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Being Uncertain: Rural Living Cardiac Patients' Experience of Accessing Healthcare

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Being Uncertain: Rural Living Cardiac Patients' Experience of Seeking Healthcare

by

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A THESIS

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Abstract

Cardiovascular disease is a leading cause of morbidity and mortality worldwide and secondary prevention strategies such as physical activity, diet and weight management, stress management, emotional health, and education are necessary to reduce disease progression to heart failure. Although cardiac rehabilitation has also been demonstrated to improve quality of life and well-being, services tend to be underutilized worldwide, particularly in rural populations. Thus, Straussian Grounded Theory was used to seek a deeper understanding of the process that rural cardiac patients go through to access healthcare and cardiac rehabilitation following myocardial infarction. In-depth interviews with eleven participants were undertaken resulting in emergence of several themes. Qualitative themes that emerged included comfort with health information, relationship with healthcare providers, social support, taking ownership, and availability of/for cardiac rehabilitation. These events occurred throughout a linear timeline progressing from hospital discharge to maintaining health. The core category of 'being uncertain' refers to the process rural cardiac participants will go through while accessing care after their myocardial infarction. Gaining an understanding of the process rural patient go through to access care after their myocardial infarction will assist in identifying ways to improve access and address uncertainty stemming from a lack of perceived information at and post-discharge.

Keywords: rural health, myocardial infarction, cardiac rehabilitation, aftercare, qualitative research, grounded theory

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Dedication

This study is dedicated to my husband and children. Thank you for continually being understanding and for providing me with moral, emotional, and financial support. I couldn't have done this without you!

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List of Abbreviations

AHS	Alberta Health Services
CAD	Coronary artery disease
CVD	Cardiovascular disease
CR	Cardiac rehabilitation
GT	Grounded theory
MI	Myocardial infarction
PCI	Percutaneous intervention
SES	Socioeconomic status
SGT	Straussian grounded theory

Chapter 1 Introduction

Cardiovascular disease (CVD) is a leading cause of morbidity and mortality worldwide (Berra, Fletcher, Hayman, & Miller, 2011; Deaton et al., 2011). In Canada, CVD remains the second highest cause of death (Statistics Canada, 2015), affecting 1.3 million Canadians annually. Secondary prevention strategies such as physical activity, diet and weight management, stress management, emotional health, and education are necessary to reduce disease progression to heart failure (Pesut, Laberge, Sawatzky, Mallinson, & Rush, 2012). Patients with heart disease have received significant benefits from cardiac rehabilitation (CR) programs and clinical practice guidelines encourage CR as a standard part of continuity of care (Shanmugasaram, Oh, Reid, McCumber, & Grace, 2013; Stone, Clark, & Arena, 2009).

The Canadian Association of Cardiac Rehabilitation (CACR) defined CR as: the enhancement and maintenance of cardiovascular health through individualized programs designed to optimize physical, psychological, social, vocational, and emotional status. This process includes the facilitation and delivery of secondary prevention through risk factor identification and modification in an effort to prevent disease progression and the recurrence of cardiac events (Stone, Arthur, & Austford, 2004, p. 2)

Cardiac rehabilitation can vary significantly by geography. In central Alberta, CR “provides people with heart disease with individualized exercise programs, blood pressure monitoring, and electrocardiograms (ECGs)” (Alberta Health Services (AHS), 2018). It also includes education regarding heart disease and risk factors, stress management, medication, heart healthy eating, emotional health, and energy

conservation. Eligibility and format vary by location and referral is typically required by a family physician, cardiologist or internist (AHS, 2018). An analysis of the current research evidence suggests that hospital readmissions, use of interventional procedures, cardiac risk factors, and mortality combined are decreased by 25% when patients engage in CR (De Angelis, Bunker, & Schoo, 2008; Heran et al., 2011; Lawler, Filion, & Eisenberg, 2011).

Cardiac rehabilitation has also been demonstrated to improve quality of life and well-being (Aude, Hill, & Anderson, 2005; Leon, 1999) among both men and women, helping them return to an active and satisfying life (De Angelis et al., 2008; Heran et al., 2011; Lawler et al., 2011), decreasing depression and anxiety, and increasing a sense of control over the disease (Blanchard, Rodgers, Courtney, Daub, & Black, 2002). Despite the fact that the most recent CR guidelines suggest the rehabilitation process should begin following an acute cardiovascular event or at the time of risk identification (Lewanczuk, Suskin, & Arthur, 2009) services tend to be underutilized worldwide (Aude et al., 2005; Daly et al., 2002; Thompson & Clark, 2009). Only 10% to 30% of patients typically attend (Kotseva, Wood, De Backer, & De Bacquer, 2013; Norris et al., 2004; Suaya et al., 2007).

Access to CR is one particular barrier, that is especially concerning for rural-living patients (Thompson & Clark, 2009). Research suggests that geographic barriers, including location, distance, transportation, parking costs, and patient driving ability, influence utilization of CR (Shanmugasagaram et al., 2013). In fact, distance to CR services can be one of the greatest barriers for rural patients (Ades et al., 1996; Johnson,

Weinert, & Richardson, 1998; King, Humen, & Koon, 1999) and rural residents tend to have limited access to acute and specialized services (Caldwell & Arthur, 2009).

Personal Experience

I have been a registered nurse for eleven years, working principally in cardiac and rural settings. In my experience working as a registered nurse in a rural Alberta hospital, patients have poor follow-up after a myocardial infarction (MI). Many rural residents that experience a cardiac event, are transferred to a tertiary care centre for advanced treatment. Following initial treatment, they are either discharged back to their local rural hospital for further treatment and recovery or return to their home. From my clinical observations, many patients have had limited education about their disease, are confused regarding their disease process, and are discharged while waiting for follow-up care. As a result, it is my belief that many patients do not understand their disease processes well enough to facilitate a positive change in health. Alternately, there are others that may have a significant understanding of their disease process but for other reasons cannot or do not make changes. Many of the patients who lack understanding of their disease process are elderly and require assistance from friends and family to support and transport them to and from appointments within their communities and into larger urban centres. This leaves their care fragmented, and patients are left feeling neglected and frustrated.

A recent conversation with a patient and his wife suggested that they had received plenty of relevant and helpful information and education to make positive changes to health, were proactive in making the necessary changes, but they lacked access to CR for ongoing support. They had started CR at a nearby rural centre but were told shortly after

that the program would be closing due to budget cuts and restructuring within AHS. They were referred to a larger urban centre for CR but had been waiting for several weeks to hear whether they would be accepted into the program. They also had concerns about travelling to a larger centre in winter weather and about being able to keep up with the rigorous in-hospital program due to accessibility. This experience has led me to wonder about the process that rural patients undergo to access care after they have an MI. How is it that some patients access care and others do not? These personal experiences and observations were the driving force behind my research and have informed the development and implementation of this research.

Chapter 2 Literature Review

In this chapter, I will discuss the current literature surrounding access to CR for patients living in a rural setting. I will focus on what it means to live in a rural environment, followed by a discussion on barriers and facilitators to CR attendance.

Living in Rural Environments

The term rural has a diverse meaning and has not been defined the same in all literature, though it is often referred to as a community of less than 10,000 people (Statistics Canada, 2001), and/or greater than 30 minutes (or 50 – 200 km) from the nearest metropolitan centre (Caldwell & Arthur, 2009; Shanmugasegaram et al., 2013) or a population density of less than 150 people per square kilometer (Statistics Canada, 2001). Rural has also been described as “a social representation, a community of interest, a culture, or a way of life” (du Plessis, Beshiri, Bollman, & Clemensen, 2002, p. 4). Currently, one in five Canadians (18.9%) lives in rural areas (Statistics Canada, 2015), and more specifically 13.7% of Albertans live rurally (Alberta Government, 2017).

Rural residents tend to be older (Dandy & Bollman, 2009), have a lower socioeconomic status (SES), be less educated than those living in urban areas (including having fewer years of education, lower math and reading levels, and greater likelihood of school dropout) (Rosigno, Tomaskovic-Devey, & Crowley, 2006), have higher rates of unemployment (Hornberger & Cobb, 1998), have poorer perceptions of health, have higher incidences of chronic disease (Magilvy & Congdon, 2000), are more likely to be obese (Sangster et al., 2013), have higher smoking rates (Doescher, Jackson, Jerant, & Hart, 2006), and are less likely to partake in preventive health measures (Pullen, Walker, & Fiandt, 2001; Sangster et al., 2013). Rural-living people “tend to have close personal,

long-term relationships with family and friends; place more confidence in local versus larger institutions; and value self-care” (Winters & Mayer, 2002, p.78).

Although Canada is well known for its universal health care system, which offers access for all (Romanow, 2002), access to care remains an issue for rural patients who suffer MI. This is in part due to the more limited access to acute and specialized services in rural centres (Caldwell & Arthur, 2009). The evidence also suggests that with the decreased length of hospital stays after MI, patients receive inadequate information, counseling, and support necessary to further their recovery and rehabilitation (Pesut et al., 2012). Similarly, patients who were released from hospital immediately following their MI received delayed access to secondary prevention programs (i.e. CR) or did not receive access to these services at all (Pesut et al., 2012). Patients who experienced an MI noted a lack of information in the time frame immediately after discharge from hospital (Hanssen, Nordrehaug, & Hanestad, 2005; Worth, Tierney, & Watson, 2000). Although many of them felt well cared for during their MI, they felt abandoned by the health care system after, leaving them with feelings of vulnerability (Pesut et al., 2012).

It is clear in the literature that delays in the referral process can lead to inadequate flow of information between the primary and secondary care providers of CR (Clark, Barbour, & MacIntyre, 2002; Tod, Lacey, & McNeill, 2002). It may also lead to fragmented care and limited support for patients (Clark et al., 2002; Tod et al., 2002), resulting in longer wait times to begin programming (Daly et al., 2002) and leaving patients in states of uncertainty regarding their plan of care. Although cardiology and general internal medicine resources are often unavailable in rural settings, even basic access to family physicians can be an issue for rural residents (King, Thomlinson,

Sanguins, & LeBlanc, 2006). This lack of consistency in care, has caused frustration for rural patients concerned about the lack of communication between care providers, leaving their health concerns unaddressed (King et. al, 2006).

Barriers to Cardiac Rehabilitation Attendance

Barriers to participation in CR are well documented in the literature. The primary barrier to CR attendance is lack of referral in the first place (Servio et al., 2019). In Alberta, all patients are automatically referred to CR by physicians upon discharge from hospital after MI (AHS, 2018), to address potential delays in the referral process. Another significant barrier to attendance is related to geographic barriers, including location and distribution of services, distance to services, transportation access, parking and gasoline costs, patient driving ability, accommodation costs, timing of services (De Angelis et al., 2008; Shanmugasegaram et al., 2013; Valencia, Savage & Ades, 2011), and difficulty taking time off work (Strickland & Strickland, 1996). Distance to CR services can be one of the greatest barriers for patients (Ades, Waldman, McCann, & Weaver, 1996; Johnson et al., 1998; King et al., 1999). For example, Johnson et al. (1998) conducted a study focused on rural residents' use of CR programs. They had 254 participants complete questionnaires at three points (immediately after discharge from hospital, two-weeks post, and at the end of the CR program). Analysis focused on predisposing factors, enabling factors, and need factors to CR. Only 28.3% of participants attended CR and of those, only 17% completed the full program. Additionally, those with less social supports and a further distance to travel to attend were even less likely to attend.

Rural patients and patients living far-removed from CR programs, which are generally centralized, have lower program participation rates (Evenson & Fleury, 2000; King, Humen, Smith, Phan, & Theo, 2001a). Evenson and Fleury (2000) surveyed CR programs and found that barriers to CR attendance included intrapersonal factors (e.g. patient motivation, not seeing value, comorbidities, fear, and time) interpersonal factors (e.g. lack of family or physician support), organizational factors (e.g. work conflicts, transportation, and distance) and policy factors (e.g. financial constraints and timing of classes). A prospective study conducted in Ontario revealed that patients with drive times of more than 60 minutes were less likely to participate in CR (Brual et al., 2010).

Age has also been shown to be a contributing factor when extended distance to CR is involved; older individuals are more likely to identify access as a barrier to attending CR (Harrison & Wardle, 2005). Caldwell and Arthur (2009) completed a critical ethnography of participants in four rural communities in Southwestern Ontario to examine CR participation. Study participants cited increased stress when having to travel outside their own communities to access necessary services, particularly when weather conditions were poor or there was unfamiliarity with the destination community.

Parking and accommodation costs are often added for those patients who live an extended distance from hospital or care services, or who choose to stay in accommodations close to CR to prevent missing appointments due to inclement weather (De Angelis et al., 2008; Shanmugasagaram et al., 2013; Valencia et al., 2011). In a cross-sectional study of cardiac patients from eleven hospitals across Ontario, Shanmugasagaram et al. (2013) focused on CR utilization and barriers by rurality and socioeconomic status. Findings suggested that rural residents had greater barriers to CR

attendance overall compared to their urban counterparts. In addition, the main barriers for both groups included distance, cost, and transportation issues (Shanmugasegaram et al., 2013). In a qualitative study of 101 rural participants aged 60 years and older, Goins, Williams, Carter, Spencer and Solovieva (2005), found five main barriers to healthcare access. These categories included transportation difficulties, limited health care supply, lack of quality healthcare, social isolation, and financial constraints. These findings suggest that those on a limited income may not be able to afford the costs associated with travel and potential accommodation, leaving them unable to access necessary CR services. Considering that CR encompasses more than exercise (AHS, 2018), additional costs of a heart healthy lifestyle, such as the purchase of fruits and vegetables, exercise equipment, or gym memberships, has been cited as a burden to rural living residents with financial and resource constraints (King et al., 2006), which may contribute to the reason that rural residents are less likely to follow a heart healthy diet and lifestyle, including CR (King-Shier, Mather, & LeBlanc, 2013).

Valencia, Savage, and Ades (2011) identified work schedule conflicts and timing of services as a barrier that often interfered with patients' ability to attend CR. Many were unable to get paid time off work to attend and could not financially afford to take time off without pay. Many identified a need for services to be offered outside of working hours, to include the working population. Rural patients cited work on the farm as taking precedence over health-related concerns, often ignoring warning signs and working until their health symptoms became severe enough to affect day to day functioning (King et al., 2006).

Although women, the elderly, and those from lower SES groups have worse cardiac risk factor profiles, they are less likely to take part in CR (Cooper, Jackson, Weinman, & Horne, 2002; Halm, Benque, Doll, & Beahrs, 1999; King, Humen, Smith, Phan, & Teo, 2001b; Lane, Carroll, Ring, Beevers, & Lip, 2001; McGee & Horgan, 1992; Melville, Packham, Brown, Weston, & Gray, 1999; Pell & Morrison, 1998). Many women and elderly feel that CR is not appropriate for them (Campbell, Ritchie, & Rawles, 1994; Radley, Grove, Wright, & Thurston, 1998), and women may perceive that they will be unlikely to complete the activities associated with the program (Blanchard, Rodgers, Courney, Daub, & Knapik, 2002), even though those who have limited functional ability can benefit from the non-exercise components of rehabilitation (Department of Health, 2000).

Caldwell and Arthur (2009) identified that rural residents travelling to urban centres for care, may feel like ‘outsiders’. They also found that urban caregivers lacked familiarity with rural life and context which created a psychological distance between patient and caregiver. Additionally, some participants reported healthcare providers had a lack of understanding of the context of their recovery and of the minimal resources available to them.

Family commitments were identified as barriers (De Angelis et al., 2008). Farm living residents perceived a strain between wanting to live a healthier lifestyle and keeping up with the roles within the home or on the farm (King et al., 2006). Women often do not see their spouses as a source of support (King et al., 2006). Additionally, women who suffer an MI are often elderly, have multiple comorbidities, and lack social

support (Galati et al., 2018). Women are also known to place the needs of their families before their own health (Galati et al., 2018).

Negative attitudes and beliefs about CR and its value have also been identified as barriers to attendance (Cooper, Weinmann, Hankins, Jackson, & Horne, 2006; De Angelis et al., 2008; Dunlay et al., 2009; Farley, Wade, & Birchmore, 2003; Kerins, McKee, & Bennett, 2011). Wachtel (2011) found that rural residents did not view their heart disease as serious and that they viewed their MI as an acute event rather than a chronic condition. Some patients spoke about having a healthy lifestyle prior to their MI and did not see the need for change (Pesut et al., 2012). Additionally, rural farmers perceived the work they were doing on the farm as exercise (King et al., 2006).

Home based CR programming has been developed to address accessibility issues (Dalal, Zawada, Jolly, Moxham, & Taylor, 2010). However, most of these programs still require the patient to attend a clinic at some point, which does not accommodate patients in deeper rural areas (Lear et al. 2014). In a systematic review by Anderson et al. (2017), researchers found no evidence to suggest a difference between home and centre-based CR in clinical primary outcomes. However, there was evidence to suggest a marginally higher level of completion in those that participated in home-based programming. Lear et al. (2014) completed a randomized controlled trial of eight cardiac patients using virtual CR programming to address challenges and gaps in access to CR. Although a small clinical trial, findings suggested virtual CR was a safe and effective way to decrease CVD risk. Additionally, findings suggested improved access to healthcare for rural patients, greater condition awareness for them, and a way to support self-management of care.

Of note, the majority of the literature searched focused on rural patients' recovery from MI, was directed to CR access and lacked focus on other potential and even less accessible resources for rural residents, such as mental health resources, social/peer support, financial support, specialty services (i.e. cardiology), family physicians, and services that focus on return to work and daily life.

Facilitators of Cardiac Rehabilitation Attendance

Facilitators of attendance at CR are not as well documented in the literature. Easy access to transport, including the ability to transport oneself and to be transported by family or friends, was a key enabler to CR participation (De Angelis et al., 2008). Sinclair, Conroy, Davies, and Bayer (2005) found that home-based CR was a feasible option to counteract some of the uncertainty around cardiac support for the elderly, and was shown to improve confidence, self-esteem, and reduce hospital admissions.

Patients cited several alternate models of CR as facilitators to participation (DeAngelis, Bunker, & Schoo, 2008). These included CR offered outside of working hours, intensive formats, gender and age specific formats, peer support groups, individualized home exercise programs, phone-based follow-up formats (DeAngelis, Bunker, & Schoo, 2008), practitioner-led support groups, and occasional individual consultations (Pesut et. al, 2012).

Family support, including encouragement to participate and availability to help with transport, was identified as a primary enabler to attendance (De Angelis et al., 2008). Support from health care professionals and other patients was also cited as important (Baird & Pierce, 2001; Clark, Barbour, White, & MacIntyre, 2004). For example, women are more likely to attend CR at the suggestion and encouragement of

their family physician (Sanderson, Shewchuk, & Bittner, 2010). For men, having the support of their spouse contributed to a positive experience and was identified as an indicator of healthy management of coronary artery disease risk (King et al., 2006). Neighbors were identified as sources of support, willing to help out with farm related duties when illness kept residents away from work (King et al., 2006), as well as assistance with household duties and transportation (Pesut et al., 2012). Finally, pharmacists were seen as essential support by offering crucial information and advice about medications (Pesut et al., 2012).

Patients were more likely to participate in CR when they recognized the importance of and benefits (Dunlay et. al, 2009) such as a decrease in coronary artery disease (CAD) risk, enhanced cardiovascular functioning, improvement in quality of life and mental well-being, a social support network, access to healthcare professional expertise (Clark et al., 2004; Kotseva et al., 2013; Polk & Tran, 2011), and having better perceived health prior to their MI (Dunlay et. al, 2009).

There are a variety of barriers and facilitators to CR access and uptake identified in the literature. Some of the key barriers are geography related (i.e. distance to services), while others include financial constraints, timing of services, family commitments, negative beliefs about CR, and being a woman. Key facilitators include access to transportation, options for alternate models of CR, family support, and recognition of the benefits. Knowing these barriers and facilitators already exist, it is important to understand the process that rural patients go through to access healthcare and CR following an MI in order to understand more fully the experiences of rural patients from a process viewpoint. Having this information will help to guide healthcare and CR for rural

patients and assist in providing them with a better experience. Thus, the research question was what is the process that rural patients go through to access healthcare and CR following MI.

Chapter 3 Methods

In this chapter, I will discuss the methods I used to answer my research question. First, I will discuss how I arrived at my research question. Next, I will discuss the use of Straussian grounded theory (SGT) as my research design, including the philosophical considerations associated with SGT. I will then focus on my sampling and participant recruitment strategies, followed by a discussion about how I collected and analyzed the data. Last, I will discuss rigour in GT and the ethical considerations associated with my study.

The Research Question

It is important that the perceptions and beliefs about accessing care after MI are understood (Pawson & Tilley, 1997) in the context of the rural population so that their needs can be met. Furthermore, understanding of the facilitators and barriers to follow-up healthcare after MI and how rural patients access these resources, could improve patient adherence to CR (Daly et al., 2002), and improve overall healthcare for cardiac patients (Horwood, Williams, & Mandic, 2015). This has led to the research question: What is the process that rural patients go through to access healthcare and CR following an MI?

Research Design

A qualitative research design was used for this study as it enables a detailed exploration of experiences and processes from those within the natural context (Morse et al., 2002). Using a qualitative research approach, I aimed to develop an understanding of aspects of experiences, and to explore words as data for analysis rather than numbers (Patton & Cochran, 2002). Understanding the process that rural patients go through to access care following a MI is well-served by attending to “meanings, concepts,

definitions, characteristics, metaphors, symbols, and descriptions of things” (Berg & Lane, 2012, p. 3). Understanding the process in this way offers a deeper inquiry into the experiences and attitudes of patients, with a further aim of looking to answer the questions about what, how, and why of a phenomenon (Patton & Cochran, 2002). By using a qualitative research methodology for this research study, the aim was to uncover what the process of accessing care after an MI is like for rural patients, how they access care, and why they may or may not access care. Having an understanding of these things may help to explain cardiac follow up care from the patient perspective and provide some direction about ways to improve access and patient experience.

Grounded theory (GT) was used to explore the research question and to gain an understanding of the process that rural patients go through to access healthcare and CR after MI. GT directs the attention to particular aspects of an experience and assists in moving from a description of what is happening to an understanding of the process (Corbin & Strauss, 2008). It enables one to see patterns of health in groups, communities, and populations, while predicting health and practice burdens in nursing care (Singh & Estefan, 2018). Furthermore, GT assists in developing a theoretical understanding of a given psychosocial phenomenon (Singh & Estefan, 2018) through investigating the social problems or situations to which people must adapt (Corbin & Strauss, 2008).

There are three main approaches to grounded theory: classic, Straussian, and constructivist. Classic or Glaserian GT, originated with the work of Glaser and Strauss (1967) who sought to change how research was undertaken. Rather than collecting data to verify a predetermined theory, the intent for classic GT was to discover a theory from data through constant comparison (Evans, 2013; Glaser & Strauss, 1967). Classic GT is

not restricted to any one theoretical viewpoint (Evans, 2013). That is to say Glaser and Strauss (1967) did not purport to follow a particular philosophical position. However, this has come under some scrutiny. For example, Kenny & Fourie (2015) have contended that in fact, Glaser and Strauss took a positivist approach to research, meaning that the grounded theorist was in search of a single and unbiased truth when constructing theory. Additionally, in Classic CT, researchers were not expected to engage in a literature review prior to the research to avoid contaminating the analysis process.

Straussian GT (SGT) was a development of, and departure from, classic GT. In the course of their theoretical and research work, the views of Glaser and Strauss began to differ. Although Strauss and Corbin shared many of the same tenets as Glaser, they moved away from pure induction and included deduction (the testing of abstract ideas against emerging data) in their analysis (Strauss & Corbin, 1998). In response to criticism about the rigour of GT, Strauss and Corbin revealed a more structured approach to data analysis rather than the discovery of a theory (Evans, 2013). For example, rather than taking Glaser's (Glaser & Strauss, 1967) approach of refraining from examining the literature (to reduce bias), SGT compels the reader to examine the literature as part of the constant comparison process and incorporates personal experience to gain theoretical sensitivity (Strauss & Corbin, 1998). In addition to stimulating theoretical sensitivity, the literature review allows a secondary source of data, stimulates questions, directs theoretical sampling, and allows supplementary validation (Strauss & Corbin, 1990).

Constructivist GT represents a more recent revisioning of GT method.

Constructivist GT allows more room to incorporate and consider the position of the researcher, as well as the constructed nature of knowledge that arises in interactions with

others (Charmaz, 2006). As such, constructivist GT differs from the other GTs.

Constructivist GT goes against the structured approach to coding and instead uses highly adaptable and flexible coding guidelines. This flexible approach allows for a more interpretive, intuitive, and impressionistic coding procedure and later allows the findings or interpretations to be shared using a narrative approach (Charmaz, 2006).

A Straussian approach (Corbin & Strauss, 2015) was selected to guide this work. There were three reasons for choosing the Straussian approach: First, this approach can be used to produce an explanation and theory that can help to guide future practice for healthcare providers working with rural cardiac patients; Second, the requirement of my masters degree for using a literature review to guide my research; Third, my preference for a more stepwise approach for data analysis (Corbin & Strauss, 2015). As I am new to this research method, the steps in SGT allowed me to have a clear and defensible process to generate a theory.

Philosophical considerations of Straussian grounded theory.

SGT occupies a theoretical space in the midst of objectivist and constructivist epistemology. Objectivist epistemology implies an objective reality, waiting to be known (Crotty, 1998). Constructionism implies, instead, that reality is more negotiated and mutable (Crossy, 1998; Gergen, 2001). SGT proceeds from a postpositivist perspective, acknowledging the possibility of multiple viewpoints about a given phenomenon (Strauss & Corbin, 1998). However, the systematic approach to inquiry and treatment of data in SGT is an attempt to, insofar as it is possible, maximize objectivity; the systematic approach minimizes subjective bias of the researcher and maximizes objectivity (Singh & Estefan, 2018).

Straussian grounded theory is rooted in symbolic interactionism (Chamberlain-Salaun, Mills, & Usher, 2013; Richards & Morse, 2007). Symbolic interactionism, developed by Mead and Blumer (Blumer, 1980) takes on the perspective that meaning is developed between people, always changing, and continuously unfolding (Chamberlain-Salaun, Mills, & Usher, 2013; Richards & Morse, 2007). The central principle is that meaning is constructed by social interaction and is therefore focused on how we interpret symbols (culturally-derived social objects) to communicate with each other, how we present a version of self to the world, and how we construct a reality we perceive as true (Blumer, 1980). Blumer further explained social interactionism as interpretive interaction, when humans associate with each other (Annells, 1996).

Grounded theory methodology can be used to develop a theoretical understanding of psychosocial phenomenon (Singh & Estefan, 2018). Although there are several approaches to GT, as described above, the SGT was most fitting to use for this study as it allows for production of a theory, the use of a literature review, and offers a stepwise approach to data analysis.

Grounded Theory Design

Although the main purpose of SGT is not necessarily considered theory development, studies may be directed at developing a substantive theory as it emerges from the data (Corbin & Strauss, 2015). Corbin & Strauss (2015) stressed the importance of concept and theme discovery from data, with a focus on balancing between theory development and description. The outcome of this methodology is conceptual description (Corbin & Strauss, 2015).

The Straussian method begins with a statement of the research problem or question (Corbin & Strauss, 2015). My research question is: What is the process that rural patients go through to access healthcare and CR following an MI? By using this research question, potential gaps in the process that rural patients go through after they experience an MI were identified, so future care may be more directed towards this unique population.

Induction, deduction, and verification are considered essential to grounded theory analysis (Strauss, 1987), with induction identified as the key process in which the researcher moves from data to empirical generalization, and finally to theory (Heath & Cowley, 2004). Validation, rather than verification, compares concepts and relationships against data during the process of research to resolve data that comes under scrutiny (Strauss and Corbin, 1998). This approach also includes abduction as a:

type of reasoning that begins examining data and after scrutiny of these data, entertains all possible explanations for the observed data, and then forms a hypothesis to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data. (Bryant & Charmaz, 2007, p.33)

The intention is not to validate a hypothesis, as this would indicate a more quantified approach to research, but to gain a deeper understanding of the process, in hopes of developing an explanation into the process. Personal experience as a healthcare provider has highlighted the policy and health care system barriers to cardiac care for rural patients. Alternately, personal experience has shown some of the facilitators for post cardiac care to include education for the patient, socioeconomic status of the patient, and advocacy on the part of the healthcare provider. The research findings should assist in

developing a way to understand the process and assist in recognizing patterns that contribute or negate optimal care for rural patients.

Sampling Strategy

Participants were selected using an amalgam of convenience, theoretical, and snowball sampling. Initially convenience sampling was used to recruit participants from a rural hospital and pharmacy in central Alberta. As findings emerged, theoretical sampling was used. For example, additional women were recruited to balance out the male to female ratio. Additionally, two participants who had attended a CR program locally, before it closed, were recruited to offer an alternate perspective on the experience of accessing care after MI. Additionally, recruitment occurred through snowball sampling, where participants or those close to them suggested others who might wish to participate in this study. This was undertaken to ensure that a breadth of participants was recruited.

Consistent with grounded theory methodology (Liehr, Taft Marcus, & Cameron, 2005), participant interviews were conducted until data saturation in the emerging analysis occurred. Saturation occurs when no new significant themes arise (Glaser & Strauss, 1967). It indicates that no further data will be found and the researcher reaches conceptual density (Glaser & Strauss, 1967). Data saturation was achieved with 11 participants.

Inclusion criteria for the study were: (a) living in a rural area; (b) confirmed myocardial infarction, as reported by the patient; (c) age between 35 and 75 years (chosen based on low incidence of CAD before age 35 and increased incidence of multiple co-morbidities after age 75); and (d) English speaking. Exclusion criteria for the study were: (a) residing in a long-term care facility (chosen as residents in assisted living

facilities have chronic diseases that are more difficult to manage) (b) having a severe chronic disabling disease (chosen as patients accessing care for severe chronic disabling disease is different from cardiac care specifically); (c) having cognitive disabilities (chosen as those with cognitive disabilities may not be able to provide an accurate account of their experience), (d) and unable to provide informed consent.

The Location

The location for initial study recruitment was a town of less than 10,000 citizens in central Alberta. The town contains a small hospital with services including emergency department, acute care (medical/surgical/palliative/post-partum/labor and delivery), day surgery, and operating room. Additional services include access to family physicians, mental health, homecare, public health, and continuing care.

Participant Recruitment

Participants were recruited between September 2018 and May 2019. After receiving institutional approval from the clinical site and research ethics board approval from the Conjoint Health Research Ethics Board at the University of Calgary, flyers (Appendix A) were placed in strategic positions at the hospital acute care and emergency departments. The flyer contained a telephone number and email to which potential participants could respond to learn more about the study. An informal in-service was held at the hospital to inform nurses about the study and participant recruitment details. I visited the hospital acute care and emergency departments 2 – 3 days per week to recruit participants. On the other days, hospital nurses screened patients who fit the inclusion criteria and provided me with the patients contact information after verbal consent was

given. All interested participants were contacted by phone and a time arranged to obtain informed consent (Appendix C) and conduct the interview.

Recruitment was also undertaken with the assistance of a pharmacy in the town. The managing pharmacist was given information about the study and the participant recruitment details. The pharmacist screened patients who fit the inclusion criteria and provided the potential participants with a flyer (Appendix B) containing a telephone number to which they could respond to learn more about the study. Due to a slow recruitment process, a local family physician was subsequently added to further assist with recruitment. Like the pharmacist, the physician screened patients who fit the inclusion criteria and provided the potential participants with a flyer containing a telephone number to which they could respond to learn more about the study.

Data Collection and Analysis

Demographic and clinical data were collected from participants to characterize the study sample and to facilitate theoretical sampling (see Appendix D). Demographics included participants' age at the time of event, gender, marital status, habitation, education level, and employment status. Clinical characteristics included MI and intervention while in hospital. Demographic data was entered into IBM SPSS Statistics 23 and analyzed using descriptive parametric (e.g., means, standard deviation).

In keeping with SGT, data were collected using face-to-face in-home and telephone semi-structured interviews, beginning with open-ended questions (see Appendix E for beginning questions) (Streubert & Carpenter, 2011). As interviews and concurrent analysis progressed, more focused questions were asked to clarify concepts as necessary. Interviews were audio recorded to allow the researcher to explicitly focus on

the conversation, and on observation of the participant. Note taking during interviewing was kept to a minimum to limit distractions and focused on the recording of questions that arose from conversation. Memos were created before and after each interview and included as part of the data. The first interview was transcribed by me to allow complete immersion and familiarity with the data. The remaining audio-recorded interviews were transcribed into Microsoft Word documents by a professional transcriptionist who signed a confidentiality agreement.

The process of grounded theory involves a design driven by data or theoretical sampling. Data analysis and data collection occur concurrently, with the research focus beginning to emerge during the analysis process (Strauss & Corbin, 1990). Wuest (2012) suggested diagramming as part of analysis and category relation, particularly if one is a visual thinker. With each subsequent interview, the researcher starts with the broad overview question, but begins to listen through the lens of the theory that is emerging (Wuest, 2012). Emergence remains a part of SGT, indicating that as ideas and hypothesis are generated, they may be discarded if their importance fails to unfold in the data (Heath & Cowley, 2004). Despite this, one must remain open and true to discovering new theory rather than being swayed to confirm existing knowledge (Heath & Cowley, 2004).

As interview data were collected from the first participant, data were also analyzed using coding. Strauss and Corbin (1990) described coding as transforming raw data into theoretical constructions of social processes. Codes in data are clustered to form categories, which are broadened and developed or collapsed (Liehr et al., 2005). Strauss and Corbin (1990) described three types of coding as part of this process: open, axial, and selective.

Data analysis began with open coding, examining data line by line, constantly comparing indicators (constant comparative method) for similarities and differences (Liehr et al., 2005; Wuest, 2012). Open coding is defined as “the process of breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss & Corbin, 1990, p. 61), dividing data into categories (Kendall, 1999). Open coding involves further forming categories that eventually lead to description and theory development (Wuest, 2012). Line by line, significant data were noted, giving rise to emerging categories in the data, with the goal to discover as many conceptual codes as possible to fit with the data (Strauss & Corbin, 1990). The process of open coding allowed the researcher to use questioning and constant comparison as a way to recognize, address, and limit subjectivity and bias (Strauss & Corbin, 1990). As categories were developed, the features and characteristics within each category were separated (Strauss & Corbin, 1990). Features and categories were then analyzed in terms of dimensional ranges (i.e. frequency, intensity, degree, and duration) (Strauss & Corbin 1990). This allowed each category to have a complex dimensional profile (Strauss & Corbin, 1990). Theoretical coding was also used for data analysis, and began during open coding (Wuest, 2012).

Following open coding, data were grouped into larger categories using axial coding. Strauss and Corbin (1990) defined axial coding as “a set of procedures whereby data are put back together in new ways after open coding, by making connections between concepts” (p.96). The axial codes were then used to create memos, to further interpret and make sense of the categories. Data were analyzed and coded, and ideas and potential insights began to develop, leading to theoretical memos (Heath & Cowley, 2004). As the analysis process proceeded, memos were written to gain insight into

emerging ideas about concepts and relationships about the data, theoretical codes that emerged, and links among the codes (Glaser, 1998). The memos became a large part of the discussion when recording the results of the study, assisting in constructing a grounded theory (Strauss & Corbin, 1990).

Finally, selective codes were chosen based on the research question as relating to the process that rural patients go through to access CR and healthcare after MI. Selective coding involves the selection of a core category that accounts for most of the variation of the central phenomenon and within which all other categories are able to be integrated (Strauss & Corbin, 1990). Axial codes were combined during this process to condense the categories and assist in coming up with overarching categories. Throughout the coding process, data were constantly compared; from the first interview to second interview, the second interview to the third interview, and so on, resulting in the emergence of categories, and ultimately a core category (Strauss & Corbin, 2008). Mapping was used to examine the interconnections and relationships with the data, assisting in determining the final themes and categories. Throughout data collection and analysis, related literature was reviewed continuously (Liehr et al., 2005). The reviewed literature is considered data and is compared with the researcher's emerging theory as it progresses (Liehr et al., 2005). Data was continually tested against subsequent participants and either brought forward or left behind. This allowed testing of the emergent theory of being uncertain. The process of data analysis and interviewing continued until data saturation was reached, allowing for the report to be written.

Rigour in Grounded Theory

As a qualitative research methodology, grounded theory is judged by criteria of rigour, or trustworthiness. There are different ways that rigour of qualitative research can be judged. In this study, the criteria used to ensure rigour were credibility, auditability, and fittingness (Beck, 1993). Credibility is established when others can recognize the experience after having read about it (Cooney, 2011). Auditability includes maintaining a comprehensive record during the research process so that it is possible for other researchers to repeat the same enquiry in the same setting if they so choose (Beck, 1993). Fittingness, or transferability, focuses on demonstrating that the findings could fit with others in similar situations (Beck, 1993).

When determining the rigour of grounded theory research, emphasis is placed on the analysis process: how the researcher draws conclusions, and how much the conclusions are grounded in the data (Cooney, 2011). There is also consideration of the adequacy of the research process and the grounding of its findings (Strauss and Corbin, 1998). That is to say, whether a defensible process has been followed, and whether the findings from that process are embedded in existing knowledge and practice content.

All participants in this study were engaged and willing to share their thoughts and experiences about the process they went through to access healthcare and CR following their MI. Credibility was enhanced by engaging in theoretical sampling and ensuring accuracy of data. To ensure that the emerging theoretical data reflected the views of the participants, interview questions were further developed and honed in on the emerging theoretical data. Meetings with my supervisor were held regularly to discuss ongoing analysis and to reflect on memos, ensuring theoretical sensitivity. Theoretical sensitivity

is the ability of the researcher to generate themes from the data and relate them to the abstract (Corbin & Strauss, 1990). It ensures that biases do not appear in the results of the study (Corbin & Strauss, 1990).

The use of coding and memos were used to assist in theory development and add to the credibility of the study (Corbin & Strauss, 2015). On initial recruitment, the study sample included more men than women. Therefore, theoretical sampling was used to gain a sample that was more representative of the rural-living population who had MI's. Finally, accuracy of the data was maintained by carefully studying interview transcripts (Corbin & Strauss, 2015).

Reflexivity was considered as part of the research process. Reflexivity is the process of recognizing biases that influence the research process (Guba & Lincoln, 2005) and is essential in GT research, as it increases the rigour of the research (Engward & Davis, 2015). It includes self-awareness (Engward & Davis, 2015) and allows the researcher to question the assumptions about the research topic, concepts, and theories that are created through past experiences and knowledge (McDermott & Varenne, 2010). It allows the researcher to further consider whether past experiences and knowledge are silently influencing the research and allows for transparency about decisions made during the research process (Engward & Davis, 2015).

To increase reflexivity in my research, memoing and reflecting about thoughts and feelings was incorporated before and after each participant interview. Following the interviews and during data analysis, acknowledgement of my own assumptions was made, recognizing how it might influence my research findings. For example, exploring my own presuppositions and clinical knowledge as it related to the data I was

discovering. Doing this, allowed me to re-evaluate my findings based on the data and assisted in bringing reflexive insight into subsequent interviews. Frequent discussions with my supervisor about research findings also assisted in maintaining reflexivity.

Ethical Considerations

This study was approved by the Conjoint Health Research Ethics Board at the University of Calgary. Participants were anonymized and were provided with coded identity (i.e. transcripts shared with committee members had participant names removed; data was kept secure). Each participant received verbal and written information explaining the purpose and background of the study, their role as a participant, as well as potential risks. Each study participant provided written informed consent which explained how results would be stored and used and provided contact information for the researcher should any concerns arise. Participants were allowed to withdraw from the study at any time, meaning their data would not be used in any dissemination activity, prior to data analysis. No participants withdrew from the study.

There are special considerations when working with people in close-knit communities such as those in rural Alberta. These considerations include that people are often very much aware of their neighbors' wellbeing and they tend to have closer relationships with their healthcare providers which could result in potential confidentiality issues.

Chapter 4 Findings

In this chapter, I present the findings of the study. First, I describe the study sample in order to provide context and insight into the informants whose data form the basis of the grounded theory. I then offer a summary of the timeline for accessing services that informed the theory development. I then turn to discuss the grounded theory, *Being Uncertain*, which describes and explains the process for people accessing health care in a rural environment following an MI.

Characteristics of the Study Sample

As identified in Table 1, seven men and four women participated in this study. Their ages ranged from 48 to 73 years (mean age men= 63.29 years; standard deviation (SD) = 7.18; mean age women = 61years; SD=6.06. The majority of the participants were married and were educated to high school level or greater. None of the participants underwent coronary artery bypass graft surgery, however, all but two women underwent a percutaneous coronary intervention following their MI. Participants were at varying points in their recovery, ranging from less than one year up to five years post MI. The longer time frame from experiencing an MI gave participants time to reflect on all elements that entered their decision making.

Table 1. *Characteristics of the Study Sample*

	Sex (M/F)	Age at time of MI (years)	Marital Status	Habitation	Highest Level of Education	Employment Status	PCI?	Time Since MI (years)
Pseudonym								
Louie	M	54	Married	Spouse	>high school	Outside home full time	PCI	1
Will	M	71	Divorced	Alone	high school	Retired	PCI	1
Alice	F	59	Divorced	Alone	>high school	Outside home full time	No	<1
Marshall	M	73	Married	Spouse	high school	Retired	PCI	<1
Robert	M	64	Married	Spouse	>high school	Outside home full time	PCI	<1
Stan	M	63	Married	Spouse	>high school	Retired	PCI	<1
Evelyn	F	60	Married	Spouse	high school	Retired	PCI	1
Kathleen	F	61	Married	Spouse	>high school	Retired	PCI	2
Elizabeth	F	48	Married	Spouse	>high school	Outside home full time	No	<1
Don	M	63	Married	Spouse	>high school	Retired	PCI	4
Bruce	M	55	Married	Spouse	>high school	Outside home full time	PCI	5

The Timeline

To explicate the process that the participants in this study underwent to access healthcare following an MI, the data will be explained based on the following inductively identified stages: discharge (from hospital), waiting (for access to services), accessing (services), and maintaining (health) (see Figure 1).

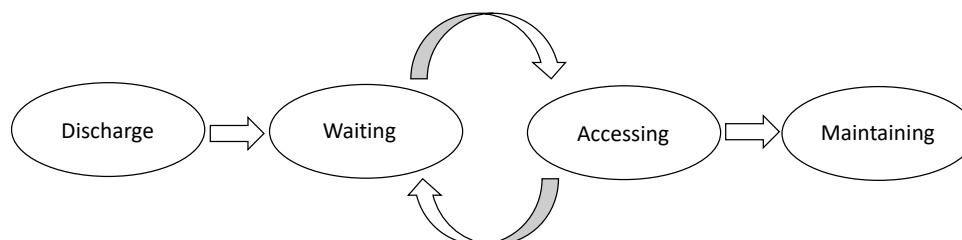


Figure 1. Timeline

Discharge.

This part of the process refers to discharge from hospital following the MI. The initial discharge from hospital experience and the information received on discharge appeared to set the trajectory for the participants' as they moved through the timeline. A large part of this phase included the receipt of information on discharge from the hospital after their MI and the impact of having/not having that information. Those that perceived that they received minimal or no information at discharge reported a much greater challenge as they navigated through the system relative to those who received information. For example, Will (71 years old) shared his experience, stating "Nobody in their ultimate wisdom really explained kind of what they thought should happen after...Nothing really stating that you should immediately contact cardiology and sign up

for this aftercare program”. He further shared that “there wasn’t an awful lot of information at the hospital that I can remember”.

Another participant felt frustrated about the lack of information provided. At several points during the interview she repeated “I was told nothing about anything at all” (Alice, 59 years old). She continued by saying:

I was told diddly nothing. Nobody said you should follow up with this or you should try this or that. Nothing! They just said oh, here’s your prescription and they gave you the papers and a prescription for Plavix and baby Aspirin and that was it. (Alice, 59 years old)

This participant then continued to show me the documents she had been given. They were print outs of her admission history and she commented that these were not easily understandable to her. She shared her frustration with this, saying “How am I supposed to make sense of this?”. Likewise, another participant felt disappointed by the lack of information. Marshall (73 years old) shared that the only information he received on discharge was to “go home”. He expressed his concern about the plan after his percutaneous coronary intervention (PCI) by saying “It’s confusing, very confusing”.

Some participants were told they had referrals to a cardiologist and CR, while others were surprised when they received calls from a CR program regarding participation. Marshall (73 years old) shared his experience, saying “They gave me the sheet and the dates of when these courses were, and we had already missed the first one, so we did three, and then I picked up the first one again...”. Alice (59 years old) said she received the following direction on discharge: “They gave me a stack of papers and they said, ‘Go home and in three months see your cardiologist’.” She was given the name of her cardiologist but did not know how to contact him. “It was hard to get a hold of (my

cardiologist)” she shared. Kathleen (61 years old) experienced some frustration on discharge with the direction she was given:

(They told me that) I needed to book an appointment with the cardiologist in the cardiac department in (urban) hospital in three months, and they didn't offer to do that, they didn't say they were going to, there's no phone call, no nothing.

One man thought he would receive more direction on discharge and said, “I didn't ask enough questions, you know, about what I could do and couldn't do immediately” (Don, 63 years old).

Three participants had a different experience and received ‘some’ information on discharge. “Dr. XXXX was clear” Robert (64 years old) shared about what he had been told by his cardiologist. Likewise, Stan (63 years old) went home from the hospital knowing that he would be contacted. He shared that “somebody from cardiac rehab would contact me in (the urban hospital) and they did”. Elizabeth (48 years old) received the most information of all the participants:

They gave me a book, like pamphlets and stuff like that to read. They kind of went through all my medication, they kind of went through what I can do, what I cannot do, like exercise and all of that... they had me make an appointment to go in and see the dietician...Nothing was said about going to the (urban centre) for my rehab...but they did give me what I should to do for my treadmill and things like that...(Elizabeth, 48 years old)

She further shared that, “The hospital was pretty good at what I should and shouldn't be doing. They kind of explained stuff within reason”.

Waiting.

This part of the process refers to the time spent between discharge and accessing services. There was often a ‘back and forth’ between waiting and accessing and these were a significant part of the timeline for most participants. More specifically, some

participants waited for long periods of time to access care, only to find that they were waiting again for other elements of care access. Participants waited for a variety of services and for varying amounts of time. Alice (59 years old) had already resumed her normal routine when she was contacted by CR:

I went back to work and then all of a sudden, I was sent some papers from (urban) hospital saying I was booked for some kind of assessment and for cardiac rehab. I waited probably 3-4 weeks for those papers to come.

She also shared that because her MI happened in the summer, she was waiting longer to see the cardiologist and to have a stress test done. “Everything’s waiting, just sitting around and waiting” she said, “I don’t know where to go from here”. Another woman had a similar experience stating, “I kind of got a little bit of a release from everything for the summer. I phoned the cardiologist and talked to the receptionist and it’s going to be probably 6 to 7 months to see her” (Elizabeth, 48 years old). One woman, who was having some unexplained symptoms after her MI, experienced some frustration as she waited for appointments with specialists, who were on holidays. “I really didn’t have anybody” she said, “there wasn’t anybody locally to actually go see because it was holiday time” (Evelyn, 60 years old).

One man shared his frustration while he tried to connect with CR:

It took a while for the cardiac rehab clinic, or whatever they all themselves, to contact me This trying to book a time with the physio one on one, that has been a bit of a variable. They said not to phone and that they will phone me when another opening comes up. (Stan, 63 years old)

Another man shared that he had already been waiting a few months to get into CR and was told “it’s going to be slow” because one of the HCP had injured herself, and that “there’s lots of people going through these courses” (Marshall, 73 years old).

Several participants mentioned they had difficulty scheduling an appointment with their family physician for follow-up care after their MI but waited as long as necessary because they had a positive working relationship with them. The positive working relationship was described in terms of open communication, trust, and a deeper connection that had been developed over several years. Evelyn (60 years old) spoke of her family physician saying, “Sometimes you can get in to see her right away, and sometimes you’ve got to wait a week”.

One woman referred to her situation as *playing the waiting game*. “Because I couldn’t get the MRI done initially” she shared, “they didn’t know (what the plan was) either, so they were playing the waiting game as well. It was just playing that waiting game that was the worst part for me than anything” (Elizabeth, 48 years old). The same woman felt helpless as she waited for an appointment with the cardiologist, but felt that the waiting was normal: “It’s the cardiologist being so busy and not being able to get in and see them right away (that frustrates me) ...which I think is kind of a common thing, isn’t it?” (Elizabeth, 48 years old)

Louie (54 years old) shared his frustration with the disconnect he felt while he waited for care.

There seems to be a disconnect between where patient doesn’t get as much information as they need. I didn’t feel there was a lot of back and forth...with information. There was a little bit of information thrown my way.

Accessing.

This part of the process refers to participants seeking out and obtaining care after their MI. Participants accessed a variety of services, including: their cardiologist, family physician, pharmacist, CR, counseling, general internist, emergency room, and Health

Link (phone-based services offered in Alberta). Most participants had accessed their cardiologist within three months of their MI, while one woman had been waiting nearly four months and another upwards of seven months. Nine participants had followed up with their family physician and one participant followed up with her nurse practitioner. The family physician and nurse practitioner assisted with managing medications and organizing related referrals. One participant was frustrated because she did not have a family physician to follow up with “They weren’t wanting to see me at the clinic because I didn’t have a family doctor” she said, “so there was very poor follow up” (Kathleen, 61 years old). All participants accessed their pharmacist, who provided medication-related information.

Nine participants accessed CR to varying degrees. Louie (54 years old) started CR but had to go back to work before he could complete it. “I attended one meeting” he said, “and we were going to start an exercise program, but I was kicked to work before the exercise program started”. One woman did not attend CR at all because she was already back to work and the availability was not conducive to her schedule. Another woman was early in her recovery and was waiting to hear about whether she would be referred to CR.

Only one woman mentioned accessing the counseling services available. “After several months, I went for the counselling that’s available through Alberta Health Services” she shared “and so I went to talk to a psychologist for a little while, just to process some things and frustrations and stuff” (Kathleen, 61 years old). A few participants mentioned accessing other specialty services, including an endocrinologist related to diabetes care and a general internist for other symptoms. Others had to access their local ER because they were experiencing acute symptoms of chest pain that could

not be managed at home and required immediate attention. “I went back in (to the local hospital) and they did some more tests” Louie, 54 years old, shared. He further described that he had to go to the city hospital to receive another stent and that the experience had gone well. Kathleen (61 years old) shared her challenging experience at her local hospital:

I did go into the (local hospital) a couple of times when I didn't have a doctor, and I was, you know, in pain or having chest pains which wasn't a good experience... You know, coming and going to the hospital, for me, to Emergency is the absolute last resort... So when I go in there, I don't expect to get attitude like I've got nothing better to do with my life than to bother them.

Maintaining.

This part of the process refers to the time when participants had accessed all healthcare resources related to their MI and were following up with their family physicians as necessary to monitor medications and concerns. Two of the eleven participants had reached this phase. Nearly five years following his MI, Don (63 years old) shared “I’m still going in for continuing monitoring (to the family physician)”. Another man had been in the maintenance phase for a few years but returned to the accessing phase when he began experiencing chest pains again. “They set me up with a cardiologist in Edmonton and I’ve gone for a stress test and everything” he shared, “Within a month I was in to see the cardiologist...they gave me the results and everything immediately” (Bruce, 55 years old). Those that had not yet reached this phase were still accessing services on a consistent basis, outside of the follow up appointments with their family physicians. This appeared to be related to length of time since their MI.

Grounded Theory: Being Uncertain

The core category identified was being uncertain. The model offers an explanation of the process of being uncertain and how uncertainty was linked to all five main concepts of the process that rural patients go through to access care following MI. Additionally, the timeline and being uncertain are closely linked, as the process of being uncertain occurred within the timeline. Three subcategories further emerged in the data that assisted in describing being uncertain: plan of care; feeling lost/alone in the system; having questions and asking how to proceed. Five other categories related to uncertainty emerged from the data: comfort with health information, relationship with healthcare provider, social support, taking ownership, and availability of/for cardiac rehabilitation (see Figure 2).

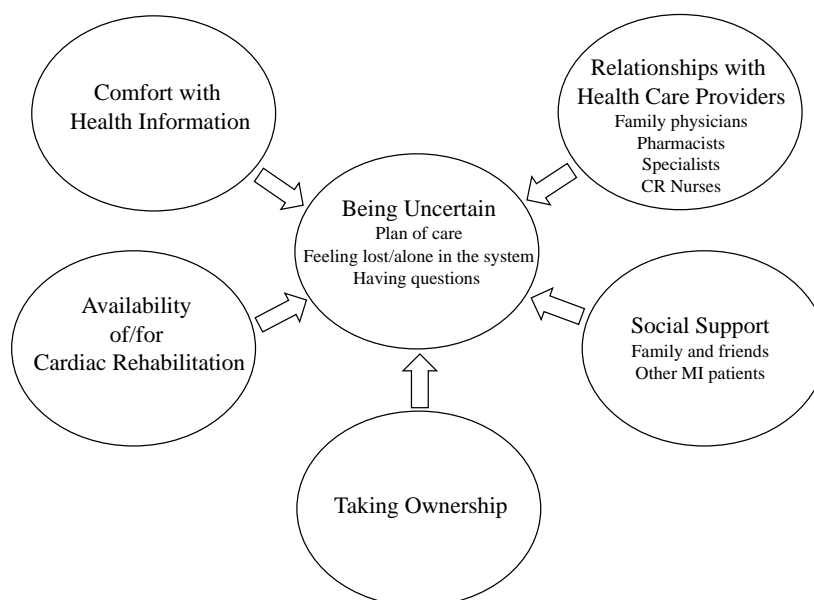


Figure 2. Being uncertain.

Plan of care.

This refers to refers to the uncertainty that participants felt about their plan of care after their MI. Six participants did not have a definite plan of care. Louie (54 years old) shared that “A year later, I supposedly had my final visit (with the cardiologist), but I don’t know if that’s true yet or not”. Stan (63 years old) stated that “besides taking the medication and meeting with the physio, I don’t really have a plan that I am aware of... they said I don’t really have to do anything different or unusual, so I guess that’s the plan”. Evelyn (60 years old) had a similar experience and said, “they didn’t say anything about any follow-up or anything”.

One woman had been waiting a few months to hear from her cardiologist for an appointment and appeared resigned to the fact that this was the norm:

They have not phoned me to let me know and I have not heard anything, other than from the receptionist of the cardiologist, so I am just taking her word for it...with them not following up with me after I have had stuff...I am having to chase them. (Elizabeth, 48 years old)

Two participants had a different experience from all of the others. Both attended a local CR program before it closed and received clear direction about their plan of care on discharge from hospital. Don (63 years old) was instructed to “report to cardiac rehab”. He further shared that he was told by the cardiologist “If you have any issues make sure you come see me”. Another man who attended the same local program shared his experience: “At that time, they told me, if I remember right, to follow up with my cardiologist, and then that I would be going to see somebody in (anonymized small town). They gave me a number and a contact at that time”. He also received direction to “get this set up, start doing your cardio rehab, so I did immediately as soon as she gave

me the word” (Bruce, 55 years old). The same participant spoke of his CR nurse, saying “she set me up with a dietician at the hospital in (local town)” (Bruce, 55 years old).

Feeling lost/alone in the system.

This describes participants feelings of being unsupported and unable to navigate the healthcare system during the process of accessing care. A woman who had gone back to work just a few weeks after her MI described her experience as she tried to navigate the system and shared that:

There’s just nowhere to go and I don’t know what to do... you feel very, well, I don’t know just kind of lost, like you don’t know what to do as far as trying to prevent this from happening again. (Alice, 59 years old)

Another woman identified a lack of consistency in her care when she did not have a family physician to follow up with. She saw several physicians at a walk-in clinic but was concerned they would not take the time to get to know her and her medical history before choosing to prescribe more medication.

Most of the doctors at our clinic, if they’re there for three months, they’re usually not taking any more patients... and we have no walk in clinic in (local town) and so (urban hospital) or (nearby town) have a walk in clinic... that’s a 25 minute drive from (local town), or it’s about 40 minutes into (urban hospital). So, the hope is that somebody will take enough time to read my file, know what we’re doing and what the possible complications could be, rather than just, I don’t know...saying here, take some aspirin. (Kathleen, 61 years old)

Having questions and asking how to proceed.

This refers to the questions participants had about various parts of the process and recovery, and how to proceed without knowing what was next. One participant was concerned about whether the health changes he was making were making any difference. He expressed his concern stating, “You’re out there trying everything, and you don’t know if it’s gonna work or not” (Louis, 54 years old). He further shared “I’m not sure

how to proceed from there... If it's to happen again, do I just do the same or ignore it?... What do I do?... How do we proceed?... What's the expectation?" (Louis, 54 years old). Alice (59 years old) wondered, "Is there anything I should be doing or could be doing?". Poor communication was cited by one participant when he stated, "I wasn't 100% sure...do they contact me, or do I contact them?" (Stan, 63 years old). Robert (64 years old) stated "I don't know what to expect so I'd like more information you know".

Comfort with Health Information

This refers to the participants ability to find and understand health information in order to make decisions about their heart health. Comfort with health information varied between participants. More comfort was evident in participants who had skilled communication with healthcare providers, knowledge of their disease, and the ability to positively engage in making improvements to their health. Less comfort was evident in participants who lacked knowledge about their disease and health. This appeared to negatively affect their ability to advocate for themselves and for positive care. Those that were more comfortable with health information asked more questions of their healthcare providers and seemed to question the health information they were receiving and their plan of care. Robert (64 years old) was purposeful in asking questions, saying "Don't take everything as it's presented...don't just say they said it [healthcare providers], or it must be true especially if it's on the net. The same participant was skeptical of some of the research he was reading because of where the funding might be coming from. He wondered how he would be able to trust a study that had been funded by big pharma.

Marshall (73 years old) appeared to be more comfortable with health and shared that he "knew most of it [health information], being a firefighter for...(many) years...but

there was some stuff that I didn't know". He further shared that he had helped build a physical fitness program for his local fire department, and had people with advanced education working with him, so he understood the importance of healthy eating and physical fitness.

Most participants relied on the internet for part or all of their health information and found it to be overwhelming. Louis (54 years old) shared his concern that "there's a lot out there on the net...telling you what's good and what's bad...about eating and exercise", which he found to be overwhelming. Robert (64 years old) was particularly concerned about the information available citing "there's also some conflicting information and that's disturbing to me". The same participant shared that "I think that there's lots of resources available, choosing the right ones is the challenge".

One woman, with previous education in nutrition and exercise, shared her concerns, saying "It was very frustrating for me because they were giving standard advice, just the most basic that I am kind of surprised everybody wouldn't already know" (Kathleen, 61 years old). The same woman had come up against some barriers when she attended the CR nutrition courses. "They just got frustrated with me" she said, when she questioned the validity of the information they were providing (Kathleen, 61 years old). She came up against similar barriers when she met with the cardiologist:

I went back to the cardiologist, I printed out the reports from the internet, from the studies done...Mayo Clinic and other teaching universities...the cardiologist gave me a blank stare and said that this is our standard of practice. He wouldn't even discuss it...(Kathleen, 61 years old)

Those with less comfort with health information found the CR classes more helpful, tended to attend all of the available CR classes and tended to receive information

as it was presented to them, without question. Stan (63 years old) spoke of his experience at the CR nutrition class he attended, saying “she told me a lot of stuff that I didn’t realize”. Some participants were selective in the CR classes they attended. Louie (54 years old) felt that he did not need to go to the exercise portion of CR, saying, “my work being physical labor as a plumber... I was already exceeding the work that they were going to do, so I did not go to that”.

Relationship with Healthcare Providers

This refers to the participants’ degree of connection with the various healthcare providers involved in their care following their MI. Some participants had close relationships with their healthcare providers, while others saw their healthcare providers as only a point of contact with the healthcare system.

Family physician.

Several participants had well established relationships with their family physicians. One man described his longstanding relationship with his family physician and shared that, because of it, he could “do a lot of the work over the phone” (Louis, 54 years old). This made it simpler to access his physician as he had already returned to work after his MI. Marshall (73 years old) had a positive relationship with his family physician but had changed physicians after his MI to make services more accessible. “No point in us going to (the family physician in another town) anymore” he said, “because if anything goes wrong, we go to the hospital right here. Dr. XXXXX is good. I really like her, but you have got to go to (another town) for everything”. One woman referred to her relationship with her family physician as “a lady doctor and she is very good, very

knowledgeable...thorough on everything she does” (Evelyn, 60 years old), but never mentioned whether having a female physician was more beneficial for her.

Another man knew his physician on a more personal level sharing that they were “on a first name basis” and that they “were working together the way we should be as patient and doctor and I’m happy about that” (Robert, 64 years old). He further shared that “He’s a great guy, he is lovely, personality very friendly”. The same man also shared his appreciation that his physician was young and “into research and eager”. Bruce (55 years old) had a positive relationship with his family physician, but found it difficult to get an appointment with him:

He was the busiest man on earth, so I didn’t really see him very often. I would see other doctors within the clinic. To see him was easily anywhere from 30 to 55 days. I would say, book me in with anybody.

Having to see a variety of physicians in the same clinic did not appear to affect the care Bruce received. He was pleased with the physicians he saw, stating “I had good doctors...they were really good”.

One man’s family physician had retired around the time of his MI, so he was assigned a new physician from the same clinic. “I just got the cards dealt and I got a new doctor” (Will, 71 years old) he shared. This did not appear to affect the care he received. Another man had a similar experience. “I had a family doctor in (urban centre) who retired” he shared, “so I ended up going to see somebody and he became my family doctor by default” (Don, 63 years old). When asked about his relationship with his new family physician, he described it as “indifferent” (Don, 63 years old). He further shared that, “He is competent, that’s all I ask. He doesn’t have to be charming”.

A woman had a similar experience but lived in a community where permanent family physicians were rare. “They weren’t wanting to see me at the clinic because I didn’t have a family doctor” she shared “the family doctor I had left because he was a quack” (Kathleen, 61 years old). She further revealed that she had developed a working relationship with a physician on locum in the community:

There was one fellow...he was quite helpful. He would listen. He would just listen to my concerns and he didn't roll his eyes when I said I have read two library books, I've been online...I am finding out and doing my own research too. He seemed like he was well read and even up to date on information. (Kathleen, 61 years old)

One woman did not have a family physician because one was not available in her town, but she described her relationship with her nurse practitioner:

I am comfortable with her. I have known her for ...many years. Her daughter and my daughter were in the same class in school. I've known her since they started kindergarten, so I am comfortable with her. That to me is a huge thing. She's difficult to get into just because she is so busy. She's only in town 2 days a week, but it's still worth it. (Elizabeth, 48 years old)

Pharmacist.

Many of the participants had a positive relationship with their pharmacist. One man described appreciating how the pharmacist could provide information:

The pharmacist that I had here in town, he was an excellent individual. When I had a new prescription, he would print me out all this different stuff off of the website and hand it to me so I could read up. (Will, 71 years old)

Another man echoed this, saying “They’re good where we go. They explained everything and yeah, I am pretty happy with them” (Marshall, 73 years old). One man went to his pharmacist rather than his family physician when he had a question about his medications. “Their job is to know drugs” he shared, “I don’t want to take the wrong drug, that’s why I called my pharmacist” (Robert, 64 years old). Another man spoke of

his pharmacist “He was unbelievable, he was great to deal with, always checking my blood pressure” (Bruce, 55 years old). A few participants did not share the same sentiments of their pharmacist. One man described his relationship with his pharmacist as “just dispensing drugs (Stan, 63 years old). One woman, who was questioning the reasons for her medications, received a response from her pharmacist saying, “You should do what the doctor says” (Kathleen, 61 years old).

Specialists.

Some participants spoke about their relationships and experiences with their cardiologist and other more specialized healthcare providers with whom they came in contact. One man had a positive encounter with his cardiologist who took time with him, and spoke of his experience:

I was really impressed with him, like, he took at least a half hour of actually talking to me and went over my results, you know. Most doctors kind of give you the bums rush, two or three minutes of your time, they are busy. I was very impressed; he just took his time and I never felt rushed or anything. (Stan, 63 years old)

Another woman (Kathleen, 61 years old) had a different experience when she questioned her cardiologist’s plan of care. “I have seen three cardiologists so far” she shared. She had been passed from cardiologist to cardiologist, each trying to convince her to pursue treatments she was not comfortable with. She had been hesitant to take the medications she was prescribed because of the severe side effects they caused and wanted to know what other options were available to her. Her advocacy was met with resistance and frustration by each cardiologist as she refused to simply follow their plan of care without a reason.

One woman had been sent to a general internist to assist in determining the source of some continuing symptoms she was experiencing. The internist she wanted to see was away on vacation, so she was referred to another. She shared her experience:

There was another doctor she [my family physician] had sent me to in (the city). He's a specialist in internal, or an internalist. They took me for ultrasounds and stuff, but I never followed up with him, I think he's a quack... I never went back and saw him again...he was different. (Evelyn, 60 years old)

Cardiac rehabilitation nurse.

Two of the participants had been able to attend a local CR program before it closed. Both participants spoke about the positive experiences with the nurse who ran the program:

I was very impressed with the quality of service...maybe because the lady that ran it was really sharp. She was very committed to it...she had wonderful people skills, she was used to dealing with people, you know. It's not what you always expect of the medical system [someone charming, pleasant, and competent], quite often it's chaos, when you get into the system. No one knows who is doing what, you know, you get passed down the line, but this was good. I should've written a letter; it was so stupid. Right from the first second when I remembered this is a good deal, this lady is smart, somebody should be sending a letter to whoever, saying, hey, they are doing a good job of the program. (Don, 63 years old)

She was great to deal with, very open about everything, very professional, very honest...this is serious stuff, take it serious. I thought she was very personable and yet professional and very to the point. She was very, very upfront but personable still. (Bruce, 55 years old)

Social Support

This refers to the assistance and encouragement participants received as they recovered from their MI, accessed resources, and navigated the healthcare system. Participants had varied amounts of support. Those with more support reported having a more positive experience than those with less support. Stan (63 years old) shared about the importance of support. "I had excellent support" he said, "you wouldn't want to do

this alone". Evelyn (60 years old) had a high level of support, stating "I had people around all the time, which was nice because you do feel secluded just when you lose your license and live in the country". Alternately, when asked about her support systems, Elizabeth (48 years old) shared "I think that has been lacking", which caused her to feel lonely as she recovered from her MI and navigated the healthcare system.

Social support was obtained from family and friends, as well as other MI patients. All of the male participants reported having adequate support, while only two of the four female participants reported the same.

Family and friends.

Most participants cited their spouse as their main support. Louis (54 years old) relied on his wife to help him with nutritional changes. "My wife's done a lot more reading...she's trying to steer us in the proper dietary areas" he shared. Several other participants echoed this and had spouses who supported them by doing most of the cooking. They shared that they found it difficult to know how and what to cook now that they had to follow strict guidelines. One woman was thankful that her husband was able to take time off work to be with her. She shared that "he stayed home with me for the first three weeks" (Evelyn, 60 years old). She also shared that she was "lucky to have family [living] within 20 minutes (Evelyn, 60 years old). Another woman agreed that her husband had been supportive: "He has been wonderful. I cannot complain at how he has been at all. If anything, he is pretty much there helping me doing everything" (Elizabeth, 48 years old). Alternately, one woman indicated that she did not have support from her spouse: "He is not very supportive" she shared, "He's pretty healthy, so he doesn't understand anything [about my health problems]. She further revealed that "he wasn't

responding to me very well...and I was quite frustrated with that” (Kathleen, 61 years old).

Two participants had family members who were healthcare providers. One man shared that “they encouraged me, they told me what I needed to do, or not to do” (Bruce, 55 years old). Another man shared that his wife was a nurse and that she knew the best options for physicians in the area:

Because my wife is a nurse and we know people who are in the hospital, they are in the medical community, you get feedback on who is who. They would tell me he shouldn't be your first choice. (Don, 63 years old)

One of the older participants (Will, 71 years old) talked about the support he received from his daughters. “I got two daughters” he said, “They got their nose in my healthcare”. He also shared that “they try their best to keep me honest and make sure I eat lots of raw vegetables”. Kathleen (61 years old) shared that her daughter had been very supportive, but that she was busy with her own family.

One participant mentioned that there had been plenty of support for him, but that his wife was struggling with the lifestyle changes and felt she needed someone to talk with. The spouse shared how she felt:

I didn't know who to talk to about my stuff, about how it affected me. I felt selfish for even thinking that way because this is about him, it's not about me. But that feeling of wanting to control everything he does, almost panicking when he put something in his mouth, even dealing with the trauma of what happened [to him]. (Wife to Robert, 64 years old)

Several participants indicated that they had friends who were supportive. One woman had a group of women who supported her, particularly when she was unable to drive after her MI. “I was lucky enough to have good coffee row ladies” she shared, “They always made sure somebody picked me up or my husband dropped me off and

they brought me home” (Evelyn, 60 years old). After receiving support from a friend, one man decided to reciprocate the support to his friend, who had some health challenges:

We're good friends and good neighbors. It shocked him because he has some health problems and is way overweight, and he can't get laid up. So, I said, let's go to the college and look at the gym. Maybe we'll go over and see, take it for a month and see if we like going to the gym and working out. (Marshall, 73 years old)

Another man found support from his close friend who was a local doctor:

I bounced a few things off of him and informally he has given me his opinion of things. It helped alleviate a little bit of anxiety from time to time, and I was able to bounce a few things off my friend...that helped. (Stan, 63 years old)

Other MI patients.

Support from other MI patients was not something that was available to most participants, although several mentioned that they would have benefited from it:

If there were some sort of support groups for information...for people with previous heart attacks so they could get information about how they did things or what they did. And what was good and what wasn't good. Really, what worked and what didn't. (Louis, 54 years old)

The one thing I wouldn't have minded is one of those, you know, in-services to kind of just sit around with other heart attack patients and sort of discuss, well what was it like for them...compare notes. (Stan, 63 years old)

One of the participants commented that she had been part of a peer support program and had received visiting from another woman who had suffered a MI. This was found to be helpful:

She set me up with another lady...just to talk to...because of the pains I was having and she was having issues too...for the two of us to talk and say, hey, you're not the only person that's going through this, that they can't figure it out on. It was just nice to talk to somebody that was kind of going through similar things. (Evelyn, 60 years old)

Another woman found it beneficial to talk to her clients when she returned to work as a hair stylist, “I have clients and stuff that have had heart attacks, so we have talked about it...they are just kind of a sounding board really, I guess it just helps when you talk about it” (Elizabeth, 48 years old).

Taking Ownership

This refers to the participants’ willingness to take responsibility for and action over their health following their MI. Taking ownership was met with frustration for some participants and success for others.

Frustration was high for one woman, who had returned to work only two weeks after her MI and had tried several avenues locally in an attempt to begin her recovery. She had tried to access the local primary care network for advice on nutrition and exercise but had been denied access due to the acuity of her health. She also went to a local college to see if they had any exercise programs available. “They won’t even let me join any of the groups because I have had a heart attack” she shared, “I have tried everything” (Alice, 59 years old). Despite her fears and reservations, she decided to start her own exercise routine. “I am a competent swimmer” she said, “but I was scared to death” (Alice, 59 years old).

Another woman had a similar experience and was particularly frustrated with the lack of answers she was receiving to the questions she asked:

It was very disappointing...you are coming into (the city), you’re needing some input, you now, already feeling like I wasn’t being looked after because of the doctor situation in (local town), and then not even being able to ask questions without getting attitude. So, what was available at the (city hospital), I did make use of that. I even went and had my genetic, the DNA done to see if I have ...I don’t have any of the standard reasons for a heart attack. So, I am an oddball, I’m not the standard, you know what I mean. And even at the classes for the

cardiac aftercare, I was the only one who was asking questions. (Kathleen, 61 years old)

She ended the conversation by saying, “if you don’t fight for yourself, you don’t get the care. And even when you do fight for yourself, it [the care] seems to be quite limited” (Kathleen, 61 years old).

Having a positive outlook appeared to increase the success participants were having in taking ownership. One man showed acceptance of his life following an MI and shared his positive attitude saying, “You can’t cry because you don’t do it anymore, you’ve got to smile because you did it for 44 years” (Marshall, 73 years old). Having a positive attitude, he decided to take a closer look at his lifestyle. “Our diet has been fairly good” he shared, “I haven’t exercised enough, that’s the main thing, so I am up and moving” (Marshall, 73 years old).

Another man was not able to attend CR as often as he would have liked because of the distance to services and financial constraints he was experiencing, so he committed to doing more from home. “I’ve got a bike stand for my mountain bike and a roller and I am trying to do that with the recovery” he shared, “I am using whatever things I can that don’t cost as much” (Robert, 64 years old). He also accepted responsibility as a patient to “ask more questions and do a lot more research” when he was unsure (Robert, 64 years old). He finished his interview, saying

It’s your obligation to ask questions and to challenge whether or not the care that you are getting is the right care...I think that if I lacked the knowledge or determination to seek medical care I could be in trouble. I would rather do what I can for my health and not make those demands on the system. (Robert, 64 years old)

One woman was early in her recovery from her MI and had not accessed many of the resources that were available. After seeing her sister-in-law go through a heart attack and bypass surgery the previous year, she chose to be more independent and shared that “I’m trying to help myself a little bit more” (Elizabeth, 48 years old). Another woman had advice about moving forward: “The biggest thing is to get out of your house” she said, “You go crazy sitting in your house when you’re housebound”. Bruce (55 years old) said, “I just read on my own, books, and whatever I could find on the net” and gave advice to “make sure you’re pushing forward, you know, do your homework, understand your body a little bit”.

Availability of/for Cardiac Rehabilitation

Availability of CR refers to distance from services. Ten participants were referred to CR, but not all of them knew about the referral. One man got a call from CR a month after his MI asking why he “hadn’t come to see them” (Louis, 54 years old). A woman had a similar experience “I went back to work and then all of a sudden, I was sent some papers from (anonymized) hospital saying that I was booked for some kind of assessment and for cardiac rehab” (Alice, 59 years old). Most participants had to travel upwards of one hour to access CR, while two were able to attend a local CR program before it was closed by Alberta Health Services (AHS). One man described his challenge of getting to CR:

That’s part of the challenge...to get in there takes an hour. They want you to be on your meds at least two hours before you go in, and to have eaten at least two hours before you go in there, and you can’t go in there after 11 o’clock because you will pass their available slot...It would be a lot handier if I could just walk across town and just go across the tracks to the gym rather than having to use up a whole day or half day at least going to rehab in (urban centre). (Robert, 64 years old)

When asked about what made it difficult to access care, one man shared the following:

Just the physical distance. I have been told by some people, I know they used to have this cardiac rehab in (local town) until about two years ago, so that would have been nice, you know, to especially if you got into a physio program. Driving up to (urban hospital) two to three times a week can be a bit of a pain, I guess. (Stan, 63 years old)

Two of the men who attended the local CR program before it was closed had a different experience from those who had to travel outside of the community. They described their experience:

It made perfect sense for rural; you don't have to drive to (urban centre) ...It would've been a pain in the ass to drive to (urban centre]. This is summertime, right, so it's not that big a deal to go to (urban centre) but you know traffic is always bad. If it had been January, it's dicey times on the road... (Don, 63 years old)

The first months [after your MI] you don't drive, so for someone to take me to (local town) versus to (urban centre) is quite a difference, rural versus the city... even though after I did get my license back or was able to legally drive I preferred the going to (local town) versus going down to (urban hospital) or wherever it was in (urban centre). Trying to get someone to drive me into the city in the middle of the city versus (local town), it was quite a difference. (Bruce, 55 years old)

Bruce (55 years old) further shared what made it easy for him to access care, “I think (local town) because it was right at the bottom of the hospital, you know, a 10-minute drive for me to get there...”.

Availability for cardiac rehabilitation refers to the patient's ability and availability to attend CR. Findings indicated that availability was limited or non-existent for those who were working. A few participants who were back to work shared their difficulty:

There's no real availability for cardiac rehab that I saw... their stuff was scheduled from 8:00 in the morning 'till 3:30 in the afternoon. Those were the

hours they were available ... those hours I'm in the city...already working.
(Louis, 54 years old)

I haven't gone because I can't get to (urban hospital) because I have gone back to work now... I have gone back to work and the appointments were all set for during the day, so I have to take the whole day off work and I don't feel like driving to (urban hospital), staying there for an hour and coming back. (Alice, 59 years old)

I have just taken so much time off work that I don't wanna take anymore off and so I can't get any sort of rehab or counselling or nutritional advice and I think it's terrible, absolutely terrible. (Alice, 59 years old)

One woman shared that the inability to drive for the first month after her MI limited her ability to be fully immersed in the program. She shared that “we only went in twice a week. They would like you to go three times, but I didn't have a driver and my husband works so we went twice a week” (Evelyn, 60 years old).

One of the men interviewed was unemployed at the time of his MI, so he had the time to attend CR, but financial restraints were a concern for him. He shared that “I don't have a lot of money to go spend on training programs...I don't have a healthcare program or insurance right now” (Robert, 64 years old). He further shared that, “I am impressed that they have got a flexible fee schedule... they don't want the fees to be a barrier” (Robert, 64 years old).

Those participants who were retired had fewer barriers to attending CR. Most found the location inconvenient but travelled to attend regardless. One gentleman shared that “when you live out of town it is (an inconvenience). I mean it's not like I had anything pressing going on, but it was a bit of an inconvenience” (Will, 71 years old). Another man who was waiting to start the exercise portion of CR shared that it “was my

preference, to go to (smaller urban hospital instead of larger urban hospital) from traffic point of view” (Stan, 63 years old).

Chapter 5 Discussion

The process that rural patients go through to access healthcare, including CR, after a MI was explored in this study. The core category was being uncertain (which included being uncertain about plan of care, feeling lost/alone in the system, having questions, and asking how to proceed). Five other categories related to uncertainty emerged from the data: comfort with health information, relationship with healthcare providers (family physician, pharmacist, specialists, and cardiac rehabilitation nurse), social support (family and friends, and other MI patients), taking ownership, and availability of/for cardiac rehabilitation. The study findings have helped to further identify the process that rural patients go through to access care after they have a MI and illuminated areas where rural healthcare can be improved.

Being Uncertain

Participants expressed varying degrees of uncertainty while accessing care after their MI. Uncertainty was exemplified in not knowing the plan of care, feeling lost/alone in the system and having unanswered questions. Some uncertainty is expected as a component of the illness experience (McCormick, 2002). Consistent with other studies (Brieger & Redfern, 2013; Waibel, Henao, Aller, Vargas, & Vazquez, 2012), some participants planned and coordinated their own care by contacting physicians or CR and organizing other appointments as necessary. In a study by Valaker et al. (2017), using in-depth interviews of 22 patients at six to eight weeks following PCI, findings suggested that participants were not always happy that they had to make appointments and organize arrangements themselves. This additional work provided a degree of uncertainty for participants about how to live during the recovery period. These patients identified

feeling anxious and confused as they waited for ‘a call’, and some participants felt abandoned by the health care system (Valaker et al., 2017). We found similar results in our study, where some participants were frustrated that they had to organize their own appointments and care, while others chose to wait for healthcare professionals to contact them with details of care plans, sometimes waiting weeks to receive any direction. Some of these uncertainties rest within some key transitions, particularly the transition from hospital to home after MI. Kangovi et al. (2012) found that some of most common reported challenges for patients during the transition from hospital to home were feeling unprepared for discharge and having a lack of social support. Similarly, many of the participants in our study felt unsupported in their hospital to home transition. It is essential that patients are well-supported in their transition home, particularly for those that live in rural settings with more limited access to supports and healthcare services. Improvement in this area would not only improve the experience of care, but potentially lead to improved patient outcomes. Snow et al. (2009) suggested that implementing standards of care, such as a minimal list of patient data (i.e. diagnosis and problem list, medications, contact numbers for physicians and institutions involved in care, patient cognitive status, and test results) as part of the transition record to address the gap in patient transition from hospital to home, would be beneficial in reducing these issues.

Having unanswered questions increased uncertainty for participants. Patients need to be able to ask questions and discuss issues related to their health and plan of care (Brasher, Neidig, Russel et al, 2003; Grimsbo, Finset, & Ruland, 2011), otherwise informational needs remain unmet (Chewning et al., 2012; Weiner et al., 2013) Knowing what questions to ask and lack of comfort in asking questions have also been shown to

influence the patient experience (Powell, Doty, Casten, Rovner, & Rising, 2016). Studies have shown that increased clinician-patient communication can assist in mitigating uncertainty by allowing patients to ask questions, getting them involved in the decision-making process, and helping to clarify their individual goals for treatment (Street, Gordon, Ward, Krupat, & Kravitz, 2005). Further, for communication to be more patient-centered, it needs to be uncomplicated, specific, repetitious, minimizing medical jargon, and ending with a confirmation of patient understanding (Silk, Westerman, Strom, & Andrew, 2008; Zolnierek & DiMatteo, 2009).

Information at Discharge

The perceived amount of information received on discharge from hospital appeared to set the trajectory for the participants' experience of accessing care following their MI. Many of the participants perceived that they did not receive sufficient information and therefore, did not know what to expect in their recovery. These findings are consistent with other studies, where patients felt discharge communication was poor causing them to have difficulty navigating the healthcare system (Barnason et al., 2012; Haggerty, Roberge, Freeman, & Beaulieu, 2013; Mead, Andres, Ramos, Siegel, & Regenstein, 2010; Sampson, Cooper, Barbour, Polson, & Wilson, 2015; Waibel et al., 2012; Zimarino, Ruggieri, & De Caterina, 2010). Without adequate information at discharge patients are at risk for complications and for readmission to hospital (Askham et al., 2010; Ryan, Aloe, & Mason-Johnson, 2009) and lower quality of life (Haggerty et al., 2013). In a qualitative metasummary of 33 studies, Haggerty, Roberge, Freeman and Beaulieu (2013) found that knowing what to expect on discharge provided a sense of security for patients, in addition to having continuity of care.

Most participants in our study noted that bedside nurses gave discharge instructions. Indeed, bedside nurses are usually responsible for discharge teaching (Yu, Thompson, & Lee, 2006) and assisting the patient to understand medications, diet restrictions, appropriate activity levels, and guidance about follow-up appointments (Dickens, Lambert, Cromwell, & Piano, 2013). Depending on the hospital (urban or rural) or hospital unit on which the patient is placed, nurses may not always have specialized training related to cardiac care (Manning, 2011), which may alter the types and quality of discharge information that patients receive. Redfern and Briffa (2014) noted the importance of discharge teaching for patients as they transition to a new lifestyle, start medications that may be new to them, and learn how to coordinate the many healthcare providers involved in their care. Similarly, Valaker et al. (2017) found that patients needed clear instruction in order to navigate the healthcare system and participate in their plan of care. Yet, research indicates that patients are not receiving this valuable person-centered information and are instead, receiving routine discharge instructions (Halasyamani, Kripalani, Coleman et al., 2006; Jack, 2009).

Kilonzo and O'Connell (2011) found that shortened hospital stays and increased emotional strain may contribute to poor synthesis of health information. In a qualitative study of 40 patients, Foust, Vuckovic, and Henriquez (2012) found that patients preferred receiving discharge instructions both verbally and in writing, so they would have something physical with them to refer to if they had questions. Receiving only verbal instruction was met with forgetfulness later, especially for patients who were overwhelmed with the whole experience (Foust et al., 2012). Most of the participants in this study described feelings of shock and emotional strain on initial diagnoses and would

have benefitted from having both verbal and written discharge instructions they could refer to later. Some participants did receive written discharge information, but it was described as either 'basic' or the medical jargon included in it prevented them from gaining any real value from it. Thus, greater consideration of the development of appropriate educational materials, along with effective strategies for supporting the uptake of information, should be prioritized.

Information Post-Discharge

Following discharge, most study participants relied on the internet as a resource for health information, which is not uncommon today and important for those who are rural living as they do not always have access to in-person education and health information. Consistent with other research, navigating the vast amount of health information available on the internet proved to be a challenge, particularly with understanding medical jargon and determining credibility of information (Bates, Romina, Ahmed & Hopson, 2006; Wathen & Harris, 2007). This leaves the patient seeking information to distinguish reliable versus unreliable websites themselves (Goldman, Braasch, Wiley, Graesser, & Brodowinska, 2012). Challenges are well documented regarding conflicting information found on the internet. In a secondary study of 328 patients focused on conflicting medication information, Carpenter et al. (2014) found that amongst other information sources, the internet was a common source for conflicting medication information. The internet further presented an overabundance of conflicting information about a variety of health topics (Mashiach, Seidman, & Seidman, 2002; Mankoff, Kuksenok, Kiesler, Rode, & Waldman, 2011). The ability to navigate and

discern which of the various websites are acceptable resources is also linked to health literacy, as described below.

Comfort with Health Information

Health literacy is defined as “the degree to which individuals can obtain, process, understand, and communicate about health-related information needed to make informed health decisions” (Berkman, Davis, & McCormack, 2010, p. 16). Though health literacy was not explored specifically in this study, it was clear that some participants appeared to have greater ease with managing health information relative to others. Although research indicates that those living in rural areas are at risk for lower levels of health literacy (King et al., 2006; Nielsen-Bohlman, Panzer, & Kindig, 2004), health literacy levels varied amongst our study participants. Higher levels of health literacy were exemplified in those who were able to use the information presented to them, ask questions, and advocate for themselves in their care journey. In a re-post observational analysis study of 191 patients enrolled in a CR program, findings indicated that those with higher levels of health literacy had a greater increase in knowledge after participating in CR education compared to those with lower health literacy (Mattson, Rawson, Hughes, Waechter, & Rosneck, 2015). We found that those with apparent lower levels of health literacy identified they also increased their knowledge after participation in CR.

Alternately, lower levels of health literacy were exemplified in those had some degree of difficulty implementing the information provided and using it to ask necessary questions or advocate for themselves. Dickens, Lambert, Cromwell, and Piano (2013) found that nurses often overestimated patients health literacy levels in hospital, which translated to poor communication about patient expectations before they were even

discharged home. This left those with lower health literacy misinformed or lacking understanding of their disease and plan of care. Additionally, Mattson et al. (2015) indicated those with lower levels of health literacy would require additional education to improve their knowledge level even after attending CR education classes.

With the use of the internet as a resource for health information by most study participants, it is important to recognize eHealth literacy. Degree of eHealth literacy has been shown to effect patients' ability to effectively navigate online health information. A study by Neter and Brainin (2012) found that those with higher eHealth literacy were more likely to cautiously evaluate and analyze the online health information they found, examining it for validity and reliability. Additionally, those with higher eHealth literacy were able to gain a deeper understanding of their disease, improving their ability to self-manage their care (Neter & Brainin, 2012). Although e-Health literacy was not measured in our study, participants appeared to have varying levels. The majority appeared to have lower levels of eHealth literacy as they had difficulty discerning credible sources of health information to answer their health-related questions and assist them in their recovery.

Relationship with Healthcare Providers

Most participants developed positive relationships with healthcare providers and particularly with their family physicians. This is consistent with findings from Wathen and Harris (2007), who discussed the value of a positive relationship with HCP. However, when physicians were not seen as supportive, participants sought out answers from those that were willing to spend more time hearing their concerns, often family and friends who worked in the healthcare field (Wathen & Harris, 2007). Most participants in

our study discussed their relationship with their cardiologist on a basic level. They were satisfied with the relationship as long as there was two-way communication during their appointments and understood that the cardiologist had limited time to spend with them in their full schedule. Further supported by literature, trust in the physician as someone who communicated clearly was also found to be important to participants (Cain et al., 2012; Petricek, Buljan, Prljevic, Owens & Vrcic-Keglevic, 2015). Participants in our study and others (Cain et al., 2012; Petricek et al., 2015) appreciated when their thoughts and concerns were heard, when they were able to openly converse with their physician, and when the physician made time for them (Tarrant, Windridge, Boulton, Baker, & Freeman, 2003). More positive relationships were found amongst those who had consistent providers and more frequent visits to them, giving them time to establish a trusting relationship (Spooner, Salemi, Salihu, & Zoorob, 2016). This was echoed in further research, where seeing the same family physician had a positive impact on the patient-doctor relationship (Von Bultzingslowen, Eliasson, Sarvimaki, Mattson, & Hjortdahl, 2006; Pandhi, Bowers, & Chen, 2007). Conversely, and consistent with findings from Spooner et al. (2016), those that felt their health needs were not being adequately met were less satisfied with their HCP relationship. Participants commented on the personability of their family physician as a potential indicator for satisfaction, as well as their ability to explain things clearly and involve them in decision making, which is supported in other literature (Von Bultzingslowen et al., 2006; Pandhi et al., 2007). Others were satisfied with their physician, regardless of the relationship, and commented that they were satisfied as long as the physician was knowledgeable and competent. Supporting a therapeutic relationship between the patient and healthcare provider may

optimize patient satisfaction and care. Wathen and Harris (2007) found that satisfaction with HCPs, including family physicians and cardiologists, was linked to satisfaction with health outcomes.

Pharmacists were also seen by most participants as integral to their recovery. They were seen as the expert for all things related to medications, even over the family physician. Consistent with our study, a study by Phatak et al. (2016) found that pharmacists can have a positive impact on helping patients transition from hospital to home by providing much needed education about medications and their side effects.

Social Support

Social support was an important part of each participants recovery. It is particularly important for rural patients, as they are unable to drive to appointments in the weeks following their MI and do not have the same access to public forms of transportation as urban dwellers. Cain et al. (2012) echoed our participants description of the importance of support from family, friends, and neighbors as they relied on others to drive them to and from appointments and to help with household duties during the initial recovery phase.

Often women, compared to men, report a lack of social support following their MI (Kristofferzon, Lofmark, & Carlson, 2003) as well as desire to have social support (Kristofferzon et al., 2003; Sjostrom-Strand & Fridlund, 2007). However, this was not the case with all of the women in our study. Lack of social support, in general, can have a greater impact on how patients adjust to their life after their MI (Lurie, Myers, Goldbout, & Gerber, 2015), increasing the risk for a repeat MI and decreasing their quality of life (Bucholz et al., 2014; Bucholz et al., 2011; Leifheit-Limson et al., 2012; Sararoudi,

Sanei, & Baghbanian, 2011). Conversely, all of the men in the study perceived they had adequate social support from family and friends and determined that they would not have been able to cope well without it. Spouses were found to be the most important social support for participants, followed by children and friends. These findings are corroborated by the outcomes of other studies that have examined spousal support following cardiac events (Jensen & Petersson, 2003). For example, Jensen and Petersson (2003) found that spouses were the primary support person following MI.

One aspect that most participants felt was missing was support from other MI patients. Many felt they would have benefited from talking with other MI patients about their experiences. Only one participant was connected formally with another MI patient for support. The results of this connection were positive for the patient as she felt encouraged by being able to talk with someone who was going through the same things. Other research also indicates it is beneficial for patients to be able to talk with others who were going through the same experience as it assisted them in managing their daily lives (Junehag, Asplund, & Svedlund, 2014). There is need for greater access to peer support during the early recovery period following an MI. A systematic review by Sokol and Fischer (2016) found that peer support is a powerful strategy for reaching groups that are often disengaged from health services. Increasing opportunities for peer support could be a viable option for rural communities that may lack access to other more formal forms of support.

Taking Ownership

The findings of this study showed that participants took ownership of their health following their MI in a variety of ways and that it was met with either frustration or

success. It is important for patients to be active participants in their recovery (Sol, van der Graff, van Petersen, & Visseren, 2011) as it enhances the recovery from a cardiac event (Maeda, Shen, Schwarz, Farrell, & Mallon, 2013; Rodgers, Murray, Selzler, & Norman, 2013; Sharp & Salyer, 2012) and minimizes learned helplessness (Smallheer & Dietrich, 2019). The literature describes ownership more in terms of self-efficacy, which can be described as how an individual thinks, feels, behaves and motivates themselves (Bandura, 1995). Additionally, “people’s self-efficacy beliefs determine their level of motivation, as reflected in how much effort they will exert in an endeavor and how long they will persevere in the face of obstacles” (Bandura, 1989, p. 1176).

Those participants that were dissatisfied had taken ownership by seeking out the necessary resources to aid in their recovery but were met with roadblocks or turned away by local healthcare resources. Those participants who had to return to work were unable to access out-of-town resource in urban centres, increasing their dissatisfaction and feelings of helplessness. In a correlational, cross-sectional study of 75 patients focused on social support, self-efficacy, and helplessness following MI, Smallheer and Dietrich (2019) found that when patients were active participants in their recovery, they were less likely to have feelings of helplessness. Some of the participants in our study took active roles in their recovery, but still had feelings of helplessness.

Having a positive attitude and outlook on life appeared to contribute to the success of taking ownership of health for some participants, regardless of whether or not they were met with resistance in accessing care. A study by Jensen and Petersson (2003) found similar results including positive life-orientation, happiness, stubbornness, and humor as contributors to a successful experience in recovery from MI.

Availability of/for Cardiac Rehabilitation

Availability *of* CR refers to distance from services. CR services tend to be located in larger urban centres, which are not always easily accessible to rural patients. A well-documented barrier to CR attendance is the location (i.e. distance from home) of the program (Caldwell, Arthur, & Rideout, 2005; Fernandez, Davidson, & Griffiths, 2008; Macintosh, Lacey, & Tod, 2003; Wingham, Dalal, Sweeney & Evans, 2006) and is one of the main reasons these rural patients choose not to attend. Though most of the participants in this study attended CR to some degree, they certainly identified location of services as being an inconvenience for them.

Availability *for* CR refers to the patient's ability and availability to attend CR. Consistent with a study by Jensen and Petersson (2003), findings suggested that participants were not always available to attend CR due to timing of services, expenses of transportation, returning to work, or not seeing the value of attending. Those participants who were back to work cited timing of services as a barrier for them. Services were only offered during daytime hours, which was not conducive to the schedule of several participants. Similar to other studies (McCorry et al., 2009; Tolmie et al., 2009) one participant saw limited value in attending CR as he felt he was provided with enough exercise at his job and in his day to day living. The need for support from family or friends to get to and from CR is also documented in the literature (Caldwell et al., 2005; Rolfe, Sutton, Landry, Sternberg, & Price, 2010) and was seen as necessary to participant attendance, particularly in the weeks following MI when participants were unable to drive. Encouragement from physicians was a facilitator for attendance and has been shown to be a motivator (Banerjee, Grace, Thomas, & Faulkner, 2010).

Notably, some study participants would have benefited from access to home-based programming, as they were unable to access services due to timing and location. Madden, Furze, and Lewin (2011) found that many patients could benefit from home-based programming, but it is not always offered as an option. Evidence shows that there are no differences in outcomes for home-based versus centre-based CR and that those who participate in home-based programs have marginally higher levels of completion and program adherence (Anderson et al., 2017; Turk-Adawi, Sarrafzadegan, & Grace, 2014). Additionally, use of innovative smartphone enabled homecare CR models (Varnfield et al., 2014), technology, and tele-health interventions have been found to assist in overcoming barriers to accessing centre-based CR programs (Huang et al., 2015) and tailored home-based programs have offered support for patients and their families, increasing coping skills (Frohman, Lin, & Chaboyer, 2015). However, these types of programs tend to be costly (Anderson et al., 2017) and are not available in all areas (Turk-Adawi et al., 2014).

Rural-Urban Disparities

There were no striking differences in the rural living participants' access to care post MI. The only notable difference was the location of services for rural patients (i.e. the distance for traveling to services), which has been well-documented in previous literature (De Angelis et al., 2008; Shanmugasegaram et al., 2013; Valencia et al., 2011). Perhaps services for rural-living patients are improving relative to what earlier literature reports about barriers. The research identified in the literature review is often upwards of ten years old and may not reflect current disparities.

Study Strengths and Limitations

While there have been studies undertaken about rural patients accessing healthcare and CR following MI, the majority are focused mainly on the facilitators and barriers to accessing care. To our knowledge, this is the first study using a grounded theory approach in gaining a better understanding of the process that rural patients go through to access healthcare and CR following an MI.

This study has some limitations to consider. A relatively small sample size (though consistent with grounded theory research (Corbin & Strauss, 1990)), could render limited generalizability of the results. Participants were self-selected, and those who volunteered to participate could have a different experience from those who declined. Additionally, this study was limited to one region. Further study is needed across Canada and beyond to further explore this.

Implications for Practice

Providing patient-centered discharge information and instructions is essential to set patients up for a successful experience following MI. This process includes assessing health literacy level prior to health teaching, having discharge information in writing for patients to refer to when they go home, providing a list of credible online resources for patients to access for information regarding their diagnosis and care, and providing an expected plan of care prior to discharge. In a system where hospital discharge is often rushed and generic, it is essential that healthcare providers, particularly nurses, take the time to address patient education needs. As nurses may not be trained specifically in cardiac care in rural areas, additional education may be necessary to assist them in

offering adequate discharge instructions and information to patients to set them up for a successful recovery.

Research has shown that home-based CR programs can be successful and are beneficial for rural patients (Anderson et al., 2017; Dalal et al., 2010). Therefore, it might be prudent to offer more patients the opportunity to participate in these programs, particularly those that are unable to attend urban-centered CR programs.

Lack of access to support from other MI patients and families appears to be a common issue amongst MI patients. Having access to this type of support may help to alleviate some of the stress patients feel about dealing with their diagnosis and new life as MI survivors. Additionally, having support for spouses and family members who are involved in their day-to-day lives could assist them in offering positive support to their loved ones.

Implications for Research

There are a series of studies that could spring from this research. They include an investigation of : (1) whether health literacy impacts a rural individual's choice to follow through with CR; (2) the effectiveness of discharge information based on level of health literacy; (3) the relationship between health literacy and education level to determine if further educational interventions need to be done with individuals who have higher education levels; (4) and the impact of home-based versus hospital-based CR programming for rural individuals. Additionally, a larger scale research study, such as a survey, could be used to determine educational preferences

Chapter 6 Conclusion

While there have been several studies undertaken about CR access and the facilitators and barriers to CR for rural patients (Caldwell & Arthur, 2009; De Angelis et al., 2008; Shanmugasegaram et al., 2013; Valencia et al., 2011), none have focused upon the process of accessing CR and its impact. In a Straussian grounded theory study of 11 participants, we examined the process that rural-living MI patients go through following their hospital discharge. Though participants identified uncertainty as they navigated the healthcare system from hospital discharge to maintaining health, much of their experience was not different than the experience of urban-living patients. However, distance to access resources was indeed a concern that could be addressed through better access to distance/online programming. A large part of increased uncertainty stemmed from a lack of perceived information at and post-discharge. This could be addressed through more individualized discharge teaching and plans of care.

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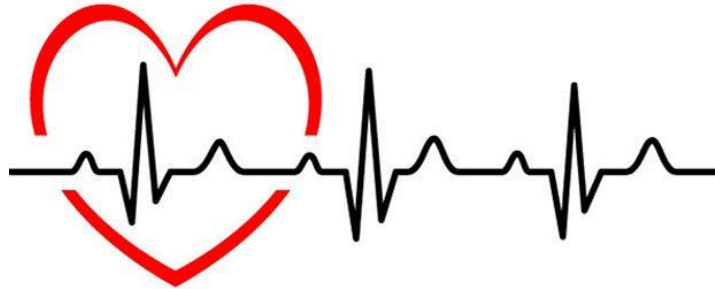
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APPENDIX A: RECRUITMENT FLYER - HOSPITAL

Have you recently had a heart attack?

We are looking for research volunteers!

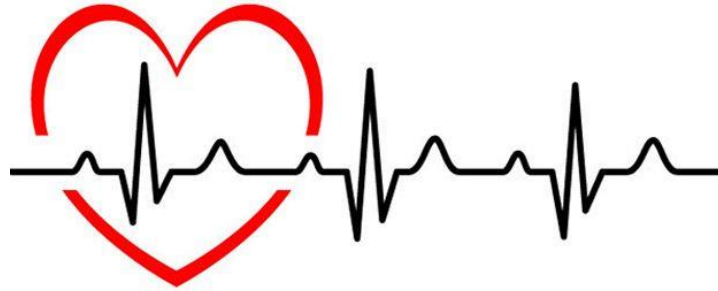
We would like to talk with you about your experience with accessing care after your heart attack. We can talk to you by phone or in person.

For more information and to see if you qualify, please **tell your nurse** and he/she will connect you with the researcher.

Or you can call local **403-220-8069** or toll free **1-866-867-5055** and leave a message (including your name and telephone number). We will return your call to explain the study.



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APPENDIX B: RECRUITMENT FLYER – COMMUNITY

Have you recently had a heart attack?

We are looking for research volunteers!

We would like to talk with you about your experience with accessing care after your heart attack.

We can talk to you by phone or in person.

For more information and to see if you qualify, please call local **403-220-8069** or toll free **1-866-867-5055** and leave a message (including your name and telephone number).

We will return your call to explain the study.



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APPENDIX C: CONSENT FORM



STANDARD CONSENT FORM

TITLE: How patients access cardiac rehabilitation and care after acute myocardial infarction.

INVESTIGATORS:

Kathryn King-Shier, RN, PhD, FESC, Principal Investigator
Andrew Estefan, RPN, PhD
Davina Banner-Lukaris, RN, PhD
Erin Lowe, RN, Master of Nursing Student

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

BACKGROUND

It is important that people who have had a heart attack have regular checkups with their doctor. It is also important that heart attack patients attend cardiac rehabilitation. Yet, researchers have found that people living in rural areas may find it hard to access health care and cardiac rehabilitation.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to examine how rural patients access health care, including cardiac rehabilitation, after they have a heart attack.

WHAT WOULD I HAVE TO DO?

If you have recently had a heart attack, you will be asked to participate in up to 3 interviews over a period of 2-3 months. If you had a heart attack more than 6 months ago, you will be asked to participate in one interview that will last approximately one hour. You will be asked some questions about your experience of accessing care after your heart attack. You do not have to answer any questions you do not wish to

answer, and you may terminate the interview at any time. The interview will be audiotaped to make an accurate record of what you say during the interview.

WHAT ARE THE RISKS?

There are no foreseeable risks to you as a result of your participation in this research. However, you may become fatigued as a result of study participation. In that case you may ask to stop the interview and resume at another more comfortable time.

WILL I BENEFIT IF I TAKE PART?

There are no direct benefits as a result of your participation, although the information provided for this study may be of benefit to other heart attack patients in the future.

DO I HAVE TO PARTICIPATE?

Voluntariness and Withdrawal of consent

Your participation in the study is voluntary and you may withdraw from the study at any time without jeopardizing your health care. You may withdraw by contacting the central research office (see number below) and leaving a message.

Withdrawal of Study Data

You cannot withdraw from the study once data analysis has begun. Data cannot be withdrawn if it has been published or otherwise disseminated.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for participation in this study and you do not have to pay for participating.

WILL MY RECORDS BE KEPT PRIVATE?

The research investigators, transcriptionist, and the University of Calgary Conjoint Health Research Ethics Board will have access to the information collected. Your identity will only be disclosed to the researcher conducting the one-on-one interview. You will remain anonymous as a study participant by: removing any identifying details from the interview transcripts and reporting only aggregate data (e.g., the average age of study participants) or anonymized data. Authorized representatives from the University of Calgary and the Conjoint Health Research Ethics Board may look at your identifiable study records held at (*Kathryn King-Shier's office, University of Calgary*) for quality assurance purposes.

SIGNATURES

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Kathryn King-Shier

Or

Pamela LeBlanc (research manager)

Local: 403-220-8069

Toll free: 1-866-867-5055

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

Participant's Name	Signature and Date
Investigator/Delegate's Name	Signature and Date
Witness' Name	Signature and Date

The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX D: DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

Age: _____

Marital Status:

Married/common-law _____

Divorced/separated/widowed _____

Single _____

Habitation:

With spouse only _____

With spouse and (un)married children _____

With (un)married children _____

With other family members _____

Alone _____

Highest Level of Education:

None _____

<High School (or equivalent) _____

>High School _____

Employment:

Employed outside home full-time _____

Not employed/retired _____

Homemaker throughout life _____

AMI:

STEMI _____

Non-STEMI _____

Intervention While in Hospital:

Cardiac catheterization _____

PCI _____

CABG _____

Other _____

APPENDIX E: INTERVIEW GUIDING QUESTIONS

Interview Beginning Guiding Questions

1. Tell me about your heart attack and what happened after you were discharged from hospital.
2. What referrals did you receive?
3. What advice were you given, if any?
4. Tell me what has made it difficult for you to access care after your heart attack?
5. Tell me about what has made it easy for you to access care after your heart attack?
6. Where have you gone to access care after your heart attack?
7. What have you done to access care after your heart attack?
8. Have you had any help accessing care after your heart attack?
9. Have you been satisfied with the process? If so, why? If not, why?