walked with me, we’ve been walking outside since January I think” (P17F – Older adult, 77 years old)

From the perspective of healthcare providers, family members play an important role in engaging patients in rehabilitation activities and behaviour changes that can contribute positively to their recovery. In addition, family members often offer practical support and help make sure that the older adult is attending their meetings online, taking their medication properly and exercising.

“There’re practical things, like getting them online [laughs] a lot of the time or making sure they get their medications organized and sorted through, making sure that they’re taking them and checking up on that more frequently. You know, sometimes it’s as simple as they [family members] actually go into the walks with them. If the person is feeling nervous doing that, they have someone beside them” (P14F – Healthcare provider)

All older adult participants reported that they received practical support from family members, including spouses and adult children. The majority of older adult participants were married and lived with their spouses. Walking together with a spouse was often reported as a good strategy to start the rehabilitation process shortly after hospital discharge.

4.2.3.2 Subtheme: Emotional support

Family members were also reported to provide emotional support to older adults. Some older adult participants talked about how family members cared for them after their cardiovascular event, especially shortly after discharge. Participant P02M indicated that his son stayed with him after the surgery, and that he had to be in quarantine two weeks prior.

“I had my son at home with me for a week. He went into quarantine before I went into the hospital and when I got out of the hospital he came and stayed with me for a week” (P02M – Older adult, 68 years old)

For some older adults, their family members could not provide practical support, but they perceived that they were providing moral and emotional support during their healthcare journey, particularly during appointments with healthcare providers.

“She [wife] just... gives me moral support” (P10M – Older adult, 82 years old)

“She [wife] sits and listens and, sometimes we refer to her, like regarding past history, to help, you know, that type of thing, she is very helpful” (P09M – Older adult, 79 years old)

For some older adults, their family members supported them as much as they could, even when the COVID-19 restrictions prevented them from being in the hospital with their loved ones. Participant P20F expressed that her husband would take her as far as he could at the entrance of the hospital and watch the nurse take her into the hospital.

“Well, my husband, he takes me to the appointments, but he is not allowed to go in, so, he takes me as far as the door and the doctor’s nurses comes down and takes me in” (P20F – Older adult, 74 years old)

Most older adults reported that their family members provided emotional support to some extent, some more explicitly than others do. However, sometimes just going for walks together, and other supportive gestures such as staying outside of the hospital or clinic were also reported by older adults as helpful and meaningful for their healthcare journey.

4.2.3.3 Subtheme: Involvement of Family Members

As reported by healthcare provider participants, often the spouse who would sit at home with the participant during their phone appointments. They would listen and offer advice as needed. The input of family members during appointments was reported as very helpful by healthcare providers, particularly because family members might remember important information about

their loved one's care. They were also reported to provide support when using technology and navigating the logistics of the appointments

“I think it's a huge support because they are there to support them, and even sometimes being on like, zoom, you know, we have like an older lady and she doesn't know how to use it and her daughter joined with her to be able to support. So, yes, I think it's a huge support for them” (P23F – Healthcare provider)

In terms of decision-making, partners, spouses and adult children might contribute to a more in-depth conversation with healthcare providers by asking questions and requesting information. In addition, family members can help older adults engage in rehabilitation activities by finding a connection between the lifestyle change and something the person loves. For instance, linking the benefits of exercise to having enough energy to cook for family.

“It can certainly be beneficial to have a family member or a caregiver involved [...] for instance, I had an elderly woman who really liked to cook, and she wasn't sure about the exercise and things that she was able to do. Her family talked about exercise; you know. She didn't really exercise, she wasn't really interested in that... but her daughter would frame in in a way that said, you know if you are more fit, you have more energy and then you're able to start doing more cooking again for the family and take on those roles that she liked. She helped her to see kind of what the benefit would be for her, and because I don't know her well enough to be able to frame things in that way” (P16F – Healthcare provider)

Healthcare provider participants often identified the value to the involvement of family members, particularly adult children. Family members were considered as key for the active participation of older adults in their care by helping them to find meaningful connections between their rehabilitation and activities that they enjoy or that are important to them.

4.2.4 Theme 4: Information about Medical Care and Rehabilitation

The theme of “Information about medical care and rehabilitation” relates to access to medical information and rehabilitation information for older adults, as well as the quality of this information and whether or not the information was received in a timely manner. For some older adults, the information they received during their health care journey was perceived as adequate and satisfactory. For other older adults, information about their medical care or rehabilitation was reported as insufficient, and sometimes overwhelming. In addition, some older adults expressed that the information they received was not tailored to their specific needs. The theme of Information about Medical Care and Rehabilitation includes two subthemes: the first one refers to Timely and Clear Information, and the second one refers to Difficult and Insufficient Information. In this section, information from the document analysis will be used to provide context and expand on the findings. For a complete list of documents, please see Chapter 3 (Section 3.4.1).

4.2.4.1 Subtheme: Timely and Clear Information

Some older adult participants reported that easy and clear information about their medical care contributed to their overall satisfaction and to a positive experience from hospital to cardiac rehabilitation. Understanding instructions regarding their medical care was perceived as very important, both regarding written and verbal information. Older adult participants reported that healthcare providers offered detailed information about their care, and that this information was both clear and easy to understand. Information that was considered easy by the participant, contributed to a more positive experience and to give the patient more direction in terms of next appointments, daily activities, self-care, rehabilitation and medication. A few older adult participants talked about the book they received after surgery, containing relevant information about their procedure and next steps. This book is called *Heart Surgery: A guide for patients, families and caregivers*, and it was available to them in hard copy and in an electronic version.

“They [providers] gave me a book, you know, it’s illustrated. The rehab program has been good, they’ve been very straightforward and the uh, you know, they have

nice diagrams and pictures and, they basically take you point by point through your booklet” (P02M – Older adult, 68 years old)

“They [providers] sent me home with all the pills and when I had questions, I just asked, you know, why am I taking this pill? [...] They did send me home with a book, as to what I should do when I’m home, and how I should care for myself” (P12F – Older adult, 72 years old)

This book, containing information on heart surgery, is available to patients on the cardiac rehabilitation website. The book contains 58 pages of relevant information about how the heart works, the blood circulation and a simple explanation on coronary artery disease and the types of surgery to address this condition. The book includes diagrams and pictures, and it provides detailed information about the surgery process, including what to expect during pre-operative activities, on the day of surgery, during hospitalization and upon discharge, as well as information related to medications, emotions that the patient might feel and the post-operative guidelines to start cardiac rehabilitation.

Other relevant information, such as how to navigate the hospital and get to the appointment was reported by older adult participants. Participants also commented on the quality of the information that healthcare providers offered and that they received satisfactory answers to their questions. Satisfactory information was perceived to facilitate the active engagement in rehabilitation activities.

“I knew exactly what was going on with my care [...] It’s easy to read and it also gives you a lot of information, gives you exercises and everything... that you can do, and how much you can uh, move, let’s say” (P20F – Older adult, 74 years old)

Another useful resource for older adult participants was the *Lifestyle Change and Self-management Workbook*. This resource contains a simple guide to exercise with pictures, including stretching, resistance training and how to manage symptoms that might worsen with exercise, such as angina, shortness of breath, dizziness, fatigue, light-headedness, etc.

Recommendations for safety were also outlined, such as ensuring that medication is taken as directed, avoiding caffeine and alcohol and other substances before exercise, using appropriate clothing and footwear, and instructions on what to do if the person experiences pain when exercising.

All written information that healthcare providers shared with their patients is generally grade six level of comprehension. Some healthcare providers reflected on the written information that they give to their patients. In some cases, as one healthcare provider explained, patients are encouraged to create their own material, based on their needs.

“We give written stuff. Yes, so we have workbooks and guidebooks and a website that is, I think it’s grade six. But we do run it through all of the stuff, we created... has been ran through software and I think its grade six level” (P14F – Healthcare provider)

“I use a little library of resource materials that I would often use to supplement explanations, provide education. They are typically quite short, 1-page things, and I would also, actually this has been happening online to some degree or on the phone, I would have a person develop their own material” (P21M – Healthcare provider)

Receiving timely and clear information about their medical care and rehabilitation was considered very important by older adult participants. Older adults who considered the written material helpful and easy to understand reported more positive experiences when engaging with the information they received post hospital discharge, including positive experiences related to recommendations for exercise and diet.

4.2.4.2 Subtheme: Difficult and Insufficient Information

According to some older adult participants, insufficient and unclear information was a significant challenge during transitional care from hospital to cardiac rehabilitation. Information was

reported to be sometimes insufficient, not tailored to specific needs, or difficult and overwhelming. For instance, participant P02M talked about how arthritis has been a barrier to exercise and to engage in daily activities. From his perspective, more information regarding this condition is missing from the material.

“I think a little more, more direction. To your specific issues, right? I mean, the orientation book, that was great, but it was in general, right? So, if a person didn't have many other chronic problems, you know, then the booklet would probably be sufficient. But nobody is, you know, like the template, everybody has issues, different issues. so, in my case the arthritis was an issue, it just limited the amount, and it still does, limited the amount I can do at the moment, and the high blood pressure again, was an issue” (P02M – Older adult, 68 years old)

It should be noted that, in the *Heart Surgery: A guide for patients, families and caregivers*' book, there is information on diabetes in relation to heart disease, hypertension and stroke, however, there is no information on arthritis. In terms of exercises after surgery, the book does not address recommendations for people living with arthritis. In the *Patient Education Guide* (126 pages), arthritis is mentioned to offer an example of conditions that might affect exercise. In the *Lifestyle change and Self-management Workbook* (36 pages), arthritis is referred to when suggesting types of exercise, such as swimming. However, no further information is provided in the material.

In the member checking session that participant P02M had with the primary investigator (CFS) a month after the interview, he reported that healthcare providers at the Cardiac Rehabilitation program were very helpful and informative, but providers at the hospital were reluctant to give information. Participant P02M indicated that an area of improvement would be more explanation and adequate information before and/or at the time of discharge from the hospital, as well as more direction in terms of who to call to obtain additional information.

Regarding the length of the written material, some older adult participants reported that the information was 'too much' and that completing all the forms was overwhelming. Participant P03F reported that healthcare provider asked too much information from her and that she was

not comfortable discussing her weight and the types of exercise she was doing. Also, filling out the pages of the forms and writing down her weight, diet and exercise habits, as well as her blood pressure, was too overwhelming.

“They [providers] have about three different things that they want me to complete. One for my exercise program, and the next one is my diet. And to me, all this information is just too much... meaning I don’t want to complete all these forms, and I know they wanna go into detail about my weight etcetera, how I exercise. But the information they want is just too much [...] the information that required, they wanted me to fill out pages, one of my exercise, what I was doing, I had to take my blood pressure [...] To me this is just too much” (P03F – Older adult, 81 years old)

The *Lifestyle Change and Self-management Workbook* contains an exercise diary that the patient can refer to with the help of their rehabilitation trainer. The diary also comes in a separate word document that the patient can download. The diary requires the patient to record the date, location of exercise, time of day, resting heart rate, type of exercise, exercise time and heart rate. Nutrition instructions require patients to also record everything they eat and drink in three typical days. Food intake record includes the time of day, if they were home or somewhere else, the type of food, the amount, the cooking method and the fat used in cooking (e.g., olive oil). Surveys and action plans are also included in this document. For some older adults, the information might be too overwhelming or sometimes confusing or difficult.

“Too much. Really, I have a book full and again, it’s repetitive, plus the referral to websites. It was overwhelming [...] I guess, first of all, don’t put all at once, right? So, I was given a book at the hospital, which was fine, I was then given two PDF files, which were anywhere 100 and 300 pages each, I was supposed to check internet sites. It was very overwhelming, to the point where I think it lost its value. So, how would you improve that? Maybe, have someone filter it out before you get it” (P18M – Older adult, 65 years old)

As participant P18M indicated, the *Heart Surgery Guide*, the *Lifestyle Change and Self-management Workbook* and the *Patient Education Guide*, are 220 pages in total. According to healthcare provider participants, information needs to be improved due to the difficulty that some older patients have when interacting with it.

“The communication we get is basically electronic, we would build from whatever is written in the electronic record, a bit of a medical background. We also sent the patients a form, like a fillable form we are trying to improve that because it’s not a sleek system right now. It’s clunky, and people have challenges doing it” (P14F – Healthcare provider)

Some older adult participants reported barriers to obtaining relevant and sufficient information about their care after surgical procedures. The importance of tailored information and attention to their individual conditions was also a concern. For instance, participant P12F shared her experience trying to get the information she needed from healthcare providers.

“They [providers] don’t know that I’ve suffered with anemia for many years and I don’t think they knew that. And I tried to tell them, but I think they’re mostly thinking, you know, heart... and when I brought up the fact that I had a pacemaker... they said well you have to contact the pacemaker people. So, you are going from one, to the next, to the next...” (P12F – Older adult, 72 years old)

In the member checking session participant P12F had with the primary investigator (CFS) a month after the interview, she reported that she ‘still has questions’ and that insufficient follow-up is still a problem for her. The participant considered that an area of improvement would be having someone to call, instead of going ‘from place to place’ to get answers. She acknowledged that the pandemic has been a great barrier to access care; however, she thinks that better support for patients is needed. It should be noted that anemia was not mentioned in the *Patient Education Guide* or in the *Lifestyle Change and Self-Management Workbook*.

Some older adult participants reported having difficulties engaging with the written material and the information they received about their medical care, particularly after hospital discharge. The most frequently reported barriers were related to how long the material was, unclear information and difficulties accessing information relevant to their health conditions and unique personal circumstances.

4.2.5 Theme 5: Decision-making and Participation

The theme of ‘Decision-making and participation’ refers to how older adult participants made decisions about their care with the help of family members, often spouses, and healthcare providers. Some older adult participants reported engaging in shared decision-making with their healthcare providers and that they trusted that providers were experts and had the best advice possible. Collaboration between patients and healthcare providers was reported to contribute to a more positive experience with decision-making and increased opportunities for older adults to participate in their care. Healthcare providers reported that they contributed to this collaboration by learning about the patient on a personal level, about their goals and unique circumstances.

The majority of older adult participants reported satisfactory interactions and collaboration for decision-making with their healthcare providers. Unfortunately, not all experiences were perceived as satisfactory and some older adult participants reported barriers for their participation. These barriers were related to insufficient opportunities for participation and healthcare providers not asking patients what their concerns or preferences were. From the perspective of healthcare providers, barriers for participation are mostly related to the age of the patient as a relevant factor, in relation to functional status, vision or hearing difficulties, etc. The theme of Decision-making and Participation includes three subthemes: Shared decision-making, Barriers for Decision-making and Age of the Patient as a Factor.

4.2.5.1 Subtheme: Shared Decision-making

According to older adult participants, shared decision-making with both providers and family members was reported as the preferred method to make decisions about their medical care and rehabilitation. Trust in providers was reported as an important factor, some older adult

participants reported that they appreciated the help from providers and valued their knowledge and expertise.

“They [providers] laid out all the options, go ahead and go with whatever option you wanted... if you didn’t want something, that was fine. So yes, there was no problem here [...] a decision was made to update my meds for my blood pressure because they thought it was too low. So, between the cardiologist and the nurse they discussed it and uh, within ten minutes after their discussion, I got a call back from both of them [...] I’m happy with all the decisions we’re making”
(P06M – Older adult, 73 years old)

Some older adult participants reported that the decision-making process was more satisfactory when healthcare providers considered their unique circumstances. For instance, participant P07M reported that he wanted to go back to work and that healthcare providers helped him do it gradually.

“We talked about exercise, and what was allowed and what wasn’t... and what degree of physicality my work involved... that wasn’t going in the direction of getting me back too much, but, as I say, at one point they said, do you want to go back to work and I said hey! I wish to go! Get me out of here! And we did a gradual return to work when I would go one week, for the next four, five, until I was comfortable full time. I’m full time now” (P07M – Older adult, 67 years old)

Preserving their autonomy to make decisions related to their medical care and treatment was reported by older adults as an important aspect of the decision-making process. Participant P13M reported that his healthcare provider did not make any decision by herself. Instead, she offered options, as well as information to help him decide what was best for him.

“My medical care? I make decisions for me, for my medical care [...] The healthcare provider, that’s right. No decisions were made on her part. She did say... and again... kudos! She did say that, you know, when I had that initial

concern regarding my heart, and the sense of contraction and that sort of thing that I mentioned to her. She said, this is what you can do, and she provided information as to... to moderate my exercise program, and but like, you know, things are left to you as the individual, to make that decision” (P13M – Older adult, 65 years old)

From the healthcare provider perspective, learning about the patient and their unique goals is an important first step to promote participation in decision-making, particularly collaborative goal setting. Making sure all questions are answered and offering adequate explanation about procedures and medications was also reported as essential for shared decision-making.

“I try to give them [patients] an understanding about... from the medical perspective [...] talk to them about kind of risks and benefits of procedures and medications, and try to explain why we consider benefit out weights the risks, um, and then from there, answer any questions that they have” (P16F – Healthcare provider)

“A big emphasis is put on goal setting, teaching participants how to set goals [...] I help them set a goal so that they participate in the decision-making” (P22F – Healthcare provider)

Healthcare provider participants expressed that they would help their patients to set goals and actively work to achieve them. Some healthcare providers reported that they use motivational interviewing to help patients set goals that are meaningful for them and that are feasible according to their functional status and unique circumstances. Some healthcare providers also reflected on the shift from a more paternalistic medical culture to a patient-centered approach.

“I do like motivational interviewing, so, you know, I teach them [patients] and I kind of try to help them, you know, make a smart goal, you know, how confident are you in this? A lot of people say, I want to lose weight, right? You can’t just

say 'I want to lose weight'. You have to say, 'I want to exercise for 20 minutes a day', 'I want to cut back on sweets', like that, so we just kind of guide them to make smart goals" (P23F – Healthcare provider)

"As [providers] we are transitioning from a very paternalistic culture historically to one that is more patient-centered [...], that it's their decision what to do with their health, while we educate them about the consequences of certain actions as well as the benefits of other actions, but ultimately it is in their hands, what they do" (P25M – Healthcare provider).

Older adult participants reported that they preferred to engage in shared decision-making, with family members, healthcare providers, or both. Preserving the autonomy of older adults when making decisions was reported as beneficial, especially from the perspective of healthcare provider participants. In addition, getting to know the patient on a personal level was considered a fruitful strategy by healthcare providers, and it was reported as a facilitator to establish meaningful relationships with patients and to set rehabilitation goals together.

4.2.5.2 Subtheme: Barriers for Participation and Decision-making

Participants in the older adult group were asked if they perceived that they were supported and encouraged to talk about their concerns, personal preferences and/or experiences during the medical encounter. Most participants reported engaging in shared decision-making with their healthcare providers and family members. Some older adult participants, however, reported barriers for their active participation in their care and in the decision-making process. These barriers often involved lack of spaces or timely opportunities to voice their concerns, insufficient one-on-one sessions with providers, and the perception that their care was 'rushed'.

"No, they [providers] never asked me, no, what my concerns were" (P03F – Older adult, 81 years old)

“They [providers] asked questions on that direction, but again, with my lack of experience in the area, it was not easy to get a good straight answer, is that the answer you want from me, my experience is not 100% positive [...] for the most part. Decisions about my care were made during emergency circumstances, so I realized there was not a lot of time for discussion, debate, etcetera, under those circumstances, but it would have been nice when they knew that something had changed, if I would have actually been informed at that point, rather than further along” (P07M – Older adult, 67 years old)

While most participants reported engaging in shared decision-making with their healthcare providers and family members, participant P09M reported that healthcare providers were entirely in charge of making decisions about his care.

“I would say my doctor makes the decisions, if I need help, I would go to the doctor, and he makes the decisions” (P09M – Older adult, 79 years old)

From the perspective of healthcare providers, challenges for participation can be related to a variety of factors, including the physical or mental status of the patient, as well as personal motivation.

“What are the challenges? I think exhaustion, fatigue, depression, helplessness, you know, that attitude of kind of giving up, and that’s in the very elderly, also if there was something quite traumatic that occurred in the hospital, I think, often it can be a distress of the medical system because, you know, if there was a complication or they had a lot of pain or something [...] certain elderly people when they have a heart attack, it is a sign to them that they’re approaching the end of life and often they feel like what’s done is done [...], often that’s a misled thinking but that becomes an obstruction to how they go about making decisions for their future” (P25M – Healthcare provider)

Most barriers for participation reported by older adult participants included lack of spaces for participation, limited time to engage in shared decision-making, as well as not getting timely answers from healthcare providers related to their medical care.

4.2.5.3 Subtheme: Age of the patient

The age of the patient was reported by healthcare providers as a factor that impacted the way older adults engaged with their care, in particular with cardiac rehabilitation-related activities. Some older adult participants reflected on their age, compared to other people receiving cardiac rehabilitation services; however, age as a factor was mostly reported by healthcare providers.

“Maybe the fact that I was older, might have some impact. The people there they were younger [...] They seemed to get more attention. But maybe that’s because they wanted more attention” (P12F – Older adult, 72 years old)

Reported age-related barriers included difficulties using technology, the presence of poor vision and/or hearing difficulties, medication tolerance, and polypharmacy, co-morbidities, health literacy and cognitive decline.

“The very older patients, like they’re 80, 85... even more senior patients, I believe they engage differently with the program [...] they also just have a different comfort level with technology [...] if they are not seeing very well, how you coordinate that they’re on the right medications? How do you know they’re not taking the wrong ones? [...] we certainly have to make adjustments to their medical care, for example, because older people have difficulty tolerating different medications or polypharmacy” (P14F – Healthcare provider)

“So, certainly as people get older, they tend to have more comorbidities and impairments can be, you know, more common [...] certain patients would have some significant comorbidities, may, you know, not consider their heart kind of

their primary issue, or they're less engaged, in kind of medication and therapies related to the heart” (P16F – Healthcare provider)

The age of the patient was also reported to be often a barrier in terms of self-management, especially if patients are living with cognitive impairment, have less energy or are not very committed to engage in lifestyle changes because of their advanced age.

“Depending upon the age, in later ages, I think, as in, you know, mid-seventies and later, as cognition declines there might be less reliance on strategies of self-directed self-management, you know, perhaps the as the executive functioning declines or memory declines [...]sometimes a sense of, you know, ‘I’m an old dog and you’re not gonna teach me new tricks’ See? You know, ‘I’ve been smoking for 40 years, what do you think you’re gonna do now?’ [...] Sometimes, other disabilities, physical pain, arthritis, injuries and so on, as people get older, they, generally speaking, have more pain and less energy” (P21M – Healthcare provider)

The age of the patient as a factor was also reported to impact participation during hospitalization and surgery care. Participant P25M reflected on how older adults are at risk of more complications and they might be on several medications by the time they get hospitalized, making it harder for them to participate in their care.

“I do procedures on people’s hearts, and the more elderly you get them, a higher risk of a complication, or the higher risk of it not being effective at preventing morbidity or mortality, and there is a lot of discussion about the benefit of the same approach in a 55-year old as the approach in a 90-year old, and some individuals, some physicians would say, if someone is above 90, they won’t even do anything [...] Particularly older people per se, you know, they probably already have a bunch of medications for other conditions prior to their heart attack so they are probably on ten to fifteen medications potentially and then

there are issues of polypharmacy, grogginess, side effects, drug interactions”

(P25M – Healthcare provider)

Healthcare provider participants reported the age of the patient as an important factor that impacted the meaningful and active participation of older adults in their care. Older adults, especially those in the oldest cohort and those living with cognitive impairment, were reported to have more difficulties related to self-management and adherence to lifestyle changes. Advanced age was also reported by healthcare provider participants as a factor that can impact the active participation of older adults in their care and their meaningful involvement in decision-making.

4.2.6 Theme 6: Healthcare Journey during COVID-19

The theme of “Healthcare Journey During COVID-19” refers to the impact of the pandemic on the healthcare journey of older adults who received transitional care from hospital to cardiac rehabilitation. Older adults who participated in this study were hospitalized, discharged and enrolled in cardiac rehabilitation during the COVID-19 pandemic. Difficult experiences in hospital were reported, as well as difficulty adapting to life post-discharge. Perspectives on the impact of the COVID-19 pandemic were mixed. Some older adult participants reported that the pandemic was a huge barrier and that they had negative experiences because of it, while other older adults reported that the pandemic was not a concern, and sometimes it was reported as positive. The perceptions related to the use of virtual care and telemedicine were also mixed, depending on the circumstances of the patients, their levels of comfort using technology, their preferences for face-to-face contact and their geographical location. The theme includes three subthemes: Hospitalization during COVID-19, Transitional Care during COVID-19, and Use of Virtual Care and Telemedicine.

4.2.6.1 Subtheme: Hospitalization during COVID-19

Older adult participants reported difficult experiences in hospital after admission due to a cardiovascular event. Hospitalizations for this group were heavily impacted by the pandemic and some participants reported feelings of isolation and fear related to COVID-19, especially those

who experienced outbreaks while in the hospital and could not have a family member with them. Also, some older adult participants perceived that the discharge process was ‘rushed’.

“The day after I was released from the hospital, it went into full lock down. So, the impression that I had that I was being pushed along was probably very true, you know. They probably realized that this is getting out of hand and they were trying to get me, moving as quickly as possible and discharged” (P02M – Older adult, 68 years old)

“I really needed my family and I got cut off from my family just because I got sick, cause I ended up in the hospital for 33 days and then I went in for another 12 days more [...] When I was in isolation my husband was not allowed in the hospital” (P20F – Older adult, 74 years old)

Isolation during hospitalization was also reported by some older adult participants. Participant P03F talked about her experience in the cardiac care unit, she did not have any family members present with her and had to communicate using the phone provided by the hospital.

“I was taken by ambulance to [hospital name], and they put me in the cardiac care unit, and I was there for five days and uhm I had to be very careful because of COVID and I was very... very, how should I say? Isolated? Cause it didn’t even have a television and they did have a phone and that was my lifeline” (P03F – Older adult, 81 years old)

Difficulties identifying healthcare providers while in hospital because of the use of protective equipment was also reported. Participant P07M reflected on his hospital stay and reported that could not identify the different healthcare providers who were caring for him.

“I woke up in the morning and about 8 o’clock, I had someone come in, asked me questions and they were wearing a mask, so I had no idea who is who” (P07M – Older adult, 67 years old)

Participant P12F reported that she witnessed the death of another patient in her unit. She also expressed that she was constantly tested for COVID while in the hospital because of the high number of cases. For her, not seeing the healthcare providers' faces was also a concern.

“A lady died from COVID while we were there, on our floor [...] And then everybody had to like, gown up and gown down, and they wouldn't let me take a shower [...] I was tested four times for COVID when I was in the hospital [...] well, because they had a lot of COVID cases there [...] I think COVID makes a lot of difference, the fact that you don't get to talk personally with the health care [provider]. It's nice to see someone's face” (P12F – Older adult, 72 years old)

Constant COVID-19 testing while in the hospital was also reported as difficult by other older adult participants. Some older adults expressed that they were tested multiple times and that sometimes their discharge was delayed because of delays in COVID-19 testing.

“I had to wait to an extra day because of that, because of the mix up with the COVID test [...] told about that delay I had, I spent another day in the hospital initially because of COVID, because they lost my test” (P13M – Older adult, 65 years old)

“I got tested six times for COVID [...] six COVID tests and they all came back negative. I couldn't understand why [...] it didn't make sense and I don't know why they had to test me so many times” (P20F – Older adult, 74 years old)

A rushed discharge from hospital and feelings of isolation during hospitalization were the most commonly reported experiences among older adult participants who had an acute cardiovascular event during the COVID-19 pandemic. Feelings of uncertainty, frequent testing and not having a family member with them or any visitors were reported as distressing experiences for older adults.

4.2.6.2 Subtheme: Transitional Care during COVID-19

Some older adult participants reported that COVID-19 impacted their transition from hospital to cardiac rehabilitation. Delayed medical procedures and surgeries because of COVID-19 were reported and one older adult reported that he is still waiting to have his procedure. Delays in discharge from hospital, as well as delays in terms of follow-up were also reported.

“They [providers] had scheduled an angiogram, that’s when they put the dye, up your leg. You should know about that. And it was scheduled for near the end of March but then COVID came calling. That got delayed, so that procedure, was rescheduled.... I believe it was about mid-August” (P04M – Older adult, 72 years old)

In terms of delayed procedures that are still pending, participant P09M reported that he still has a catheter, and the operation has been delayed because after his heart attack, he was prescribed blood thinners. He expressed that he still has the catheter and that has greatly impacted his life.

“Well, it [COVID-19] affected. I also have a catheter, okay? And that was February 2019, and finally in April, my urologist, had made an appointment for me to have an operation to correct this, but of course COVID came along and they couldn’t get into the operating room. So, about, I guess a month later, the doctor called and asked me, that... okay so I supposed you are in a lot of blood thinners, and I say, yes, I am, they put me on blood thinners, he says well, I can’t do this operation when you’re on blood thinners. He says, it would be at least six months, up to a year before I can even want to think about doing it, and so, here I am sitting with this thing, I’ve had it for two years now” (P09M – Older adult, 79 years old)

Long waits to be discharged from hospital were also reported, as well a sense of ‘uncertainty’, not knowing what would happen after discharge. Some older adult participants expressed that they would have liked to have more information or guidance about what to expect after hospital discharge.

“There was such as wait though, there was I guess a lot of people that were being discharged that day [...] on the date of discharge things perhaps could have been done better by saying, this may happen in the first day, or two or three, and this is what you do or who you call” (P04M – Older adult, 72 years old)

“I’m wondering if maybe, the hospital should make these appointments before you go home. And that way they’re already set up, so that when you go home, you’re not stressing cause now I’m not going to see my doctor until January, and then you don’t see them, you just talk to them on the phone” (P12F – Older adult, 72 years old)

For older adult participants, insufficient access to healthcare providers was also a concern during their healthcare journey. The perception that discharge occurred very fast, or that follow-up did not occur in a timely manner was also reported. In addition, getting home safely was a priority at the time of discharge.

“Our family doctor is good about answering emails but is not seeing any patients and I don’t blame her, um, there was no blame for the system because it is a pandemic [...] It felt very lonely the first two months. Because of the pandemic, I couldn’t access what normally would be there” (P17F – Older adult, 77 years old)

The COVID-19 pandemic also impacted the rehabilitation activities of older adult participants, particularly in relation to exercise after discharge. Some older adult participants also reported that they had to cope with the COVID-19 restrictions, such as the closure of gyms, pools and recreation centers.

“So yeah, so from the visit to the hospital, up to the rehab, COVID has impacted every step. No visitations, less interaction with people face to face, and no rehab class program... not being able to go to the YMCA” (P01M – Older adult, 75 years old)

“When I was released from the hospital, they just tell you to go home, go home and walk, you know, basically. Now, I get it’s in the middle of a pandemic, everything is closed, there is no exercise facility [...] That was impacted by COVID, because you know, you couldn’t go to a gym, you couldn’t go to a pool, you know what I mean? Sort of denied, that was. That was the hardest part”
(P02M – Older adult, 68 years old)

Lack of interaction with others due to COVID-19 restrictions was also reported by older adult participants, and this was often perceived as negative for their mental health.

“There’s restrictions on, on friends and... uh, how should I say? We’re isolated and can’t socialize but I don’t know what else to say, it’s a little bit uh, um, ah, how should I say? A little bit depressed... depressing” (P03F – Older adult, 81 years old)

For some older adults, except for a few inconveniences, the COVID-19 pandemic was not reported as a concern, especially for those who perceived that the hospital was a safe environment and those who spent most of their time indoors pre-pandemic.

“You know, I really don’t think in this situation, in my situation, that the COVID factor was much of a factor. Because, you know, the examinations that were taken, were taken on site, in hospital, so, I didn’t have face-to-face with medical staff, other than when I did go to the hospital. And that was in a secure environment, so, I don’t think COVID was an issue for me” (P13M – Older adult, 65 years old)

Delayed medical procedures, long waits to receive care and insufficient access to healthcare providers were reported as negative experiences by older adult participants as they transitioned from hospital to cardiac rehabilitation. Older adults were also affected by public health measures such as distancing and the closure of recreation spaces. Lack of social interaction and adequate

spaces to exercise contributed to feelings of isolation among older adults and hindered their active engagement in rehabilitation activities.

4.2.6.3 Subtheme: Use of Telemedicine and Virtual Care

Due to the COVID-19 pandemic and the restrictions associated with face-to-face interaction, patients who received cardiac rehabilitation had most of their interactions via phone call or video call. Older adults reflected on the use of technology to engage in rehabilitation and communicate with their healthcare providers. For some older adults, the use of virtual care and telemedicine affected their experiences negatively. These negative feelings were associated with the lack of face-to-face interaction, and perceived lack of the emotional component or intimacy.

“I couldn’t have my rehab program happening in class... um, setting... together. Couldn’t have meetings of... face to face, you... kind of have them face to face but.... Affects mostly the rehab, as a whole team, as a class” (P01M – Older adult, 75 years old)

“One to one in person is much more personal and satisfactory. It feels better, more comfortable. Talking to the air on the phone... is not as intimate or a satisfactory experience” (P07M – Older adult, 67 years old)

Some older adults expressed that engaging in virtual sessions with healthcare providers was difficult, particularly in virtual sessions with multiple participants. Some older adult participants reported that virtual sessions were confusing and that identifying their healthcare providers was a challenge.

“The virtual one, you mean? It was fine, it was a little confusing based on the number of members that were... participants who were in it. I think it was more of a distraction, people trying to get on the camera, if you will... but it was fine. It was a little confusing trying to figure out all the different members of the team

[...] and I'm still not 100% sure who they all are" (P18M – Older adult, 65 years old)

Participant P20F reported that sessions with her healthcare providers were not very satisfactory and even though she purchased a blood pressure machine, she feels that the use of virtual care and telemedicine has been difficult, and it has affected her.

"They [providers] tried to connect the three of us in the conference call, and it just wouldn't work [...] I'm not very happy with it because I can talk to the doctor over the phone... but the doctor isn't there to take my heart rate, he is not there to do my blood pressure. Now, I've got my own blood pressure machine, but if there was a family that didn't have a blood pressure machine... they wouldn't take their blood pressure, so they won't know if their blood pressure is up, if their blood pressure is below a 100, and you call the doctor cause you don't know [...] it has really affected me and I'm not very happy with it" (P20F – Older adult, 74 years old)

For some other older adult participants, the use of virtual care and telemedicine was associated with a positive experience. Not having to physically be in the medical office or the hospital was perceived as positive by older adults. Also, they reported that the use of virtual care and telemedicine helped them, and their healthcare providers save time.

"Is new to me [use of virtual care and telemedicine], I'm not used to doing it. Uh, but it saves a lot of time both on your part and my part [...] we can do it here for an hour or two quarters of an hour instead of taking two hours to go to the hospital and back as long as we got good internet connection [laughs]" (P10M – Older adult, 82 years old)

Timely access to healthcare providers was reported as a major benefit, particularly for those who live outside of the London area and were required to travel to the hospital to participate in the cardiac rehabilitation program.

“We should do it this way, with somebody calling me once... but if they have to, they have to see me... they have to see me, but if they can just have a good solid conversation. That’s fine by me too. That is a lot of stuff we should do in the future [...] have that kind of stuff going on... rather than me... have to go, find a place to park, walking to the hospital” (P15M – Older adult, 67 years old)

Healthcare provider participants also reported that virtual care and telemedicine offered more flexibility, particularly for patients who live outside of the London area. According to healthcare providers, the use of virtual care and telemedicine has enhanced patient attendance and engagement in their rehabilitation.

“People are thrilled that they don’t have to drive to London. They don’t have to park at the hospital. They can do the things in the comfort of their own home in their own time, and, so, we built in some flexibility, I think. I think in a dreamworld, we would have both options, simultaneously and patients could choose what, which one is... you know, most agreeable to them” (P14F – Healthcare provider)

Due to the flexibility that virtual care and telemedicine offer, more patients have enrolled in cardiac rehabilitation as reported by healthcare provider participants. The use of virtual care and telemedicine has also helped provide better accessibility to patients and a higher percentage of patients are able to attend the program, especially if they live in remote areas or come from out of province.

“A lot of people, if they don’t have transportation, they can’t get to the hospital or they live in a different city, they are able to actually join us. So, there is a lot of positivity for sure [...] we have even a higher percentage of participants and a higher percent of people actually attend our program, you know, whereas, as I remember in the past some people wouldn’t show for their appointment, but now

you are calling them, right? So, they are not going to forget the appointment”

(P23F – Healthcare provider)

The use of a virtual model involved learning new skills for healthcare providers and the implementation of numerous strategies to help patients navigate the new system. According to healthcare provider participants, accessibility has improved with this new model because the system has been designed to accommodate for different needs that patients might have, such as vision or hearing difficulties, language preferences.

“We started off with [a] virtual model to incorporate more telephone use, internet use and try to get people to do one-on-one appointments when they are more vulnerable [...] We have been able to utilize virtual care to be able to offer services for our patients, I think in one aspect it’s helped us to move forward in a lot of projects that we wanted to [...] I think we’re learning and adapting, to try to help, you know, make sure that we are incorporating all ages and abilities, into our virtual programming” (P16F – Healthcare provider)

Some healthcare provider participants reported that, even though they were skeptical, and the virtual model was new to them, the use of virtual care and telemedicine has been helpful to their patients and it has many advantages for people who cannot leave their home.

“I have to say that, before COVID hit, I did not do phone work. I was very skeptical and never did online work, and I rarely did phone work [...] I can be quite effective in working by phone or by WebEx with patients, even with some relatively complex difficulties like obsessive compulsive disorder with major depression, PTSD [...] It certainly is useful, and my feelings about it have changed” (P21M – Healthcare provider)

One healthcare provider participant shared that healthcare settings might transition to a hybrid mode of care, incorporating both virtual care and in-person care.

“We’re learning that maybe the first meeting can be in person but then, subsequent follow ups don’t need to be in person, so I think what we’re going to see in the future is a more hybrid approach to clinics, where some patients are seen in-person and some are on the phone, and it really depends on the needs of each appointment. [...] I think virtual care is here to stay. Even clinics in hospital are investing in their virtual care platforms, so that they’re faster. They are more reliable” (P25M – Healthcare provider)

Despite the benefits that some healthcare participants reported, the use of virtual care and telemedicine also presented challenges for communication between healthcare settings and healthcare professionals across the continuum. In addition, forming relationships with patients has been difficult for healthcare providers.

“From a systems perspective, one of the things I feel has happened since the pandemic, and switched to virtual care is... we’ve become more siloed again, um, we were trying to build more and more connection with our upstream referral partners, and now we’re not... it’s not that easy to do... their priority has shifted especially in the in-patient world” (P14F – Healthcare provider)

“It would be amazing to having them come into the office and then, you know, you are just forming relationships and it’s more like, from my end, it’s more like education and teaching them how to self-manage [...] Teaching how to check their blood sugar. I can’t do that so, certainly, it has its limitations” (P23F – Healthcare provider)

Some healthcare providers expressed that older adults benefit more from in-person interactions and physical contact. Also, according to healthcare provider participants, when interactions are often on the phone, patients might not know what their healthcare providers look like and this can greatly affect the patient-provider relationship.

“The nature of virtual care, that is the barrier [...] being able to be in person makes a difference and it is more beneficial for older adults” (P22F – Healthcare provider)

“Most of our interactions are on the phone now and we don’t get to physically examine them and also, it does interfere with the rapport that we can build with our patients because they don’t know what we look like, you know, vice versa, and to the elderly, often the physical contact is very important” (P25M – Healthcare provider)

Both older adult participants and healthcare provider participants reported mixed feelings and different experiences with virtual care and telemedicine. The majority of older adults, especially those who lived outside of the London area, acknowledged the advantages of having their appointments by phone or video call; however, some older adults reported that they preferred face-to-face appointments with their providers. This need for in-person medical care and patient education was also reported by healthcare providers, who reflected on the importance of building relationships and trust with their older adult patients.

4.3 Summary

This chapter included a description of the characteristics of participants and the presentation of findings. Analyses of the data revealed six themes and fifteen subthemes: (1) The theme of Follow-up from Healthcare Providers included two subthemes, Adequate and Timely Communication and Insufficient Communication, (2) the theme of Interactions with Healthcare Providers included two subthemes, Supportive Interactions and Suboptimal Interactions, (3) the theme of Support from Family Members included three subthemes: Support for Rehabilitation, Emotional Support, and Active Involvement of Family Members, (4) the theme of Information about Medical Care and Rehabilitation included two subthemes: Timely and Clear Information, and Difficult and Insufficient Information, (5) the theme of Decision-making and Participation included three subthemes: Shared Decision-making, Barriers for Decision-making, and Age of the Patient as a Factor, (6) finally, the theme of Healthcare Journey during COVID-19 included

three subthemes: Hospitalization during COVID-19, Transitional Care during COVID-19 and Use of Virtual Care and Telemedicine.

Participants' quotes were presented with each theme, as well as information from the document analysis and member checking sessions. Analyses of the data suggest that, despite the abundance of positive experiences during their healthcare journey, there is a gap in the provision of transitional care services for older adults who transition from hospital to cardiac rehabilitation after a cardiovascular event. Several challenges experienced by older adults were associated with the COVID-19 pandemic, including public health measures and hospital restrictions. The use of virtual care and telemedicine was related to mixed reactions and perceptions from both older adults and healthcare providers. However, despite specific barriers created by the pandemic, there are still gaps in terms of care delivery during transitional care for this population and a disconnect between health care providers and older adults transitioning from hospital to cardiac rehabilitation. Chapter 5 includes a discussion of findings in relation to previous literature concerning patient participation and transitional care for older adults who need cardiac rehabilitation services and healthcare delivery during the COVID-19 pandemic.

Chapter 5

5 Discussion

Chapter 5 includes a discussion on the significance and implications of the six identified themes and their associated sub-themes in relation to relevant literature.

5.1 Theme 1: Follow-up from Healthcare Providers

Theme 1, titled “Follow-up from Healthcare providers” showed the importance of ensuring that older adults receive adequate follow-up from healthcare providers after hospital discharge and during their transition to cardiac rehabilitation. Some older adults reported that the first few weeks post-discharge were particularly difficult and that they had no contact with healthcare providers. The significance of this theme is that older adults rely on continuity of care, communication and care coordination between healthcare providers and clinical sites to have a smooth transition from hospital to cardiac rehabilitation. The implications of this theme are that interactions with healthcare providers in the early stages of the transitional care process can be highly beneficial for older adults and can help relieve feelings of isolation post-hospitalization. Having a member of the healthcare team as a ‘go to’ person can help older adults navigate the next steps in their healthcare journey and facilitate the transition. In addition, timely follow-up from healthcare providers shortly after hospital discharge can contribute to the physical and emotional well-being of older adults by providing spaces and opportunities for participation in decision-making and by helping them feel supported after a stressful event such as cardiac surgery

The theme of “Follow-up from healthcare providers” is consistent with the current body of literature on transitional care. Ensuring that patients receive adequate follow-up upon hospital discharge is essential to providing continuity of care. Before patients leave the hospital, it is critical that healthcare providers talk to patients and their families and caregivers about the next steps in the transition, including determining the best transition plan for their circumstances, medications, equipment that might be needed, follow-up appointments, lifestyle or routine changes at home, as well as information about supports and resources available (Ontario Health

Quality, 2020). A well-organized discharge from hospital involves adequate attention to the needs and conditions of the older adult, respect for their expectations of older adults and their families and caregivers, comprehensive planning and coordination, as well as strong communication with healthcare providers (Zurlo & Zuliani, 2018).

Communication and care coordination are essential for the effectiveness of transitional care (Allen et al., 2020). Participants in this study reported that adequate follow-up and timely communication from healthcare providers contributed to a smooth transition from hospital to cardiac rehabilitation. Some older adults reported that comprehensive follow-up was very positive for their healthcare journey; this finding is consistent with previous literature on transitional care. In a study on patient-healthcare provider communication in relation to cardiovascular rehabilitation referral, the authors found that discussions that involved more interaction and less patient concern and worry were related to a higher rate of referrals to cardiac rehabilitation (Pourhabib et al., 2016). In a study on transitions for older adults with musculoskeletal disorders, a strong relationship between patients and healthcare providers facilitated smooth transitions to rehabilitation settings, particularly when the patient had a primary contact in the care team (McLeod et al., 2011). In the present study, older adult participants who reported adequate communication and follow-up were likely to name a healthcare provider who would be the contact person, often a nurse or their family physician. As suggested by Naylor and collaborators (2020), the provider who is the consistent point person in communication with older adults and their families has a critical role to ensure communication and a trusting relationship with healthcare providers during transitional care.

Some older adult participants in this study described difficult experiences during their transition from hospital to cardiac rehabilitation. Insufficient follow-up and communication were reported by some participants, especially upon discharge from the hospital. Some older adults indicated that timely communication with providers was insufficient and that having more specific direction after leaving the hospital would have been helpful to move forward and start their rehabilitation. Some older adults described feelings of ‘abandonment’ and ‘feeling alone’, particularly shortly after discharge and before starting their rehabilitation. This finding is consistent with previous literature that suggested difficulties communicating effectively during

transitional care and a disconnection between acute care and other healthcare settings and healthcare providers, such as primary care providers or general practitioners (Allen et al., 2020). The relevance of timely follow-up and communication with healthcare providers was also found by Kiran and colleagues (2020) in their study on patients and caregivers experiences in the transition from hospital to home.

In a recent study on transitional care from hospital to home for patients with brain injury, both patients and their caregivers reported a strong need for improved communication from healthcare providers about patients recovery before discharge from the hospital as a strategy to help patients prepare mentally and physically for the next steps in their healthcare journey (Oyesanya et al., 2021). In a study on patient experience, Ocloo and collaborators (2020) found that some patients receiving post-hip fracture or post-stroke care, reported concerns about poor and inadequate communication and information by healthcare providers. The authors contended that power dynamics and systemic constrains negatively affected the delivery of patient and family centered care. In this study, some older adults perceived poor communication and coordination between healthcare providers, for instance, between surgeons and family physicians. Lack of follow-up and communication can be related to a systemic barrier, as fewer doctors in Ontario report that they receive reliable notifications from hospitals after their patients had visits or hospitalizations, and just over a half of family doctors indicated that it takes up to four days on average to receive this notification (Health Quality Ontario, 2016a).

As presented above, the findings from this study were consistent with recent literature. While most of the literature addressing transitional care for older adults focuses on transitions for patients with hip fracture (Stolee, Elliott, Byrne, Sims-Gould, Tong, Chesworth, et al., 2019), brain injury (Oyesanya et al., 2021), and dementia (Ashbourne & Stolee, 2015), this study focused on older adults who were referred to cardiac rehabilitation after hospitalization. It should be noted that, in this study, the COVID-19 pandemic heavily affected follow-up from healthcare providers post- hospital discharge, as well as communication across healthcare settings. Public health measures and provincial restrictions could have affected the perception of some older adults who reported feelings of ‘abandonment’ or ‘isolation’.

5.2 Theme 2: Interactions with Healthcare Providers

The theme of “Interactions with healthcare providers” highlighted the importance of the quality of the relationship between older adults and their healthcare providers. The results of this study indicated that older adults who experienced more positive interactions with their providers reported receiving better care and having more opportunities to voice their concerns and to participate in decision-making. The significance of this theme is that provider’s attitudes can act as a facilitator or a barrier to participation, depending on the perceptions of older adults in relation to the interaction. The implications of this theme relate to the relevance of treating older adults with respect and to promote a positive environment where they can express their needs and be taken seriously. Healthcare providers, particularly nurses, should be encouraged to guide older adults during the care transition and empower them to participate actively in the decision-making process, while carefully monitoring older adults’ psychological and emotional health.

In the literature, open communication between patients and healthcare providers has been considered essential to build trusting relationships and to understand the values, beliefs, feelings and wishes of patients and families (Skolnik & Butler, 2014). Facilitating strong relationships between providers and patients requires the active engagement of patients and their families, emotional support and the provision of tailored health information (Jenerette & Mayer, 2016). In the present study, in line with previous literature, having good relationships between older adults and healthcare providers, particularly nurses, during their healthcare journey facilitated a smooth transition from hospital to cardiac rehabilitation, and promoted spaces for participation in the decision-making process.

Getting to know older adults and their families is an important step to build trusting relationships between healthcare providers and older adults (Olsen et al., 2021). In a study on the experiences of older adults transitioning from hospital to home, Allen and collaborators (2018) found that caring relationships with healthcare providers were essential to foster patients independence during their transition. The importance of supporting relationships between healthcare providers, patients and families was also reported by Stolee and colleagues (2019). The authors found themes related to trust and respect, and family members who interacted with healthcare provider

who inspired trust were more likely to ask questions, to take advice and to be involved in the decision-making.

In the present study, older adults reported that nurses were particularly helpful and an important source of support, this finding highlights that nurses are key for promoting patient participation and ensure a smooth transition after discharge from acute care (Backman et al., 2018; Moyer & McGillen, 2018). The pre- and post- operative period of a cardiac surgery is a very complex transition for older adults and their families, the potential of nurses to improve patient function and quality of life, and to support transitions for patients with cardiovascular disease should not be overlooked (Coskun & Duygulu, 2021). Nurses spend more time with patients and their families, are able to connect with them, know their goals, plans and preferences, and their competency in patient-centered care is a relevant factor that can influence patient participation (Hwang et al., 2019; Oxelmark et al., 2018).

For some older adult participants in the present study, interactions with healthcare providers during their healthcare journey were not reported as positive. From the perspective of older adults, some healthcare providers exhibited dismissive attitudes and lack of interest in patients, especially when patients sought medical advice or expressed concerns. This finding is consistent with previous literature that found gaps in the provision of transitional care in relation to healthcare providers' attitudes towards older adults. In a study by Lemetti and colleagues (2019) on transitional care from hospital to primary care, older adults felt that providers did not always listen to their concerns, were skeptical about patients' needs and sometimes careless when providing services. In their study on patient experience, Ocloo and collaborators (2020) also found that some patients had concerns regarding healthcare providers' behaviours such as lack of compassion, unkindness, and rudeness, that resulted in patients feeling significantly disempowered and not listened to.

This negative perception of healthcare providers' attitudes can be related to systemic constraints or communication barriers. In the literature, the perceptions of providers and patients of the medical encounter have been found to be different from each other (Kenny et al., 2010). In addition, time constraints and lack of interest from healthcare providers can be a significant

barrier to enacting person-centered care (Moore et al., 2017). Some authors have found that older adults who are hospitalized have expressed concerns about poor quality of communication with their healthcare providers and overall low expectations of positive interactions (Naylor et al., 2013). Negative experiences in terms of relationships with healthcare providers have a significant impact on care coordination and transitional care, especially when several healthcare providers are involved, and older adults have difficulties identifying them and trusting them (Allen et al., 2018).

Older adults who received transitional care after hospitalization might not be discharged after a full psychological and physical recovery (Zurlo & Zuliani, 2018). The results of the present study suggested that some older adults perceived a significant gap in the provision of psychological services and in some cases, lack of acknowledgement from healthcare providers regarding their mental health. From the perspective of healthcare providers, despite numerous efforts to screen patients for mental health conditions, sometimes patients do not exhibit symptoms at the time of the screening. For older adults living with cardiovascular disease, the prevalence of mental health conditions is higher compared to other age groups (Schopfer & Forman, 2016), particularly depression and anxiety (Peterson, 2020). As outlined by Sever and colleagues (2020), characteristics of patients who have a new onset of depressive symptoms can influence the depression outcome after cardiac rehabilitation. These characteristics include comorbidities such as angina, diabetes, stroke, chronic back problems, increased weight, high anxiety scores and physical inactivity. The finding of the present study suggested that older adults who had a cardiovascular event that resulted in hospitalization have a strong need for mental health supports. Given that the COVID-19 pandemic has exacerbated feelings of vulnerability, anxiety and helplessness for people living with cardiovascular disease (O'Neil et al., 2020), the relevance of mental health supports for older adults during transitional care from hospital to cardiac rehabilitation should not be overlooked.

In line with the current body of literature on patient-provider relationships, the findings of this study suggest that older adults who had an acute cardiovascular event are emotionally vulnerable and in need of mental health support as they transition from hospital to cardiac rehabilitation. Even though the pandemic exacerbated feelings of vulnerability and anxiety for some older

adults, healthcare providers should be encouraged to ensure that adequate supports are provided. While there are not many studies addressing effects of the COVID-19 pandemic on transitional care for older adults living with cardiovascular disease, the present study contributes to an in-depth understanding of the needs of this population during a very vulnerable time.

5.3 Theme 3: Support from Family Members

Theme 3, titled “Support from Family Members”, underscored the importance families for the quality of the transitional care process and for the active participation of older adults in their care. The significance of this theme is that families play a central role as care partners for older adults and they can contribute to a smooth transition, as well as to a more active engagement in rehabilitation activities. Families were found to be a major facilitator for the participation of older adults in their care, particularly by motivating older adults during their recovery process and by encouraging them to adhere to lifestyle changes. Families not only provided practical and emotional support, but actively participated in the decision-making together with older adults. The implications of this theme are that family members, particularly older children and spouses/partners are key for empowering older adults to partner with providers, ask questions and engage in shared decision-making.

In the literature, the relevance of family member involvement in the transitional care of older adults has been historically recognized, including participation in medical visits and decision-making, as well as helping older adults navigate multiple healthcare settings and providers (Cypress, 2012; Gitlin & Wolff, 2011). Families play a central role as care partners for older adults (McNeil et al., 2016). In this study, older adult participants reported that family members had a central role during transitional care from hospital to rehabilitation, providing emotional and practical support, as well as facilitating engagement in rehabilitation activities and actively participating in the decision-making. This finding is consistent with the literature; older adults usually involve their family member or a companion in decision-making. Family members can be very active and engaged in communication behaviours, often facilitating the understanding of medical information and decision-making (Wolff et al., 2017), as well as supporting engagement in physical activity and other cardiac rehabilitation activities (Birtwistle et al., 2021). Some

authors have found that patients who live alone and have no family support after discharge can experience more difficulties than people who live with family (Kiran et al., 2020). In the present study, 14 older adults lived with family, and only one older adult lived alone. However, the participant living alone did not consider living alone as a major barrier after discharge from hospital.

In their study on family-assisted therapy, Lawler and colleagues (2019) found that engaging families and patients in a meaningful way could facilitate rehabilitation for older adults who transition from hospital to the community. This theme was also found in a study by Stolee and colleagues (2019) on post-acute transitions of older adults with hip fracture. The authors contended that families are consistently moving through the healthcare system with the patient, therefore, they play a very important role for the transitional care of older adults. In the study by Allen and collaborators (2018), older adults transitioning from hospital to home emphasized that supportive relationships with family members, friends and neighbours facilitated their recovery at home after hospital discharge. The authors found that older adults, similarly to the participants in this study, relied on their family and friends for practical support, personal care, self-management, transportation and safety after discharge.

5.4 Theme 4: Information about Medical Care and Rehabilitation

The theme of “Information about medical care and rehabilitation” emphasized the importance of the quality of the information about medical care and rehabilitation, more specifically, information about what to expect after cardiac surgery and how to engage in cardiac rehabilitation. The significance of this theme is that receiving and understanding information is critical for older adults across their healthcare journey. Older adults encounter several challenges while seeking medical information, particularly if multiple providers are involved in their care. Additionally, receiving information deemed too complex, confusing or overwhelming impacted the perceptions of older adults regarding the quality of their care. The implications of this theme are that the way older adults engage with written and online resources can facilitate or hinder their participation in decision-making, as well as their adherence to rehabilitation activities.

In line with the literature on transitional care, an adequate and holistic provision of information upon discharge is crucial (Dolu et al., 2020). In the present study, some older adults reported that easy and clear information was very important for the transition from hospital to cardiac rehabilitation. Understanding instructions, both written and verbal, concerning their medical care, follow-up appointments, and self-care and rehabilitation activities were related to a positive experience. Information that was deemed as easy and clear by the participant was related to a positive experience with healthcare providers both at the hospital and health care providers from the cardiac rehabilitation team. This finding is consistent with previous studies on transitional care that found information sharing as an essential aspect to ensure a smooth transition (Stolee et al., 2019).

Providing tailored information and meeting health literacy needs supports relationship building for older adults and healthcare providers (Brooks et al., 2017). In the present study, detailed and tailored information contributed to a more positive experience for older adult participants. It should be noted that most participants were very highly educated and two of them reported having a health sciences/medical degree. High education could have impacted the perceptions of some older adults regarding how easy and clear the information was. In addition, older adults with higher education and more experience using the internet could have encountered less barriers to access information and resources online.

Some older adult participants in this study reported that difficult and insufficient information was a challenge during their transition from hospital to cardiac rehabilitation. Information was considered often insufficient, not tailored to older adults' specific needs or too overwhelming, especially in terms of long written documents. This result is consistent with the study by Rustad and collaborators (2016), in which participants reported insecurity in relation to written documents and information given to them upon discharge, expressing that information was difficult to understand. In the present study, older adults perceived that written documents were too long. In addition, some older adults reported that information about their specific conditions (e.g., arthritis), was not available in the documents, further exacerbating confusion.

The relevance of information for older people transitioning from hospital to home was also found by Allen and colleagues (2018). The authors found that most older adults sought information about their medical diagnoses, treatment and medications; however, this information was not always shared by healthcare providers during hospitalization. Moreover, information seeking was more difficult when numerous providers were involved in the care of older adults. In a study by Oyesanya and collaborators (2021) on transitional care for people with brain injury, insufficient detailed and clear information, such as discharge specific instructions, was also reported as a significant barrier for patients and their families. In the present study, older adult participants have access to very comprehensive documents and resources; however, there is a gap in terms of how older adults interact with the material. When enrolled in cardiac rehabilitation, patients are required to engage in multiple rehabilitation activities and lifestyle changes, including exercise and diet, that might be perceived as too overwhelming for older adults recently discharged. As some authors suggest, there might be an intention-behaviour gap playing an important role in the rehabilitation of older adults, and healthcare providers can potentially help address this barriers (Williamson et al., 2020). The results of the present study suggested that helping older adults engage with the written material and online resources could be beneficial to bridge the information seeking gap.

5.5 Theme 5: Decision-Making and Participation

Theme 5, titled “Decision-making and participation” showed that shared decision-making is an important component of the transitional care process for older adults and their families. Engaging older adults and their families in a meaningful discussion about their care goals, their values and needs is critical to facilitate the transition from hospital to cardiac rehabilitation. The significance of this theme is that taking the time to learn about their older adults and their unique circumstances can help older adults feel heard during the medical encounter, resulting in opportunities for empowerment and active participation. However, healthcare providers should be also mindful of older adults’ preference in terms of the level of engagement they are comfortable with, and external factors that might impact those preferences, such as the cognitive and physical status of the hospitalized patient, as well as age-related factors that can hinder older adults’ participation (e.g., vision problems, hearing difficulties, etc.). The implications of this

theme are related to the relevance of promoting the participation of older adults in the decision-making to the level that they are comfortable with. Recognizing that older adults have their own personal goals and unique circumstances and empowering them to voice their concerns can facilitate an open discussion and a more active involvement of older adults in their care.

This theme is consistent with the body of literature that has established the importance of collaboration between patients and their healthcare providers in shared decision-making to improve adherence to treatments and to facilitate patient participation (Naylor et al., 2013). In this study, some older adults reported that decision-making often involved their healthcare providers and their family members. Shared decision-making was reported as the preferred method to make decisions about medical care and rehabilitation. Shared-decision making as an important component of transitional care from hospital to home was also reported by Kiran and colleagues (2020), who conducted a study with patients in Ontario. From the perspective of healthcare providers, promoting patient participation involves asking the patient about what matters to them and learn about the patient unique circumstances and goals. The relevance of engaging patients and their families during transitional care was also reported by Allen and collaborators (2020). The authors found that healthcare providers used discussion, questioning and patient engagement as strategies to support communication and coordinate transitional care.

Engaging patients and their families in their care is an essential component of effective and comprehensive transitional care; this component involves identifying the perspectives, needs and capabilities of patients and engaging them in decision-making while fostering respectful and trusting relationships (Naylor et al., 2017). However, sometimes opportunities for the active participation of patients, particularly older adults, are missing. In the present study, some older adults expressed concerns regarding opportunities to express their needs, experiences and preferences. Barriers for optimal participation were often related to lack of spaces for participation or timely opportunities for older adults to voice their concerns, as well as insufficient one-on-one sessions with healthcare providers. This finding is consistent with previous literature. In their study on patient experience, Ocloo and colleagues (2020) found that time pressures can impact patient agency in terms of participation in their care. Additionally, some patients reported lack of opportunities to ask questions. The authors suggested that, due to

structural problem and power relations, patient empowerment has not always translated into the experiences of patients.

As outlined by Petriwskyj and colleagues (2014), missed opportunities for patient participation in healthcare contexts can be related to several patient aspects, including individual behaviours and beliefs, confidence and comfort expressing views. Healthcare provider factors that impact patient engagement include a positive, responsive and caring attitude, respect for autonomy, flexibility, and level of experience, knowledge and skills. Other factors outlined by the authors were related to verbal and nonverbal communication, building trusting relationships and the active involvement of families. The findings of the present study suggested that there is gap in patient engagement during transitional care, especially in relation to the care of older adults who transition to cardiac rehabilitation. This finding also highlights the need for responsiveness in the care of older adults living with cardiovascular disease. Healthcare providers' responsiveness when interacting with patients is critical, specifically by respecting autonomy, being flexible and adapting to the needs and expectations of their patients (Bridges et al., 2019).

It should be noted that, regardless of the need for providers to be responsive and to actively engage in their care, active patient participation in hospitals is difficult to achieve as many barriers can affect interactions between patients and healthcare providers. Some of these barriers relate to the severity of the illness, and the complexities of critical care (e.g., coma, sedation, ICU stay), the patient cognitive state as affected by drugs to varying degrees, and mechanical barriers such as intubation (Falk et al., 2019). Despite potential systemic barriers, the results of this study suggest that there are insufficient opportunities for meaningful participation and engagement of older adults in transitional care. This finding aligns with previous literature that has highlighted the relevance of supporting older adults in their families during a transition, considering their perspectives and preferred level of engagement and helping them to safely navigate the healthcare system (Backman et al., 2018).

In the present study, age was considered a factor that impacted the participation of older adults, particularly in the cardiac rehabilitation program. The prevalent risk of adverse healthcare outcomes after discharge from hospital for older adults, as well as advance age as a significant

factor that can contribute to patient complexity in transitional care is well established in the literature (Lenaghan, 2019; Stolee, Elliott, Byrne, Sims-Gould, Tong, Chesworth, et al., 2019). Older adults often present multiple chronic conditions and higher levels of complexity than other age groups, therefore, they can be more vulnerable during transitions (Backman et al., 2018). In the present study, age itself was considered a relevant factor by healthcare providers, particularly related to barriers such as hearing difficulties, poor vision, medication tolerance, level of comfort while using technology, presence of co-morbidities and polypharmacy, health literacy level and cognitive decline.

This finding is consistent with the literature that underscores the impact of age-related factors in transitional care such as functional status, adverse drug reactions, limited health literacy, multi-morbidity, polypharmacy, malnutrition, etc. (Arbaje et al., 2014). Even though older adult participants in this study were highly educated, and two of them reported having a health-related degree, the complexities related to advanced age should not be overlooked. For instance, some older adults may present a combination of both cognitive and sensory impairments, and the prevalence is higher with increased age (Guthrie et al., 2018), in addition, older adults are more likely to present a combination of visual impairment and hearing loss (Ravenscroft, 2019). Besides functional status and physical barriers, challenges for the meaningful participation of older adults in their care might also be related to personal factors such as individual preferences, and personal ability to handle involvement, information and decisions (Bastiaens et al., 2007).

Preferences for level of participation in their care can be different for older adults, in particular in relation to taking a non-participative stance and low levels of involvement in decisions about their care or discharge (Bridges et al., 2010). In this regard, aligning decision-making styles with the patient preferred approach is also important to engage older adults in the decision-making, especially by using the appropriate decision-making tools such as conversation guides and other resources that help improve older adults' knowledge and enhance participation (Muscat et al., 2019). Also, working with older adults to identify their unique needs, expectations, values and personal preferences, as well as enhancing responsiveness from healthcare providers and the healthcare system is critical to overcome these challenges (Bridges et al., 2019).

5.6 Theme 6: Healthcare Journey during COVID-19

The theme of “Healthcare journey during COVID-19” highlighted the impact of the pandemic on older adults transitioning from hospital to cardiac rehabilitation. The COVID-19 pandemic was reported as a major barrier by older adults, particularly during hospitalization and shortly after discharge. The pandemic contributed to gaps in communication and to difficult hospitalization experiences, as well as to social isolation and delayed medical procedures. The significance of this theme is that the majority of older adult participants perceived that opportunities for in-person interactions with healthcare providers and emotional support during their transition are essential. The implications of this theme are that the emotional needs of older adults living with cardiovascular disease during the pandemic should not be overlooked, particularly their need for social connection. Some older adults found the use of virtual care and telemedicine helpful to connect with healthcare providers, especially older adults who lived in rural and remote areas. However, sometimes older adults reported were not comfortable using technology and needed support when interacting with websites and other online resources. From the perspective of healthcare providers, despite the benefits of virtual care and telemedicine, building relationships with older adults was very difficult during the pandemic, further exacerbating gaps in communication and delivery of comprehensive care for this age group.

The present study contributes to a better understanding of transitional care during the COVID-19 pandemic for older adults who had an acute cardiovascular event, particularly during the first two waves of the pandemic in Ontario. Older adult participants reported difficult experiences during hospitalization, often having to go through distressing situations alone. Feelings of isolation and fear related to COVID-19 were further exacerbated due to strict hospital policies that prevented older adults from having their spouses or other family members with them in the hospital. This finding aligns with the current literature on COVID-19 related disruptions to acute care. According to Chovanec and Howard (2021), the pandemic created new challenges for hospital settings in terms of transitional care management and discharge planning. Challenges in acute care settings included the sudden shift to virtual care, poor interprofessional communication, information and communication breakdowns, insufficient documentation and updates in terms of discharge plans and low levels of patient and family engagement. According

to the authors, gaps in communication between healthcare providers and family members were aggravated by the hospital visitor restrictions.

For older adult participants, experiencing a cardiovascular event and hospitalization during COVID-19 was reported as very stressful and difficult, sometimes described as a traumatizing experience, especially for participants who witnessed COVID-19 outbreaks in their floors or other hospitalized patients COVID-19 related deaths. For older adults living with cardiovascular disease, the risk of contracting COVID-19 and developing severe disease is higher. Therefore, hospitalization poses a higher risk of exposure and it can intensify feelings of anxiety, fear, vulnerability, helplessness and hopelessness (O'Neil et al., 2020). Additionally, restrictions for hospital visitors, fast-paced hospital environment and uncertainty at the time of discharge resulted in increased stress for older adult participants. Feelings of isolation and anxiety were further exacerbated by public health measures implemented during the pandemic. As Kemps and colleagues (2020) suggested, quarantine and isolation can escalate feelings of anxiety, anger and stress, leading to an unhealthy lifestyle that can impact patients living with cardiovascular disease. Also, isolation can lead to functional decline and vulnerability, and often creates barriers for older adults to access necessary healthcare services (Gustavson et al., 2020).

Transitional care has been impacted by the COVID-19 pandemic in terms of safe post-acute discharge. A study in the United States identified barriers for patients who were discharged after a COVID-19 related hospitalization, these barriers included housing challenges, barriers to safely quarantine upon discharge, diverse households (e.g., crowded, small, multigenerational), as well as patient and family anxiety, and financial constraints (Levin et al., 2021). It should be noted that older adult participants in the present study did not report challenges or issues related to housing challenges, financial difficulties, and barriers for quarantine, or safety concerns upon discharge. Most of them lived with their spouses in a safe environment and felt like they had enough space to isolate and to recover safely after hospitalization.

Older adult participants in this study reported that the COVID-19 pandemic was a major barrier for a smooth transition to cardiac rehabilitation. In a recent study in Singapore, Yeo and colleagues (2020) contended that the COVID-19 pandemic magnified existing barriers to cardiac

rehabilitation, and delays in exercise classes were likely to affect patient outcomes. The social distancing measures required to prevent the transmission of COVID-19 have increased the risk of poor mental and physical health for cardiac patients and the shift to virtual classes has promoted connection with other while socially distancing (Scott-Sheldon et al., 2020). However, some patients might still perceive that exercising at home is not enough. Some older adults in the present study who reported that they were affected by the closure of gyms and recreational facilities, not only missed the classes because of the exercise itself, but mostly because group classes enhanced their sense of social connectedness and helped them interact with other people who have similar experiences.

Given the COVID-19 restrictions, cardiac rehabilitation programs across Canada have implemented virtual care and telemedicine in lieu of the traditional, in-person, centre-based program (Moulson et al., 2020). Some older adult participants in the present study reported a positive experience using virtual care and telemedicine, especially those who used to encounter barriers for transportation before the pandemic, as well as those who lived in rural areas and remote locations. This finding aligns with recent literature, that suggest that the use of these technologies has the potential to help overcome barriers to transportation, lack of community-based programs and limited staffing, as well as improving access for patients living in remote and rural areas (Krishnaswami et al., 2020).

Despite the benefits of virtual care and telemedicine, there are multiple challenges for patients and healthcare providers, these issues include socioeconomic determinants, age, gender and education, digital literacy and social environment (Garg et al., 2020). Some patients might feel uncomfortable using technology or feel self-conscious when interacting on video, also, some patients might have limited access to internet and computers required to engage in a virtual visit with providers (Gorodeski et al., 2020). The use of virtual care and telemedicine can be especially challenging for older adults due to physical, cognitive or other barriers to adopt digital health technologies, resulting in underutilization of these services (Krishnaswami et al., 2020).

Some older adults in this study reported that using virtual care and telemedicine was a challenge and often perceived as a suboptimal replacement for in-person face-to-face interaction with their

healthcare providers. Healthcare provider participants also reported that, despite the benefits of this approach, establishing relationships with their patients was difficult when using technology, particularly when interacting with older adults. This finding is consistent with previous literature showing that patients and clinicians have both positive and negative experiences when interacting on video consultations, suggesting that virtual care is a convenient model but not superior to a face-to-face consultation (Thiyagarajan et al., 2020).

The use of telemedicine also involves use of hardware such as smartphones, blood pressure machines and exercise machines, among other various items that may potentially place an increased financial burden on patients (Tersalvi et al., 2020). In this study, older adults did not report having difficulties accessing devices for monitoring, such as blood pressure machines; however, they often reflected on how not all patients might have access to them. In addition, the use of telemedicine and virtual care also comes with challenges related to technical support and adequate internet connection, especially for low-income patients and rural communities (Smith & Raskin, 2020). Older adult participant also reported various levels of comfort with virtual care and telemedicine. As Kumar and Pina (2020) indicated, a virtual model involves heavier patient self-reliance, which can result in an added burden for older adults to self-monitor and track their rehabilitation activities.

The present study contributes to the body of literature on transitional care from hospital to cardiac rehabilitation and the participation of older adults during their healthcare journey. It should be noted that the findings of the study were heavily impacted by the COVID-19 pandemic, including public health measures and hospital policies. Despite the challenges created by the pandemic, there is still a disconnection between healthcare providers and older adults during this vulnerable time, especially shortly after discharge. As new studies addressing transitional care during the pandemic emerge, the present research contributes to a better understanding of the medical and emotional needs of older adults who had an acute cardiovascular event and transitioned from hospital to cardiac rehabilitation.

5.7 Reflexivity

In qualitative research, researchers influence data collection, selection and interpretation, as they construct meanings with participants. Therefore, it is vital that researchers use reflexivity to analyze how subjective factors impact the research process (Finlay, 2002). In line with the need to be aware of the ways in which the researcher affects both research processes and outcomes (Pellatt, 2003), this section addresses reflexivity in relation to the present study findings and how they align with the conceptual framework.

The present study findings suggested that the majority of the gaps in the participation of older adults during transitional care from hospital to cardiac rehabilitation relate to service delivery and actions taken by healthcare providers, or the lack thereof. Findings, however, should be considered in context. While the experiences that older adults shared can be transferable to other older adults living with chronic conditions or who have experienced a transition to a rehabilitation setting, the stories here presented cannot be separated from the context and the characteristics of the participant group. In addition, the influence of the COVID-19 pandemic should not be overlooked.

In terms of the conceptual framework, out of the included four factors, the findings of this research only addressed three. The factor of ‘Willingness to participate’ can be seen reflected in the data in relation to how older adults were interested in knowing more, searching information and learning, to be able to make decisions about their care. In particular, older adults expressed the need to access relevant information to engage in rehabilitation activities, as opposed to act as a passive figure. Additionally, older adults were satisfied when providers asked them questions and had meaningful conversations with them. As for the factor of ‘Caregiver/Family dynamics’, all interactions reported by older adult participants with their family members were perceived as positive. I expected to find a mix of both negative and positive experiences, not necessarily concerning abuse and neglect, but more subtle signs of a suboptimal interaction, such as a family member taking over the encounter with the provider, or a family member making all decisions on behalf of their loved one, against their wishes.

In terms of the factor of ‘Age-related changes’, only healthcare providers reported that the age of the patient was a significant factor that influenced the way patients engaged with the cardiac rehabilitation program and how they participated in their care. This factor did not appear in the data from older adult participants. The factor of ‘Ageism’ was not found in the present study, and only one healthcare participant reflected on how the oldest old are sometimes treated differently in the medical setting, especially when discussing treatment options, and how medical decisions might be different for a 55-year-old and a 90-year-old. I expected experiences of ageism to be more prevalent among older adult participants, especially older adults over the age of 80. I also expected the intersection of age and gender.

It is important to acknowledge that not all the four factors included in the conceptual framework appeared in the data presented in this study. However, other important aspects of participation and transitional care, as well as healthcare delivery during the pandemic emerged from the data and offered rich description of a very vulnerable time during a unique context of a global pandemic. Finally, I acknowledge that the experiences that my grandmother shared with me, particularly in relation to experiences of ageism and family members taking over appointments, could have influenced my interpretation of the data and my desire to explore the presence of ageism as a relevant factor in this research.

5.8 Summary

This chapter included a discussion of the study findings, aligned with the themes that emerged from the data. The results of this research are consistent with previous literature on patient participation, transitional care and the complexities of healthcare journeys during COVID-19. This chapter offered a more contextualized and comprehensive integration of relevant literature and the following themes: (1) Follow-up from Healthcare Providers, (2) Interactions with Healthcare Providers, (3) Support from Family Members, (4) Information about Medical Care and Rehabilitation, (5) Decision-making and Participation, and (6) Healthcare Journey during COVID-19.

The present research contributes to the literature on transitional care and the participation of older adults in their care during their healthcare journey from hospital to cardiac rehabilitation.

There is a need to address the emotional and medical needs of older adults, ensuring that they received adequate supports as they leave the hospital and reconnect with their communities. Clear and timely information about their medical care and post-discharge instructions are also essential. Also, involving family members in the care of older adults and promoting trusting relationships with healthcare providers can enhance shared decision-making. Chapter 6 presents the conclusions of the study, limitations and implications for the study findings, as well as recommendations for future research and clinical practice.

Chapter 6

6 Final Considerations

This chapter includes several overall implications of the study, as well as limitations. Recommendations for future research are also included, as well as recommendations for clinical practice. The last part of the chapter presents the conclusions of the present study.

6.1 Limitations

The present study has several limitations. In terms of using focused ethnography as a methodology, some key methods such as field immersion and observations were impossible to use. Cardiac rehabilitation services were offered remotely during 2020 and the first half of 2021, therefore, observing patients at the hospital or at the cardiac rehabilitation unit was not possible. Cardiac rehabilitation patients, especially older adults, are often vulnerable and at high risk of contracting COVID-19. For this reason, all interviews were conducted remotely, via Zoom or phone call. The fact that data was collected remotely could have impacted the recruitment of potential participants who did not have access to a phone or a computer, or those who are more comfortable establishing trust and rapport with researchers via face-to-face interactions.

Despite efforts to recruit a similar number of male and female participants, more men than women agreed to have an interview in the older adult group. The primary investigator (CFS) made efforts to recruit more women. However, women often refused to read the letter of information and consent. In addition, for some potential female participants, it was often a family member such as an adult child who would pick up the phone and would refuse participation. The group of older adults is mostly representative of a younger cohort; the oldest old (over 85 years old) were impossible to recruit and, similar to potential female participants, often a family member or adult child will refuse the interview. In terms of ageism, it is possible that the oldest cohort experiences more ageism than the youngest cohort, therefore, impacting perceptions of discrimination based on age. It should be noted that participants in the older adult group were highly educated and some of them had medical and health sciences degrees. Higher education could have impacted their responses and their perceptions on patient participation. Also, most

older adults reported having a very strong social support network and issues such as financial stressors or lack of housing were not reported as a concern. In terms of geographical location, the experiences of older adults living in the London area might differ from the experiences of older adults living in densely populated areas such as Toronto, or remote areas in northern Ontario.

Participants in this study had to communicate in English to read the letter of information and consent, to have the interview and to fill out the demographic forms. This impacted the recruitment of potential participants who could have been experiencing language barriers and difficulties to navigate the healthcare system. The majority of the participants in this study were white and middle to high income. Results from this study could have been different with a more diverse group of older adults, including individuals from different cultural and linguistic backgrounds, diverse gender identification, low income and other intersectional identifies.

The recruitment of healthcare providers was heavily impacted by the second and third wave of COVID-19 in Ontario. Some healthcare providers agreed to participate initially and changed their minds later, often in line with the spikes in COVID-19 cases in London and the increasing numbers of people in hospital that required their immediate attention. In addition, the number of healthcare providers who care for older adults who transition from hospital to cardiac rehabilitation in London is not very large, therefore, the pool for recruitment was smaller than expected.

The personal identity of the primary investigator (CFS) could have also impacted recruitment and the interpretation of the findings. For instance, participants could have felt uncomfortable having an interview with a student instead of a healthcare provider. In addition, some older adults did not understand what a PhD degree was, the reason the research project was being conducted or what the research project involved. Despite efforts to make the information as accessible and simple as possible, lack of trust was present in some instances and several older adults refused participation. Being a young woman could have also impacted the interactions of the primary investigator (CFS) with participants.

6.2 Implications

This research study used focused ethnography to explore the perspectives of older adults and healthcare providers on patient participation in transitional care from hospital to cardiac rehabilitation. While many participants reported very positive experiences, the findings of this study indicated a number of gaps in the provision of transitional care services for older adults who had a cardiovascular event. Most of the reported gaps in care were reported to occur in the first few weeks post hospital discharge, a time that older adults described as vulnerable and lonely, with little to no support from healthcare providers. This information can potentially inform interventions aimed to improve care for older adults who were recently discharged after cardiac surgery. In addition, the perspectives of older adult participants can highlight current issues related to navigating of the health care system after an acute cardiovascular event and hospitalization.

The positive experiences reported by older adult participants can be used to help gain a better understanding about what strategies have been effective in transitional care services, from hospital and cardiac rehabilitation and beyond. Negative experiences and perceptions of abandonment can contribute to meaningful conversations about what is missing in the provision of services, and what can be done to provide more comprehensive follow-up to vulnerable older adults and make sure their emotional needs are met. Despite the fact that COVID-19 heavily influenced their experiences, older adults deserve to be heard and their concerns must be taken seriously, in hopes to improve the provision of health care services for older adults and their families, as well as to promote more opportunities for active participation and decision-making.

6.3 Recommendations for Future Research

The results of this study indicated that adequate follow-up post hospitalization, positive interactions with healthcare providers, timely information and meaningful support from family members have been reported to contribute to a smooth transition from hospital to cardiac rehabilitation. However, a few gaps in the provision of services remain. Particularly, attention to the emotional needs of older adults and the need for more follow-up after hospital discharge.

Future research should focus on the emotional component, especially for adults living with cardiovascular disease, or who recently had cardiac surgery.

The older adult group in this research was highly educated and reported having a strong social support network. Future research should focus on other groups of older adults who might have lower education level and health literacy needs. The present study did not consider aspects such as income, race, ethnicity, housing and other socioeconomic factors that might shape the participation of older adults in their care, as well as their healthcare journey after a cardiovascular event. Future research should address health equity and accessibility for diverse groups of older adults who transition from hospital to cardiac rehabilitation, as well as expanding on the role of gender, age, race and socioeconomic situation.

Patients who have pre-existing cardiovascular disease have an increased risk of contracting COVID-19 and a higher risk of severe disease and outcome (Vigorito et al., 2020). In this regard, cardiac rehabilitation services might be needed for a large number of patients who had a COVID-19 infection, adding an extra layer of complexity to an already complex population. In terms of virtual care and telemedicine, future research has the potential to explore outcomes for older adults who engage in remote cardiac rehabilitation, as well as gaps related to access to internet, and technology use among older adults.

Hearing the voices of older adults and learning what is important to them is critical to ensure a smooth care transition. Conversations that uncover what is important to patients can facilitate a person-centered and family-centered approach, particularly by establishing an empathetic relationship, understanding the unique context of the patient and making time and space for questions (NHS, 2019). Some older adult participants reported positive experiences with healthcare providers who listened to their concerns and learned about their preferences, unique circumstances and health conditions. Future research can help address strategies to appropriately identify and respond to the emotions of older adults in a non-judgemental environment.

Future research should also focus on the importance of patient experience as evidence in healthcare decision-making, as well as on the active involvement of patient groups and families

in decisions related to health services and healthcare priority settings (Rand et al., 2019). In addition, future research should consider the patient experience as key for quality improvement, in particular the experiences of older adults who felt abandoned by the system, alone and vulnerable after hospital discharge, and those who perceived suboptimal care.

6.4 Recommendations for Clinical Practice

The results of this study can contribute to a meaningful conversation about what supports are potentially missing for older adults during their healthcare journeys, and their transition from hospital to cardiac rehabilitation. Some older adult participants reported that they did not receive enough follow-up after hospitalization, including some key pieces of information regarding their unique circumstances (e.g., living with arthritis, anemia) and next steps to engage in rehabilitation activities. Some older adults also perceived that healthcare providers did not know their whole history and that often their care was not personalized enough. In terms of information, some older adults found the online documents very long and difficult to read, therefore, there is an opportunity to re-evaluate how older adults engage with the material and what strategies can be implemented to make it more accessible and easier to read.

Given that all hospitalizations in this study occurred during the COVID-19 pandemic, rushed discharges and gaps in the provision of comprehensive follow-up and lack of face-to-face interactions are expected to some extent. However, healthcare providers should be encouraged to pay attention to the emotional needs of older adults who are discharged after surgery. For instance, ensuring that the patient knows who they are communicating with and who their doctors and nurses are. In this study, some older adults reported that they did not know their surgeons, and those who received care from an interprofessional team reported that they had difficulties identifying the members of the team. Giving special attention to introductions at the bedside can potentially help older adults identify their healthcare providers and to build stronger relationships with them, especially during vulnerable times such as hospitalization.

Motivating and empowering older adults to work together with their healthcare providers and to actively participate in their care is critical to ensure better outcomes for patients (Robert Wood

Johnson Foundation, 2014). Contact during the first few weeks after discharge was missing, as reported by some older adult participants, resulting in feelings of abandonment and vulnerability. Ensuring that healthcare providers have the resources and tools to offer patient-centered care at the hospital and upon discharge, as well as careful consideration of the patient experience can help improve care delivery for older adults (Baker, 2014) and promote a smooth transition from hospital to rehabilitation settings or to the community.

Applying the principles of inclusive patient engagement can be a fruitful strategy to provide more comprehensive transitional care for older adults and to ensure that older adults have adequate spaces and opportunities for meaningful participation in decision-making. For instance, focusing on relationship building for older adults and their healthcare providers, through the development of trust, self-awareness, acceptance, understanding, education and communication (Canadian Foundation for Healthcare Improvement, 2020). Even though these principles are presented in the context of engagement in research initiatives, focusing on relationship building, as well as incorporating reflexivity and considering the impact of intersectional identities can be beneficial for older adults receiving transitional care.

6.5 Conclusion

This study offers an in-depth understanding of the perspectives of older adults and health providers on patient participation in transitional care from hospital to cardiac rehabilitation. Older adults who transition from hospital to cardiac rehabilitation settings are often at risk of adverse healthcare outcomes such as poor communication, lack of follow-up and inadequate discharge instructions. For some older adults in this study, timely follow-up was sometimes insufficient, revealing gaps in terms of communication with healthcare providers. Interactions with healthcare providers were mostly reported as positive and supportive; however, some older adults reported dismissive attitudes and suboptimal interactions.

Support from providers was critical for a smooth transition, particularly nurses' support. Support from family members was also considered important for participation and a smooth transitional care process. Information about medical care and rehabilitation was often perceived as adequate

and sufficient, but some older adults reported that information was difficult and overwhelming at times. In terms of decision-making, shared decision-making was reported as the preferred method for the majority of older adult participants. Some barriers for decision-making included lack of spaces or opportunities for decision-making, as well as the age of the patient, as perceived by healthcare providers.

For most older adult participants, the COVID-19 pandemic was a major barrier, particularly in relation to delayed medical procedures, difficult experiences in hospital and insufficient direction when discharged. In terms of the use of virtual care and telemedicine, some older adults who sought social connectedness and emotional support reported that the use of technology had impacted them and their rehabilitation goals. For older adult participants who lived in remote areas or had transportation barriers, virtual care and telemedicine helped facilitate their engagement with rehabilitation activities and contributed to better communication with healthcare providers.

Limitations of this study included the lack of representation of female participants and the oldest cohort in the group of older adult participants, as well as lack of older adult participants from diverse cultural and linguistic backgrounds. Lack of representation of participants from different economic classes and housing situations was also a limitation, as well as the presence of other intersectional inequalities that could have impacted the results of this study. In addition, the current study was conducted during the first and second wave of COVID-19 in Ontario, resulting in difficulties recruiting healthcare providers.

The findings of the present study suggested that older adults who experience a transition from hospital to cardiac rehabilitation need to have adequate spaces and opportunities to participate in decision-making. Healthcare providers should be encouraged to identify and respond to the emotional needs of older adults living with cardiovascular disease, especially those transitioning from hospital to cardiac rehabilitation. Older adults living with cardiovascular disease have unique ways of understanding the transitional care process and their active participation in decision-making. This study highlighted the need for personalized care for older adults and the critical aspect of emotional support, attention to mental health and relationship building with

providers during the transitional care process. Addressing the emotional needs of older adults after cardiac surgery, as well as providing timely follow-up, adequate communication and clear discharge information can be a fruitful strategy to improve the transitional care process for this population. In addition, offering more spaces and opportunities for the active participation of older adults in their care can contribute to the delivery of comprehensive, patient and family-centered care for older adults who live with cardiovascular disease.

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04. Transitions

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Appendix A



TELEPHONE SCRIPT FOR OLDER ADULTS

Good morning/afternoon. May I speak with [participant's name]?

My name is Cecilia, I am a PhD student working with Professor Shannon Sibbald from Western University. We are conducting a study on patient participation when they transition from the hospital to cardiac rehabilitation.

The study is called: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation. I am calling you because you have heard about this study in your circle of care and have indicated that you agree to be contacted about research.

Do you have approximately 10 minutes to talk about the study?

If no: Thank you very much for your time. Have a good day. [Phone call ends]

If yes: Thank you. I will explain the study.

Background and purpose

This study aims to understand older adults and their health care providers' perspectives on participation. Including challenges that they might encounter and things that make it easier for them to express their opinions and views. When older adults move from the hospital to other settings, sometimes their opinions and ideas can be overlooked. It is very important that they have the opportunity to participate in the decision-making process, at a level they are comfortable with. Exploring older adults' unique perspectives on participation can lead to a better understanding of their experiences and needs when they transition from hospital to rehabilitation. This study aims to make recommendations and to promote better opportunities for older adults to be active participants in decision-making.

Participation

This study will be done remotely, all data collection will be done virtually, and no face-to-face contact will be required. Participation in this study involves filling out a demographic information form and to have a semi-structured interview (approximately 30 to 60 minutes) about your perspectives on patient

participation. You will be asked your perspectives on your participation in decision-making after you left the hospital and started receiving care at cardiac rehabilitation. You will be asked to share your thoughts on how services can be improved for older adults and how opportunities for participation can be fostered. Interviews can be done using a connection of your preference, these include telephone, Western Zoom or Lawson WebEx. The interview will happen at a time that is convenient for you. Demographic forms can be completed using a connection of your preference, these include telephone, Western Zoom or Lawson WebEx. It takes approximately 3 to 5 minutes to complete the demographic form. You can also request a Unique Qualtrics Link.

Would you be interested in reading the letter of information and consent?

How would you like to receive the letter of information and consent?

Unique Personal Qualtrics Link

Note: If you decide to give consent via Qualtrics, we ask you to keep a copy for your records. Once the researcher has signed the consent form, we will provide you with a copy.

Private Mail

Note: Please note that if you choose to receive the letter of information and consent via private mail, we will need to obtain your permission to be contacted via mail. We will send the letter of information and consent to the address you provide.

Note on Verbal Consent:

Given that we are working remotely, and offices are not open to receive mail. If you choose to receive the letter of information and consent via mail, we will ask you to provide verbal consent via phone. Verbal consent will be documented and recorded by the PhD student. The PhD student will go through the letter of information and consent with you first, before asking for your consent.

Do you have any questions?

Thank you for your time.



TELEPHONE SCRIPT FOR HEALTH CARE PROVIDERS

Good morning/afternoon. May I speak with [participant's name]?

My name is Cecilia, I am a PhD student working with Professor Shannon Sibbald from Western University. We are conducting a study on patient participation when they transition from the hospital to cardiac rehabilitation. I am calling you because you have provided your contact information and you have indicated that you are interested in learning more about our study.

The study is called: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

Do you have approximately 10 minutes to talk about the study?

If no: Thank you very much for your time. Have a good day. [Phone call ends]

If yes: Thank you. I will explain the study.

Background and purpose

This study aims to understand older adults and their health care providers perspectives on participation. Including challenges and facilitators related to the unique needs of older adults. When older adults transition from hospital to other healthcare settings, they can be at risk of adverse outcomes, including poor communication, medication adherence issues, etc. It is very important to engage older adults in their care and to promote opportunities for their participation in decision-making. Exploring older adults' unique perspectives on participation can lead to an in-depth understanding of their experiences and needs when they transition from hospital to rehabilitation. This study aims to make recommendations and to promote better opportunities for older adults to be active participants in decision-making.

Participation

This study will be done remotely, all data collection will be done virtually, and no face-to-face contact will be required. Participation in this study involves filling out a demographic information form and to have a semi-structured interview (approximately 30 to 60 minutes) about your perspectives on patient participation. The demographic form can be completed via phone call, Western Zoom, Lawson approved WebEx or via phone call. You can also request to receive a unique personal Qualtrics Link and complete the form online. In the interview, you will be asked about how do you enact participation among older adults in your clinical practice, challenges and facilitators that might impact participation, as well as older adults' specific needs and complexities. Interviews can be done using a connection of your preference, these include telephone, Western Zoom or Lawson WebEx. The interview will happen at a time that is convenient for you.

Would you be interested in reading the letter of information and consent?

How would you like to receive the letter of information and consent?

Unique Personal Qualtrics Link

Note: If you decide to give consent via Qualtrics, we ask you to keep a copy for your records. Once the researcher has signed the consent form, we will provide you with a copy.

Private Mail

Note: Please note that if you choose to receive the letter of information and consent via private mail, we will need to obtain your permission to be contacted via mail. We will send the letter of information and consent to the address you provide.

Note on Verbal Consent:

Given that we are working remotely, and offices are not open to receive mail. If you choose to receive the letter of information and consent via mail. We will ask you to provide verbal consent via phone. Verbal consent will be documented and recorded by the PhD student. The PhD student will go through the letter of information and consent with you first, before asking for your consent.

Do you have any questions?

Thank you for your time.

Appendix B



LETTER OF INFORMATION AND CONSENT FOR OLDER ADULT PARTICIPANTS

Study Title: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

Principal Investigators:

Professor Shannon Sibbald [email]

Co-investigator:

Professor J.B Orange [email]

PhD Student Researcher:

Cecilia Flores-Sandoval [email]

Introduction

You are invited to participate in this research study about the perspectives of older adults and health care providers on the participation of older adults in decision making during the move from hospital to cardiac rehabilitation. You are invited to participate because you are an older adult who receives care at cardiac rehabilitation after hospitalization.

Background and Purpose

Older adults who move from the hospital to other healthcare settings can experience negative outcomes, such as communication breakdowns and lack of support. It is important to include older adults' perspectives and views when making decisions in a clinical setting. Identifying challenges and opportunities for participation can be important to understand better the needs of older adults and to inform healthcare providers about how to better support them through a decision-making process.

This study aims to make recommendations to improve health services for older adults who move from hospital to cardiac rehabilitation.

Study Design

Focused ethnography will be used to understand the perspectives of both older adults and health care providers regarding participation when a patient moves from the hospital to cardiac rehabilitation. The study involves semi-structured interviews that will be done remotely. The purpose of the interviews is to understand better the participants' perceptions and views on patient participation in decision-making.

We will recruit approximately 14 older adults and 8 health care providers.

Study Procedures

All study procedures will be done remotely, no face-to-face contact will be required. Your participation in this study is required only on one occasion.

If you decide to participate you will be asked to complete a demographic information form that can be completed in approximately 3 to 5 minutes. In the demographic information we will ask you to provide the following data:

- Age
- Gender
- Education level
- Marital Status

In the demographic form you will also find questions related to your caregiver (if applicable), your hospital stay, your language preferences, your vision and hearing (if applicable), etc. These questions will help the researchers to know your preferences and experiences better and accommodate for your needs if you decide to participate in the study.

The demographic information form can be completed using a connection of your preference (phone call, via Western Zoom or Lawson approved WebEx). You can also request to receive a unique personal link to Qualtrics and fill out the form online.

You will also be asked to participate in an interview lasting approximately 30 to 60 minutes using a common connection of your preference (e.g., Western approved Zoom, Lawson approved WebEx, or via phone call). You will be asked questions about the time when you left the hospital and started receiving care at cardiac rehabilitation. During this interview you will be asked to share your experiences with providers and caregivers, your perspectives on your participation in the decision-making process, your opinions on what can be done better, how can healthcare for older adults in your situation can be improved, etc.

As an optional part of the study, you will be asked if you would like to verify that the researchers' interpretation of the information that you provided is correct and accurately represents your ideas. This should not take more than approximately 15 minutes. This part of the study is **OPTIONAL** and does not affect your participation in any way.

The PhD student will conduct the interviews and also transcribe them. The interview will be done using the electronic connection of your choice and will occur at a time that is convenient for you.

To facilitate data analysis, we will ask for your permission to audio record the interview. Audio recordings will only be used to analyze the data, the files will be anonymous and will not be linked participant data.

Audio recording is **OPTIONAL**. If you do not wish to be audio recorded you can still participate in this study, however, you will be required to give permission to the PhD student to actively take notes during the interview.

Voluntary participation

Your participation in this study is voluntary. Your responses will be made anonymous using pseudonyms. A pseudonym is a fake name that will be used instead of your real name, this will be done to protect your privacy.

Withdrawal from study

If you decide to withdraw from the study, you have the right to request withdrawal of information collected

about you. Please let the researchers know if you would like your information to be removed.

NOTE: Please note that a record of your participation must remain, this means that your signed letter of information and consent will not be destroyed or your name in the master list, however, all data collected (transcripts, audio recording, demographic form, notes) will be withdrawn and securely destroyed. Once the study is published, we will be unable to remove your information.

Risks

There are no known risks for participating in this study. However, with the use of any online technology there is always increased potential for data breach.

Benefits

There are no known benefits to you associated with your participation in this research study, although we anticipate that the study will help improve services for older adults in rehabilitation settings.

Confidentiality

All study data (transcripts, letters of information and consent and demographic forms) will be kept confidential and stored on an encrypted password protected folder and only the Principal investigator, the PhD student and the Co-investigator will have access to it.

All study data will be stored for 15 years per Lawson policy. After this time, all files (electronic and paper) will be securely destroyed. All electronic data will be securely stored in Western Institutional Servers. All paper data and notes will be stored in a locked secure cabinet at the Principal investigator's office at Western Campus.

Qualified and appropriate representatives of Lawson Quality Assurance Education Program and representatives of Western University and Health Sciences Research Ethics Board may look at the study records to monitor the ethical conduct of the research and to ensure that the information collected is correct and follows the appropriate laws and guidelines in accordance with the regulatory requirements for quality assurance.

Data such as name, phone number and email address will only be used to contact participants and will be kept confidential in a separate encrypted password protected file. This information will not be disclosed and will not be linked to transcripts, audio recording or demographic forms. If the results of this study are published, your name will not be used. Pseudonyms (fake names) will be used to ensure privacy.

Costs

There are no costs for participating. If you decide to participate, you are free to withdraw your consent at any moment and ask as many questions as you like.

Compensation

There is no compensation for participating in this study.

Rights as participant

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you decided not to participate or leave the study at any time, it will have no effect on your employment status.

You do not waive any legal right by consenting to this study.

Questions about the study

If you have any questions about this study, please contact the principal investigator.

Professor Shannon Sibbald

[email]

You can also contact the PhD student

Cecilia Flores-Sandoval

[email]

If you have any questions about your rights as participants or the conduct of this study, please contact The Office of Human Research Ethics [phone number and email]. The REB is a group of people who oversee the ethical conduct of research studies, the HREB is not part of the study team. Everything that you discuss will be kept confidential.

This study is affiliated with Lawson. If you have any questions about your right as a research participant or the conduct of this study, you may contact the Patient Relations Office at LHSC at ([phone number]) or access the online form at [website].

This Letter is yours to keep for future reference

CONSENT FORM

Study Title: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

I have read the Letter of Information. This study has been explained to me and I agree to participate. All questions have been answered to my satisfaction.

Contact for 'member checking' (data accuracy confirmation)

___ I agree to be contacted to confirm that the interpretation of the data is accurate

___ I DO NOT agree to be contacted to confirm that the interpretation of the data is accurate

Audio Recording

I agree to be audio recorded.

YES ___ NO ___

I consent to the use of unidentifiable quotes obtained during the study in the dissemination of this research

YES ___ NO ___

_____	_____	_____
Name of the participant	Signature	Date

My signature means that I have explained the study to the participant named above and I have answered all questions to the best of my ability.

_____	_____	_____
Name of the person obtaining consent	Signature	Date

Please keep a copy of this form



LETTER OF INFORMATION AND CONSENT FOR HEALTH CARE PROVIDERS

Study Title: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

Principal Investigator:

Professor Shannon Sibbald [email]

Co-investigator:

Professor J.B Orange [email]

PhD Student Researcher:

Cecilia Flores-Sandoval [email]

Introduction

You are invited to participate in this research study about the perspectives of older adults and health care providers on the participation of older adults in decision making during the move from hospital to cardiac rehabilitation. You are invited to participate because you are a healthcare provider that works with older adults who have been transitioned to cardiac rehabilitation.

Background and Purpose

Older adults who receive transitional care are often vulnerable and at risk to adverse health care outcomes. It is important to engage older adults in the decision-making process during their transition from hospital to another health care setting. Identifying challenges and opportunities that shape the participation of older adults in their care can be relevant to gain an in-depth understanding of their needs as they move from hospital to a rehabilitation setting. This study aims to make recommendations to improve health services for older adults who move from hospital to cardiac rehabilitation.

Study Design

Focused ethnography will be used to capture the perspectives of both health care providers and older adults regarding patient participation in transitional care from hospital to cardiac rehabilitation. The study involves semi-structured interviews that will be done remotely. The purpose of the interviews is to gain a better understanding of participants perceptions and views on patient participation in decision-making.

We will recruit approximately 14 older adults and 8 health care providers.

Study Procedures

All study procedures will be done remotely, no face-to-face contact will be required. Your participation in this study is required only on this one occasion. If you decide to participate, you will be asked to complete a demographic information form that can be completed in approximately 3 to 5 minutes. In the demographic form we will ask you to provide the following data:

- Age
- Gender

- Profession
- Specialty
- Years of experience working with older adults

The demographic information form can be completed using a connection of your preference (phone call, via Western Zoom or Lawson approved WebEx). You can also request to receive a unique personal link to Qualtrics and fill out the form online.

You will also be asked to participate in an interview lasting approximately 30 to 60 minutes, using a common electronic connection of your preference (e.g., Western approved Zoom, Lawson approved WebEx or via phone call). You will be asked questions about how to facilitate participation in decision making by older adults who have been discharged from the hospital and have been referred to a cardiac rehabilitation program. You will be asked about potential barriers and facilitators for the participation of older adults in decision making about their transition from hospital to cardiac rehabilitation.

Member checking is used in qualitative research to verify that the interpretation of the data collected is accurate and represents the ideas of the participant correctly. If you agree to be contacted for member checking, you will be asked to verify that the researcher's interpretation of your interview is correct and accurate. Member checking should not take more than approximately 15 minutes. This is **OPTIONAL** and does not affect your participation in this study in any way.

The PhD student will conduct the interviews and will also transcribe them. The interview will be done using the electronic connection of your choice and will occur at a time that is convenient for you.

To facilitate data analysis, we will ask for your permission to audio record the interview. Audio recordings will only be used to analyze the data, the files will be anonymous and will not be linked participant data.

Audio recording is **NOT MANDATORY**. If you do not wish to be audio recorded you can still participate in this study, however, you will be required to give permission to the PhD student to actively take notes during the interview.

Voluntary Participation

Your participation in this study is voluntary. Your responses will be made anonymous using pseudonyms. A pseudonym is a fake name that will be used instead of your real name, this will be done to protect your privacy.

Withdrawal from study

If you decide to withdraw from the study, you have the right to request withdrawal of information collected about you. Please let the researchers know if you would like your information to be removed.

NOTE: Please note that a record of your participation must remain, this means that your signed letter of information and consent will not be destroyed or your name in the master list, however, all data collected (transcripts, audio recording, demographic form, notes) will be withdrawn and securely destroyed. Once the study is published, we will be unable to remove your information.

Risks

There are no known risks for participating in this study. However, with the use of any online technology there is always increased potential for data breach.

Benefits

There are no known benefits to you associated with your participation in this research study, although we anticipate that the study will help improve services for older adults in rehabilitation settings.

Confidentiality

All study data (transcripts, letters of information and consent and demographic forms) will be kept confidential and stored on an encrypted password protected folder and only the Principal investigator, the PhD student and the Co-investigator will have access to it.

All study data will be stored for 15 years per Lawson policy. After this time, all files (electronic and paper) will be securely destroyed.

All electronic data will be securely stored in Western Institutional Servers. All paper data and notes will be stored in a locked secure cabinet at the Principal investigator's office at Western Campus.

Qualified and appropriate representatives of Lawson Quality Assurance Education Program and representatives of Western University and Health Sciences Research Ethics Board may look at the study records to monitor the ethical conduct of the research and to ensure that the information collected is correct and follows the appropriate laws and guidelines in accordance with the regulatory requirements for quality assurance.

Data such as name, phone number and email address will only be used to contact participants and will be kept confidential in a separate encrypted password protected file. This information will not be disclosed and will not be linked to transcripts, audio recording or demographic forms.

If the results of this study are published, your name will not be used. Pseudonyms (fake names) will be used to ensure privacy.

Costs

There are no costs for participating. If you decide to participate, you are free to withdraw your consent at any moment and ask as many questions as you like.

Compensation

There is no compensation for participating in this study.

Rights as participant

Your participation in this study is voluntary. You may decide not to be in this study. Even if you consent to participate you have the right to not answer individual questions or to withdraw from the study at any time. If you decided not to participate or leave the study at any time, it will have no effect on your employment status.

You do not waive any legal right by consenting to this study.

Questions about the study

If you have any questions about this study, please contact the principal investigator.
Professor Shannon Sibbald [email]

You can also contact the PhD student

Cecilia Flores-Sandoval [email]

If you have any questions about your rights as participants or the conduct of this study, please contact The Office of Human Research Ethics [phone number and email]. The REB is a group of people who oversee the ethical conduct of research studies, the HREB is not part of the study team. Everything that you discuss will be kept confidential.

This study is affiliated with Lawson. If you have any questions about your right as a research participant or the conduct of this study, you may contact the Patient Relations Office at LHSC at [phone number] or access the online form at [Website]

This Letter is yours to keep for future reference

CONSENT FORM

Study Title: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

I have read the Letter of Information. This study has been explained to me and I agree to participate. All questions have been answered to my satisfaction.

Contact for 'member checking' (data accuracy confirmation)

I agree to be contacted to confirm that the interpretation of the data is accurate

I DO NOT agree to be contacted to confirm that the interpretation of the data is accurate

Audio Recording

I agree to be audio recorded.

YES **NO**

I consent to the use of unidentifiable quotes obtained during the study in the dissemination of this research

YES **NO**

Name of the
participant

Signature

Date

My signature means that I have explained the study to the participant named above and I have answered all questions to the best of my ability.

Name of the

person obtaining

consent

Signature

Date

Please keep a copy of this form

Appendix C



VERBAL CONSENT SCRIPT

Title: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

[This conversation will occur after the Letter of Information and Consent has been sent via mail to the participant]

Good morning/afternoon. My I speak with [participant's name]?

My name is Cecilia, I am a PhD student working with Professor Shannon Sibbald from Western University. We are conducting a research study called: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation.

We had a phone call to talk about the study.

You have requested to receive the letter of information and consent via mail, is that correct?

We have sent the Letter of Information and Consent to the address you provided.

Did you receive the letter?

Did you read the letter of information and consent?

If no: It is very important that you read the letter of information and consent carefully. Is there any other time when I can call you?

If yes: Thank you. Do you have any questions about the letter of information and consent? Do you wish to go through the letter with me?

Now that I have answer your questions about [...] Do you have any other concerns?

[Member checking]

If you go to the last page of your letter of information and consent, there is a question about member checking. This means that the researcher will ask you to confirm the interpretation of the information you have provided to make sure it is accurate and reflects your ideas. Will take approximately 15 minutes?

Member checking is OPTIONAL, and it does not affect your participation in this study in any way.

Do you have any questions about member checking?

Do you agree to be contacted for member checking?

[Audio Recoding]

If you go to the last page of your letter of information and consent, there is a box that asks about audio recording. Audio recording is only for the purposes of analyzing the data.

Audio recording is OPTIONAL. However. If you decide not to be audio recorded, you will be asked to give me permission to take notes during the interview.

NOTE: Please note that Verbal consent needs to be recorded and documented. This information will remain confidential. Verbal consent recordings will be stored on Western Institutional Servers, in an encrypted password protected folder. Only the research team (P.I, PhD student, co-investigator) will have access to it, as well as representatives from WREB and Lawson, who ensure the ethical conduct of this research.

Do you agree to be audio recorded?

If not: Do I have your permission to take notes?

[Verbal Consent Documentation]

Before proceeding to the verbal consent. Do you have any other questions?

Do you understand the information that I have provided today?

Do you consent to participate in this study?

If no: Thank you very much for taking the time to learn about our study, have a nice day. [phone call ends]

If yes: Thank you. I have documented and recorded your consent.

To participate in this study, you will be asked to complete a brief demographic form and to have an interview. Both will be done via phone call.

- When is a good time to complete the demographic form?
- When is a good time to have the interview?

[Demographic form completion]

We had a discussion about the demographic form as part of your participation in this study. Just to confirm. Do you still agree to participate?

Is this a good time to complete the demographic form?

Thank you for agreeing to complete the demographic form. I will slowly read the questions to you on the phone. Please stop me anytime if you need me to repeat the information or clarify.

[The day of interview]

Thank you once again for agreeing to participate in this study called: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation.

We have the interview scheduled for today.

Is this time still convenient to participate in the interview?

If participant needs to reschedule: Is there any other time when you can have the interview?

Before starting the interview. Do you have any questions?

Do still wish to participate in this interview?

Thank you. Today we will have an interview to understand your perceptions on patient participation. All the information you share will be strictly confidential. You have the right to stop at any time and ask as many questions as you would like.

I will begin asking you the questions...

Appendix D



Date: 6 November 2020

To: Dr. Shannon L. Sibbald

Project ID: 116533

Study Title: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 17/Nov/2020

Date Approval Issued: 06/Nov/2020

REB Approval Expiry Date: 06/Nov/2021

Dear Dr. Shannon L. Sibbald

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

Document Name	Document Type	Document Date
Interview Guide Update August 2020	Interview Guide	10/Aug/2020
Demographic information form_ health providers Updated August 2020	Other Data Collection Instruments	10/Aug/2020
Demographic information form_ older adults Updated August 2020	Other Data Collection Instruments	10/Aug/2020
Email Script for Recruitment October 9th 2020	Email Script	09/Oct/2020
Verbal Consent - October 9th 2020	Written Consent/Assent	09/Oct/2020
Protocol - October 24th 2020	Protocol	24/Oct/2020
Telephone Script Older Adults - October 24th 2020	Telephone Script	24/Oct/2020
Telephone Script Health Care Providers - October 24th 2020 copy	Telephone Script	24/Oct/2020
Letter Information and Consent_ Healthcare Providers - October 24th 2020	Written Consent/Assent	24/Oct/2020
Letter Information and Consent_ Older Adults - October 24th 2020	Written Consent/Assent	24/Oct/2020
Links to Qualtrics Surveys October 24th 2020	Written Consent/Assent	24/Oct/2020
Qualtrics Demographic Information for Health Care Providers PDF EXPORT October 24th 2020	Other Data Collection Instruments	24/Oct/2020
Qualtrics Demographic Information For Older Adults PDF EXPORT October 24th 2020	Other Data Collection Instruments	24/Oct/2020

Documents Acknowledged:

Document Name	Document Type	Document Date
TCPS2 Tri-Council Policy Statement copy	Technology Review document	09/Oct/2020

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

Appendix E

LAWSON FINAL APPROVAL NOTICE

LAWSON APPROVAL NUMBER: R-20-557

PROJECT TITLE: Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

PRINCIPAL INVESTIGATOR: Dr. Shannon L. Sibbald

LAWSON APPROVAL DATE: 7/12/2020

ReDA ID: 10215

Overall Study Status: Active

Please be advised that the above project was reviewed by Lawson Administration and the project was approved.

“COVID-19: Please note that Lawson is continuing to review and approve research studies. However, this does not mean the study can be implemented during the COVID-19 pandemic. Principal Investigators, in consultation with their program leader or Chair/Chief, should use their judgment and consult Lawson’s research directive and guidelines to determine the appropriateness of starting the study. Compliance with hospital, Lawson, and government public health directives and participant and research team safety supersede Lawson Approval.”

Please provide your Lawson Approval Number (R#) to the appropriate contact(s) in supporting departments (eg. Lab Services, Diagnostic Imaging, etc.) to inform them that your study is starting. The Lawson Approval Number must be provided each time services are requested.



V.P. Research

Appendix F

INTERVIEW GUIDE

In line with qualitative research, these questions can be adapted/adjusted slightly when needed during the data collection and data analysis.

Questions for older adults:

Thank you for agreeing to participate in our study. I am going to ask you several questions that are grouped into topics.

My first question is related to your most recent hospitalization

1. Tell me about your experiences in the hospital.

My next set of questions is related to your transition from the hospital back to your home/place where you live normally

2. Did you feel ready to leave the hospital when you were told that you could go home? *Probe:* If not, why? If yes, why?
3. Please tell me about your experiences leaving the hospital.

My next set of questions is related to cardiac rehabilitation.

4. Please tell me about your first appointment at the cardiac rehabilitation program.
Probe: How was your first appointment booked?
5. What is the profession/specialty of your main provider (e.g., nurse/medical doctor)?
6. Did you encounter any challenges after you left the hospital and started rehabilitation?
Probe: If yes, please tell me more about the challenges. If not, why do you think that you did not have problems?
7. What do you think providers could have done better?
8. What would an 'ideal' transition in care from hospital to cardiac rehabilitation, look like for you?
9. Would you prefer to keep in contact with your hospital provider?

The next set of questions is related to the topic of 'Willingness to participate'

10. Were you encouraged and supported to talk about your concerns, personal preferences and/or experiences during your first appointment at the cardiac rehabilitation program? *Probe:* If yes, in what ways were you encouraged and supported?
11. Tell me about a decision that was made during your first appointment (e.g., prescriptions, new routines).
Probes: How was that decision made? How do you feel about this process?

The next set of questions is related to the topic of 'Caregiver/family dynamics'

12. Who went with you at your first appointment at the rehabilitation program?
Probe: How did that make you feel?
13. Who typically makes decisions for your care?
Probes: Is this how you prefer decisions to be made?
14. Does your provider ever make decisions on your behalf?
Probe: If yes, give me an example. How does that make you feel?
15. What role/roles do your caregivers or family members have during your appointments?
16. Would you prefer to talk to your provider alone?
Probe: If yes, why? If not, why not?

This next set of questions is related to the topic of 'Age-related changes'

17. When you started your rehabilitation, was the information about your medical care clear and easy to understand?
Probe: If yes, how was it clear and easy? What made it clear and easy? If not, what made it unclear and difficult?
18. Were you given any written information (e.g., pamphlet)? *Probe:* If yes, what was it? What is clear and easy to read? Was the content relevant and accurate for you?
19. What do you think can be done to make the information easier to understand, or more relevant and accurate?

The next set of questions is related to the topic of 'Ageism'

20. Did you feel respected during your first appointment? *Probe:* What kind of action or words made you feel respected (or disrespected)?
21. What can be done to make you feel more respected when decisions about your care are made?
22. How elements such as age, gender or language preferences impacted your appointment with your primary health care provider?
23. Is there anything I have not asked you about your experiences in cardiac rehabilitation since you returned home from the hospital that you wish to tell me about?

Finally, I would like to ask you two questions related to our current situation in 2020.

24. How does the Covid-19 pandemic affect any of the situations you have talked about or answers you provided?
25. How does current changes in health care delivery, such as the use of virtual care, affect any of the situations you have talked about or the answers you provided?

Questions for providers:

Thank you for agreeing to participate in our study. I am going to ask you several questions about the participation of older adults in transitional care from hospital to cardiac rehabilitation.

1. How are first appointments after hospital discharge typically booked?
2. Can you tell me about the communication with the hospital?
3. Explain how you enact 'patient participation' in your practice in terms of decision-making.
4. How does this 'patient participation' change, depending on the age of the patient?
5. What are your experiences working with older adults in your clinical practice?
Probe: In particular, what are your experiences during their first visit with you after discharge from hospital.
6. What happens when older adults cannot participate or are not willing to participate in decision making?
7. How do caregivers impact older adults' participation in their care?
8. How do family dynamics impact older adults' participation in their care?
9. What are some of the challenges in promoting participation in health care decision-making by older adults?
10. What can you tell me about the impact of age-related factors, such as poor vision or hearing problems, on decision-making?
11. Do you give written information/documents to your patients?
Probe: Tell me more about it. What is the grade level equivalent for the reading comprehension of the material?

12. How, if at all, is ageism present in this clinical practice?
Probe: Can you provide an example of this, related to first visit post-hospitalization?
13. If you had no constraints or limitations, what would an 'ideal' first appointment look like post-hospitalization for an older adult?
14. Is there anything I have not asked you that you wish to talk about?

Finally, I would like to ask you two questions related to our current situation in 2020.

15. How did Covid-19 pandemic affected any of the situations you have talked about or the answers you provided?
16. How did current changes in health care delivery, such as the use of virtual care, affected any of the situations you have talked about or the answers you provided?

Appendix G



DEMOGRAPHIC INFORMATION COLLECTION FORM FOR OLDER ADULT PARTICIPANTS

Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

1. Age:

2. Gender: Female Male Non-Binary/Neutral/Other Prefer not to say

3. Education: No formal education Elementary School Secondary School
College/University Master/PhD

4. Marital Status:

Single Married/Common-law Widow/Widower Divorced/Separated

5. Do you have a caregiver?

Spouse/Partner Adult child Grandchild Friend/Neighbor
I do not have a Caregiver Other:

6a. Date of most recent hospital discharge:

6b. How long were you in the hospital?

7a. What is the primary language you use and understand every day?

7b. What other language(s) do you use and understand?

8a. Do you have problems seeing? If yes, please describe. Are you being treated for your vision problem(s)? If so, what is the type of treatment you are receiving?

8b. Do you have problems hearing? If yes, please describe. Are you being treated for your hearing problem(s)? If so, what is the type of treatment you are receiving?

9. Do you suffer memory or other thinking related problems beyond those you consider appropriate for your age?

10. Do you suffer currently from depression or other psychiatric problems? Are you being treated for this/these problem(s)? If so, what is the type of treatment you are receiving?



DEMOGRAPHIC INFORMATION COLLECTION FORM FOR HEALTH CARE PROVIDERS

Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation

1. Age:

2. Gender: Female Male Non-Binary, Neutral, Other Prefer not to say

3. Profession:

4. Specialty:

5. Years of experience working with older adults:

<1 1 – 5 years 5 -10 years 10-15 years +15 years

Curriculum Vitae

CECILIA FLORES-SANDOVAL

EDUCATION

PhD in Health and Rehabilitation Sciences, Health and Aging Field

Western University, London, On. Canada

Thesis: “Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation”

(2017-2021)

MSc in Health and Rehabilitation Sciences, Health and Aging Field

Western University, London, On. Canada

Thesis: “Perceived patient-pharmacist communication and diabetes management: assessing medication adherence among older patients”

(2015-2017)

BA in Latin American Language and Literature

Universidad Autónoma de San Luis Potosí, San Luis Potosí, Mexico.

Major: Clinical linguistics

Thesis: “Lexical Access in Mexican Older Adults with and without hypertension”

(2010-2014)

SUMMARY OF QUALIFICATIONS

- Research experience in aging, geriatrics and gerontology education, health care teams in geriatrics, interprofessional teams, health professions education, ageism, patient participation and engagement in clinical decision-making, patient and family engagement in transitional care.
- Experience working with older adults in hospitals, primary care and long-term care. Excellent communication skills and a compassionate approach to build rapport with patients and families in clinical settings.
- Experience in both quantitative and qualitative health research. Relevant experience in academic publications, mentoring masters and undergraduate students, grant writing, academic presentations, ethics submissions and academic proposal writing.

PUBLICATIONS

Flores-Sandoval, C., & Kinsella, E. A. (2020). Overcoming ageism: critical reflexivity for gerontology practice. *Educational Gerontology*, 46(4), 1–12. <https://doi.org/10.1080/03601277.2020.1726643>

Flores-Sandoval, C., Sibbald, S., Ryan, B. L., & Orange, J. B. (2021). Healthcare teams and patient-related terminology: a review of concepts and uses. *Scandinavian Journal of Caring Sciences*, In Press, 35(1), 55-66. <https://doi.org/10.1111/scs.12843>

Flores-Sandoval, C., Sibbald, S., Ryan, B. L., & Orange, J. B. (2021). Interprofessional team-based geriatric education and training: A review of interventions in Canada. *Gerontology and Geriatrics Education*, 42(2), 178–195. <https://doi.org/10.1080/02701960.2020.1805320>

Kang, H., Flores-Sandoval, Law, B., C., Sibbald, S. (2021) Interdisciplinary Health care Evaluation Instruments: A Review of Psychometric Evidence. *Evaluation & the Health Professions*.
<https://doi.org/10.1177%2F01632787211040859>

RESEARCH AND TEACHING

Research Assistant I

Western University, London, On. Canada

Duties: provide support with ethics application, participant recruitment and data collection (surveys and interviews), preparation of manuscripts, preparation of surveys on Qualtrics and interview guides. Provide support with forum preparation with stakeholders.

(February 2021 – November 2021)

Graduate Teaching Assistant

Western University, London, On. Canada

Course: Ethics and Health

Duties: Managed course tutorials, mentored students during office hours, marked assignments and provided academic writing support.

(January 2016 - April 2016)

Research Team Member

Supervisor: Professor Shannon Sibbald. Schulich Public Health and Family Medicine.

Duties: Assisted in grant writing (CIHR/ERA/TREC), mentored undergraduate and MSc student, led seminars and group projects, collaborated in research projects, assisted with article writing and preparation of papers for publication.

(2017-present)

Peer Reviewer Experience

Research on Aging Journal

(March 2020)

Knowledge Translation Canada National Seminar Series Webinars

Co-coordinator

(January 2019 – May 2019)

RESEARCH FUNDING HISTORY

Co-investigator WeRPN 2021-2022 Academic Research Grant. Awarded.

Funding Sources: Registered Practical Nurses Association of Ontario (WeRPN)

Contributions to the project: grant proposal development, preparation of ethics applications.

EXPERIENCE IN CLINICAL SETTINGS

Academic Placements

Location: Hospital General Ignacio Morones Prieto, Department of Geriatrics. SLP, Mexico.

Duties: Provided academic and research support for health care professionals, visited patients in the geriatric unit, outpatient clinic and long-term care. Attended academic seminars on frailty, multimorbidity and palliative care. Led three different gerontology groups that promoted knowledge dissemination.

(December 2017 and May 2019)

Volunteer

Location: Parkwood Hospital, Palliative Care Unit. London, Ontario, Canada

Duties: Provided emotional support for patients and families, helped nurses and personal support workers with their daily activities, assisted patients with feeding and drinking as needed, organized clothing and medical supplies.

(August 2019 – February 2020)

CONFERENCES

Canadian Association on Gerontology

Flores-Sandoval, C., Connelly, D., Garnett, A., Smith Carrier, T., Snobelen, N., Calver, J., Salatino, S., Wilson, C. (2021, October). A scoping review of workplace factors and interventions that impact resilience in nurses and support of older adults for application in long term care homes.

(October 2021)

London Research Day

Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation.

(May 2021)

Health and Rehabilitation Sciences Graduate Research Conference, Western University

Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation.

(February 2021)

Western Research Forum

Oral presentation

Exploring the perspectives of older adults and health care providers on patient participation in transitional care from hospital to cardiac rehabilitation.

(March 2021)

Health and Rehabilitation Sciences Graduate Research Conference, Western University

Perceived patient-pharmacist communication and diabetes management: assessing medication adherence among older patients.

(February 2017)

33rd Annual Geriatric Medicine Refresher Day

Attendee
(May 2019)

The Western Conference on Science Education

Volunteer
(July 2019)

RECOGNITIONS

HRSGSS Award Certificate of achievement (February 2021)

Presented to the top PhD student who has presented a project that shows innovation in encouraging and promoting an active, healthy lifestyle for older Canadian adults that can enhance the dignity of the aging process.

CREDENTIALS

Level 1 Monarch System™, Inc. training on the Application of Motivational Interviewing and Coaching Skills in Health Behaviour Changes

The Teaching Assistant Training Program (TATP), University of Western Ontario