University of Alberta

The Perceptions of Continuity of Care of Rural Albertans Following Acute Myocardial Infarction

by

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A thesis submitted to the Faculty of Graduate Studies and Research

in partial fulfillment of the requirements for the degree of

Master of Nursing

Faculty of Nursing

Edmonton, Alberta

Spring 2006

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Your file Votre référence
ISBN: 0-494-13767-3
Our file Notre référence
ISBN: 0-494-13767-3

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This thesis is dedicated to my sisters, both of whom have shaped my academic journey throughout the years. To my sister Kay, who introduced me to nursing research in 1969 through her work at the University of Saskatchewan. She personified excellence, both in nursing and in research, and her memory motivates me still. To my sister Pat, who has always been there for me, to provide support, encouragement, and enthusiasm. She remains the personification of both continuity and caring in so many lives. I am indebted to them both.

Abstract

This study explores the concept of continuity of care from the perspective of survivors of post myocardial infarction that live in rural central Alberta. It was designed to understand the patient's perspective of continuity of care and to build on previous research conducted by experts in the field. Data analysis revealed support for the theoretical concept of antecedents and consequences of continuity of care proposed by Glenn in 1996 and the indicators of integrated health care proposed by Leatt, Pink and Guerriere in 2000. The analysis also supported the three types of continuity proposed by Reid, Haggerty and McKendry in 2002, while suggesting that relational continuity may be more significant from the patients' perspective than previously thought. The findings have relevance for researchers in the field of continuity of care and those examining ways in which clinical care and outcomes for people suffering an AMI can be improved.

Acknowledgements

I am indebted to many people for their support, encouragement, and assistance as I traveled this road to further my education:

To my husband, Jack, for his patience, good humor, and ability to "prod" me along when it all seemed insurmountable.

To my family, for their understanding and patience when "Grandma had to do her homework."

To the members of my thesis committee, Dr. Katherine Moore and Dr. Sharon Warren, whose knowledge and research expertise assisted the development and fruition of this project.

And to my supervisor, Professor Donna Lynn Smith, for her guidance and support throughout the entire process. I could not have done this without you.

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CHAPTER 1:

INTRODUCTION AND STATEMENT OF THE PROBLEM

Continuity of care is one of the important building blocks of quality healthcare for patients. It enables efficient, effective health care at an affordable cost that meets the needs of the client, the healthcare system, and society. Continuity of care can be challenged by the complex healthcare needs of patients, especially when those needs require the services of many different providers in diverse areas (Hollander & Prince, 2002; Leutz, 1999; Smith & Smith, 1999). Continuity of care has been studied extensively from the system perspective in such areas as informational, management, and relational continuity (Reid, Haggerty, & McKendry, 2002). Most research to date has focused on the benefits to the system, primarily in cost containment. Client outcomes based on observable measures of improved health, such as hospital readmission rates and decreased disease complications, have also been studied as indicators of continuity of care.

The patient's perception of continuity of care and what is important to patients as they traverse the health care system is missing from the research to date (Centre for Health Services and Policy Research [CHSPR], 2004; Glenn, 1996; Harrison & Verhoef, 2002; Newhook, 2004). Instead, health care providers have designed programs that they thought would improve continuity of care, and patients are then asked, "How did the interventions work?" The lack of the patients' perspective on continuity of care has been recognized as an important piece of information that must be explored to ensure that that which is truly effective for clients is not omitted (Haggerty et al., 2003; Heart and Stroke Foundation of Canada [HSFC], 1999; Newhook, 2004).

The literature has pointed to transitions in care, whether from facility to facility or between various providers, as areas where continuity of care is most likely to be disrupted. People who live in rural Central Alberta and suffer an acute myocardial infarction (AMI) experience many transitions in their care. Often these people cannot access care in their home community by their usual provider, but instead require transfer to a tertiary care facility in an urban center for care under a cardiac specialist. The complexity of care and the often underlying co-morbidities associated with heart disease, such as diabetes and hypertension (HSFC, 1999), often necessitates the need for a variety of care providers over an extended period of time. Adequate, appropriate follow-up and treatment of the patient who suffers an AMI is essential to prevent or limit long-term complications and to preserve the patient's quality of life.

Purpose of the Study

An exploratory descriptive study was designed to describe the experiences of patients who reside in rural central Alberta and who received specialist treatment for myocardial infarction (AMI) in an urban tertiary care center. This information will increase knowledge of the patient's perspective of important aspects of continuity of care in general and in the AMI population in particular. Specific issues related to continuity of care for rural populations will also be identified. The information will serve to broaden the knowledge base of continuity of care in an area that has been identified as deficient and will contribute knowledge to inform changes in policies and procedures to meet the needs of the client and not just the needs of the system.

Significance of the Study

As the population of Canada ages, the incidence of ischemic heart disease and AMI is expected to increase. The HSFC (1999) estimated that by 2016 there will be 70,000 hospitalizations for AMI in Canada, which is a 20% increase from the 57,000 hospitalizations for AMI in 1994. Whereas the rate of hospitalizations for heart disease has increased in recent years, the incidence of mortality from AMI has decreased. Therefore, there is an ongoing need for coordinated and integrated health care services for this population.

Research has been conducted to explore the experiences of survivors of AMI. A common theme identified is patients' desire for, or perceived lack of, relevant information related to their disease and their course of treatment (Fleury, Kimbrell, & Kruszewski, 1995; Jensen & Peterson, 2002; Svedlund & Danielson, 2004). Inadequate information about their condition and unsatisfactory follow-up were identified as consequences of poor continuity in Biem and Hadjistavropoulos's (2004) study of patients with congestive heart failure or atrial fibrillation. In their research they used patients' perspectives of continuity of care to evaluate the efficacy of an integrated care pathway for patients who experience atrial fibrillation or congestive heart failure. Information dissemination and follow-up care were improved for the group who experienced congestive heart failure after the introduction of the integrated care pathway, but no improvement was noted in the atrial fibrillation group.

Because of the high incidence of AMI and the associated potential consequences, it is important to improve the integration of services to achieve continuity of care for AMI patients. Improved continuity for this population is expected to lower the costs of care and improve the safety and quality of care that patients experience. Published research on continuity of care has focused primarily on factors such as service utilization, cost, and system organization. Little published research has focused on the perspective of patients or families or on the experiences of vulnerable populations (Newhook, 2004). The experiences of citizens living in rural communities have not been a focus in continuity of care research, and the services and patterns of service for rural residents have changed with the development of regional governance and health authorities. These factors led to the decision to conduct an exploratory descriptive study of patients who reside in rural Alberta who have experienced an AMI and who had received specialist treatment in an urban tertiary care center. The broad objective of the study was to develop an understanding of the experiences of these patients as they make their health care journeys from home to hospital to home again.

Exploratory descriptive research studies are indicated when there is very little information on the topic, as in this case, and may provide information for hypothesis generation (Brink & Wood, 1994). Although there is little information regarding continuity of care for AMI patients, previous research has been conducted on the health care journeys of survivors of traumatic brain injury (Smith, 1998). Caregivers of persons surviving traumatic brain injury were able to recount their experiences with the health care system as they arranged services for the survivor. Smith obtained the data through semistructured interviews by using guiding questions to elicit information on continuity or discontinuity of care. Content analysis of the eight interviews revealed four underlying themes: (a) the search for information, trust, and understanding; (b) the search for support; (c) the need to speak on behalf of the survivor; and (d) navigation of the system.

The same guiding questions that Smith used to gather data study were amended and used in this study.

Research Context of Study

This research was conducted as a substudy under the auspices of the nationally funded research program LINCS, an acronym referring to Listen, Innovate, Navigate, Connect and Share. The research program was designed to develop a client-focused understanding of how continuity of care can be improved through policy and management decisions in the health system.

Definition of Key Terms

1. **Patient:** In this study the term *patient* is used to describe individuals who experienced and were treated for AMI in the tertiary health care system.
2. **Myocardial infarction:** According to Smeltzer and Bare (2004), *myocardial infarction* is the "death of heart tissue caused by lack of oxygenated blood flow" (p. 725).
3. **Perception:** *Perception* refers to a thought, idea, observation, belief, or opinion formed through exposure to some circumstance.
4. **Rural Central Alberta:** *Rural Central Alberta* is the geographic area encompassed by the David Thompson Health Region (DTHR). *Rural* is defined using Statistics Canada's (Bollman, 2001) recommended rural and small-town definition: "the population living in towns and municipalities outside the commuting zone of larger urban centres (i.e., outside the commuting zone of centres with population of 10,000 or more)" (p. 3).

5. **Integrated care:** *Integrated care* is the arrangement and delivery of health care services, from both the functional and clinical perspective, that assures that "people are directed to the right care provider or service at the right time and in the service setting most appropriate to their needs" (Smith, Smith, Newhook, & Hobson, 2006, p. 84).
6. **Continuity of care:** *Continuity of care* refers to the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context (Haggerty et al., 2003).

Overview of This Report

Chapter 2 of this report reviews the literature on continuity of care, the incidence of AMI, and the recommended treatment. The method for the study is presented in Chapter 3. Chapter 4 contains a description of the results of the study, and Chapter 5 discusses the results in relation to ongoing continuity of care research. Conclusions and recommendations arising from the study are presented in Chapter 6.

CHAPTER 2:

LITERATURE REVIEW

A literature search was conducted in the CINAHL, MEDLINE, PUBMED, and Knowledge Utilization databases using the search terms *myocardial infarction*, *myocardial infarction follow-up*, *myocardial infarction aftercare*, *continuity of care*, *continuum of care*, and *client/patient perspective* alone and in a variety of combinations for the years 1985 to 2004. The objective was to uncover published information pertaining to continuity of care following AMI from the client's perspective. The search yielded large numbers of citations for either MI or continuity of care when they were used as search terms individually. The CINAHL database revealed 2,105 citations for AMI with the subheadings *rehabilitation* and *nursing* chosen, and 935 citations for continuity of care. Only two citations were identified when these searches were combined, and neither of these articles explored the patient's perspective of continuity of care.

The search of MEDLINE, using the same search terms and technique, yielded 1,341 citations for AMI and 5,761 citations for continuity of care. Six citations were found when the terms were combined. Of these, three related to postdischarge AMI patients, two concerning programs and one related to the experiences of the patients and their partners. The Knowledge Utilization database yielded 15 citations for continuity of care and none for MI. Using the term *cardiac care* in this database resulted in five citations, none of which referred specifically to AMI. There were no results from a combination of any of the terms in this database. The Canadian Health Services Research Foundation website was searched using the same keywords and resulted in 46 citations with the combined search terms. Of these, four were applicable to this study, but none dealing specifically with continuity of care for post-AMI patients were found. All of the databases were searched using the phrase *rural to urban* in conjunction with the previously identified terms, and no new articles were found. Reference lists of pertinent articles were hand-searched for articles with relevant titles. These were located when possible and evaluated for their applicability to this study. In all of the areas and databases searched, no articles were located that dealt specifically with continuity of care from the patient's perspective following an AMI. This literature search revealed that information gained from this study would add to the knowledge base of continuity of care from the patient's perspective in general and in the area of AMI in particular.

Continuity of Care

Continuity of care is important from a system perspective to ensure the efficient, effective use of health care resources in a cost-effective manner. Duplication or omission of services related to disruptions in continuity wastes health care dollars in addition to impacting the overall quality of individual patient care (Afilalo, Lang, & Boivin, 2003; Biem, Hadjistavropoulos, Morgan, Biem, & Pong, 2003; Hollander & Prince, 2002; Raval, Marchiori & Arnold, 2003; Young, Rewa, Coyte, et al., 2003). Reid et al. (2002) described continuity of care as "how one patient experiences care over time as coherent and linked" (p.i); the Alberta Association of Registered Nurses' Provincial Council ([AARN], 2003) reported that it "provides for seamless transitions" (p.1); and Smith et al. (2006) contended that it becomes important only when people need it and it is not there. Health care reform and the development of regionalized health services in Canada was influenced by the need for integrated health services to provide efficient and cost-effective health services. The work of Shortell, Gillis, Anderson, Erickson, and Mitchell (1996) was instrumental in leading the development of regionalized health services in Canada in the early 1990s, but regionalization alone did not ensure integrated health services and continuity of care for patients. Leatt, Pink, and Guerriere (2000) asserted that integrated health care did not exist in Canada at that time and proposed recommendations to achieve integrated care. They also presented a set of indicators that could be used to evaluate the existence of integrated care. It was presumed that a framework for integrated care would naturally lead to continuity of care for patients. The lack of clarity in the definition and measurement of continuity of care hampered the measurement of progress in this area.

Continuity of care has been studied extensively in many different contexts, usually from a system perspective, most often involving only one component of health care services, and rarely looking at cross-boundary continuity (Smith et al., 2006). Various scholars have noted the lack of clarity surrounding the concept of continuity of care as a significant detriment to further progress in the field (Glenn, 1996; Newhook, 2004; Reid et al., 2002; Sparbel & Anderson, 2000). These scholars noted that the patient's perspective of continuity of care is a necessary component of future research if meaningful and useful knowledge is to be generated. A model to structure research based on the concept of continuity of care as an outcome of integrated health services was developed through the LINCS research program at the University of Alberta (Smith & Birdi, 2002). This model uses antecedent factors, organizational variables, and many other factors that may influence the health of a population (Smith et al., 2006). Integral to this research is a focus on the patient's perspective of continuity of care.

Glenn (1996) conducted a concept analysis of continuity of care based on various health services literature and identified antecedents, attributes, and consequences of continuity of care. The antecedents were identified as (a) a recognition of need and first contact and (b) the availability and accessibility of service. The consequence of continuity of care was seen as the ability to do self-care.

Leatt et al. (2000) listed nine ways in which patients could identify an integrated healthcare system, and therefore continuity of care. In the context of development of frameworks to define and measure continuity of care, these can be seen as the outcome indicators of continuity of care and provide a consistent measurement tool across varied health care services and settings. The indicators are as follows:

1. Patients do not have to repeat their health history for each provider encounter.
2. Patients do not have to undergo the same test multiple times for different providers.
3. Patients are not the medium for informing their physician that they have been hospitalized or undergone diagnostic or treatment procedures, have been prescribed drugs by another physician, have not filled a previous prescription, or have been referred to a health care agency for follow-up care.
4. Patients do not wait at one level of care because of incapacity at another level.
5. Patients have 24-hour access to a primary care provider.
6. Patients have easy-to-understand information about quality of care and clinical outcomes to enable them to make informed choices about providers and treatment options.

7. Patients can make an appointment for a visit to a clinician, a diagnostic test, or a treatment with one phone call.
8. Patients have a wide choice of primary care providers who are able to give them the time that they need.
9. Patients with chronic disease are routinely contacted to have tests that identify problems before they occur, are offered education about their disease process, and are provided with in-home assistance and training in self-care to maximize their autonomy (Leatt et al., 2000).

Following a review of selected continuity of care literature, Haggerty et al. (2003) identified two core elements and three types of continuity of care. The two core elements that distinguish continuity of care from such things as service integration and coordination of care are care of the individual patient and care over time. Care over time has been studied by looking at such areas as discharge planning, patient teaching, home care resources and follow-up, information dissemination between facilities and providers, and patient access to resources. As well, disease management approaches through such avenues as specialized clinics, clinical pathways/care maps, and case management have been studied extensively. However, the patient experience of continuity of care has not been thoroughly investigated.

When patients access different health care providers for investigations or treatment, are transferred between facilities for ongoing care, or require ongoing health monitoring or services for chronic conditions, there is a potential for discontinuity of care (Afilalo et al., 2003; Deaton, Kurtz, & Weintraub, 2001; Hollander & Prince, 2002). This discontinuity may arise in any of the three types of continuity that Reid et al. (2002) identified:

> 1. <u>informational continuity</u> – information on prior events is used to give care that is appropriate to the patients current circumstances
> 2. <u>relational continuity</u> – recognizes the importance of knowledge of the patient as a person: an ongoing relationship between patients and providers, . . . connects care over time and bridges discontinuous events
> 3. <u>management continuity</u> – care received from different providers is connected in a coherent way. (p. i)

Although continuity of care is advantageous for all, certain client populations have been identified as having a greater need for integrated health care services to ensure timely and appropriate care. The most frequently identified groups are the elderly, clients with mental health problems, adults and children with disabilities, and clients with chronic health problems (Hollander & Prince, 2002; Leatt et al., 2000; Leggat & Walsh, 2000; Reid et al., 2002; Smith et al., 2006). These client groups have repeated contact with health care providers over an extended time period in a variety of venues. Each different link in the system is a potential for discontinuity. Patients who have experienced an AMI have at least one chronic condition, ischemic heart disease, and are at risk of developing more, such as congestive heart failure, angina pectoris, or a recurrent MI. They often have other underlying chronic diseases such as diabetes, hypertension, atherosclerosis, and obesity. Discontinuity in their care can seriously affect the length and quality of the patients' lives (Afilalo et al., 2003; Raval et al., 2003; Wright, Jolly, Speller, & Smith, 1999). One method that has been used to reduce the risk of discontinuity of care in people with chronic health conditions is case management.

Case Management

People with chronic health conditions require health care services on an ongoing basis from an array of providers and facilities. A challenge is to ensure efficient, effective health care at an affordable cost by providing the right services to the right patient by the right provider at the right time in the right way. Doing this requires someone who is looking at the whole picture and is able to coordinate the many different services included in one person's care. A case manager can perform this function. This role may include coordinating services and care while the patient is in hospital, on discharge, or receiving ongoing homecare services and, increasingly, as part of a health maintenance program to increase self-care and prevent health crises for people with chronic disease. It may reduce the length of stay in hospital as well as increase the quality of patient care. Many different health care professionals are able to perform the case management function, but social workers and nurses are the principal groups currently involved.

There is no agreed-upon definition of *case management*. It differs depending on the circumstances of the case manager's work (Case Management Society of America, 2004; Zander, 2002). Smith and Smith (1999) described case management as "a process and a professional service that can help to achieve the goal of more integrated and cost-effective care" (p. 176). A case manager could enhance the quality of an individual's life by assisting that person to traverse the maze of health services or coordinating services, such as facilitating access to a disease management or health maintenance clinic, for patients with chronic illness (Blaha, Robinson, Pugh, Bryan, & Havens, 2000; Powell, 2000; Riegel et al., 2002; Topp, Tucker, & Weber, 1998). Case management is not primary care, but can be a component of primary care and is certainly an adjunct to integrated health care. The results of studies on the use of case management in patients with chronic disease have demonstrated reduced length of hospital stay, decreased hospital readmission rates, increased use of primary health care services, and decreased use of emergency health care services (Blaha et al., 2000; Kaiser, Miller, Hays, & Nelson, 1999; Thompson, 2004; Topp et al., 1998).

Research has been conducted on case management approaches for patients following AMI that use disease management clinics or home care follow-up by specially trained nurses (Robertson & Kayhko, 2001; Wright et al., 1999; Young, Rewa, Goodman, et al., 2003). This research demonstrated results similar to those from using a case management approach for other chronic diseases. Many of the research studies in the outcome area of case management are exploratory. They have small sample sizes, are anecdotal in nature, are limited to a short period of time, and lack scientific rigor. The studies do, however, provide a good basis on which other, more definitive studies could be based.

Heart Disease

Heart disease is a chronic health problem that takes many forms. It may be manifested as angina pectoris, MI, or heart failure. Heart disease is the leading cause of death in Canada, and AMI accounts for almost one third of these deaths. Although the mortality rate from cardiovascular disease has declined in Canada, the number of actual cases has increased, which indicates that more people are surviving and living with heart diseases such as congestive heart failure and coronary artery disease (Bass, 2004; HSFC, 1999). Heart disease has been reported to have a significant impact on quality of life, with a high incidence of chronic pain or discomfort, activity restriction, disability, and unemployment (HSFC, 1999). Men are more commonly affected at an early age (45 years), and women catch up by age 55. Incidence and hospital length of stay for MI both increase in the elderly (Canadian Institute for Health Information [CIHI], 2004). With the projected growth in the elderly population, the numbers of people experiencing AMI and living with heart disease are expected to rise. It has been estimated that, by 2016, there will be 70,000 hospitalizations for AMI in Canada. This will have a significant impact on the health care system and the need for continuity of care.

Treatment of AMI is generally comprised of immediate treatment of the ischemic crisis, followed by a cardiac rehabilitation program and ongoing management of any underlying cardiovascular disorders. Guidelines for the management of patients with ST elevation MI (referred to in this paper as AMI) that the American College of Cardiology/American Heart Association (ACC/AHA; Antman et al., 2004) developed in collaboration with the Canadian Cardiovascular Society were released in 2004. These extensive guidelines cover the entire continuum from recognition of patients who are at risk to treatment of the acute health problems through convalescence to long-term management. The guidelines contain recommendations for both system-level and individual providers that are based on clinical evidence and expert opinion. The guidelines have been assessed by a working group of the Canadian Cardiovascular Society, and adaptations with a Canadian perspective were developed (Armstrong, Bogaty, Buller, Dorian, & O'Neill, 2004). Only those guidelines that impact the delivery of AMI care at the system level will be mentioned here, because specific information on individual patient treatment interventions is beyond the scope of this study.

The guidelines suggest that early identification and treatment of individuals at risk for AMI, including transport to hospital by ambulance under the care of highly trained emergency medical service (EMS) providers rather than family or friends, is optimum for those individuals with symptoms of AMI (chest discomfort, with or without radiation to the arm[s], back, neck, jaw, or epigastrium; shortness of breath; weakness; diaphoresis; nausea; lightheadedness). The Canadian adaptations concede that geographic realities and current EMS may not always allow the most rapid option, but it is certainly the most desirable option and should be a health system priority. Prompt initial recognition and treatment of patients with symptoms suggestive of AMI is imperative, and referral without delay to facilities that can provide the necessary ongoing care is indicated. The guidelines also provide specific recommendations for the pharmacological management, routine and specific investigations, and treatment of cardiac complications arising from AMI. The best-practice criteria used to identify which patients receive invasive diagnostic and treatment options such as angiogram and angioplasty and when these tests and treatments should be performed are also provided. Specific recommendations are included for patient education, long-term management, cardiac rehabilitation, and follow-up visits with a medical provider.

Many of the recommended medical and surgical investigations and treatments are highly specialized and therefore are available only in tertiary care centers, usually located in large urban areas. For patients who live in rural areas, this means considerable travel to access these services as well as the need to be seen and/or treated in different facilities.

These factors have been implicated in discontinuity of care (Afilalo et al., 2003; Biem et al., 2003; Hollander & Prince, 2002; Raval et al., 2003; Young, Rewa, Coyte, et al., 2003; Young, Rewa, Goodman, et al., 2003).

The psychological impact of AMI is significant, as is identified in the guidelines for care of AMI and shown in the studies of survivors' lived experiences (Jensen & Peterson, 2002; Stewart, Abbey, Shnek, Irvine & Grace, 2004; Stewart, Davidson, Meade, Hirth, & Makrides, 2000; Svedlund & Danielson, 2004; Thompson, Ersser, & Webster, 1995). Persistent post-MI depression has been related to increases in mortality and decreased compliance with medication and lifestyle modifications (Lane, Carroll, & Lip, 1999; Ziegelstein, 2003). The participation in a multidisciplinary cardiac rehabilitation program has been shown to positively impact the quality of life of the MI survivor (Robertson & Kayhko, 2001; Wright et al., 1999). For patients in rural areas, participation in a cardiac rehabilitation program often involves extensive travel because they are available only in major centers.

In 1999, 4,787 people in Alberta were discharged from hospital following an AMI. Because one third of the population of Alberta lives in rural areas, approximately 1,600 rural Albertans may have experienced an AMI that year. For rural Albertans, there is an added risk of discontinuity in their care. The journey through the health care system from rural to urban and back has numerous opportunities for disruptions in continuity of care.

Rural to Urban

The risk of discontinuity of care increases when there are transitions in a patient's care that may occur between health care providers, between facilities, or when patients are referred for specialized services or investigations (Afilalo et al., 2003; Deaton et al., 2001; Hollander & Prince, 2002). Patients in rural areas are subject to many of these transitions because of their geographical location. Health services are often not available in their community, and therefore they must be transferred to a hospital in another center, with a new physician, for their initial care. Specialized treatment may require transfer yet again to a tertiary center in a larger urban area. With each transfer, the risk of discontinuity in either informational, relational, or management continuity increases (Reid et al., 2002). Informational continuity may be impacted because necessary information on the patient's prior health events is often available only from the patient or his or her family, either of whom may not be able or available to give the precise information at the time that it is required. Relational continuity, that aspect of continuity that connects care over time and includes the knowledge of the patient as a discrete individual, is at risk when a patient is transferred out of his or her community. The risk increases with multiple transfers between facilities and with changes in health care providers within the same facility. The connection of the different aspects of care in some coherent way, which is management continuity, is challenged when there are multiple venues and providers involved in one patient's care, with no one person responsible for the coordination of that care and information. The compilation of all the necessary information and the timely transfer of that information to the appropriate caregivers is challenged for all patients who receive health services in multiple venues; rural patients are subject to this risk with each interaction outside of their home community.

Biem et al. (2003) identified five factors that challenge continuity of care for patients in rural areas from a case study of a rural senior transferred for medical care under regionalization. The identified factors that impacted continuity of care for both the patient and the system were as follows:

- Illness factors, including chronic illness with complex management or treatment regimes and co-morbidity
- Patient factors, such as immobility, lack of social support, cognitive dysfunction, or poor comprehension
- Local provider factors, such as closure of local hospitals, communication breakdown, turnover of physicians and nurses in local centers, and misunderstanding or disagreement with treatment recommended by regional physicians
- Regional center factors, such as large teams of house staff, bed shortages that necessitated short-notice transfers to the community hospital near the patient's home, inadequate and unstructured transfer of information, and shortened length of stay
- Health system factors, such as distance, lack of an integrated health information system, and lack of attention to quality improvement.

These factors are commonly identified as those that impact the various aspects of continuity of care. They can be grouped under the headings of informational, relational, and management continuity or as antecedents or outcomes of continuity of care (Glenn, 1996; Hollander and Prince, 2002; Leatt et al., 2000; Leggat & Walsh, 2000; Reid et al., 2002; Smith et al., 2006).

Raval et al. (2003) identified inadequate discharge summaries and follow-up information for patients returning to community physicians after treatment in large teaching hospitals as having possible implications for clinical outcomes and continuity of care. Young, Rewa, Goodman, Jagal, Cash, Lefowitz, et al. (2003) also noted that family practitioners sometimes did not receive notification of their patients' discharge from hospital until eight weeks after the fact. There was no mention of whether this changed when the intervention that they studied, a community pathway for post MI patients, was implemented. A survey of family physicians indicated that communication problems between acute care facilities and the community physician negatively impacted continuity of care, with information being neither timely nor complete when it was received (Geiger & Hum, 2000; as cited in Afilalo et al., 2003). This may result in costly duplication of services or, worse, absence of necessary follow-up care. Afilalo et al. conducted a pilot study of a standardized communication system between the emergency department and community physicians in Quebec City and showed that it was possible to provide useful information to family physicians in a timely manner to improve continuity of care and patient satisfaction. They showed that duplication of tests and consultations was not reduced by this system and that technological barriers existed with nonstandardized computer systems. Harrison and Verhoef (2002) looked at the consumer's perspective of coordination of care in a regional health system. They identified a need for consumers to be included in the coordination of their own care and for both the patient and the provider to have adequate information. These studies indicate that significant challenges exist for continuity of care when patients move between rural and urban venues in the health care system. This is especially important in the Canadian health care system, which has large numbers of people who reside in rural and remote areas.

CHAPTER 3:

METHODS AND PROCEDURE

The literature has identified transitions in care as a predisposing factor in interruptions in continuity of care. Patients in rural Alberta who suffer an AMI often are not able to receive care in their home community by their usual provider; instead, they must be transferred to a tertiary care facility in an urban center under a specialist's care. Follow-up care often involves the services of multiple providers in various venues. Therefore, it was determined that this group of patients would provide valuable insights from a patient's perspective of continuity of care.

Design

An exploratory, descriptive design that employed individual semistructured interview techniques was used to explore the perspectives of patients residing in rural Alberta who had experienced an AMI and required care in both rural and urban areas. Exploratory descriptive research studies are indicated when there is very little information on the topic, as in this case, and may provide information for hypothesis generation in future studies (Brink & Wood, 1994). Although there is little information on the chosen topic, previous research has been conducted to explore the perceptions of continuity of care from the perspective of the caregivers of survivors of traumatic brain injury (Smith, 1998). The interview questions that Smith developed were adapted for use in this study. A deductive approach to data analysis helped to explore three levels of coding for content analysis of the responses to the interview questions.

The study was conducted under the auspices of the nationally funded research program LINCS.

Research Context of Study

To conduct this research, the author became a Student Research Partner in the nationally funded LINCS Research Program, which was designed to develop a client-focused understanding of how continuity of care can be improved through policy and management decisions in the health system. In the first phase of this program, various health system strategies designed to improve the integration of services and continuity of care for populations in emergency and prehospital care, acute care, continuing care, and community care were examined and described. The second phase of the LINCS research focused on the client perspective and explored the perceptions and experiences of people who must make extensive journeys through the health system to receive the services that they need. The research reported in this thesis contributes to this second phase of the research through an examination of the journeys of people who made transitions from rural to urban centers, primary through tertiary care, and back for treatment of a common health problem, AMI.

Funding for the LINCS Research Program, including this substudy, was provided by the Canadian Health Services Research Foundation and the Alberta Heritage Foundation for Medical Research. Instruments, information letters, and other materials developed for the overall LINCS Research Program were adapted for use with the population for this substudy.

Sample

Because this was an exploratory, descriptive study, it was appropriate to use nonprobability convenience sampling (Brink & Wood, 1994). The target population were adults who resided in the DTHR and who had experienced a diagnosed AMI within the past two years. The participants had been referred to the Capital Health Region (CHR) for some type of health care service relating to that diagnosis. They self-referred to the study in response to recruitment material in the form of newspaper ads in local community newspapers (Appendix A), posters in community seniors' recreational centers (Appendix B), and information booths at local farmers' markets. As well, some participants had been approached by other participants and referred to the researcher for further information. In all, twelve people volunteered for the study and eight people who met the inclusion criteria were interviewed.

Inclusion Criteria

The inclusion criteria for the study included the following: (a) a self-reported diagnosis of AMI within the past two years, (b) the age of 18 years or older at the time of diagnosis, (c) ability to speak English, (d) receipt of treatment or follow-up for AMI in both the David Thompson and Capitol health Regions within the two-year period, (e) residence within the DTHR, and (f) consent to be part of the study.

Exclusion Criteria

The exclusion criteria were as follows: (a) no diagnosis of an AMI, (b) the age of less than 18 years, (c) residence in an institution, (d) no receipt of care in either the David Thompson or the Capitol Health Region, (e) residence outside the DTHR, (f) no ability to speak English, (g) documented or perceived cognitive deficits that would preclude their answering the interview questions, and (h) refusal of consent to participate in the study.

Protection of Human Subjects

Participation in the research project was voluntary. No participants responded to the recruitment ads or posters (Appendixes A and B, respectively). Four responded to the researcher at an information booth at a local farmers' market, and four were referred by community members or other participants. All participants were given information about the study at the initial contact, and further participation was voluntary. Prior to their interviews, they were all given detailed information outlining the study (Appendix C and F), and their consent to participate in the study was obtained (Appendix D). The participants were advised of their right to answer or refuse to answer any or all of the questions and to withdraw without penalty from the study at any time. To protect confidentiality, all identifying names were replaced with code names in the transcribed data. The results are reported as group data and demographics with no specific references to hospitals, services, or health care providers. No risk of harm or injury to the subjects was expected during this study.

Procedures

Data were collected through semistructured interviews with the participants. The guiding questions in the structured interview guide, based on Smith's 1998 study and further developed for the LINCS Research Program, were used (Appendix E). The instrument was designed to give the researcher an opportunity to clarify questions and to ask additional questions based on the progress of the discussion (Brink & Wood, 1994). The interview guide was used in a flexible manner, as Brink and Wood recommend, and the participants were encouraged to identify and prioritize issues that were important to them. Additional questions were asked depending on the progress of the discussion, the development of new ideas and concepts, and the need for clarification. Seven of the interviews were audiotaped with the consent of the participants. One participant preferred not to be audiotaped, but asked that the researcher record the replies in writing at the time of the interview. This request was honored. The interviews took approximately 45 minutes to one hour to complete, and the participants were asked if they could be contacted for further information or clarification after the audiotapes were transcribed. This was required on one occasion. Demographic information, including name, age, and date of MI, was gathered prior to beginning the interviews.

Data Management

All interviews, as noted, were audiotaped and copied on an additional tape. The tapes have been secured in a locked area located in the home of the researcher and will be kept for five years. All tapes are labeled with the date, time, interview number, and a codename in place of a real name to ensure confidentiality. Any information that might link the codenames to actual names is kept in a separate locked area of the researcher's home and will be destroyed after five years. Only the researcher has access to this information. All interviews were transcribed from the copy tapes and were labeled with appropriate headers to include date, time, interview number, and code name.

Management and Coding of Narrative Data

The interviews conducted for this research yielded two types of information. The demographic characteristics of the respondents were recorded and coded for presentation in numeric terms. The responses to questions in the structured interviews were in the form of narrative text that was content analyzed. As Polit and Beck (2006) pointed out, the use of concrete categories for analysis is useful in exploratory descriptive research designs. The method chosen was a template analysis style. In this method, a rough category guide is developed prior to beginning the research; in this case, the interview questions. As Polit and Beck (2006) explain, the template usually requires revision throughout the research process, which did occur in this study. Further categories were used to sort the issues and themes that were additional to the original interview questions. Computer software, NUD*IST (N6), assisted in the management, coding, and analysis of the narrative text.

First Level of Coding

In the first stage of coding the questions in the structured interview guide were used as the coding categories. Because the interviews had intentionally been conducted to enable the participants to elaborate on their responses or introduce issues of importance to them, a second stage of coding was used to categorize the issues and themes that were additional to the original interview questions. The main questions and subquestions in the interview guide were the basis for the development of the initial coding categories (Table 1).

Second Level of Coding

The researcher introduced a second level of coding to compile and analyze the narrative data that went beyond the content of the interview questions. These data served to illuminate the client perspective of continuity of care. Some coding categories were identified from the previous research of Smith (1998), who developed the structured interview guide that was adapted for this research. Newhook (2004), who analyzed seven reviews of continuity of care, suggested additional categories. Finally, the researcher organized narrative data that did not match the categories derived from previous research into additional categories and used common themes in the interview data as categories to compile and present this information. Table 2 shows the various coding structures that these researchers used.

Table 1

Questions and Coding Categories

Interview guide question	Category
What can you tell me about the events that led to your experiences with the health care system?	Precipitating Event
What can you tell me about your experiences as a patient/client following your heart attack? • Where were you sent? • Why did you go there? • What information did you need at the time? • Did you get the information? • If you did not get any help, who or what might have helped you?	Pathway of Care: Initial Entry into Health Care System Referrals/transitions following initial entry Number of Transitions in Care Reasons for Transitions in Care Information needs Information needs met Suggestions
What other health care facilities and programs have you attended? • Where were you sent? • Why did you go there?	Involved in Decisions regarding care
• What information did you need at that time? • Did you have any help, who or what might have helped when you transferred to a new location? • If you did not get any help, who or what might have helped you?	Information needs
• Do you feel you were involved in decisions that were made regarding your care?	Information Needs
Do you feel your personal likes and dislikes were accommodated during the care and transitions from one care setting to another?	Individualized care
What do you feel were the most difficult things you experienced in the process of getting or receiving services following your heart attack?	Most difficult Experiences
What do you feel were the good things you experienced?	Best Experiences
If there was one thing that you could change about the services or care arrangements, what would this be?	Things to change
Was there one person or group that helped arrange and coordinate your care? Who was this? If not, would it have helped if one person had been responsible for coordinating care? How would this have helped?	Distinct Care Coordinator Identified? Would it have helped? How?
Do you feel living in a rural area made any difference in you or your family's experience following your heart attack?	Effect of living in rural area?
Is there anything else you would like to share about your experiences following your heart attack?	Other Information

Table 2

Coding Structure: Client Perspective

Researcher	Coding structure
Smith (1998) categories	• Search for information, trust and understanding • Search for support • Need to speak on behalf of the survivor • Navigating the system
Newhook (2004)	• Patient's perspective of continuity of care • Vulnerable population represented?
Researcher	• Trust in health care providers • "Playing the system"

Third Level of Coding

Newhook (2004) identified a further shortcoming of research in the field of continuity of care. This was the lack of conceptual clarity and the absence of theoretical models to suggest or test the relationships between variables. The concepts and definitions that Glenn (1996), Leatt et al. (2000), and Reid et al. (2002) presented were chosen to develop a third level of coding for the data obtained in this study. Newhook concluded that the concept analysis that Glenn conducted in 1996 that identified antecedents and consequences of continuity of care was a valuable tool to assess relationships among variables in continuity of care research. Indicators of integrated care proposed by Leatt et al (2000) were seen to represent outcome indicators for continuity of care. Reid et al. provided a definition of continuity of care and suggested three different elements of continuity of care. Table 3 shows the coding structures that these researchers used.

Table 3

Coding Structure: Expert Opinion on Continuity of Care

Researchers	Coding structure
Glenn (1996) – antecedents of continuity	• Availability • Accessibility • Consequences
Leatt et al. (2000) – outcome indicators of continuity	• Patients do not have to repeat their health history for each provider encounter • Patients do not have to undergo the same test multiple times for different providers • Patients are not the medium for informing their physician that they have been hospitalized or undergone diagnostic or treatment procedures; have been prescribed drugs by another physician; not filled a previous prescription; or been referred to a health care agency for follow-up care • Patients do not wait at one level of care because of incapacity at another level of care • Patients have 24 hour access to a primary care provider • Patients have easy to understand information about quality of care and clinical outcomes in order to make informed choices about providers and treatment options • Patients can make an appointment for a visit to a clinician, a diagnostic test or a treatment with one phone call • Patients have a wide choice of primary care providers who are able to give them the time they need • Patients with chronic disease are routinely contacted to have tests that identify problems before they occur; provided with education about their disease process and provided with in-home assistance and training in self-care to maximize their autonomy
Reid et al. (2002) – integral components of continuity	• Informational continuity • Relational continuity • Management continuity

The Coding Process

In the coding process it is important to establish the reliability of the assignment of the subjects' responses to categories and the degree to which the categories are representative of themes and content. In this study the coding and analysis of the data were conducted by one researcher. A senior researcher analyzed a random sample of the data to assess the utility of the coding categories and the assignment of responses to the categories. The coding categories were supported by rationale from the current literature on continuity of care and were determined to be useful in a deductive approach to structuring the analysis and presentation of data.

CHAPTER 4:

RESULTS

The information obtained from the participants' interviews was analyzed through a series of coding processes based on questions in the interview guide, previous research using the same interview guide that identified caregivers' perceptions of continuity of care, and conceptual models and theories from experts in the field of continuity of care. Using three levels of coding categories enabled the researcher to identify areas of agreement between participants and agreement or disagreement with previous research, and to compare the data to the experts' concepts and opinions.

The research sample for this study included individuals from two vulnerable populations, as Newhook (2004) suggested, and people who typically suffer AMI. Six of the eight participants in the study were over 60 years of age and presented the perspective of the elderly population. All of the participants were from a rural community. The subjects who chose to participate were representative of the population typically identified as candidates for AMI, and all had received health care treatment that mirrored the established guidelines outlined in Chapter 2.

Characteristics of Subjects

As previously noted, the subjects self-referred to this study or were recommended by other subjects or community members. The characteristics of the subjects are summarized in Table 4. The sample included three females and five males who ranged between 55 and 74 years of age. Half resided in the country and half in a town or small city within the DTHR.

Table 4

Demographic Characteristics of Subjects

Demographic characteristics	Number of subjects
Male	5
Female	3
Age	
< 55 years of age	0
55 - 60 years of age	2
61 - 70 years of age	3
71 - 74 years of age	3
> 74 years of age	0
Resided in rural area outside of small city, town or village	4
Resided within a small city, town or village in a rural area	4
Retired	4
Working	4

The cardiac history of the participants in the study is summarized in Table 5. The time elapsed between the interview for this study and the participants' AMI ranged from 2 to 18 months. Five of the participants had experienced some additional cardiac event in the 10 years prior to the interview.

Table 6 summarizes the medical management of the participants following their AMI. Only two of the subjects called an ambulance for assistance at the onset of their symptoms. In all cases the closest rural health care facility was able to provide initial diagnostic and emergency treatment services. All subjects were then transferred by ambulance to a larger facility for specialized medical and nursing care. All subjects

Table 5

Cardiac History of Subjects

Cardiac history	Number of subjects
Length of time expired between AMI and interview for this study	
< 3 months	2
3 - 12 months	3
12 - 18 months	3
> 18 months	0
Participants experiencing 1st AMI	5
No previous cardiac events	3
Previous cardiac events, not AMI	2
Participants experiencing 2nd AMI	3

Table 6

Medical Management of Participants

Medical management	Number of participants
Received an angiogram	8
Required no treatment post angiogram	2
Required an angioplasty	6
Required coronary artery bypass grafting surgery	1
Attended a cardiac rehabilitation program	1

received an angiogram; six subjects required angioplasty, and one underwent coronary artery bypass grafting. One subject participated in a cardiac rehabilitation program. All of the participants' invasive procedures occurred within tertiary care centers in the CHR.

Analysis of Responses to Interview Questions

The data were initially coded using the categories identified from the interview questions to gain an overall understanding of the participants' journey through the health care system and to identify areas that were particularly significant to them. In the following discussion natural groupings of the related interview questions are introduced according to theme.

Health Care Journey

Precipitating event and initial entry into health care system. Pathways of care for the participants in this study were determined by two factors. These were the precipitating medical event and the health system resources available or perceived to be available at the time. Six of the participants identified unrelieved chest pain as the precipitating event that led to their entry into the health care system. Two participants had no chest pain, but had collapsed at home and were subsequently transported to hospital. Only two participants, one in town and one outside of the town, called an ambulance for transport to hospital with their initial symptoms. The other six arrived in vehicles driven by family members. All four participants who resided outside of town were more than 20 minutes from the closest hospital or ambulance dispatch, and the four who resided in towns were only 5 minutes from the hospital and ambulance dispatch. This information is summarized in Table 7.

Referrals and transitions. In general, transitions in care were prompted by the participants' need for specialty services, either medical or nursing care, or for specialized cardiac investigations or treatments not available at the level of care in the original facility. Table 8 summarizes the sequence of referrals and transitions that the participants

Table 7

Precipitating Event and Initial Entry into Health Care System

Prehospital Events	Number of participants
Precipitating Event	
Chest pain – unrelieved	6 participants - 2 subjects had suffered a previous MI
Collapse without chest pain	2 participants - 1 subject had suffered a previous MI
Initial entry into health care system	
Taken from home to hospital by ambulance	2 participants – 1 living outside of a town and 1 living within a town/city
Driven to hospital by family	6 participants – 3 living outside of a town and 3 living within a town/city

Table 8

Referrals/Transitions

Referrals/transitions	Number of participants
Stabilization and initial treatment in local hospital	8
Ongoing treatment in local hospital	1
Referral to DTHR hospital poststabilization	3
Referral to CHR hospital – no invasive cardiac services	2
Referral to CHR hospital with invasive cardiac services	2

in this study experienced. Depending on the precipitating event, there were three prototypical treatment approaches. However, the treatment approach was not the determining factor in the number of transitions. The participants with the lowest number of transitions were those transferred directly from the rural hospital to a facility in the CHR where angiogram/angioplasty services were available. Those with the most transitions either had complications post-MI that required varied services or had their tests or procedures cancelled and rebooked because of backlogs in the system. Information on the number of transitions for participants is detailed in Table 9.

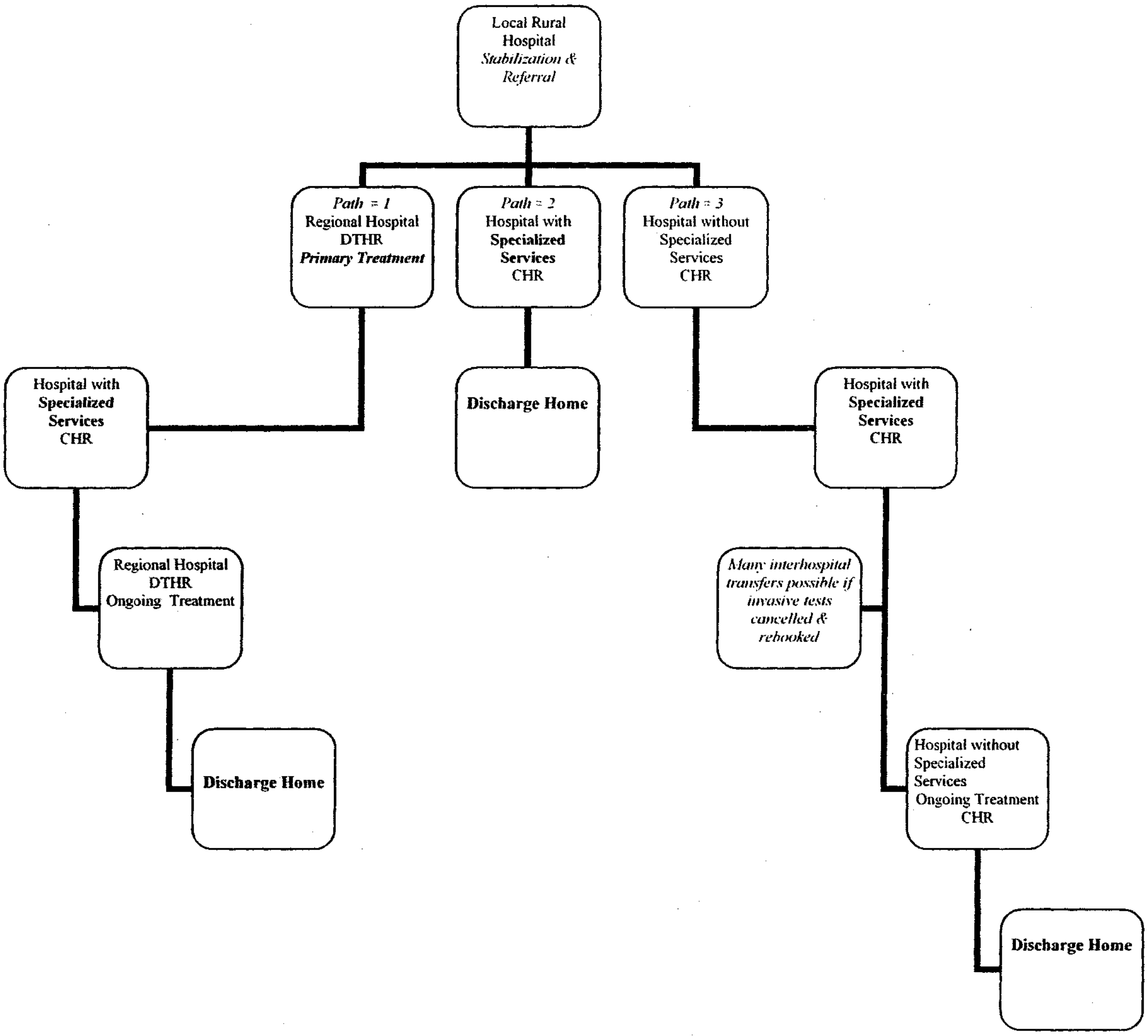
Table 9

Transitions in Care

Number of transitions in care	Number of participants
3	1
4	1
5	3
8	2
11	1

Participants perceived that the number of transitions was determined by the availability of beds in the region. For the participants in this study, if there were no hospital beds available in the Red Deer Regional Hospital (DTHR), the participants were transferred to a community hospital in Edmonton (CHR). A lack of hospital beds in the region added between one and three additional transitions for patients with similar precipitating events.

Pathways of care. The pathway traversed and the number of transitions in care differed significantly for each patient. When the journey of each participant was plotted and transitions were counted, three distinct pathways were identified, as shown in Figure 1. The pathways differed in several respects, depending on where the participants were initially transferred following stabilization at the local hospital. The number of transitions in care (i.e., the subjects went from one facility to another) ranged from 3 to 11.



Note. Complications post discharge requiring further hospitalizations are not noted on this chart.

Figure 1. Pathways of care.

The three participants on pathway 1 were transferred from the local rural hospital to the regional referral hospital for specialized medical and nursing care. Two of these three participants had a previous relationship with the receiving internist at the regional hospital because of underlying cardiac conditions. They were subsequently transferred to a hospital within the CHR, where consultation and invasive cardiac investigations and treatments were available, and then returned to the regional hospital prior to discharge.

The two participants who followed pathway 2 were transferred from the local rural hospital to a facility within the CHR, where cardiac specialists took over their care and invasive cardiac investigations and treatments were available. These participants were either hemodynamically unstable (from self-report) or had a previous relationship with a cardiac specialist who practiced at that facility. The participants on this pathway were discharged home from this facility following treatment.

The pathway 3 participants were transferred from the local rural hospital to the CHR for specialized medical and nursing care in a facility that did not have invasive diagnostic and treatment services. These three participants were transferred as day patients to another facility within the CHR for specialized investigations and treatment, and then returned to the referring hospital. The participants were subsequently discharged home from the facility to which they had initially been referred.

Information Needs

In the interviews, all of the subjects stated that their need for information about their condition and treatment while they had been in hospital had been met. They described going into a "nonfunctioning" mode immediately after their heart attack. They explained that they asked no questions and sought no information, trusting that they were receiving the help they needed and that the healthcare providers would do what was best for them. After this initial period, the participants felt that they had received adequate to excellent explanations of the treatment regime and any diagnostic procedures while they were in the hospital. However, six participants felt that they did not have the information that they needed after discharge.

Analysis of the data identified three main areas in which the participants indicated that they lacked sufficient information following discharge from hospital: (a) the psychological effects of AMI, (b) medications, and (c) the long-term consequences of their AMI and the follow-up care that they should anticipate. Five participants described feeling inadequately prepared for the intense emotional disruptions and anxiety that they experienced during the convalescent period. They also saw managing the many medications prescribed after AMI as a problem, including understanding the purpose and effects of the medication and establishing a manageable regime to ensure that they took the medications regularly. Half of the participants had binders containing all of the print information that they had received pertaining to investigations, medications, and suggested convalescent activities throughout the course of their hospitalization and following discharge. They showed them to the researcher during the interview and referred to them in a manner that suggested that they were very important, almost as a lifeline or a proof of survivorship. When the participants were asked whether any additional patient information would have been helpful, they identified the need for more information on the following: (a) the expected duration and possible treatment of emotional after effects of AMI (5 participants), (b) the medication's action and side effects (3 participants), (c) the establishment and maintenance of a medication regime (2 participants), and (d) accommodation for families of patients transferred to the CHR (1 participant).

Individualized Care

The interview questions on attention to personal likes and dislikes were grouped under the heading of individualized care. Overall, five out of eight participants felt that they had been treated as unique individuals and that the health care providers whom they encountered had taken into consideration their personal likes, dislikes, and previous medical conditions. Two subjects particularly appreciated being able to request specialized treatment in Edmonton (rather than Calgary, the usual referral center for patients hospitalized in Red Deer Regional Hospital). Two others described specific instances in which the nurses gave their personal likes and dislikes "extra" consideration. In contrast, three participants experienced having to wait up to a week in hospital for angiogram/angioplasty services and the process in specialized cardiac clinics as depersonalizing. They described feeling "like a number, not a person" and "only one of many."

The Best and the Most Difficult Experiences of Participants

When the participants were asked to identify the best and most difficult experiences of their health care journey, they all described their encounters with individual members of the health care team as the best part of the experience. In contrast, what they reported as their worst experiences varied. For some it involved the emotional distress after discharge. For others it was the ambulance rides, or the hospital food, or the wait for services. These descriptions can be seen as representative of the participants' perceptions of what works well in the system and what the system is not currently handling adequately. The best and most difficult experiences that the participants described are summarized in Table 10.

Table 10

Participants' Best and Most Difficult Experiences

Best experiences	Difficult experiences
Ambulance attendants: 5 participants	Emotional distress/anxiety post discharge: 4 participants
Nurses and nursing care: 4 participants	Ambulance rides: 2 participants
All health care personnel: 2 participants	Waiting for services at another facility: 5 participants
Blister packaging of medications by pharmacist: 1 participant	"Awful" food: 2 participants
	Having to leave spouse in critical condition in city hospital: 1 participant
	Physicians diagnostic error: 1 participant

* *more than one experience was described by various participants*

Changes Suggested to Address the Most Difficult Experiences

The participants suggested changes to address the issues that contributed to their most difficult experiences and other areas they identified as problematic. They felt that the availability of specialized cardiac services within the DTHR would improve the care of people who suffer an AMI by decreasing the wait times. The participants also saw a need for specialized cardiac services to ensure that adequate assessment and treatment by cardiac specialists was available both before and following an AMI.

The participants perceived that they were disadvantaged because specialized cardiac services were not available within their region, and they felt that their physicians had had to "pull strings" to arrange the specialized cardiac services that they needed. Individual participants advocated three other changes: (a) programs to assist with post-AMI medications, (b) a post-AMI patient support group, and (c) more information on accommodations available in the CHR for families of patients transferred to facilities within that region.

Coordination of Care Management

Six of the eight participants could not identify any one person who was responsible for coordinating their care, although two participants reported that the internist at the regional hospital was "in charge." When the question was rephrased to ask whether one person had had all of the information on their condition or knew everything that had happened throughout the participants' journey, one identified the secretary at the cardiologist's clinic, and another identified the nurse researcher at a different clinic. In response to a follow-up question, the participants indicated that some type of clinic where they could go on a regular basis for information and monitoring, possibly run by a nurse, would be helpful. Four of them felt that this would be of benefit, especially if the clinic were close and the nurse had the time to answer questions.

Effect of Living in a Rural Area

The participants were asked whether they felt that living in a rural area had any effect on the care they received. Two subjects commented that their experiences were no different from those of people living in an urban area. Six participants felt that living in a rural area did make a difference in their care. The primary reasons were the distance that they needed to travel to reach specialized cardiac services and their perceptions that the health care system did not treat out-of-region patients as quickly as those residing within the region. Table 11 summarizes the participants' responses.

Table 11

Effects of Living in a Rural Area

Effects	Number of participants
• Distance/time to reach health care services is different in a rural area—either longer or shorter.	3 participants
• Unequal access to specialty health services for people out of the region.	2 participants
• Process for health providers accessing specialty services outside of region is flawed, requiring physicians to operate outside the system to gain timely access for the patient.	2 participants
• Distance to access cardiac rehabilitation programs was too far.	2 participants
• Potential for personal health information related to AMI to not be accessible to health care providers when needed. **The subject obtained and carried copies of all personal health information in a file at all times, just in case personal health care information, related to AMI, might not be available to health care providers when needed.*	1 participant
• Patients need choice of which urban care center they attend, as parts of the local health region are closer to one than the other.	1 participant

Summary of the Interview Questions

The interview guide proved to be a useful tool in eliciting information about the experiences and health care journeys of the eight participants. Their responses to the interview questions revealed that they were generally satisfied with their interactions with individual health care providers whom they encountered throughout their health care journey. Their concerns or negative experiences were primarily in the area of the health care system and the delivery of services. The participants' responses provided information that went beyond the structured questions in the interview guide. Therefore, previous research on patients' perceptions of continuity of care was used in the second level of coding to acquire the information from this data.

Analysis Relating to Previous Research on the Patient Perspective of Continuity of Care

In the second level of coding, the themes that Smith (1998) had identified in previous research were used as categories for analysis. In the study of caregivers' perceptions of continuity of care for survivors of traumatic brain injury, Smith identified four categories: (a) the search for information, trust, and understanding; (b) the search for support; (c) the need to speak on behalf of the survivor; and (d) navigation of the system. The responses of the participants in this study were assigned, where applicable, to these categories.

Whereas the individuals interviewed by Smith (1998) were caregivers of people who had suffered an acute event, those interviewed in this study had personally experienced a health crisis and were able to speak for themselves. Both groups emphasized the need to be able to trust health care providers and were aware that they needed help to traverse the system. Both groups noted the need for information. However, the participants in this study acknowledged that at the time of their AMI, they had little choice but to trust that the health care professionals would act in their best interests. They did not express a need for information at the time of the acute episode but identified the need for information on how to manage their medications and symptoms after discharge from the hospital. They also identified a need for information on follow-up programs and services, including psychological support. The participants in this study had found written information very helpful, but, at times, they had found the verbal information confusing. In contrast, the respondents in Smith's study reported that their search for information began at the time of the injury and continued throughout their care, and they discussed how the information had been delivered and found that the terminology used affected its usefulness.

The respondents in Smith's (1998) study expressed guarded trust in health care professionals. In contrast, the respondents in this study expressed high levels of trust in the individual health professionals whom they encountered in ambulance and hospital services. They attributed problems that they encountered while in hospital and inadequate programs after discharge to "the system" and not to individual health care providers. Five participants in this study thought that the health care providers had expert knowledge and would inherently do what was best for their patients' well-being; they had felt no need to ask questions, to be given information, or be involved with decisions regarding their care. A second issue was the perception of a need not so much to navigate the system as to "work" it. Five participants reported that their physicians had needed to work outside the established protocols of the health care system, to "talk to someone," or to "pull strings" to ensure timely access to necessary services. One participant chose to circumvent the system with subsequent episodes of cardiac problems. The choice involved traveling from home and directly to the emergency department of the tertiary care hospital in the CHR where specialized cardiac services were available. This participant commented that "they could not turn me away" and that it was "a waste of my valuable time to wait so long to see a specialist."

Analysis at the second level of coding revealed that the participants in this study had high levels of trust in individual health care professionals and were skeptical about the workings of the health care system.

Analysis Based on Expert Opinion on Continuity of Care

The third level of coding in this study established whether the data from the study supported the various theoretical concepts that researchers in the field suggested. In this level of coding the categories were the antecedents and consequences of continuity of care that Glenn (1996) identified, the outcomes of continuity that Leatt et al. (2000) described, and the elements of continuity that Reid et al. (2002) listed.

Antecedents and Consequences of Continuity of Care

Glenn (1996) identified availability and accessibility of health care services and providers as necessary antecedents of continuity of care and described the consequence of continuity of care as the ability to carry out self-care. The data from this study were analyzed for availability and accessibility of health care providers and services during the prehospital period, throughout hospitalization, and in the posthospital period.

Prehospital period. Although emergency medical response was available to all of the participants, six of them felt that it was not the quickest or most reliable method of obtaining immediate medical attention when they initially experienced symptoms suggestive of AMI; instead, family members drove these people to the hospital. Those who lived outside of a town or city cited reasons such as "the ambulance might get lost trying to find this place" and "by the time they got here, I could have him at the hospital. Why would I waste half an hour?" The participants who resided within towns or cities also felt that waiting for an ambulance would only delay medical attention. In contrast, when ambulances were used for transfer between facilities, the participants found that this expedited their progress through the system.

Hospitalization period. All participants indicated that a physician and other necessary health care providers (nurses, laboratory and diagnostic imaging personnel, ambulance attendants, etc.) were available once they were in the hospital, and seven reported that this persisted throughout their entire health care journey. One participant expressed feeling that the physician was not always available, especially following transfer to a facility within the CHR where the subject was sent to await specialized cardiac services. All eight participants agreed that they had access to facilities to meet their required stabilization, management, and specialized health needs; but only two indicated that all of the required health services were always immediately available. Five participants described having to wait in one facility until the services that they required were available in another facility.

Posthospital period. The participants noted instances following their discharge from hospital in which neither health care providers nor services were easily accessible. Five participants did not recall being advised of or offered the opportunity to participate in a cardiac rehabilitation program. Two chose not to attend. Because cardiac rehabilitation programs are available only in Edmonton or Red Deer, one to three hours' travel time would have been required in addition to the program time; otherwise, it might have been necessary to arrange to stay in the city for the duration of the program. Only one participant had attended a cardiac rehabilitation program, and he had stayed in a hotel in Edmonton at his own expense for the entire two-week period. Two participants stated that because of their emotional distress following discharge from hospital, neither traveling that far on a daily basis nor staying away from home for a prolonged period were feasible options. Admission to the cardiac rehabilitation program within the DTHR is limited to those patients who have been seen and referred by a Red Deer internist (DTHR, 2000). Therefore, this program was not accessible to patients discharged from CHR facilities without a subsequent referral to a Red Deer internist. Follow-up care with a cardiac specialist post-AMI was not perceived to be consistently available or accessible. Five participants had had difficulty accessing the cardiac specialist following discharge, and three had received no follow-up with a cardiac specialist after their previous AMI. Table 12 summarizes the participants' perceptions of unavailable or inaccessible services or providers.

Table 12

Instances of Perceived Inaccessibility of Service or Providers

Prehospital period	Hospital period	Posthospital period
• Emergency Medical Services not fast enough or reliable enough: 6 participants • No follow-up care with cardiac specialist after previous AMI: 3 participants • Difficult to access cardiac specialist prior to AMI: 1 participant	• Waited at one level of care for service at another: 5 participants	• Difficulty accessing cardiac specialist: 5 participants • Cardiac Rehabilitation program offered but participant declined due to distance: 2 participants • Cardiac Rehabilitation program not offered: 5 participants

Consequences of Continuity

Glenn (1996) conceptualized the consequence of continuity as the ability to carry out self-care. When the data from this study were analyzed, it was noted that in nine instances the participants had not achieved this. They identified some of the deficiencies, and some were evident in the questions that they asked the researcher during the interviews. These questions related to their disease, their medications, their prognosis, and their treatment regime. Four participants had not been prepared for the intense psychological effects post-AMI, which had been very difficult to cope with. Three subjects did not understand and had difficulty with their medication regime, and two participants complained that they did not have adequate knowledge of the physical consequences, complications, and indicators of health problems related to their AMI. Two participants demonstrated inadequate knowledge of a heart-healthy diet, but all of the participants reported that they were now nonsmokers. Much of the information requested would have been covered in a cardiac rehabilitation program, which was offered to only three of the participants, and only one had attended.

Outcome Indicators of Continuity

Leatt et al. (2000) described nine ways in which patients could identify an integrated health care system. These indicators were used to establish another set of coding categories. The participants in this study did not comment on the following three indicators: (a) Patients do not have to repeat their health history for each provider encounter, (b) patients do not have to undergo the same test multiple times for different providers, and (c) patients have a wide choice of primary care providers able to give them the time that they require. The participants commented that an advantage of traveling by ambulance was the fact that the ambulance attendants had all of their information, which ensured a smoother transfer to the new facility. Information related to the remaining six indicators was identified in the data. The findings are summarized in Table 13.

Table 13

Nine Outcome Indicators of Continuity of Care

Indicator of continuity of care	Outcome
Patients are not the medium for informing their physician that they have been hospitalized or undergone diagnostic or treatment procedures; have been prescribed drugs by another physician; not filled a previous prescription; or been referred to a health care agency for follow-up care	• 5 participants *were not* the medium of information transfer to their physician • 3 participants *were* the medium of information transfer to their physician
Patients do not wait at one level of care because of incapacity at another level of care	• 3 participants *did not* wait for service at another level • 5 participants *did* wait at one level for service at another
Patients have 24 hour access to a primary care provider	• 8 participants *had* 24-hour access to a primary care physician
Patients have easy to understand information about quality of care and clinical outcomes in order to make informed choices about providers and treatment options	• 4 participants *had* sufficient, easily understood information • 4 participants *did not have* sufficient, easily understood information
Patients can make an appointment for a visit to a clinician, a diagnostic test or a treatment with one phone call	• 0 participants *could* make an appointment with a specialist, diagnostic services or treatment services

(table continues)

Indicator of continuity of care	Outcome
Patients with chronic disease are routinely contacted to have tests that identify problems before they occur; provided with education about their disease process and provided with in-home assistance and training in self-care to maximize their autonomy	• 4 participants *were* contacted regarding health maintenance tests • 4 participants *were not* contacted regarding health maintenance tests • 3 participants *were* provided with information regarding their disease process • 5 participants *were not* provided with information regarding their disease process • Ø participants *received* in home assistance/training

Elements of Continuity

Reid et al. (2002) concluded that continuity of care contains two elements: care of the individual patient and care over time. They described continuity as "how individual patients experience integration of services and coordination" (p. 3). Care over time may be short, such as a single hospital admission, or longer, such as an ongoing relationship with a primary care provider (p. 3). Informational, management, and relational continuity were assumed to be relevant in all health care settings. These types of continuity were the final three coding categories.

Informational continuity relates to knowledge of the patient in a holistic way, including both the disease process and the patient as a unique individual. Three participants discussed a disruption in the flow of information because their family physicians had not received their information from other providers or facilities in a timely manner. Five participants felt that certain health care providers recognized them as distinct individuals. Although this did not occur throughout the entire health care experience, all five described specific instances of this “connectedness.” However, the participants also identified five instances of significant depersonalization in which they felt that they were “a number, not a person” and “only one of many.” Their concerns or negative experiences had to do with “the system,” not the health care providers, and all instances had occurred while the participants were receiving care in specialized clinics or treatment areas. They said that although they understood that speed and efficiency are necessary to process a high volume of patients, the process resulted in their feeling that they were objects of care rather than persons.

Management continuity relates to coordination and connection of services by multiple providers in various facilities in a timely, coherent manner. All of the participants in the study had received initial medical treatment and stabilization in a timely manner. Five reported having to wait for needed specialized treatments, but they all received them within two weeks of their initial AMI. Five participants believed that their timely access to services occurred only because their physicians operated outside the established protocols of the system, “pulling strings” to ensure that they received care quickly.

Relational continuity refers to the connections or relationships between providers and patients that link past, current, and future care. It can be seen as contributing to the holistic view of the client and bridging discontinuous events. The data revealed that establishing a relationship with the health care provider, whether it was the ambulance attendant, the cardiac specialist, or the nurse, was of significant importance to the subjects. They frequently and positively referred to repeat encounters with the same provider who seemed to remember them.

Five participants indicated they had an overall sense of coherence and predictability in their care. It was most noticeable when they described the care that they had received in their local hospitals from their primary care provider, but was also apparent when they described the teaching and information that they received regarding their care while they were in hospital. In contrast, seven of the subjects mentioned specific instances in which they experienced a lack of coherence in their care. These included having to wait for services, having scheduled treatments or procedures cancelled after the participant had arrived, never having the same nurse for more than one day, and having limited access to cardiac specialists following discharge. The participants believed that the individual care that they received enhanced the coherence and predictability of their journey; however, elements within the system detracted from that same sense.

Chapter Summary

A deductive approach involving three levels of coding was used to analyze the data. The participants expressed a great deal of trust that health care providers would offer them the best care possible. Although the participants expressed satisfaction with their individual health care providers, they also felt that problems of access and availability within the health care system affected their care. A further discussion of the information obtained from the data analysis follows in Chapter 5.

CHAPTER 5:

DISCUSSION

The participants in this study reported a great deal of satisfaction with individual health care providers, which seemed to mitigate any problems that they encountered with the health care system. Most felt that there was room for improvement in the accessibility and availability of services for rural patients with MI. Analysis of the data revealed support for some theoretical concepts on continuity of care. As well, the analysis established some commonalties and differences among client perceptions of continuity of care in different patient populations and addressed Newhook's (2004) recommendations that the patient perspective of continuity of care be examined, especially that of vulnerable populations. Some areas of discontinuity and areas where best-practice recommendations for AMI have not been implemented were identified. This chapter will discuss the implications of these findings.

Antecedents of Care

Glenn (1996) concluded that availability and accessibility of services and providers are necessary antecedents of continuity of care. When the data were analyzed, it was evident that some participants in this study did not perceive EMS (Emergency Medical Services) as being available and accessible. Three of the four participants who lived in the country did not even consider calling an ambulance when they experienced chest pain because they believed that it would take the ambulance too long to get to there. As well, these participants felt that there was a good possibility that the ambulance would get lost in trying to find the residence. Not having support from trained professionals during this journey placed the participants at significant risk. However, they did not perceive this as a gap in their care, and all of these participants were fortunate in that they did not experience serious deterioration in their health on the journey to the hospital. In the ACC/AHA guidelines for management of AMI, Antman et al. (2004) recommended that all patients who experience symptoms of AMI "should be transported to hospital by ambulance rather than by friends or relatives" (p. 3) and that people in the community be educated on the need to do so. The Canadian Cardiovascular Society Working Group, which developed a Canadian perspective on these guidelines, acknowledged that this may not be feasible in all areas of Canada, but recommended that "all regional health authorities should implement coordinated, comprehensive paramedical systems to enhance prehospital diagnosis, management and triage to the most appropriate health care facility" (p. 3). The perceived lack of accessibility and availability of EMS to those participants who resided outside of towns or cities is an area of continuity of care that must be addressed to ensure safe, effective health care. Education pertaining to the need for all people to use EMS when symptoms of AMI occur must also be addressed.

Initial emergency care and stabilization were readily available in local hospitals for all participants. All were referred for ongoing care in an intensive care unit. They were referred to the regional hospital within the DTHR or, if the participant was hemodynamically unstable or there were no beds available within DTHR, to a facility within the CHR. The sequence of hospital care for each of the participants in the study was plotted and revealed differences in the number of transitions that took place. There were also differences in the lengths of time that they remained in hospital waiting for specialized diagnostic procedures and treatments. The participants who were referred initially to a facility within the CHR with angiogram/angioplasty services had significantly fewer transitions in their care; one such participant had the shortest length of stay of all of them. The six other participants noted that their length of stay was extended because they had to wait for the cardiologist to see them or for their angiogram and angioplasty. Because the participants self-reported their medical information, it is beyond the scope of this study to comment on whether the treatments were received within an appropriate timeframe.

When the participants were asked what one thing they would change about their experience, half of the responses centered on the need for availability and accessibility of specialized cardiac services. Participants perceived that they did not have equitable access to those services because they came from outside the CHR. A participant's wish to not to have to go "to Edmonton to have the angiogram and angioplasty and have it right in Red Deer" exemplified this issue. Another participant said "I found the middle of the province just doesn't have facilities for heart people"—indicated that both saw travel as a problem. The subjects perceived that there is unequal access to specialized tertiary care services for patients from outside the CHR and that physicians need to negotiate or "pull strings" or work outside established protocols to obtain necessary services in a timely manner. As one person stated, "[The doctor] had obviously talked to someone to make sure I got in." Patients talked of their physicians' "fighting" to get them admitted to a city hospital and complained that "the whole rigmarole is really hard on you." They perceived living within a health region that does not have specialized cardiac services as a disadvantage. One patient who had been sent outside of her region to a hospital without specialized cardiac services commented:

> They told him [her physician] that I would get in quicker if I was in a city hospital, a closer hospital. . . . I just couldn't figure out why I could get in faster up there than down here because we're all Alberta.

Another patient had waited in the regional hospital for specialized services on two occasions. When she had a subsequent episode of chest pain, she chose not to go to the local or regional hospital; instead, her husband drove her directly to the emergency department of a hospital in the CHR where she had been previously treated. She remarked:

> They can't turn you away because you are their patient, and you have a doctor there, . . . [and] I'm not supposed to do it, I suppose, but I'm going to do it anyway because it's a waste of my valuable time to go through the other system. I should be able to get in to see a specialist just as fast as someone in that district.

She felt that transferring from rural hospital to regional hospital and then to specialized services in the city was a greater risk to her health than it was to extend the transport time to receive initial services at a facility where the specialized services were readily available. This participant had taken the initiative to take measures on her own that would enhance her continuity of care.

Recommended treatment for patients who have suffered an AMI involves both immediate in-hospital care and ongoing care after discharge to promote recovery and prevent a reoccurrence of infarction (Antman et al., 2004; Leon et al., 2005; Stewart, 2003). The participants would have preferred more contact with a cardiac specialist after their AMI, but not all were referred to a cardiology clinic or had follow-up appointments with specialists arranged. Although three patients mentioned having specialized cardiac testing such as stress tests, they did not have contact with an internist or cardiologist to discuss the test results. Those patients who were referred to cardiology clinics after their

AMI were pleased with the interaction, but felt that their concerns were not always adequately addressed because the physicians and nurses were so rushed.

Cardiac rehabilitation programs are recommended in the ACC/AHA guidelines (Antman et al., 2004) as an essential component of the treatment of AMI and for management of underlying coronary artery disease. These programs have been shown to reduce both morbidity and mortality post AMI (Leon et al., 2005, Steward, 2003). Cardiac rehabilitation programs for the participants in this studywere available only in Red Deer or Drumheller in the DTHR, or in Edmonton in the CHR. The referral process for the DTHR cardiac rehabilitation program is only through referral from one of the internists who practice within the region. Therefore, if patients had not received care within the region from one of the internists, they were not able to receive cardiac rehabilitation without being referred for an appointment with one of the internists. This additional step in the treatment protocol, along with the fact that the program is offered in only two locations, the Red Deer Regional Hospital and the Drumheller Health Centre, limits the availability of this important health care service. To attend either the DTHR or the CHR cardiac rehabilitation programs, the participants would be required to travel 30 to 60 minutes one way or make arrangements to stay in the city where the program was offered. Only one patient in the study attended a cardiac rehabilitation program, and stayed in an Edmonton hotel for the entire two-week period. Two other patients considered the program, but in each case the daily travel to reach the program or the cost of remaining in the city precluded their doing so. The other five patients could not recall being informed of a cardiac rehabilitation program. It is unclear whether this was never offered or whether the participants just could not recall its being offered.

Other concerns that the participants expressed related to pharmaceutical issues, psychological issues, and the course of their disease might have been addressed if they had attended a cardiac rehabilitation program. Glenn (1996) described the consequence of continuity of care as self-care. It appears from the data that the participants who had questions for the researcher or who indicated emotional and psychological difficulties postdischarge had not attained self-care.

Cardiac rehabilitation programs have been shown to improve cardiac-related outcomes, reduce hospital readmission rates, and improve quality of life (Warner & Hutchinson, 1999; Young, Rewa, et al. 2003). Four participants sought personal health-related information from the researcher about cardiac medications and symptoms. They were asked whether a clinic in the area, possibly run by an expert nurse who could provide information and monitor on a continuing basis postdischarge, would be helpful; all felt that having such a resource would be beneficial. One participant wondered whether, if he had gone to a clinic like that on a regular basis following his first AMI, the second AMI could have been prevented. Using a disease management or health maintenance clinic as a strategy within a case management approach would appear to be beneficial for this group of patients. Direct referral from primary care providers would be a key element of such a program. Information sharing, collaboration, established consultation protocols, and procedures that link primary care physicians, cardiac specialists, and clinic health care personnel would provide integrated cardiac care following discharge.

Outcomes of Continuity

Leatt et al. (2000) developed nine indicators of integrated care. For purposes of this study these were conceptualized as outcome indicators of continuity of care. Information on six of these indicators was present in the data from this study. The inclusion of specific questions relating to all nine indicators would have provided more detailed information and should be considered for future research. Comparison of the data to the remaining six indicators of continuity of care suggested that two of the six criteria had been met, but four had not.

Indicators Met

The two outcome indicators of continuity of care that were found in the data were 24-hour access to a primary care physician and adequate information. All participants had 24-hour access to their primary care providers or their alternates, and all indicated had adequate information to make informed choices about providers and treatment options. Many of the patients tried to keep every piece of printed information that had been given to them throughout the journey, often in a binder that they brought out during their interviews with the researcher. The information seemed to serve an emotional as well as an informative purpose, almost as a chronicle of their journey, with their angioplasty pictures having particular importance. The participants used the information and the handouts, especially those that were related to activity and diet, as a guide when they were initially discharged post-AMI. It appears that in the absence of cardiac rehabilitation programs, pertinent, comprehensive, and easily understood print information for patients is imperative.

The teaching that the participants received prior to the angiogram/angioplasty was singled out as being particularly helpful. They commented, “They did some good teaching there. . . . They brought me all the papers on the stents, and she showed me the stents and what they did. She was good about that”; “A nurse came and explained exactly what was going to be done, which I already knew because you get the information in written form on the cardiac ward”; and “They told me all about it, and they showed me those pictures they took.” The participants appreciated the nurses’ verbal information and explanations: “At each stage everything was explained to me,” and “They told you what to expect.” However, it appears to the researcher that postdischarge information was missing.

Indicators Not Met

When the data were compared to the remaining four indicators, it became evident that continuity of care was not achieved. Information transfer to family physicians did not always arrive in a timely manner. The participants stated that they were the medium of information transfer in several instances, or in other instances were the “information retrieval prompt”—it was only their questions that prompted the primary care physician to search for their missing health care information. Three of the participants specifically commented that their family physicians had not received the information on tests or treatments that had been performed in specialized centers. Two mentioned their family physicians’ “getting on the computer” or “phoning the other doctor to get my result,” and another commented that the specialist “has a lot of paper work and he [her family physician] knows that it will be slow going.” Another participant reported, “He [the physician] had to phone up there and find out what had been done to me and what my results were and all that." One respondent described it as getting "lost in the system. . . . They have information on you, but it's vague, like if you were doing a book report and taking out the high points." One participant decided not to take any chances on his information being unavailable; he requested copies of reports, ECGs, and discharge summaries and has carried them with him at all times just in case future cardiac problems should arise when he is away from familiar health care providers.

All but three of the participants had waited at one level of care for service at another. This, according to Leatt et al. (2000), is an outcome indicator of discontinuity and was certainly identified by the participants as an area for improvement of services. Nonparticipation in an educational program such as cardiac rehabilitation and the absence of a consistent routine for ongoing monitoring and follow-up for these participants, all of whom have chronic coronary artery disease, was evident for seven of the eight participants. This indicates discontinuity in care according to the outcome indicators. Leatt et al. also proposed that continuity of care would be evidenced by patients' being able to make appointments to visit clinicians, to have a diagnostic test, or to access treatment with one phone call. This continuity was not available for the participants in this study.

Concordance With Other Populations

The most striking finding in the data was the trust of the participants that individual healthcare providers would have the knowledge and ability to do what was in their best interests. This echoed the theme of the search for information, trust, and understanding identified in Smith's (1998) earlier research. Most subjects commented on this, but not necessarily about the same members of the health care team. Frequently, the comments referred to the physicians; for example, “Yes, but the doctor knows best, so you would be silly not to listen to them”; and “I just knew they were doing what had to be done for me.” When the trust was violated, the participants experienced significant distress. One participant’s cardiac condition was not diagnosed when he presented at the rural hospital, but was diagnosed and treated on a priority basis when he was transferred to the CHR for specialist care. He lamented, “That shouldn’t happen. They are professionals.” The comments of three other participants reflected their trust in nurses—”You knew they knew what they were doing”—or in ambulance attendants—”The young guy that saved my life was with me again. He’s so good. I just trust him so much.”

Many participants acknowledged that they did not ask questions related to their treatment or care because of their trust in health professionals, which is evident in comments such as, “No, I don’t think I asked any questions because I figured the people that were doing it knew what they were doing”; and “I certainly never argue with someone who is infinitely more qualified than I.” The patients’ willingness to attend appointments and participate in tests after their AMI also demonstrates trust. Notification of appointments and tests often comes in the mail, with the date and time and often specific instructions for the tests. The patients were not always sure who was organizing the tests or appointments and who would receive the information, but because the notification included a specialist’s name or the Department of Cardiology, they felt that they should attend.

The theme of trust in the data was not unexpected. In the literature, trust in health care providers has been associated with patients’ feelings of vulnerability and their need for assistance in a life-threatening situation. This trust may serve as a form of coping, and the highly emotional quality of this trust may lead to "augmenting the effectiveness of treatment . . . or . . . to a profound sense of betrayal when they [expectations] are not met" (Hall, Dugan, Zheng, & Mishra , 2001; Hupcey, Penrod, Morse, & Mitcham, 2001).

Age is one of the few demographic characteristics of patients found to correlate positively with trust (Hall et al., 2001), and all of the subjects in this study were adults over the age of 55 years. In contrast, the brain-injured participants in Smith's (1998) study were significantly younger than those in this study, and the information was obtained from their caregivers. The participants were in direct contact with the health care system and health care providers for a longer period of time in Smith's study, which may change the perception of the infallibility of health care providers. Information from future studies using a variety of populations would clarify this further. Newhook (2004) recommended this as necessary to provide conceptual clarity in the field of continuity of care research.

Types of Continuity

In a multidisciplinary review of continuity of care, Reid et al. (2002) concluded that continuity of care contains two elements: care of the individual patient and care over time. Continuity is seen as "how individual patients experience integration of services and coordination" (p. 3). Integral to these are three types of continuity: informational, management, and relational. As stated at the beginning of this chapter, the participants in this study were not dissatisfied with their care, although they felt somewhat disadvantaged by having to go out of the region for specialized cardiac services. They made positive comments about the health care providers who treated them. However, they described some instances of omission (such as test results that are missing or delayed in being sent to a family physician), inconvenience (such as traveling by ambulance for procedures or having the procedures cancelled once the participant had arrived), less than optimal physical settings (such as having to spend two days on a stretcher in the emergency department post-MI), and inattention (such as being left waiting for tests for long periods in a hallway). However, these incidents did not prevent them from feeling connected to their caregivers. Their perception of being treated as individuals seemed to mitigate even the most compromising events that they experienced.

Relational continuity has traditionally been seen as most important in mental health and primary care, but the data from this study demonstrate its importance to these participants as well. Relational continuity was most evident in their descriptions of the care that they received at the local rural hospital. In three cases the participants described the nurses and/or doctors at the rural hospital as "waiting for me" when they arrived with chest pain and reported receiving individualized, high-priority, immediate treatment. The spouses of two of the participants had also received special attention at the rural hospital. Three subjects gave examples of being acknowledged as individuals by the specialists with such comments as "And he remembered me," and "So he must have read my chart, because I was on that medication before." Three participants mentioned instances during their journey when they had been treated with extreme compassion or when special considerations were taken, which reinforced their individuality. This seems to provide the "sense of predictability and coherence" that Haggerty et al. (2003, p.iii) suggested that patients require in stressful situations.

The lack of relational continuity was evident when the participants came into contact with specialized acute care services. Four of them described instances of significant depersonalization with comments that they felt “like a number, not a person”; that they needed “to accept that you are just one of many that is seen by the team”; that they felt forgotten and like a “spare tire” as they waited for tests; and that “you’re not special; you’re just one of many.”

Management continuity is the coordination and connection of multiple providers in various facilities in a timely, coherent manner. The participants in this study perceived their acute hospital care as generally well coordinated and delivered in a coherent manner. However, their referral and follow-up care lacked management continuity. The participants identified the postdischarge period as the most problematic for them because of the many unanswered questions associated with their disease and medications, their problems with anxiety and emotional upset, and their uncertainties about their future health. The family physicians of the study participants were not always able to assist with these concerns because they had not received referral information from specialists in a timely manner. Whereas Reid et al. (2002) defined management continuity as coordination and integration of care *within facilities*, the findings from this study reveal that postdischarge care also needs a coordinated and integrated approach. Reid et al.’s definition of management continuity does not adequately encompass the entire scope of health care services for patients and should be expanded.

Reid et al. (2002) defined informational continuity as “the common thread linking care from one provider to another and from one healthcare event to another” (p. 3), and the analysis of the data in this study suggests that informational continuity is affected by management and relational continuity. The participants could not identify a single person who they felt had complete and comprehensive information about them as a person or their health care issues. They trusted that the necessary information would be available and that their health care providers would have access to this information to use it in the best interests of the patient. Therefore, a reliable system that ensures that all members of the health care team have information on both the person and his or her disease process available to them is vitally important.

The analysis of the data obtained in this study reveals support for the theoretical concepts of continuity of care proposed by previous researchers. It also suggested associations among various concepts. When Glenn's (1996) antecedents of continuity were not present, Leatt et al.'s (2000) outcome indicators were not met. The data also supported the three types of continuity that Reid et al. (2002) identified while suggesting that relational continuity may be more significant from the patient's perspective than was perhaps thought. The findings also reveal that the definition of management continuity does not encompass all aspects of health care services, which draws attention to the need to focus on processes such as referral postdischarge, rehabilitation, and ongoing care. These processes were highlighted in Smith's (1998) study that involved younger participants who had longer exposure to nonacute health services. In the following chapter, conclusions and recommendations arising from this research study will be presented.

CHAPTER 6:

CONCLUSIONS AND RECOMMENDATIONS

There has been limited theoretical development in the area of continuity of care. One purpose of this study was to validate and enhance theoretical development by focusing on the patient's perspective, which has not been well represented in any research in this field. Conceptual elements from the work of Glenn (1996), Leatt et al. (2000), and Reid et al. (2002) were applied in the analysis of the data from this study. The research question was, "What are the perceptions of continuity of care of rural Albertans post-MI who receive services in both the David Thompson and Capital Health Regions." Issues that relate to continuity of care for vulnerable populations, the elderly, and those who reside in rural areas, as well as issues particular to clients who experience MI, were targeted. The conclusions and recommendations arising from the analysis of the data are presented in this final chapter.

Conclusions

Analysis of the data provided new knowledge on two levels: (a) how the participants in this study perceived continuity of care, what elements were important to them, and what areas they identified as problematic; and (b) the theoretical underpinnings of continuity of care that previous scholars have identified, especially Glenn (1996), Leatt et al. (2000) and Reid et al. (2002). This provides information that can be used in considering immediate changes to the health care delivery system and for future research in the area of continuity of care.

Patients' Perspective

The research revealed that the participants were satisfied with the care that they received from individual health care providers. However, they also perceived problems with "the system." The importance of relational continuity and the ability of the participants to develop some type of connection with their caregivers in which they felt that they were seen as an individual and not just another body to be processed was emphasized as critical to satisfaction with their care. The presence of relational continuity appeared to mitigate system problems that caused the participants discomfort or distress. Although relational continuity has previously been seen as important in providing both mental health and primary health care services, this research suggests that relational continuity has far wider implications in acute care areas.

Some system problems that the participants identified affected either the quality or the safety of their care. Prior to hospitalization, they avoided using the EMS in their area, believing that it would not be the quickest or most reliable method of obtaining medical care. This posed a significant risk for the participants' safety and is contrary to best-practice guidelines for management of AMI.

Throughout their acute care journey, it was necessary for the participants to make a number of transitions between facilities and providers before they received the comprehensive specialized care that they required. This has three implications: (a) The degree to which patients are able to receive care as outlined in the best-practice guidelines may be compromised, (b) the risk to patients increases as they are transported from one facility to another, and (c) there is an increased cost to the system incurred by both the prolonged length of stay for patients when they wait in one facility for specialized services at another facility, as well as the cost of the ambulance trips that are required to transport patients between facilities. Although the participants from rural areas identified this problem, it also affects patients within urban health regions who receive care in community hospitals without specialized cardiac services.

The data from this study also demonstrate that the participants did not consistently receive the health care services recommended for AMI patients following discharge from acute care. Seven of the eight participants did not attend a cardiac rehabilitation program, either because they were not referred to one or because they perceived it to be inaccessible because of the distance. The participants reported that they were not satisfied with the services available for medical follow-up care with cardiac specialists and ongoing health or disease management surveillance and information. The lack of support following discharge from hospital demonstrates a significant shortfall in the health care system that has been supported by the broader body of research on continuity of care.

Theoretical Perspective

Newhook (2004) identified the lack of conceptual and definitional clarity surrounding continuity of care as impeding valid measurement of continuity of care. This study applied Glenn's (1996) antecedents of continuity, Leatt et al.'s (2000) indicators of integrated care, and Reid et al.'s (2002) definition of continuity of care and its related components to the data. The findings from this study support Glenn's conceptual analysis. Health care services and providers must be both available and accessible for continuity of care to be achieved. The participants perceived that deficiencies in their care centered on either inaccessible or missing services or inaccessible or missing providers. This research also shows that self-care, which Glenn identified as the outcome of continuity, was not achieved when the antecedents, available and accessible health care services and providers, were not present. These conceptual elements have been validated in this study, which suggests that Glenn's work contributes to theoretical development in continuity of care research and further research based in her conceptualization is warranted.

The indicators of integrated health care that Leatt et al. (2000) developed were supported by the patients' perceptions of continuity of care in this study. These indicators could be developed further to become quantifiable outcome indicators of continuity of care. This would advance quantitative measurement of continuity of care in a variety of settings and add rigor to future research in the area.

This study also confirmed the importance of the work of Reid et al. (2002) and identified areas within this work for further investigation and clarification. Their definition of management continuity, as presented, is incomplete because it includes only reference to multiple providers in various *facilities*. However, this research demonstrates that management continuity must extend beyond services and providers in *facilities* to include those available in the prehospital and posthospital periods. The importance of relational continuity for patients is also highlighted in this study. Whereas relational continuity has been seen as particularly important in long-term client-provider interactions, such as those in the field of mental health and primary care, the participants in this study indicated that it was of high importance to them in all patient-provider interactions.

It was apparent from the data that the elements of continuity that Reid et al. (2002) listed relate to the process through which continuity of care is achieved, whereas the concept of continuity of care that Glenn (1996) described refers to the resources required within the health care system to ensure that continuity of care is possible to enable patients to achieve the outcome of self-care. The indicators of integrated care that Leatt et al. (2000) proposed are related to the health care delivery process and to health system resources and could contribute to consistent measurement of both.

Recommendations

Because of the small sample size of this study and the diversity of rural regions, it is recommended that this study be replicated within other regions using a larger, representative sample. Replication of the study within urban areas would determine whether the findings are particular to rural areas alone or apply generally to the whole population. The findings of this study lead to recommendations in two areas, the health care system, and theoretical development in the field of continuity of care research. The recommendations include the following:

Health Care System Implications

1. Further research should be conducted on the number of transitions in care and congruence with best practice guidelines for patients who are recovering from AMI in this rural and other rural areas.
2. Replication studies should also explore these issues for patients in urban areas.
3. The need for disease management or health maintenance programs, including cardiac rehabilitation and ongoing health teaching and monitoring was identified to achieve congruence with best practice guidelines.

Advancing Continuity of Care Research

1. Glenn's (1996) conceptual model of continuity of care was found to have analytical and explanatory value when applied to the data in this study. Researchers should consider this concept in the design of further continuity of care research. More specifically, it is recommended that Glenn's (1996) concept of the antecedents of continuity be further refined and tested using a larger sample of patients who have suffered an AMI.
2. Leatt et al.'s (2000) nine indicators of integrated care be should receive additional attention by researchers seeking continuity of care outcomes standardization measures.

Limitations of the Study

This study was designed as an exploratory descriptive study. It had several limitations. First, it had a small sample size of eight nonrandomized participants who were interviewed only once. Second, since half of the participants self-selected, they may have had specific issues to address that they considered problematic. Third, the definition of rural is not static, but depends on the individual researcher's choice of definition and statistical reference. Therefore, conceptual clarity of what constitutes *rural* would enhance future studies. Generalizations from the findings of the study are not warranted based on the small sample size. However, it is possible to implement the recommendations for the population included in the study and to substantiate the theoretical concepts proposed by previous scholars in the field of continuity of care.

Summary

Continuity of care is important to patients to ensure that they receive safe, high-quality, appropriate, and timely health care services. Continuity of care is important to the health care system to ensure efficient, effective, and economical use of resources. Knowledge development in the area of continuity of care has been hampered by the lack of conceptual clarity and a unilateral view of continuity of care from the administrative or system perspective. This study, designed to understand the patient's perspective of continuity of care and to build on previous research conducted by experts in the field, makes a contribution to knowledge development in the field of continuity of care. More specifically, it suggests ways in which clinical care and outcomes for people suffering an AMI can be improved.

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APPENDIX A: RECRUITMENT ADVERTISEMENT

UNIVERSITY OF ALBERTA

Have you experienced a Heart Attack within the last two years?

Did you receive care in both the David Thompson and the Capital Health Region?

Nurse Researchers from the University of Alberta are interested in what the health care system is like for someone who lives in a rural community who needs treatment in a major center. If you are over 18 years of age, live within the David Thompson Health Region and have experienced a heart attack within the last 2 years where you received care in both the David Thompson Health Region and the Capital Health Region (i.e., Edmonton) we would like to talk to you. Your participation in this study can help health professionals understand and improve the continuity of care for people in rural areas who have had a heart attack. Participants in the study will meet with a nurse for about an hour to describe their experiences following their heart attack.

If you would be willing to talk about your experiences, please contact Judy Bowie RN at (403) 342-3131(work) or (403) 783-6262(home) for further information.

APPENDIX B: RECRUITMENT POSTER

UNIVERSITY OF ALBERTA

Recruitment Poster

Have You Experienced a Heart Attack Within the Last 2 Years?

Did You Receive Care in Both the David Thompson and Capital Health Regions?

Nurse Researchers from the University of Alberta are interested in what the health care system is like for someone who lives in a rural community who needs treatment in a major center. If you are over 18 years of age, live within the David Thompson Health Region and have experienced a heart attack within the last 2 years where you received care in both the David Thompson Health Region and the Capital Health Region (i.e., Edmonton) we would like to talk to you. Your participation in this study can help health professionals understand and improve the continuity of care for people in rural areas who have had a heart attack. Participants in the study will meet with a nurse for about an hour to describe their experiences following their heart attack.

If you would be willing to talk about your experiences, please contact Judy Bowie RN at (403) 342-3131(work) or (403) 783-6262(home) for further information.

APPENDIX C: INFORMATION LETTER FOR PARTICIPANTS

UNIVERSITY OF ALBERTA

Information Letter for Participants

Phase II: Client/Caregiver Interview

Study Title: LINCS Research Program – Phase II		
Principal Investigator:	**Donna Lynn Smith** RN, MEd, CPsych, CHE	(780) 492-9544
Co-Principal Investigator:	**Judy Bowie,** RN, BScN	(403) 783-6262

What is the purpose of the study?

The purpose of the LINCS Research Program is to develop an understanding of how continuity of care can be improved through policy and management decisions in the health care system. We are interested in how patients feel continuity of care can be achieved. We will learn about programs or service integration strategies for specific populations by interviewing people like yourself who have experience with these programs.

What will happen?

Judy Bowie, a Master of Nursing student, would like to interview you about your experiences in moving between health services and health care providers in the David Thompson Health Region and the other centers in the Capital Health Region where you received care. We would like to learn more about how you or someone you know became a patient there and the transitions you have experienced in your journeys through the health care system.

Judy Bowie will ask you a series of questions related to your care experience. The interview will be tape-recorded and she may take some notes while you are talking. This is to ensure that she understands what you have told her.

Once the interview is complete Judy Bowie may contact you if any further clarification is needed.

How much time will be taken?

The interview will take approximately 45 minutes to 1 hour.

Are there any risks?

There are no known risks from being in this research study.

Participation in this study

You do not have to participate in this study. You can drop out whenever you wish. You do not have to give a reason for dropping out. Just tell the interviewer that you do not wish to continue with the interview.

Privacy and confidentiality

Your confidentiality and anonymity is assured in this process. Your name will not appear on the written transcript of your interview or in any reports about this research.

Only Professor Donna Lynn Smith and Judy Bowie will have access to the tapes and the information transcribed from the interviews.

The responses to the questionnaire will be kept in a locked drawer for five years. The consent forms will be kept in another locked drawer for five years. They will then be destroyed.

The findings from this study may be published or presented at a conference.

Your care will not change if you are in the study. If you decide not to be in the study or drop out, your care will not change as a result.

Concerns?

If you have any concerns about any aspect of this study, you may contact Dr. Kathy Kovacs Burns, Research Administration, Faculty of Nursing, at (780) 492-5991. This office has no affiliation with the study investigators.

APPENDIX D: CONSENT FORM

UNIVERSITY OF ALBERTA

Consent Form

Phase II: Client/Caregiver Interview

Study Title: LINCS Research Program – Phase II		
Principal Investigator:	**Donna Lynn Smith** RN, MEd, CPsych, CHE	(780) 492-9544
Co-Principal Investigator:	**Judy Bowie,** RN, BScN	(403) 783-6262

What is the purpose of the study?

	YES	NO
Do you understand that you have been asked to participate in a research study?		
Have you read and received a copy of the attached information sheet?		
Do you understand the benefits and risks involved in taking part in this research study?		
Have you had an opportunity to ask questions and discuss the study?		
Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect your care.		
Has the issue of confidentiality been explained to you? Do you understand who will have access to your records/information?		

This study was explained to me by:

Researcher: ________________________________

Printed Name: ________________________________

Date: ________________________________

I agree to take part in the part of the study indicated.

Signature of Research Participant: ________________________________

Witness (if available): ________________________________

Printed Name: ________________________________

Date: ________________________________

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

Researcher: ________________________________

Printed Name: ________________________________

Date: ________________________________

APPENDIX E: CLIENT/CAREGIVER INTERVIEW GUIDE

A product of the **LINCS**

LINCS
Research
Program

Client/Caregiver

Client/Caregiver

Client/Caregiver Interview Guide

Preamble

Thank you for taking the time to talk with me about your experiences with the health system following your heart attack. We would like to learn more about your experiences in moving between health services and health care providers in your own community and in the other centers where you received care. This information will help health care professionals understand the factors affecting continuity or discontinuity of care from the patient's point of view.

Judy Bowie, a Master of Nursing student, will ask you some general questions about your experience. The interview will be tape-recorded and she may take some notes while you are talking. This is to ensure that she understands what you have told her.

Before we get started, do you have any questions?

You will be given a chance to review your statements to confirm their accuracy. Your confidentiality and anonymity is assured in this process. You have the option to drop out of the interview at any time. If you have any further questions or concerns, you may contact Professor Donna Lynn Smith at (780) 492-9544. She is the leader of a nationally funded study we are conducting related to continuity of care.

Guiding Questions

1. What can you tell me about the events that led to your experiences with the health care systems?
2. What can you tell me about your experiences as a patient/ client following your heart attack?
    (a) Where were you sent?
    (b) Why did you go there?
    (c) What information did you need at that time?
    (d) Did you get the information?
    (e) Did you have any help when you transferred to a new location?
    (f) If you did not get any help, who might have helped you?
3. What other health care facilities and programs have you attended?
    (a) Where were you sent?
    (b) Why did you go there?

   (c) What information did you need at that time?

   (d) Did you get the information?

   (e) Did you have any help when you transferred to a new location? (Coordination)

   (f) If you did not get any help, who might have helped you?

   (g) Do you feel you were involved in decisions that were made regarding care?

4. Do you feel that personal likes and dislikes were accommodated during the care and transitions from one care setting to another?

5. What do you feel were the most difficult things you have experienced in the process or getting or receiving services following your heart attack?

6. What do you feel were the good things you experienced?

7. If there were one thing that you could change about the services or care arrangements, what would it be?

8. Was there any one person or group that helped to arrange and coordinate and arrange your care? Who was this?

9. If not, would it have helped if one person had been responsible for coordinating care?

10. How would this have helped?

11. Do you feel that living in a rural area made any difference in you or your family's experience following your heart attack?

12. Is there anything else you would like to share about your experiences following your heart attack?

Thank you for your assistance.

APPENDIX F: CLIENT/CAREGIVER INTERVIEW GUIDE PROTOCOL

We would like to interview you about your experiences in moving between health services and health care providers in your own community and the other centers where you received care. We would like to learn more about how you became a patient and the transitions you have experienced in your journeys through the health care system between the David Thompson Health Region and the Capital Health Region.

Judy Bowie, a Master of Nursing student, will ask you a series of questions related to moving between these venues. She will take notes and your session will be tape-recorded and later transcribed.

You have the option to drop out of the interview at any time. You will be given a chance to review your statements to confirm their accuracy.

Your confidentiality and anonymity is assured in this process. Your name will not appear on the written transcript of your interview or in any reports about this research.

If you have any further questions or concerns you may contact Judy Bowie (investigator) at (403) 783-6262 or Donna Lynn Smith (principal investigator) at (780) 492-9544.

Thank you for your assistance.