

Exploring the Health Behaviour Practices of Elective Ad-hoc Percutaneous Coronary
Intervention (PCI) Patients

by

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Abstract

Interventional technologies such as elective percutaneous coronary interventions (PCI) are increasingly used to manage the symptoms of coronary artery disease (CAD); however, this treatment approach is associated with poor risk factor management. The purpose of this study was to understand the factors that influence the health behaviors of elective PCI patients. A qualitative approach, using Interpretive Description, was used to explore the ten participants' healthcare experiences, their perceptions of CAD, and the rationale for their health choices. This generated a profile of these individuals and their post-PCI health behaviours. Health behaviours were influenced by multiple factors and are reflected in the themes: *what a relief – I'm better*; *uncertainty* about their future health; the *importance of relations*; and *barriers to lifestyle change*. These findings not only extend our understanding of the elective PCI patients' health behaviour choices but also provide insight into key areas to target for improving health service delivery.

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Dedication

This thesis is dedicated to participants of this study and my family.

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Exploring the Health Behaviour Practices of Elective Ad-hoc Percutaneous Coronary
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Chapter 1: Cardiac Disease, PCI, and Disease Prevention

Chronic diseases have become the dominant pattern of illness in Canada. Since the early 1900's, mortality rates from infectious diseases have been declining and chronic illnesses such as heart disease and cancer have become the most prevalent causes of death in developed nations (Young, 2005). This change in disease pattern has prompted some epidemiologists to refer to this era as the age of degenerative diseases (Young, 2005). Consequently, chronic illnesses are creating huge burdens on the global health care system. For example, in the United States (US), chronic illness accounts for 70-80% of health care expenditures (Coleman & Newton, 2005). In Great Britain, the Department of Health estimates that 80% of primary care consultations and two thirds of emergency admissions are related to chronic conditions (Singh, 2005). Here in Canada, we are also struggling with a growing chronic disease burden. In 2000/01 almost 87% of Canadians 65 years or older reported that they had at least one chronic illness (Statistics Canada, 2006). Although much of the increasing chronic disease burden is attributed the concurrent increase in our aging population, it is important to note that in 1996/1997 an estimated 58% of Canadians aged 12 years or older reported that they had a least one chronic condition (Schultz & Kopec, 2003). Evidently, chronic illnesses are not only affecting the elderly, but also individuals in their prime.

The major mortality causing chronic diseases in Canada includes: cancer, respiratory disorders, diabetes and cardiovascular disease (CVD; Klein-Geltink, Choi, & Fry, 2006). Not only is CVD associated with increased mortality but also morbidity, and

is linked to debilitating symptoms that tend to affect an individual's physical, personal, and psychosocial functioning. The non-modifiable risk factors for CVD including gender, age, and family history (genetics), along with numerous individual modifiable risk factors contribute to disease development and progression. It is the modifiable risk factors, including elevated cholesterol, obesity, diabetes, sedentary lifestyle, smoking, hypertension, diabetes, and low birth weight (Conway & Fuat, 2007), that are the primary targets for disease management and prevention strategies. There is also solid research evidence that the broader determinants of health also influence the cardiovascular illness trajectory (Gonzalez, Atralejo, & Calero, 1998; King, 2010).

The CVD burden is not surprising given that nine out of ten Canadians reportedly have at least one cardiovascular risk factor (Heart & Stroke Foundation, 2011). Since effective chronic disease management is largely dependent on modifying unhealthy lifestyles and reducing risk factors, understanding the health behaviour practices of individuals with CVD is critical. Health behaviour practices refer to any action that is related to disease prevention, health maintenance, health improvement, or the restoration of health. In this study the Health Belief Model provided the framework, which explored the health behaviour practices of individuals who had undergone an elective ad-hoc percutaneous coronary intervention (PCI) for the treatment of coronary artery disease (CAD). There has been a dearth of research related to the unique perspectives and experiences of the elective ad-hoc PCI patients. Consequently, there has been a general lack of understanding of these patients and their differences from other with CVD.

This chapter will provide an overview of the increasing burden of CVD, as well as the evolution of revascularization procedures, including PCI. Personal experience

working with the elective ad-hoc PCI patient population, the uniqueness of these patients'; as well as the challenges associated with this treatment strategy will be highlighted. This chapter concludes with a summary of the statement of the problem, purpose, and significance of the study.

Background: Cardiovascular Disease

The Burden of Cardiovascular Disease

Despite declining rates of heart disease mortality since the 1980's related to medical and technological advancements, CVD is still the leading cause of mortality in Canada (Hu et al., 2006). In 2004, CVD accounted for 32% of all deaths (Statistics Canada, 2007); of these deaths, 54% were due to ischemic heart disease (Heart & Stroke Foundation, 2009). As well, CVD continues to place huge health and financial burdens on all Canadians. CVD often has a negative effect on quality of life because of associated activity restrictions, disabilities, depression, chronic pain, and unemployment (Statistics Canada, 2006). Moreover, heart disease and stroke costs the Canadian economy more than \$18 billion every year in physician services, hospital costs, lost wages and decreased productivity and represents the largest segment (11.6%) in health care spending (Public Health Agency of Canada, 2003). Although cardiovascular related mortality has decreased, it is projected that CVD morbidity will increase over the next fifteen years due to our aging population, as well as increased rates of diabetes and obesity within society (Statistics Canada, 2006).

Advancements in surgical and interventional technology have resulted in the successful treatment of CVD, and a consequent decrease in mortality rates. According to a recent study, the 35% decline in ischemic heart disease mortality in Ontario between

1994 and 2005 was attributable to medical and surgical treatments (43%), and improved prevention and risk factor management (48%), while increasing diabetes prevalence and obesity was associated with higher mortality (8%; Wijeyesundera et al., 2010). However, considerable debate remains around these findings and the relative benefit to the population as a whole as studies consistently report a higher CVD mortality burden to Canadians of lower socioeconomic status (Alter, Naylor, Phil, Austin, & Tu, 1999). While the optimal approach to CVD prevention and management includes the use of current medical technologies along with evidence-based prevention strategies, there is substantive evidence to suggest that current prevention strategies are suboptimal (IOM, 2001; Barr et al., 2003; Glasgow et al., 2001) and not accessible to many Canadians, particularly those of lower socioeconomic status (Alter, Iron, Austin, & Naylor, 2004).

Reducing the Burden of Cardiovascular disease

When compared to other chronic illnesses, patients living with CVD have reported a much lower awareness of their condition (Byrne, Walsh, & Murphy, 2005). Since much of our chronic disease burden is preventable through health promotion and disease prevention, this is a grave concern. According to Byrne and associates, the illness identity score (3.23, S.D.= 2.67) found in their sample of participants with CAD (N=1,084) was considerably lower than those found by researchers investigating other chronic diseases, such as diabetes, rheumatoid arthritis, chronic fatigue syndrome, or patients with chronic pain. They contend that this low score may explain the weak relationship noted between the participants beliefs and behaviours and that patients with a higher illness identity may be more motivated to follow medical advice and prevention strategies. A strong contention of the Health Belief Model is, individuals who feel

susceptible to a disease or who perceive the disease to be a significant threat to their health, will act to minimize the threat of that disease (Becker, 1974). Therefore, in order to effectively reduce the CVD burden, education along with a population-based strategy for the prevention and management of CVD can no longer be ignored (Barr et al., 2003; Glasgow et al., 2001).

Preventative strategies incorporate primary, secondary, and tertiary levels of prevention. Primary prevention refers to preventing illness before it occurs (Lupton, 1995). These types of programs are usually targeted at a population level, such as nutritional and physical education programming within the school system. Secondary prevention focuses on early detection such as the use of angiograms to diagnose CAD (Lupton). Tertiary prevention focuses on treatment of the illness and rehabilitation (Lupton). The primary goal of tertiary prevention is to prevent the illness from worsening or causing premature death or disability. For individuals diagnosed with CVD, tertiary prevention is aimed at prolonging the length, as well as the quality of their lives.

Strategies to reduce the major modifiable CVD risk factors of smoking, diabetes, obesity, poor diet, and sedentary lifestyles are central to tertiary prevention. Unfortunately, to date, prevention strategies have been largely ineffective. Therefore, these risk factors continue to plague the cardiac population, with detrimental consequences (Health Canada, 2007). In particular, the tertiary prevention strategies for elective PCI patients are poorly understood. What we do know is that these patients have: poor attendance in cardiac rehabilitation programs (Bethell, Evans, Turner, & Lewin, 2006; Bethell et al., 2008; Hamilton & Haennel, 2004; King, Humen, & Teo,

1999; Worcester, Murphy, Mee, Roberts, & Goble, 2004), lack understanding of the disease process (Astin, & Jones, 2004; Campbell, & Torrance, 2005; Fernandez, Griffiths, Juergens, Davidson, & Salamonson, 2006; Lauck, Johnson, & Ratner, 2009), and fail to initiate lifestyle changes (Astin & Jones, 2006; Fernandez et al.; Gaw-Ens & Laing, 1994; Gulanick, Bliley, Perino, & Keough, 1998). In a descriptive survey of 98 elective PCI patients Lauck et al. (2009) found that 77% of the participants did not plan on attending a cardiac rehabilitation program (CRP). Unfortunately, the participants provided no explanations for their lack of attendance. It is not surprising then that Astin and Jones (2006) reported a “significant proportion” of the 117 elective PCI participants surveyed failed to adopt healthy lifestyle behaviours. Therefore, it is of paramount importance that we gain an understanding of the experiences, beliefs, and perceptions of these patients so we can plan and implement more effective prevention strategies. Succeeding in this endeavor will ultimately decrease the burden of illness and improve the quality of life for these individuals.

Background: Percutaneous Coronary Interventions

History of PCIs

Over the past 50 years, one of the great advances in the treatment of CAD has been the development of coronary artery revascularization techniques. This process began with the development of coronary angiograms. Dr. Werner Forssmann performed the first human cardiac catheterization in 1929; however, its adoption as a diagnostic tool to measure cardiac output did not occur until 12 years later (Angioplasty.Org, 2008). In 1958, Dr. Mason Sones accidentally discovered the ability to image the coronary arteries while injecting dye into a patient’s aortic valve (Angioplasty.Org, 2008). He went on to

perfect this new technique using specially designed catheters to produce high quality diagnostic images of the coronary arteries. This technique is now known as the coronary angiogram (Angioplasty.Org, 2008). Coronary angiograms are now routinely performed on many cardiac patients as a secondary prevention strategy, to accurately diagnose CAD. The advent of this procedure also set the stage for subsequent advances in therapeutic interventions, including bypass surgery and coronary angioplasty (Angioplasty.Org, 2008).

The revascularization of coronary artery blockages began in 1962 when Dr. David Sabiston performed the first coronary artery bypass graft (CABG) surgery (Noon, 2009). Although the patient did not survive, this event was a catalyst for increased interest in this procedural technique. In 1964, the first successful CABG operation, performed by Garrett, Dennis, and DeBakey, resulted in an evolution in the treatment of coronary artery blockages (Noon, 2009). The treatment of CAD has continued to progress, resulting in the development of an alternative intervention called a coronary angioplasty or a percutaneous coronary intervention.

PCI, first introduced in 1977 by Dr. A. Gruentzig, further revolutionized interventional cardiology by facilitating the treatment of CAD without invasive surgery (Fernandez et al., 2006). The purpose of a PCI is to improve blood flow, thus decreasing heart-related chest pain (i.e., angina). The PCI procedure consists of inserting a catheter into a peripheral artery and directing it towards the coronary arteries. Under X-ray fluoroscopy, dye is injected into the coronary arteries to visualize any blockages (Heart & Stroke Foundation, 2009). During the procedure, blockages are pushed to the side of the vessel wall by either a balloon or stent. Many refer to the current practice of PCI as the

‘stent revolution’ as stents are now used in 90% of all PCI procedures (Mack et al., 2008). This quick and relatively pain-free procedure has fast become the treatment of choice for many individuals with CAD.

In Canada, overall cardiac revascularization rates increased by more than 10,000 cases between 2001/02 and 2005/06; while the number of CABG surgeries has decreased, PCI rates have been steadily increasing (CIHI, 2008), and currently account for three of every four coronary revascularization procedures (Mack et al., 2008). In Manitoba, 1590 PCI procedures were performed in 2008 (Dr. R. Philipp, personal communication, January 30, 2009), compared to 914 CABG surgeries (Dr. R. Arora, personal communication, April 29, 2009), thus demonstrating a more moderate but similar trend within this province.

In Manitoba, PCIs are currently performed at Winnipeg’s two tertiary care centers: St. Boniface General Hospital and the Health Sciences Centre. PCIs are typically categorized as elective staged, elective ad-hoc, urgent, or emergent/primary (see Table 1). Although these categories are used to assess the urgency of diagnostic testing and intervention required, they do not always accurately reflect the severity of the underlying CAD.

Table 1. PCI Categories

	<i>Elective Staged</i>	<i>Elective Ad-hoc</i>	<i>Urgent</i>	<i>Emergent</i>
Origin	Home	Home	Hospital	Home
Patient Teaching	Pre procedure	Pre procedure	Pre & post procedure	Post procedure
Timing of PCI	Delayed usually about 2 weeks post angiogram	Immediately (during angiogram)	Usually immediately	Immediately
Post procedure Length of Hospital Stay	10-24 hrs post PCI	10-24 hrs post PCI	Usually 3-5 days	Usually 3-5 days
Hospital Rehabilitation	Nil	Nil	Phase 1	Phase 1

Primary or *emergent PCI* is the latest advance in the use of PCI to treat CAD.

This intervention is used to treat an evolving ST elevation myocardial infarction (STEMI), whereby the patient's status is communicated from the ambulance to the cardiac interventionalist. This allows the patient to bypass the emergency department and go directly to the heart catheterization laboratory. As is evident by the speed of events, these patients receive limited information/teaching prior to the procedure. The patient is then recovered in hospital for 3-5 days, depending on their recovery.

A patient undergoing an *urgent PCI* is typically someone who is currently hospitalized with a diagnosis of acute coronary syndrome, a non-STEMI, or unstable angina. These patients are referred to the cardiac catheterization laboratory by the

attending physician and have a diagnostic angiogram to determine the reason for their symptoms. A PCI may be performed at this time if blockages are amenable to PCI. Pre and post procedure teaching is usually done by both the nurses and physiotherapists on the ward and generally consists of instructional videos, information booklets, and the opportunity to ask questions. These patients are also hospitalized for 3-5 days, depending on their health status and test results.

An *elective staged PCI* patient is generally someone who presents to a primary care physician with potentially cardiac-related symptoms. These individuals are then referred either to the heart catheterization laboratory, or to a cardiologist who may request an angiogram. Prior to their angiogram procedure, these patients are seen in a teaching clinic a few days before their test. This provides an opportunity to instruct the patient about the procedure, for the patient to ask questions, and for the nurse to collect specific patient information including their health history, as well as blood work, and an electrocardiogram. On the morning of the procedure, the patient is admitted to hospital through the day surgery department and then proceeds to the catheterization laboratory. Immediately following the angiogram, the patient is informed of the results; if there are blockages amenable to PCI, an appointment will be made for the patient to return in a few weeks for this procedure. The patient is then discharged 3-4 hours post procedure that same day.

An *elective ad-hoc PCI* follows essentially the same process as an elective staged procedure; however, when blockages are diagnosed during the angiogram procedure, the cardiac interventionalist proceeds immediately to PCI, rather than having the patient return at a later date for the intervention. Following the PCI procedure, patients return to

the ward to recover and are observed for 10-24 hours, depending on their health status. If no complications arise during this period, they are discharged home. Although elective staged and elective ad-hoc PCI patients are both admitted from home for a diagnosis, have minimal opportunity to receive post-procedure teaching, and only stay in hospital 10-24 hrs post procedure, we should not assume they have the same procedural experience or understanding of their CVD. The research findings of Angus et al., (2005) indicate that an important process in a patient's comprehension of a disease threat is to link the symptoms along the stages of the diagnosis and "it is the understanding of this link that makes the diagnosis believable to him" (p. 2124). Therefore, health care professionals need to explore how the ad-hoc PCI experience may contribute to the perceptions, beliefs, or knowledge regarding CVD for this patient population.

The Elective Ad-hoc PCI Patient

In Manitoba, the vast majority of elective PCI patients are treated with ad-hoc procedures. In 2008, 411 patients underwent elective PCI procedures at the Health Sciences Centre and St. Boniface General Hospital, 89.5% of which were ad-hoc procedures (Dr. R. Philipp, personal communication, January 30, 2009). Although researchers have found no significant differences between in-hospital major adverse effects in ad-hoc versus staged (elective) PCI strategies (Feldman, Minutello, Gade, & Wong, 2007; Khater, Zureikat, Alqasem, Alnaber, & Alhaddad, 2007; Krone, Shaw, Klein, Blankenship, & Weintraub, 2006), little is known about the ad-hoc PCI patient's experience or their post-PCI health behavior practices. The rapid transition from diagnosis to treatment results in minimal time for the ad-hoc PCI patient to process the ramifications of their diagnosis. This may contribute to what Reid et al. (2006) describe

as a ‘drive through’ mentality, which results in lack of motivation for sustained lifestyle change. However, this label may be unfair and unmindful of the contribution the health care system has in the development of this attitude. As Lauck et al., (2009) contend, the treatment advances in PCI have driven the shortened hospitalizations and increased demand for PCI services, however this trend has not been supported by research evidence on how best to meet the needs of these patients. Therefore, a comprehensive understanding of the beliefs, experiences, and perspectives of the elective ad-hoc PCI patient will provide insight into the how to optimally care for this population.

Personal Experience With the Elective Ad-hoc PCI Patient’s

My experience with the elective ad-hoc PCI patient population is derived from being employed by the cardiac catheterization laboratory at the Health Sciences Centre in Winnipeg from 2002-2006. During my four years working in this area I was fascinated by the remarkable technology, which facilitated the opening of narrowed or blocked arteries. I was also distressed by the apparent lack of services offered or provided to these patients. At many points I had the distinct feeling that I was working on an assembly line, unfortunately this sentiment was occasionally mirrored by patients who asked, “what number am I”. Medical and nursing staff involved in the care of these patients spent a great deal of time and effort to adequately prepare these patients for their procedure, but to what end, when after the procedure was completed they were sent home with no formal follow-up care or program of prevention. Yes, the blockages were treated; however, limited follow-up and poor referral to secondary prevention programs inhibited the patients’ ability to manage their chronic illness, prevent disease progression, and reduce the burden on our health care system. As health care providers we need to

seriously reflect on how we deliver health care and recognize that individuals in the early stages of disease are as much in need of expert care and guidance as those who have suffered myocardial infarctions (MIs), had coronary artery bypass graft (CABG) surgery, or have heart failure (HF). Prevention must become a core component of our practice.

The PCI Population and Tertiary Prevention

The World Health Organization has defined health promotion as “the process of enabling people to increase control over, and to improve, their health” (Raphael, 2000, p. 356). Based on this definition, tertiary prevention strategies for the cardiac population focus on health promotion. The Ottawa Charter for Health Promotion (1986) further states that the responsibility for health promotion in health services must be shared among individuals, communities, health professionals, health care institutions, and governments. When viewed within this context, health care institutions have an obligation not only to treat patients but also to promote health, and prevent disease. This mandates follow-up and risk factor modification programs that are directed toward patient populations based on their specific needs, abilities, preferences, and goals. Barr et al., (2003) contend that, with chronic diseases such as CVD approaching epidemic levels, our health care system needs to shift from its current focus on acute problems to a proactive approach, which promotes health and prevents disease.

Cardiac Rehabilitation Programs and PCI

To accomplish the goal of halting or slowing the progression of the disease, all patients with documented CAD should be engaged in tertiary prevention. To date, the primary mode of tertiary prevention for the cardiac population has been provided within CRPs. While CRPs are an effective strategy for some patients, these programs do not

meet the needs of the majority of cardiac patients. Elective PCI patients are a specific population of cardiac patients that fail to enroll in traditional CRPs. The history of CRP development may provide some insight into this unfortunate phenomenon.

CRPs were developed in the 1960's, with early strategies focused on the needs of middle-aged men to promote return to work and avoidance of complications following an MI (Bjarnason-Wehrens et al., 2007). These programs evolved during the 1970's, and incorporated multifaceted strategies consisting of physical, social, and psychological components. As a viable treatment option for those with CAD, PCI was not introduced until the 1980's, well after CRPs had been established. Consequently, PCI patients were integrated into existing rehabilitation programs with other cardiac patients. Recent evidence suggests that this strategy has been less than ideal (Bethell et al., 2006; Bethell et al., 2008; King et al., 1999; Hamilton & Haennel, 2004; Worcester et al., 2004). For example, Bethell and associates (2006) followed CRP enrollment over a two-year period and found that the greatest proportion of participants were CABG surgery patients (75%), followed by MI patients (25%), and PCI patients (20%). As well, the majority of these post-PCI CRP participants fall into the category of having a PCI following a cardiac event, such as acute coronary syndrome (ACS) or an MI. In a study of new CRP participants, Hamilton and Haennel (2004) found that less than 5% of new recruits were elective PCI patients. In addition, high attrition rates plague tertiary prevention programs (Paquet, Bolduc, Xhignesse, & Vanasse, 2005; Worcester et al., 2004). According to Paquet and associates less than 20% of eligible cardiac patients in Canada begin and maintain a CRP. Although there are no data available regarding the specific dropout rates for cardiac populations, the already low enrollment of elective PCI patients,

combined with high dropout rates, compounds our inability to successfully promote lifestyle changes in this population.

In 2008, 47.4% of cardiac rehabilitation referrals attended one of two CRPs offered in Winnipeg, Manitoba (L. Greenslade, personal communication, June 16, 2009). The two sites, offering CRPs are the Wellness Institute and the Reh-Fit Centre. CRP participants were predominantly male (68.8%), with an average age of 63 years (range of 22-96 years). The participant profiles, based on diagnostic categories, included: 28.3% *post MI*, 27.0% *post surgical*, 39.5% *general*, which includes self referrals or referrals from physicians outside of a hospital setting, and 4.9% were *other*, which captures diagnoses such as heart failure or angina (L. Greenslade, personal communication, June 16, 2009). The elective PCI patients participating in CRPs in 2008-2009 were enrolled under the *other* category (R. Vaags, personal communication, July 6, 2009). Thus, the Winnipeg recruitment of elective PCI patients is consistent with those found by Hamiton and Haennel (2004), in which less than 5% of CRP participants were elective PCI patients. Evidently, the recruitment of these patients into CRPs is problematic for multiple centers.

Given that elective ad-hoc PCI patients are generally diagnosed and treated relatively early in the atherosclerotic disease process, they are ideal targets for aggressive tertiary prevention strategies. For example, in a descriptive study of 90 post-PCI patients, Perkins and Jenkins (1998) found that this was the first PCI procedure for 71.1% of participants and this procedure marked the initial diagnosis of CAD for 42.2% of their cohort. In addition, unlike some of their CABG surgery or MI counterparts, elective PCI patients often have normal ejection fractions and fewer vessels affected by CAD

(Lisspers et al. 1999), which makes them model candidates for targeting prevention strategies.

As a result of earlier diagnosis and treatment, many elective ad-hoc PCI patients are relatively young and in their prime. However, despite evidence to suggest that younger individuals are more likely to attend CRPs than their older counterparts (King et al., 1999; Suaya et al., 2007), Eastwood (2001) found that individuals with dependants had greater difficulty with enacting lifestyle changes. Additionally, Stafford, Jackson, and Berk (2008) reported that younger patients with CVD were less likely to adhere to secondary prevention regimes. These findings may be related to inflexible work schedules and family obligations that do not always accommodate CRP requirements (Eastwood, 2001). Therefore, health care providers must consider the needs of patients trying to juggle family and work obligations while recovering from an elective ad-hoc PCI. Current prevention strategies are not meeting the needs of many patients with CVD; however, given the under-representation of elective PCI patients in CRPs, research evidence pertaining to the health behaviour practices of this population is urgently needed.

The dramatic increase in elective ad-hoc PCI procedures over the past decade substantiates increased attention to the tertiary prevention needs of these patients. Although their lack of engagement in CRPs provides a strong argument for alternative intervention programs, research evidence is needed in order to develop appropriate tertiary prevention strategies. Tertiary prevention aimed at health promotion and halting or slowing disease progression is critical to the long-term health of these patients. Early intervention, which includes the patient's adoption of risk reduction behaviours, is key to

effective chronic disease management. Clearly, health care professionals need to focus on both the treatment and the tertiary prevention of the elective ad-hoc PCI population.

The Problem

As chronic illnesses, such as CVD, can only be managed, not cured, health care professionals must focus on effective management and tertiary prevention. Tertiary prevention strategies are an integral component of chronic disease management and especially important for elective ad-hoc PCI patients. While PCI often provides immediate relief of symptoms, it does not halt or cure the underlying disease. Unfortunately, a chronic disease management model has not been adopted with this population, which means the long-term needs of the elective ad-hoc PCI patients are not being addressed.

The acute care focus in health care is evident in the treatment of the elective ad-hoc PCI patient population. Although these patients are quickly and effectively treated for their coronary occlusions, tertiary prevention and follow-up care are lacking. Campbell and Torrance (2005) contend that while PCIs are a ‘technical fix,’ this procedure is failing to meet the long-term needs of the elective PCI patients. CAD is a chronic condition, and as such, effective chronic care management, including tertiary prevention, should be initiated as early as possible in the disease trajectory.

In general, there are few tertiary prevention strategies that specifically address the elective PCI patient population. Although elective PCI patients often have well-established risk factors, they may not be aware of the risks. For example, King and associates (2002) found that only 35% of women undergoing a coronary angiogram recalled being told that they were at risk for CVD, despite the fact that 84% had three or

more risk factors. Moreover, Lauck et al., (2009) reported that only 50% of their sample of elective PCI patients (N=98) knew what lifestyle changes were needed to prevent disease progression. Thus, being unaware of the risks may account for some elective PCI patient's failure to participate in a CRP. The real benefits of interventional cardiology should not only be the eradication of a coronary artery blockage, but also increased awareness of risk factors and the opportunity to adopt risk reduction behaviors that can halt or slow the disease progression.

Although multiple factors influence health behaviour practices, the role of the individual's knowledge, beliefs, experiences, expectations, and perspectives are the central focus of this study. In order to improve prevention and overall patient outcomes, there is a need to understand the factors that influence the health behaviour practices of the elective ad-hoc PCI patient population. Given, the limited research specific to their perspectives and experiences there is currently inadequate evidence on how to best address their needs.

Purpose of the Study

The Health Belief Model will provide the framework for exploring the beliefs, perceptions, expectations, and experiences of the elective ad-hoc PCI patients. The purpose of the proposed study is to understand the factors that influence the health behavior practices of the elective ad-hoc PCI patient population post-procedure. The four main objectives of this study include: a) to understand the patients' perceptions of the ad-hoc PCI experience and their beliefs regarding the perceived threat of CVD; b) to identify the factors that underlie the perceived belief that one is cured; c) to explore the role health care professionals have on the health behaviour practices of the elective ad-

hoc PCI patients; d) and finally, to understand the rationale for the health behaviour practices pursued by these patients.

Significance

Elective ad-hoc PCI patients are understudied, yet they represent a growing segment of the cardiac population. Our ability to engage these patients in healthy lifestyle behaviors has significant implications for their health. The non-urgent nature and seemingly stable disease condition have contributed to a lack of focus on this population. Because these patients do not present to the emergency room, they tend to be an overlooked and marginalized cardiac population. This has resulted in the needs of the elective ad-hoc PCI patient being greatly overshadowed by those of the more acute cardiac patients. Consequently, this has led to a dearth of follow-up, prevention strategies, and research specific to this population. Secondary and tertiary prevention strategies need to be aligned so that monitoring of the chronic condition closely follows diagnosis and treatment, thereby ensuring a seamless approach to health care.

This qualitative study will explore the factors that influence the elective ad-hoc PCI patient's health behaviour practices. The ad-hoc treatment strategy used in this patient population may also influence the patient's perception of the illness and their subsequent health behaviors choices so requires further investigation. The information gained from this research will establish the foundation for developing tertiary prevention strategies specific to this population. As well, the insights gleaned may be applicable to other patient populations.

Chapter Summary

Quality care for individuals with chronic illness is dependant on much more than procedures and interventions. It requires that patients receive care that meets their needs and is based on the best scientific knowledge (IOM, 2001). Tertiary prevention is a cornerstone of chronic disease management; it is central to halting or slowing disease progression in the elective ad-hoc PCI patient population. Although barriers to the adoption of healthy lifestyle choices may exist within individuals, communities, and health care systems, it is the perspective of the individual that matters most when trying to enact difficult lifestyle changes. Therefore, understanding the influence of these factors through the patient's perspective is vital to improving the quality of post-PCI care and increasing their participation in tertiary prevention strategies.

Chapter 2: The Conceptual Frameworks

A theory is “a creative and rigorous structuring of ideas that projects a tentative, purposeful, and systematic view of phenomena” (Chinn & Kramer, 2004, p. 91).

Theories and models provide frameworks for understanding, describing, and evaluating knowledge. Numerous models and theories postulate about the individual’s role in maintaining health and preventing disease; however, the Health Belief Model (HBM), published in 1974 by Becker, is a classic model aimed at understanding an individual’s health behaviour practices. Therefore, the HBM will provide the governing framework for the proposed study.

According to Lincoln (as cited in Raphael, 2000, p. 358) “the most effective way of understanding the kinds of health-related issues that health promoters are concerned with is by discerning individuals’ perceptions and constructions of events.” Therefore, the HBM will provide a psychological-phenomenological approach to explain human behaviour. It is a motivational theory, which assumes that individuals themselves shape what they will or will not do (Becker, 1974). This model was chosen because of its focus on the factors that influence individual health behaviours. Based on our limited understanding of the health behaviour practices elective ad-hoc PCI patients engage in following their procedure, this model provides a good fit for gaining insight into their experiences, perceptions, and beliefs.

Although the personal factors that influence the health practices of these patients are the central focus of this study, one would be remiss to ignore the impact of the health system and the community in influencing the lifestyle choices of individuals. Therefore, the Chronic Care Model (CCM; Wagner, Austin, & VonKorff, 1996) will be used to

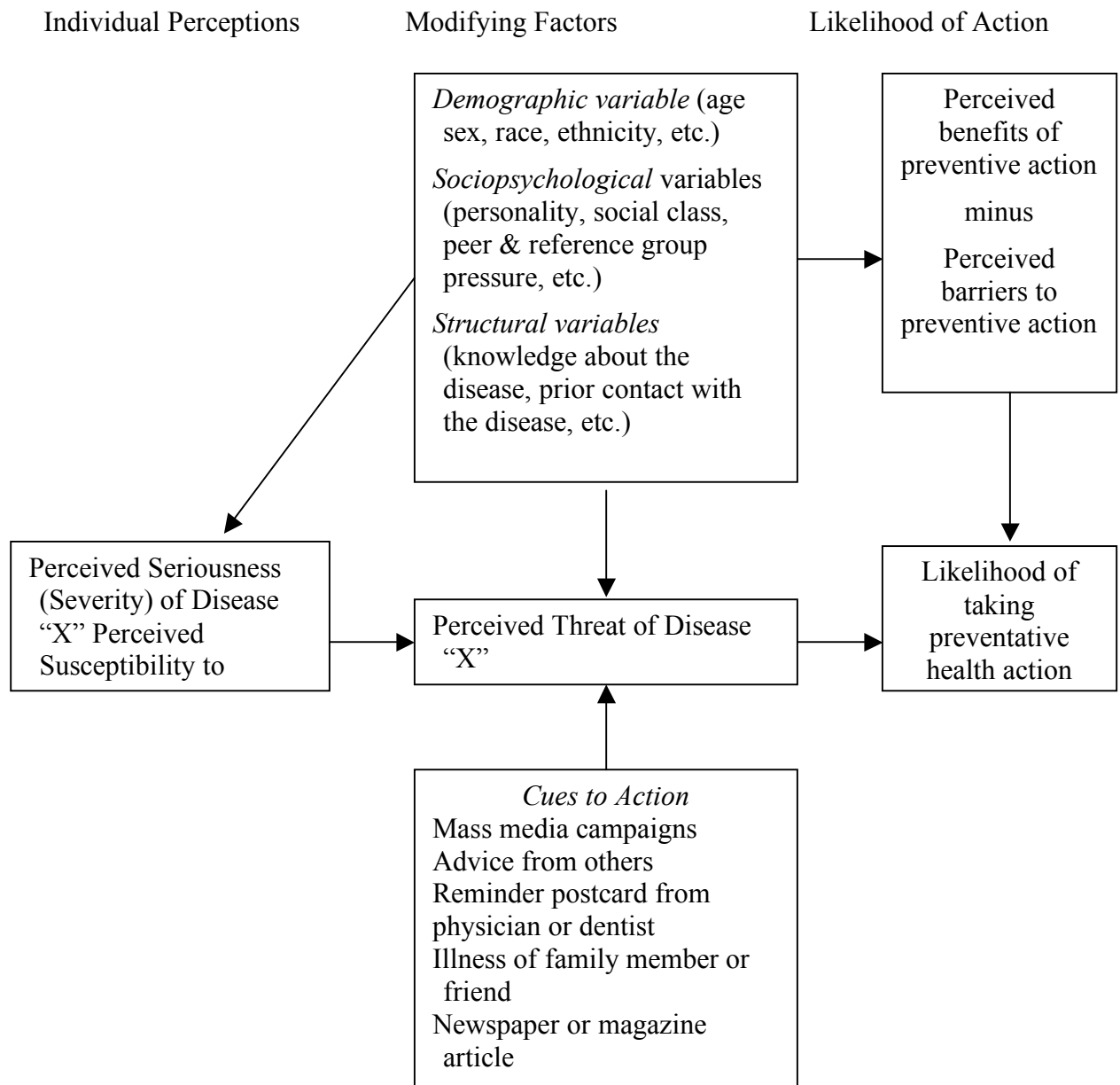
supplement and address some of the broader system issues these patients may identify as either barriers or facilitators in their efforts to change health behaviours.

In this chapter, the origins, components, and limitations of the HBM and the CCM will be reviewed. Together these models will provide a framework for understanding the role of personal factors, the health care system, and the community in influencing health behavior choices in the elective ad-hoc PCI patient population.

The Health Belief Model

The purpose of the HBM is to provide a theoretical framework for understanding an individual's perception of a health threat and the actions that they will or will not make based on that threat. It provides a framework for evaluating the reasoning behind health behaviour practices. The HBM (see Figure 1) asserts that it is the person's perceptions and health motives that drive health related behaviours (Becker, 1974). In general, the contention of this model is that individuals will take action to prevent disease if they believe they are susceptible to the condition; if the disease has serious consequences; if they think a course of action will be beneficial; if they believe that the anticipated barriers to taking action are outweighed by the benefits; and if they believe they are capable of the action (Strecher & Rosenstock, 1997). Therefore, utilizing this model to explore the elective ad-hoc PCI patient's beliefs surrounding CVD and tertiary prevention will facilitate an understanding of the factors that influence their choices in health behaviour practices. An overview of the HBM will highlight the relevance of utilizing this model to understand the rationale for the adoption of health behaviours on an individual level.

Figure 1: The Health Belief Model: Public domain material as adapted from
www.google.ca/image, 2011



Background

The HBM was developed over several years, beginning in the early 1950s. The specific origins of the model are difficult to trace because this model emerged out of multiple research questions, which attempted to resolve clinical problems (Becker, 1974).

During this time, a group of social psychologists working for the Public Health Organization in the USA became interested in understanding the factors that explain individual preventative health behaviours. These theorists were intrigued by the intrinsic paradoxes of human behaviour, specifically, the failure of individuals to take advantage of easily accessible preventative health care services (Finfgeld, Wongvatunyu, Conn, Grando, & Russell, 2003). In their attempt to explain this behaviour, the contributing investigators used a phenomenological orientation, which emphasized that it is the world of the perceiver that will determine his or her actions (Becker). This explains the model's focus on individuals and their behaviours.

Another strong influence in the development of this theory was the work of Kurt Lewin, who is considered to be one of the pioneers of social, organizational, and applied psychology. Lewin hypothesized that behaviour is dependant on two variables. The first is the value or valence one places on a particular outcome or action; the second pertains to the likelihood that a given action will result in the expected outcome (Becker, 1974). These concepts of value-expectancy provided the foundation for the HBM (Strecher & Rosenstock, 1997). The seminal theory of Kurt Lewin also inspired other behavioral/motivational models, such as Rotter's Social Learning Model, Edward's theory of Subjective Expected Utility, and Atkinson's theory of Achievement Motivation (Becker, 1974). However, the HBM is the most widely adopted of these models (Mirotznik, Feldman, & Stein, 1995)

The investigators of the Public Health Organization were interested not only in answering practical problems but also in theory development. Thus, the HBM marks the beginning of systematic and theory based research on health behaviour (Strecher &

Rosenstock, 1997). The goal was to develop a theory that was not only useful in explaining preventative health behaviours but also one that could be adaptable to other clinical problems, such as chronic illnesses and sick role behaviours (Becker, 1974). Hochbaum, Kegels, and Rosenstock initially conceptualized the HBM; however, it was Dr. Hochbaum who initiated the first research on the HBM. In 1952, he explored the factors that underlie an individual's decision to obtain a chest x-ray for the early detection of tuberculosis (Strecher & Rosenstock). The model was subsequently modified by Rosenstock in the 1960s and has since been adapted to its most commonly used form by Marshall Becker in the 1970's (Ali, 2002; Strecher & Rosenstock). A subsequent notable change to the model in the 1980s was Rosenstock's addition of self-efficacy as an independent concept (Rosenstock, Strecher, & Becker, 1988). This concept allows for better understanding of some of the challenges that face individuals who are attempting to alter unhealthy behaviours, because confidence in one's ability is recognized as an important component to health behaviour change.

The HBM is considered one of the more robust theoretical models of health behaviours and has provided a theoretical framework for numerous multidisciplinary health research studies (Al-Ali, & Haddad, 2004; Ali, 2002; Bennett, Milgrom, Champion, & Huster, 1997; Mirotznik et al., 1995; Oldridge & Streiner, 1990; Schmitz, Spiga, Rhoades, Fuentes, & Grabowski, 1999). According to Painter, Borba, Hynes, Mays, and Glanz (2008) the HBM was one of the three most often used theories in health behaviour research between 2000 and 2005. This benchmark framework has also provided a template for subsequent models, such as Connelly's Model of Self-Care in Chronic Illness (Connelly, 1987).

Behavior change is complex and no single theoretical approach addresses all the complexities of human actions; however, researchers continue to strive to improve on health behaviour theories and models. Alternative behaviour change models have emerged over the years, including the Precede-Proceed Model by Green and Kreuter (as cited in Young, 2005, p. 278), the Transtheoretical Model (TTM) of Stages of Change (Prochaska & DiClemente 1983) and the Self-Regulation Model (Leventhal, Nerenz, & Steele, 1984). In a recent study exploring fluid control in hemodialysis within the context of the HBM and the TTM, Ghaddar, Shamseddeen, and Elzein (2009) found that a significant association was observed between HBM constructs and the TTM stages. This finding emphasizes the importance of the core components in the HBM, which have established the foundation for new models and numerous research studies on these concepts. While these later models may target understanding health behaviours in order to intervene and change unhealthy lifestyles, the HBM provides a sound theoretical framework for investigators interested in capturing the experiences, beliefs, and perceptions of a patient population. The HBM may have limited scope for intervening and changing behaviour, but as a template for understanding and exploring the rationale for health actions, it is a classic model and therefore the model of choice for this study.

Components of the Health Belief Model

According to Becker (1974), three major components of health beliefs influence a person's perception of disease threat and their decision to initiate health related actions. These variables are: individual perceptions, modifying factors, and variables affecting likelihood of initiating action. Individual perceptions encompass the beliefs about the susceptibility and the seriousness of the disease and work directly to influence ones

tendency to act. Conversely, modifying variables affect behaviour indirectly. These factors act together with the perceived barriers and benefits to produce health related actions.

Individual perceptions. The individual perception variables are based on perceptions of the seriousness of that disease and the beliefs about personal susceptibility to a certain disease. These factors contribute to the perceived threat of that disease for the individual; however, individuals display large variations in their beliefs of disease threat.

The interpretation of disease severity is variable among individuals and also influences the degree of threat perceived by the individual (Becker 1974). The perception of severity affects the degree of emotional arousal mounted toward any given threat. Individuals may perceive the seriousness of a health problem based on the medical or clinical consequences, such as the symptoms experienced or the likelihood of disability or death. However, individuals may also perceive their condition in broader more complex terms, such as the impact of the illness on their work, family, and social obligations (Becker, 1974). The value of these perceptions in motivating behaviour is individual and based in part on the person's perceived threat of the illness.

Mirotznik et al., (1995), found that general health motivation and the perceived severity of CVD were both positively associated with attendance of exercise sessions by cardiac patients. Conversely, Ali (2002) found that in women with heart disease, seriousness was not as strong a predictor of health behaviours as susceptibility and accounted for only 3.5% of the variance in health behaviours. Furthermore, an earlier study by Oldridge and Streiner (1990) found that patient compliance in cardiac

rehabilitation was actually negatively associated with the perceived severity of the disease. Perceived seriousness may also have contributed to the research findings of others that heightened levels of anxiety or fear following a cardiac event resulted in patients being less likely to engage in healthy behaviours, particularly exercise participation (Broadbent et al., 2006; Christian et al., 2005; Homko et al., 2008; van Steenkiste et al., 2004). Clearly, there is mixed evidence related to the perception of disease severity. Therefore, further research is required to fully understand the role of disease severity in the perception of threat and how that influences behaviours.

Susceptibility relates to one's risk or chance of contracting a condition (Becker, 1974). Risk perception is a difficult concept for many individuals to grasp, and like disease severity it is dependant on accurate information and knowledge about the disease process. Research evidence lends support for the hypothesis that there is a relationship between perceived susceptibility of CVD and the likelihood of taking preventive health action (Ali, 2002; Katz et al., 2009). For example, Ali found that 66% of the variance of CVD preventative behaviours was explained by susceptibility. However, Katz and associates found that individuals treated for chest pain in the emergency department reported lower susceptibility to CVD at 3-month follow-up than at baseline. Katz et al., contended that these individuals may have felt less susceptible because they were attempting to adopt healthy behaviours. This finding may also be reflective of the timing of health information or the contribution of anginal symptoms at baseline. Additional research is needed to fully understand the temporal nature of susceptibility and the factors that influence this perception.

Modifying factors. Factors that modify the likelihood of taking preventative action encompass demographic, sociopsychological, and structural variables, as well as cues to action, and the perceived threat of disease. *Demographic variables* include factors such as age, sex, race, income, and education. These factors may provide clues to particular health beliefs exhibited by particular age groups, genders, ethnicities, or race. For example, Al-Ali and Haddad (2004) provide research evidence to support the impact of income and health motivation on the health preventative behaviour of exercise participation post-MI. They found that higher annual incomes were significantly associated with greater exercise participation (Al-Ali & Haddad).

Sociopsychological variables refer to personality types, social class, and reference or peer group pressure. These variables explain perceptions as a manifestation of group dynamics or associations. For example, peer pressure can provide insight into the rationale for teen smoking behaviour. Self-efficacy is included in the more recent adaptations of the HBM. This concept was borrowed from the work of Bandura. Self-efficacy is a core component of Bandura's Social-Cognitive Theory and plays a critical role in influencing activities, motivational level, knowledge acquisition, and skill development (Bandura, 1997). Self-efficacy is a "multifaceted causal structure that addresses both the development of competencies and the regulation of action" (Bandura, 1997, p. 34). Therefore, self-efficacy is closely tied to competence and confidence, and relates to one's ability to execute behaviour and produce the desired outcome. Although initially not included in this model, it was later added in recognition of the need for self-efficacy to enact many preventative health behaviours, as well as chronic illness, and sick role behaviours. Self-efficacy as an independent concept has been extensively researched

and found to be associated with improved preventative behaviours (Clark & Dodge, 1999; Hamilton, & Haennel, 2004; Ghaddar, Shamsedden, & Elzein, 2009; Newell, Modeste, Marshak, & Wilson, 2009; Perkins, & Jenkins, 1998; Sarkar, Ali, & Whooley, 2007; Sullivan, LaCroix, Russo, & Katon, 1998). For example, Ghaddar and associates utilized a HBM framework and found that increased self-efficacy corresponded to higher adherence to recommended behaviours in hemodialysis patients. Therefore, self-efficacy is an important concept to explore when attempting to explain or understand preventative health behaviours.

Finally, *structural variables*, such as knowledge level and prior contact with the disease, also influence how individuals perceive their susceptibility or threat of a particular disease. Thus, for example, if multiple family members have had a particular disease condition they may be more inclined to engage in preventative health behaviors in an attempt to avoid that illness. Ali (2002) found that, among women with CVD, knowledge of risk factors accounted for 19.5% of the variance in health preventative behaviours.

According to the HBM, *cues to action* include such factors as media campaigns, advice from others, reminders from health care providers, and the illness of a family member or friend. These factors may act singularly, or in combination and may be internal or external to the individual. Cues to action have been found to be marginally significant in predicting compliance in cardiac rehabilitation (Oldridge & Streiner, 1990). However, testing the role of cues in influencing behaviour has been problematic because it is often difficult for individuals to remember cues they chose to ignore (Becker, 1974). It is much easier to remember those cues that have been acted upon. Therefore, when

testing for the impact of cues on influencing behaviour, a prospective design may be more preferable. However, if one is testing for the saliency of these cues over time and their ability to influence behaviour in the mid to long-term, a retrospective design may be more informative. For example, what do patients remember and why do they remember some cues as opposed to others?

The *perceived threat* of the illness is the core component of the HBM. The individual's perception of a disease threat is the motivation for the likelihood one will take action to alleviate that threat (Becker, 1974). The individuals' perceived seriousness of and susceptibility to a disease directly influences their perception of disease threat. In addition, cues to action and modifying variables also contribute to the perceived threat of a disease. These multiple interacting beliefs establish an overall belief of the disease threat, which, in turn, drives the motivation for behaviour change. These beliefs are weighed against the benefits and barriers to behaviour change, which result in the likelihood one will take action.

Likelihood of action. According to the HBM, *perceived benefits* and *perceived barriers* affect the probability of taking action (Becker, 1974). Perceived benefits are based on the belief that the action will be effective in reducing the risk or seriousness of the condition. Conversely, perceived barriers are based on one's opinion that the action will be costly or have additional negative aspects that deter action. Health behaviours are thus dependant upon how beneficial or unfavorable one views the various options. Therefore, success of a health action is a function of the perceived benefits minus the barriers or costs of that action (Becker).

Perceived benefits and barriers are important constructs to consider in behaviour change. According to Elder, Ayala, and Harris (1999), one of the first tasks in determining the importance of health behaviour change is to assess an individual's perceived barriers and benefits to engaging in a behaviour. Pender, Murdaugh, and Parsons (2006) contend that perceived barriers is the most powerful HBM dimension in explaining or predicting health behaviours. Bennett and associates (1997) developed instruments to test beliefs about compliance with medication and dietary behaviours in heart failure patients. They found that beliefs about the benefits and barriers of these behaviours were important constructs and contributed to preventative health behaviour. Sethares and Elliot (2004) developed a tailored intervention for patients with heart failure and found that the belief patterns around the perceived benefits and barriers to medication compliance can be influenced by education. Moreover, those changes progressed as predicted by the HBM.

Assumptions

An assumption within the HBM is the concept of valence, which is the result of Lewin's influence on this theory. According to Lewin (as cited in Becker, 1974), an individual exists within a life space composed of regions, which are positively, negatively, or neutrally valued. One's daily behaviours are then explained as a combination of forces consisting of pulling positive forces and repelling negative forces (Becker, 1974). According to Becker (1974) diseases or illnesses represent a negative value and therefore exert a force that moves the individual away from that experience. However, this assumption may also be considered one of the model's limitations, as some individuals may appreciate the threat of the disease, but still choose to accept those risks

and continue with the risky behaviour. Thus, not all negative values necessarily produce actions.

Limitations

No model or theory is without limitations and the HBM is no exception. One limitation of this model is its complexity. For example, Finfgeld and associates (2003) contend that on the surface the model may appear easy to understand, based on the limited number of components; however, the interrelationships among these components are complex and difficult to measure or quantify. Furthermore, the HBM has been criticized for lacking clear definitions of the concepts and poorly defined cause and effect relationship between the variables, beliefs, and behaviours (Finfgeld et al.; Munro, Lewin, Swart, & Volmink, 2007; Oldridge & Streiner, 1990; Pender et al., 2006). This is evident by the conflicting findings of many research studies; however, one must keep in mind that beliefs are individually enacted, that there may be a strong temporal component to beliefs, and that we do not fully understand all elements of human behaviour.

The HBM has also been criticized for not providing explanations for behaviours that are linked to socially determined or unconscious motivations, such as smoking behaviour. As smoking is a habitual behaviour and not based on cognitive decision-making, the ability of the HBM to address this particular health behaviour is limited (Munro et al., 2007). Social pressure may also modify behaviors, and this lies beyond the scope of the HBM. Similarly, the assumption of valence, inherent in this model, may not always influence behaviour as anticipated.

Another limitation of the HBM is the emphasis on the current state of affairs as being central to determining actions “with history playing a role only in so far as it is

represented in the present dynamics” (Becker, 1974, p. 2). As an individual’s historical perspective or prior experiences contribute greatly to their current beliefs or actions, they may act as contributing factors in their individual perceptions, as opposed to being seen as only modifying variables.

The Model’s narrow scope on the individual is also problematic for understanding all health behaviours. For example, it is difficult to ignore the impact that unsafe walking spaces, unaffordable gyms, or the lack of available rehabilitation services have on individual health behaviours. Although these factors are addressed as barriers within this model, the lack of service available to a patient group, or demographic population may be more accurately characterized as a system failure rather than an individual barrier to action. Therefore, a broader view of how health systems and communities contribute to health beliefs and behaviour change is needed when considering individual health behaviours. It is for this reason that the Chronic Care Model will be used to address some of the larger system issues and community resource and allocation problems that may affect an individual’s health behaviour practices.

Summary

Health behaviours are complex and challenging for health care providers and their patients. Health behaviours are influenced by multiple interacting factors, including individual perceptions and modifying variables, which all contribute to the likelihood one will act on the perceived threat. How a threat is perceived, assessed, and acted upon varies as individuals are complex and deal with a multitude of contextually unique circumstances. Although the HBM may be limited in its ability to predict or change behaviour, it is a useful model for exploring the factors contributing to an individual’s

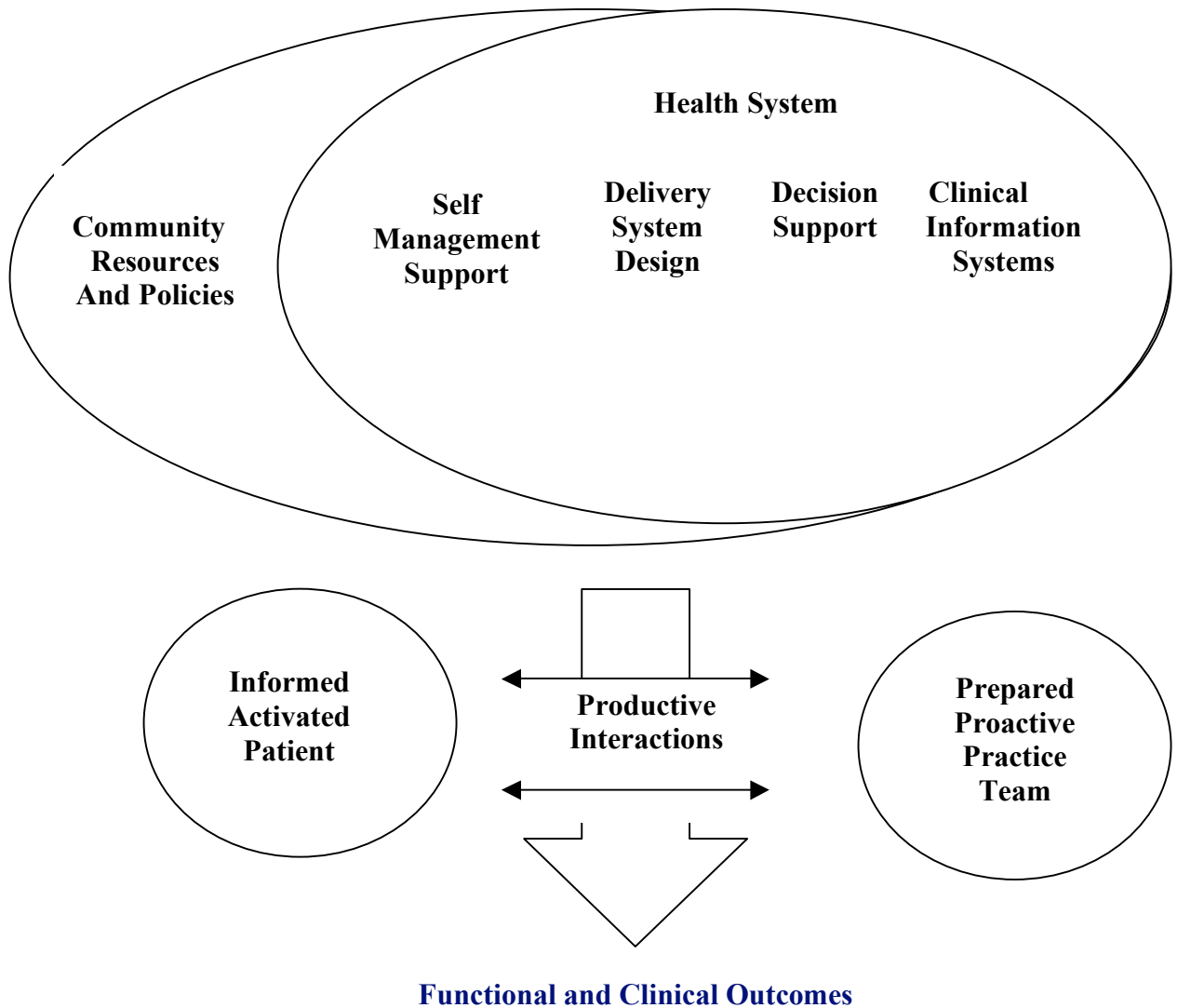
health behaviours. Therefore, the HBM provides an appropriate theoretical framework for understanding the health behaviour practices of the elective ad-hoc PCI patient.

The Chronic Care Model

The Chronic Care Model (CCM; see Figure 2) advocates for organizational change aimed at assisting health care teams to develop effective solutions for chronic care, thereby decreasing the burden of chronic diseases. To achieve this goal, patients need self-management skills and support. As well, multidisciplinary practice teams must have the expertise, time, and skill to provide this care. As effective chronic disease management is preventative in orientation, the CCM also applies to prevention strategies, such as individual behavior change (Barr et al., 2003; Glasgow et al., 2001).

This model was utilized to help explain some of the broader issues that emerged when trying to understand and explain the health behaviour practices of elective PCI patients. “There is growing recognition that lifestyle behaviours... are influenced not only by individual choice, but also by a variety of social, economic, and cultural factors inherent in the environments where people live, learn, work, and play” (Barr et al., 2003, p. 75). Therefore, the CCM may be beneficial in identifying factors that impede or facilitate change within the broader context of the health system and the community. The following overview of the CCM and its use in chronic disease management and prevention will highlight the importance of utilizing this model to provide quality patient care to those with chronic illnesses, such as CVD.

Figure 2: The Chronic Care Model: Used with permission from *Effective Clinical Practice*, 2011.



Background

The Chronic Care Model was developed by three physicians, Edward Wagner, Brian Austin, and Michael Von Korff, in an attempt to improve the quality of care provided to those with chronic illnesses. The CCM is the most widely adopted and studied model for chronic disease management (Morgan, Zamora, & Hindmarsh, 2007);

it has also been adopted for use in health promotion and disease prevention (Barr et al., 2003; Glasgow et al., 2001; Hung et al., 2007).

The CCM is a heuristic model that provides solutions to the problems and challenges facing those with chronic illnesses. It provides a formula aimed at assisting patients to cope and adjust to fluctuations in their everyday life by gaining the necessary confidence and knowledge to self-manage their illness. At the same time, the CCM attempts to provide health care providers with the necessary expertise and organizational support to meet the patients' needs.

In their endeavor to improve chronic illness care, Wagner, Austin, and Von Korff studied best practice models and chronic care research trials. Based on their findings, they contend that the following five elements constitute high quality chronic illness care: the use of explicit plans and protocols; the reorganization of the practice to meet the needs of the patient, including more time, resources, and closer follow-up; systematic attention to the information and behavioral change needs of the patients; access to necessary expertise; and supportive information systems (Wagner, Austin, & Von Korff, 1996). These elements of effective chronic care management have been incorporated into the CCM and form the basis on which the model was developed (Wagner et al., 2001).

According to Bodenheimer, Wagner, and Grumbach (2002) the CCM "envision[s] an informed, activated patient interacting with a prepared, proactive practice team, resulting in high-quality, satisfying encounters and improved outcomes" (p. 1777). Thus, the CCM provides a template for how organizational change can facilitate improved practice. The aim of the organizational change is to alter the interface between the

patient and the practice team in order to improve care to the chronically ill and optimize patient outcomes (Wagner et al., 1996).

Components of the Chronic Care Model

The major components of the CCM include the *productive interactions* between an *informed activated patient* and the *prepared proactive practice team*, the *community*, and the *health system*. The health system is further divided to address the important clinical aspects of chronic disease management including the use of self-management support, delivery system design, decision support, and clinical information systems. Each of these components plays a central role in optimal functional and clinical outcomes of chronically ill individuals (see Figure 2).

Productive interactions. These interactions between the patients and their practice teams are dependant on both parties have the skills and support needed to address clinical and behavioral management. Wagner and associates (1996) contend that this requires consistent assessments, support for self-management, optimization of therapy, and follow-up. All other elements in this model are defined in terms of how they assist and support these interactions.

The *informed activated patient* is integral to productive interactions. Patients must have the information, skills, and confidence necessary to be active, informed participants in their care. This not only requires that patients have knowledge of the disease and its treatment, but also the confidence and skill to manage their condition. The CCM asserts that individuals with chronic illnesses should have the confidence and skills to manage their condition; access to appropriate treatments to assure optimal

disease control and prevention of complications; a mutually understood plan; and careful, continuous follow-up (Wagner et al., 2001).

Similarly, the *prepared proactive practice team* must have the expertise, relevant patient information, time, and resources to ensure effective clinical management (Wagner et al., 2001). Critical to this approach is that the team must have resources available to provide proactive care rather than just reacting to clinical problems. Additionally, health care teams need to focus on behavioural management strategies, not just treating the biomedical aspects of chronic illnesses (Glasgow et al., 2001).

Community resources and policies. These factors play a critical role in supporting and expanding care for the chronically ill. Wagner et al., (2001) contend that practices providing care to the chronically ill benefit from a variety of patient services that are not available within the health system. They also realized that communication with other providers within the community enhances the continuity of care. It is now recognized that the community plays a critical role in improving chronic care by providing linkages with community-based resources, such as exercise programs, self-help groups, and home care (Bodenheimer et al., 2002).

Health system. This refers to the structure, goals, and values of a provider organization and its relationship with purchasers, insurers, and other providers. The leaders within the health system need to be committed to improving the care provided to those with chronic illnesses (Bodenheimer et al., 2002). Critical to the success of any health system is the support and commitment of administrators. The health system sustains the final 4 concepts of the CCM: self-management support, delivery system design, decision support, and clinical information systems.

Self-management support pertains to collaboratively helping patients acquire the skills and confidence to manage their chronic illness. Self-management teaches problem solving skills, increases patients' confidence in their ability to manage their health, focuses on realistic goal setting, increases self-efficacy and emotional well-being, leading to improved clinical outcomes (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Coleman & Newton, 2005; Kralik, Koch, Price, & Howard, 2004; Lorig, Sobel, Ritter, Laurent, & Hobbs; 2001; Wagner et al., 2001).

Delivery system design refers to the reorganization of practices to include the integration of multidisciplinary practice teams. This facilitates a better match between patient need and provider skill and optimizes resource utilization. Thus, primary care physicians, or specialists are able to treat patients with more acute problems and to provide advice in difficult chronic cases. Employing other health care professionals (i.e., nurse practitioners, physiotherapists, etc.) to provide services such as: patient self-management, lifestyle counseling, education, and follow-up care allows for more effective utilization of services (Bodenheimer et al., 2002; Wagner et al., 1996).

Decision support pertains to the use of guidelines and protocols in the provision of care. Evidence based guidelines have become the hallmark tool for practices to measure their ability to provide optimal care. According to Bodenheimer and associates (2002), these guidelines establish the optimal standards for chronic care delivery, which, in turn should be integrated into daily practice. Wagner et al., (1996) contend that working within a system that values guidelines, incorporates specialist within practice teams, and uses proactive care would enhance evidence-based, planned care.

Clinical information systems can provide powerful support for following and maintaining the plan of care, corresponding with other health professionals, and monitoring progress, thereby ensuring continuity of care for the patient (Wagner et al., 1996). A shared plan of care provides structure, coherence, and continuity as the patient negotiates the health system, physician visits, and hospitalizations. An integrated communication system reduces fragmentation of care by providing a means of keeping all members of the health care team informed of treatments, plans, and goals (Bodenheimer et al., 2002).

Assumptions

Three main themes or assumptions are implied in the CCM. These assumptions, which provide the philosophical underpinning of the CCM, include: evidence based practice, universality of care, and patient-centered care (Wagner et al., 1996). Austin, Wagner, Hindmarsh, and Davis, (2000) provide explicit descriptions of these themes in a subsequent article about the model. Accordingly, evidence based practice means that assessments, treatments, and delivery approaches must be based on the best available clinical evidence. Universality pertains to care that is population based, with care delivery to ensure that all relevant members of the population receive the healthcare services they need, and that patients are tracked to determine whether they have received needed services. The goal of patient-centered care is to increase the participation, confidence, and skills of patients and their families.

Limitations

A limitation to this model is the rather vague explanation of what constitutes an activated patient and a prepared, proactive, practice team; their core qualities,

experiences, beliefs, perceptions, and characteristics have not been well defined.

Although this model may be helpful in discussing elements within the health system and community that facilitate quality chronic care, it is limited in its ability to address individual behaviours that contribute to effective chronic disease management. Just as we cannot ignore the influence of the community or health system on health behaviour practices, it is also erroneous to believe that the individual does not have a central role in disease management or prevention strategies. Consideration of the individual, as well as the health system and community, is required to gain insight into health behaviour choices.

Summary

In summary, the components of the CCM are interdependent and play a critical role in supporting the quality of interactions between the informed, activated patient and the prepared, proactive health care team. As is evident in Figure 2, the community and the health system influence the quality of productive interactions and relationships between the patient and the practice team and can foster or impede those interactions and their outcomes. Transforming this environment into one that is patient-centered and responsive to both patient and practitioner needs is the aim of the CCM.

Chapter Summary

This chapter has provided an overview of the HBM and the CCM. The HBM was selected as the primary conceptual framework for this study because it provides a comprehensive approach to understanding the elective ad-hoc PCI patients' experiences, perceptions, beliefs, and rationale for their health behaviour choices. Since the CCM is designed to improve the quality of chronic care provided to patients, it was helpful in

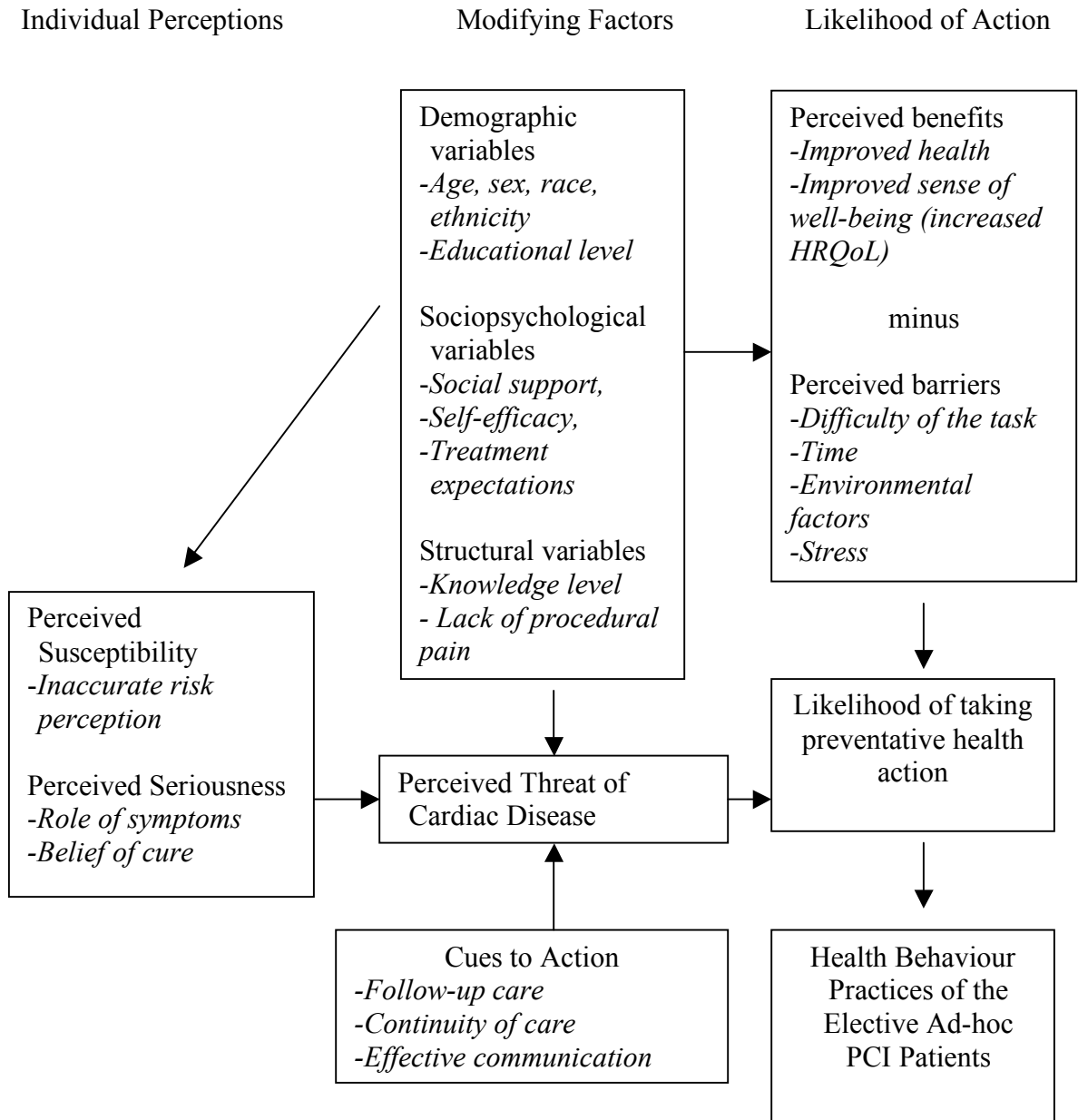
understanding some of the system or community barriers that may influence the patient's health behaviour practices. Together these models provided a foundation for understanding the elective ad-hoc PCI patient's perspective on the factors that influence their individual health behaviour practices. A clear understanding of the patient's perspective is central to advancing appropriate services and critical to appreciating our role in assisting with the prevention of disease progression.

Chapter 3: Experiences, Beliefs, and Behaviours: A Literature Review

A review of the literature related to the factors that influence the health behaviours of cardiac patients was conducted using PUBMED, and CINAHL databases, as well as the Internet and a manual literature search for key articles. Primary subject terms included: chronic illnesses, cardiovascular disease, angioplasty, coronary artery disease, health beliefs, causal attributions, self-efficacy, risk perceptions, and cardiac rehabilitation. In addition, information on public Canadian websites was reviewed and included: the Heart & Stroke Foundation, the Canadian Institute for Health Information, Statistics Canada, Health Canada, and the Public Health Agency of Canada. To ensure relevance to the Manitoba population, information was also elicited from the Cardiac Sciences Program at St. Boniface General Hospital and the Winnipeg Regional Health Authority Cardiac Rehabilitation Program.

This literature review will include an overview of the multiple factors, which affect the health behaviors of cardiac patients in general, and elective PCI patients in particular. The Health Belief Model will be used as an organizational framework for this review (see Figure 3). According to Becker (1974), an individual's behaviour is based on the perceived threat of a particular disease. An individual's interpretation of a disease threat is influenced by the individual perceptions and modifying factors, which influence one's likelihood of taking action. Thus, the review of the literature established the context and rationale for this research study.

Figure 3: The Health Belief Model and the Elective Ad-hoc PCI Patient: Adapted from public domain material www.google.ca/images, 2011.



Individual Perceptions

The perceived threat of a disease is influenced by one's perception of disease susceptibility and severity (Becker, 1974). These perceptions can have profound implications on the health behaviours of individuals. Therefore, it is important for health care professionals to understand how elective ad-hoc PCI patients interpret their disease threat, which is directly based on their individual's perceptions of disease severity and susceptibility.

Disease Severity

An individual requires an accurate evaluation of the consequences related to treating a disease or leaving a condition untreated before they can determine an appropriate course of action in response to a disease. Patients commonly have difficulty understanding the severity of their disease; as one primary PCI participant stated: "How serious is serious.....how do you define it?" (Astin, Closs, McLenachan, Hunter, & Priestley, 2009, p. 77). The important factors to consider in the evaluation of disease severity for the PCI patients are the role of symptoms and the belief they are cured. The symptoms that a patient experiences as a result of an illness may have a direct impact on the perceived seriousness of that illness. For individuals undergoing elective ad-hoc PCI, relief of anginal pain is the therapeutic goal. However, patients must realize that even when symptoms are alleviated by medications, PCI, or CABG surgery, CVD is a chronic condition and has not been cured. Unfortunately, many PCI patients believe they are cured post procedure (Astin, et al., 2009; Campbell, & Torrance, 2005; Eastwood, 2001; Gaw, 1992; Fernandez et al., 2006; Lauck et al., 2009; Peterson et al., 2010; Radcliffe, Harding, Rothman, & Feder, 2009; Sampson, O'Cathain, & Goodacre, 2009). Health

care professionals must understand how the perception of disease severity in the elective ad-hoc PCI patient population influences their health behaviours. The important factors to consider in the evaluation of disease severity for these patients are the role of symptoms and the belief they are cured.

The role of symptoms. According to the HBM, symptoms play an important role in the individuals' perception of disease severity (Becker, 1974). As elective PCI procedures are initiated for the relief of symptoms, freedom from angina is an important therapeutic goal and a measure of the effectiveness of treatment; however, this may result in a reduction in their perception of disease severity. In general, many elective PCI patients experience a renewed feeling of wellbeing, decreased symptoms, and improvements in their quality of life following their procedure (Astin & Jones, 2006; Eastwood, 2001; Kimble, 1998; Ozkan, Odabasi, & Ozcan, 2008; Pocock, Henderson, Clayton, Lyman, & Chamberlain, 2000). For example, in the large (N=1,018) randomized control trial RITA-2 trial, PCI patients perceived a significantly higher health-related quality of life (HRQoL) following PCI compared to those receiving medical therapy following three years of follow-up (Pocock, et al.). Not surprisingly, the PCI patients' perceptions of increased quality of life were largely due to symptom reduction, such as decreased shortness of breath, improved exercise tolerance, and less angina. In fact, this difference in quality of life scores was primarily attributed to a decrease in the frequency and severity of angina (Pocock, et al). However, the existing literature does not fully explore the relationship between improvement in symptoms and HRQoL, on the health behaviours pursued by elective ad-hoc PCI patients post-procedure.

Unfortunately, approximately 40% of elective PCI patients complain of chest pain post procedure (Barnason, Zimmerman, Brey, Catlin, & Nieveen, 2006; Campbell, & Torrance, 2005; Cronin, Freeman, Ryan, & Drake, 2000; Kini, Lee, Mitre, Duffy, & Sharma, 2003; Lauck et al., 2009). Although not all chest pain is associated with myocardial ischemia, Venkitachalam et al., (2009) found that angina following PCI affected 18-24% (depending on stent selection) of the 8879 patients evaluated at one-year follow-up. In a much smaller, (N=37) descriptive longitudinal study of recovery patterns post-procedure Barnason and associates (2006) found that in addition to chest pain over one third of participants reported fatigue, depression, anxiety, and shortness of breath. Although all of these symptoms are important, pain may be the most significant because of its impact on health behaviours.

The high rates of post procedural angina have been noted to negatively affect the patients HRQoL (Gravely-Witte, De Gucht, Heiser, Grace, & Van Elderen, 2007; Holubkov et al., 2002; Pocock, et al., 2000; Wong & Chair, 2007). For example, Wong and Chair (2007) found that while elective PCI patients experienced improvements in their HRQoL at 1 month, these improvements did not continue beyond three months. Furthermore, angina stability was lower at three months than at the baseline measurements. It is noteworthy that the decline in the patients' angina stability corresponded with a similar declining trend in their HRQoL. However, the overall impact of a decreasing HRQoL on the health behaviours of elective ad-hoc PCI patients is largely unknown.

Many elective PCI patients experience emotional distress post procedure. Researchers have found increased rates of depression and greater feelings of uncertainty

related to the return of symptoms in the PCI population (Astin, Jones, & Thompson, 2005; Gravely-Witte et al., 2007; Le Grande et al., 2006; Odell, Grip, & Hallberg, 2006). In particular, Astin and associates found that some patients who underwent elective PCI had elevated levels of depression 6 to 8 months following the procedure. The reasons for this finding are unclear; however, the researchers contended that these patients are vulnerable due to their short hospitalizations, limited contact with health care professionals, and low enrollment in cardiac rehabilitation (Astin, et al.). Although the existing literature recognizes the occurrence of depression and anxiety in the elective PCI patient population, there is limited evidence regarding the role of these symptoms on the perceived threat of illness and subsequent likelihood of engaging in healthy behaviours.

There is a dearth of information in the literature specific to the health behaviours of patients experiencing residual or poorly relieved pain or emotional distress following an elective PCI. Thus there is a gap in the research about the role of these symptoms on the preventative health behaviours of the elective ad-hoc PCI patient.

Belief of cure. Many PCI patients have the erroneous belief that they are cured (Astin, et al., 2009; Fernandez et al., 2006; Peterson et al., 2010; Radcliffe, et al., 2009; Sampson, et al., 2009). This belief may be a significant factor in influencing their subsequent health behaviour practices. In a fairly recent study, Fernandez and associates surveyed 202 patients following elective and post-MI PCI procedures and found that one-third of the participants believed they were cured and no longer had heart disease. Unfortunately, the researchers did not distinguish between the two patient subgroups. Several research studies have, however, provided substantive evidence of this belief in the elective PCI population (Campbell & Torrance, 2005; Eastwood, 2001; Gaw, 1992;

Lauck et al., 2009). For example, in a descriptive survey, Campbell and Torrance found that 42% of elective PCI patients believed they no longer had CAD. It is concerning that these findings are similar to those of Gaw more than a decade earlier. Consequently, the health care community and health practitioners are still failing to adequately address the misconception that patients have about being cured. Clearly, this belief is not only prevalent, but also a long-standing misperception in the elective PCI patient population, and one that may have serious implications for disease management and tertiary prevention.

By comparison, other cardiac patients seem more inclined to recognize the seriousness of their health problem and focus on controlling the disease through better management and/or enrollment in tertiary prevention programs (French, Cooper, & Weinman, 2006; Gaw-Ens & Laing, 1994; Hirani, Pugsley, & Newman, 2006; Lau-Walker 2007). For example, in a descriptive survey (N=210), Gaw-Ens and Laing reported that medically managed post-MI patients focused on controlling their symptoms, which resulted in greater adoption of lifestyle changes compared to their PCI counterparts. Similarly, in a small qualitative study (N=9), Odell and associates (2006) found that post-PCI patients only grasped the seriousness of their condition after they experienced in-stent restenosis and recurrent angina post-PCI and had been scheduled for CABG surgery. Other qualitative research findings (Radcliffe et al., 2009) echo this perception, as participants who were treated with primary PCI (N=15) felt their heart attack was less severe because they did not need CABG surgery. One participant stated, “the five other men on the ward, they had chests like zips but then again they probably had a lot more done to them and had quite severe heart attacks” (Radcliffe et al, p. 218).

Therefore, the belief of being cured may be more complex than simply having symptom relief, and may be influenced by their perception of the PCI procedure in relation to the alternatives.

The research evidence related to the relationship between perceived disease severity and the likelihood of taking preventative health action is inconclusive. While Campbell and Torrance (2005), Gaw (1992), and Fernandez et al., (2006) found that post elective PCI patients were failing to engage in risk factor reduction behaviours, Radcliffe et al., (2009) reported that although their primary PCI patients believed they were “fixed” this belief did not result in non-concordance with lifestyle modifications. However, Radcliffe and associates provide little evidence to support the participant’s engagement in prevention strategies other than stating that “most [participants] had the intention of engaging with cardiac rehabilitation but none had started a course at the time of interviewing” (p. 221). Given that intention is not the same as participation, the question of how a belief of being cured influences the health behaviours of PCI patients is still unanswered.

The HBM contends that patients who accurately perceive the disease severity and threat are more likely to participate in disease control or preventative health behaviours. Interestingly, while Lau-Walker (2007) conducted longitudinal surveys with cardiac patients (N=253), Gulanick et al., (1998) used qualitative focus-group interviews with post-PCI patients (N=45) and both reported the finding, that the engagement of health behaviors in the long-term was based on the patient’s belief that their cardiac condition was controllable. Thus, the misperception of being cured versus the drive to control one’s disease may be a significant factor in the initiation and maintenance of tertiary

prevention programs in the elective ad-hoc PCI population. Unfortunately, the variables that contribute to the belief of being cured have not been fully explored; therefore, this research study attempted to identify the factors that contributed to this belief and the role these factors had in influencing the individual's subsequent health behaviours.

Disease Susceptibility

According to the HBM, an individual's risk perception or their assessment of disease susceptibility is another factor that motivates the likelihood of taking preventative health action (Becker, 1974). A patient's belief of disease susceptibility, therefore, may be an important consideration in the adoption of a healthy lifestyle. According to Broadbent et al. (2006), optimal cardiac care consists of patients having an accurate idea of their future risk based on the information and interactions with clinical staff. Therefore, the ability of health care providers to convey an accurate risk profile to patients is of critical importance.

Individuals do not necessarily perceive their disease risks in the same way as their health care providers; this discrepancy in perception poses challenges for caregivers trying to convey risk profiles to their patients. The Framingham Risk Score provides a means by which health providers estimate a patient's risk for CVD (Homoko et al., 2008); however, individuals may have limited understanding of what that score means to their health (van Steenkiste et al., 2004). While the physician's perception of risk is predominately framed by quantitative data, the patient's perception of risks is strongly influenced by: emotions, prior experiences, families and friends, as well as cultural beliefs (Henriksen & Rosenqvist, 2003; Tod, Lancey, & Abbott, 2001; van Steenkiste et al., 2004). For example, in a qualitative study investigating coronary risk (N=22), van

Steenkiste and associates found that patients with CVD seemed to base their risk perception on emotion and past experience rather than facts. Individuals may also draw incorrect comparisons between their own risks and those of others, such as one participant who stated, “my father is 105 and he still smokes” (van Steenkiste et al., 2004, p. 303). Thus, demonstrating that individuals will look for examples to support their behavioural choices. According to Bjerrum, Hamm, Toft, and Kragstrup (2002), differences in the frames of reference are likely responsible for the lack of agreement between the risk perceptions of physicians and their patients. Health care providers must ensure that they have an accurate understanding of the patient’s perception of susceptibility in order to address any misconceptions.

The overestimation of cardiac risk may also be problematic for the adoption of risk reduction behaviours. Researchers have found that some individuals with heart disease overestimate their risks of future cardiac events (Broadbent et al., 2006; Christian, et al., 2005; Homko et al., 2008; van Steenkiste et al., 2004). For example, in questionnaires distributed to MI patients regarding their risk of future cardiac events (N=79), Broadbent et al., found that participants who had higher risk perceptions experienced greater emotional distress and lower belief in their ability to reduce their risk. Heightened anxiety and fear can be a significant barrier to physical activity in particular. In a qualitative study of primary PCI patients (N=29), Astin and associates (2009) found that some participants were very fearful of engaging in activities as one participant stated, “I can’t walk, I’m not going. I’ve no intentions, I’d be frightened to death of walking now” (p. 79). Thus, a patient’s overestimation of risk may also be a significant barrier to the adoption of risk reduction behaviours.

Previous research suggests that many cardiac patients perceive their overall risk to be lower than the physician's evaluation of their risk (Al-Hassan, & Omran, 2005; Astin et al., 2009; Bjerrum et al., 2002; Christian et al., 2005). Interestingly, researchers have found that individuals who were calculated to be at moderate to high risk tended to be the individuals most inclined to underestimate their risk of CVD (Bjerrum et al.; Christian et al.; Homko et al., 2008). For example, in a large cross-sectional study that assessed risk factors for CVD (N=1414), Bjerrum and associates found that among those who considered their risk to be low, more than half (58%) were judged by their doctors to be high risk. The individuals found to be particularly vulnerable to underestimating their risks for CVD are: women, younger adults, and those of lower socioeconomic status (Al-Hassan, & Omran; Hammond, Salamonson, Davidson, Everett, & Andrew, 2007; Homko et al.). This finding is significant as high-risk patients are at greatest risk for future cardiac events and patients who do not recognize their risks are in jeopardy of delaying or denying health problems and treatment.

PCI patients tend to have limited understanding of their disease and consequently are prone to underestimate their risk for future cardiac events (Astin et al., 2009; Fernandez et al., 2006). While the focus groups conducted by Angus et al., (2005) revealed that for post-MI patients the 'shock' value associated with having a MI removed some of the uncertainties associated with risk for these patients, the qualitative studies of Astin and associates (2009) and Radcliffe, et al., (2009) found that some primary PCI patients (post-MI) felt so well after the procedure it seemed as if they had not had an MI. One participant stated "I don't feel as though there's been any problem that's stopped me, I don't feel as though I've had a heart attack, it's as simple as that" (Astin et al., p. 77).

Health care professionals must consider how difficult it may be for patients to understand their risk, given that PCI is a minimally invasive procedure, which many patients see as a “quick fix” rather than a lifelong problem requiring tertiary prevention strategies, such as medications and lifestyle changes.

Because elective ad-hoc PCI patients undergo their procedure prior to having a cardiac event, they may have even greater difficulty understanding their risk. The research evidence is, however, inconclusive. While Kimble (1998) found that heart disease threat in elective PCI patients (N=74) remained stable over three time measurement periods (i.e., pre-PCI, 24hrs post-PCI, & 2 weeks post-PCI), in a more recent study Ozkan and associates (2008) found that before their elective PCI 83.3% of patients (N=60) took their heart disease seriously; however, by 1 week post-procedure that rate fell to 40.0%. Similarly, in the descriptive study of 117 elective PCI patients, Astin and Jones (2006) reported a decrease in the participants’ perception that their illness had serious health consequence 6-8 months following their procedure. It is unclear what the decrease in perceived risk is related to, but it may be associated with symptom relief, the expectations of treatment, or the belief they have been cured. The patients understanding of their future risk for cardiac events may be a significant factor in the initiation of healthy lifestyles.

To date, the role of risk perceptions on the health behaviours practices of elective PCI patients is also inconclusive. While Kimble (1998) found that many elective PCI patients’ reported improvements in risk reduction behaviours despite only moderate perceptions of heart disease threat, Astin and Jones (2006) found that after PCI a “significant proportion” of participants failed to adopt healthy lifestyle behaviors.

Therefore, this research study attempted to address the gap in information pertaining to how the risk perception of elective ad-hoc PCI patient's influences their health behaviours.

Modifying Factors

According to the HBM, modifying factors have an indirect effect on the likelihood of taking preventative health action by influencing the perception of disease susceptibility, severity, and threat, as well as perceived benefits and barriers (Strecher & Rosenstock, 1997). These factors include an array of demographic, sociopsychological, and structural components, as well as cues to action and self-efficacy (Becker, 1974, all of which are important considerations for understanding health behaviour practices.

Sociopsychological Variables

Sociopsychological variables include aspects of one's personality, as well as the influence of others on a person's thoughts, feelings, and behaviours (Becker, 1974). Specific to the elective ad-hoc PCI patient population health care providers must consider the role of social supports and self-efficacy on the health behaviour practices. In addition, societal expectations of medical care may influence the expectations of these patients. Therefore, it is important for researchers to investigate how these expectations affect their illness experience and subsequent health behaviours.

Social support. Social support is recognized as an integral component for the successful adoption of a healthy lifestyle. Numerous studies indicate the role of social support is central to providing a supportive network and environment for health behaviour change in the cardiac population (Clark, Whelan, Barbour, & MacIntyre 2005;

Gregory, Bostock, & Backett-Milburn, 2006; Karner, Tingstrom, Abrandt-Dahlgren, & Bergdahl, 2005; Riley, Stewart, & Grace, 2007). For example, in a qualitative study of CRP participants (N=47), Clark and associates found that the rapport within the group increased motivation and fostered encouragement for lifestyle change. While Riley and associates found that participants who attended a CRP perceived greater tangible support, Berkman (1995) contends that interventions aimed at restructuring and strengthening naturally occurring social networks are more effective for sustained behaviour support than those that rely on short-term constructed support programs. The research findings of Clark and associates support this contention; they found that once participants completed their CRP, there was a need to maintain health behaviours through a continuing community program. Although they envision this as another support program, Berkman's recommendation of encouraging naturally occurring support networks seems like a logical solution. Thus families, health providers, communities, and worksites can have a significant role in health promotion and prevention strategies, as all of these groups form the basis for long-term supportive networks that serve to sustain health behaviors over time.

Studies within the PCI population also support the importance of a strong social support network to ensure the adoption of healthy lifestyles (Campbell & Torrance, 2005; Gulanick et al., 1998; Peterson et al. 2010). While the qualitative study (N=61), Peterson and associates found that social support was vital to the success of adopting a healthier lifestyle. Similarly, Gulanick and associates found that lack of spousal support was a significant barrier to adopting healthy behaviours. In this study, many participants felt they were leading double lives by cooking separate meals for themselves and their

families (Gulanick et al.). Thus, the degree of social support appears to have significant implications for the adoption of healthy behaviours. Although this research study did not directly address the role of social support as a modifying factor in behaviour change its contribution to the likelihood one will take action emerged within the interviews.

Self-efficacy. Self-efficacy is related to the confidence individuals have in their own ability to perform certain tasks. According to Bandura (1997), self-efficacy beliefs are constructed from four principle sources of information:

Enactive mastery experiences that serve as indicators of capacity; vicarious experiences that alter efficacy beliefs through transmission of competencies and comparison with the attainments of others; verbal persuasion and allied types of social influences that one possesses certain capabilities; and physiological and affective states from which people partly judge their capableness, strength, and vulnerability to dysfunction. (p. 79).

When considering health behavior practices, self-efficacy pertains to the individuals' perceived ability to manage their illness and adopt healthy lifestyles that can improve their health (Sarkar et al., 2007). In a descriptive survey (N=248), Moore, Prior, and Bond (2007) found that self-efficacy plays a key role in the successful management of CVD and therefore concluded that it should be evaluated in these patients.

Self-efficacy has been demonstrated to affect health behavior and chronic disease management in patients with cardiac disease. Higher levels of self-efficacy are positively associated with improved functional ability (Clark & Dodge, 1999; Hamilton, & Haennel, 2004; Perkins, & Jenkins, 1998; Lau-Walker 2007; Sarkar et al., 2007; Sullivan, et al., 1998) and decreased levels of anxiety and depression (Sullivan et al.). For example, in a

small randomized control trial (N=80), self-efficacy was found to be the strongest predictor of exercise behavior over a 6-month period in a population of CRP participants (Carlson et al., 2001). Moreover, Lau-Walker (2007) found that the strongest determinants of self-efficacy related to exercise included the patient's view of the illness as long-term and controllable, as well as fewer symptoms and admissions on an emergency basis. Based on this evidence, elective ad-hoc PCI patients may demonstrate lower self-efficacy for the adoption of healthy behaviours because their illness is treated electively, they are generally in better health than emergency patients, and they often believe they are cured.

Research evidence specific to the PCI patient population indicates that self-efficacy is an important component of behaviour change (Perkins & Jenkins, 1998). For example, in a descriptive survey (N=90), higher self-efficacy scores were directly linked to higher health behavior scores in the areas of diet and exercise (Perkins & Jenkins, 1998). While these are important indicators of lifestyle change, this is an older study in which elective angioplasty patients had a mean hospital stay of 3.9 days; elective PCI patients now typically experience hospitalizations of less than one day. This difference may have a profound effect on the amount and quality of teaching provided to the elective ad-hoc PCI patient, which may in turn have implications for their self-efficacy and subsequent adoption of lifestyle changes.

A more recent descriptive study (N= 98) explored the relationship between self-efficacy and self-care agency and found that PCI patients demonstrated a high degree of adherence to discharge instructions in the early recovery period (3-5 days); however, how this would translate into long-term disease management was not investigated in this study

(Lauck et al. 2009). Recent research also suggests that self-determination is critical to the adoption of a healthier lifestyle (Peterson et al. 2010). Self-determination closely parallels self-efficacy and has been described as the will to succeed coupled with the motivation to spur action (Peterson et al.) Accordingly, in their qualitative study (N=61) PCI patients who were successful in the sustained adoption of a healthier lifestyle (i.e., 3 years post-PCI) demonstrated self-determination. Although this research study did not expressly explore the role of self-determination on long-term behaviour changes, insights into this relationship were gleaned from the interviews.

Expectations of care. Significant problems are emerging with the expectations that society places on its health care system. According to Kleinman (1988) “there is in North America a wholly unrealistic popular expectation that all diseases should be treatable and that no medical encounter should lead to a negative outcome” (p. 241). Cheek (2008) refers to this belief as healthism. Healthism is a term used to represent “a particular way of viewing the health problem, and is characteristic of the new health consciousness and movements” (Cheek, 2008, p. 974). This term describes the expectation a society has of its health care system. Our current consumption of technology and health care services is voracious; the notion that disease, aging, and even death can be fixed or prevented with improved technology is irresistible (Cheek). The influence of such a societal view on an individual's expectations and perceptions of medical treatment may modify their perceived threat of the disease, thus influencing their likelihood to engage in preventive health behaviours. Therefore, the role of treatment expectation on the elective PCI patient population may influence their engagement in tertiary prevention.

The expectation that technology can prevent or fix problems has been explored in several research studies of CVD patients. Several studies have found that cardiac patients often express unrealistic expectations that a procedure or treatment could fix their health problem (Hirani et al. 2006; Johansson, Swahn, & Stromberg 2007; Odell et al., 2006; Whittle, Conigliaro, Good, Kelley, & Skanerson 2007). For example, in a qualitative study (N=15), Johansson and associates found that patients who had a prior MI felt calm even with the reemergence of symptoms because they “almost took it for granted that they would get well again” (p. 189). According to Hirani and associates (2006) the decisions to have a revascularization treatment, such as PCI, provided hope that their problems would soon be resolved, whereas the decision to follow a medical regime was seen as an ongoing condition which lasts longer.

In a descriptive survey (N= 214), Hirani, Patterson, and Newman (2008) found medical, surgical, and angioplasty interventions for CAD were all associated with a high overall anticipation of treatment benefit. However, the revascularization groups tended to have “greater faith” in treatment benefit compared to those who were medically managed (Hirani et al.). The health behaviours that these patients pursued based on their “faith” in treatment benefit was not investigated in this study and remains a central question for researchers interested in how these beliefs shape future health behaviours.

PCI patients also have high expectations of treatment benefit. In a qualitative study (N=9), Odell and associates (2006) found that despite the return of angina, patients believed the situation not to be that serious and anticipated that insertion of another stent would solve the problem. Similarly, Radcliffe, et al. (2009) and Sampson and associates (2009) found that participants were impressed by the technology, expected improvement

in their symptoms, and viewed their treatment experience very positively. They perceived this as medical progress, as one participant stated, “you can put a couple of stents in or one stent and they can lead a healthy happy life afterward. Well, that’s brilliant to me like” (Radcliffe et al., p. 219). Although it is wonderful that many patients are impressed with the technology, have positive experiences, and are satisfied with their PCI procedures, a serious gap in the research exists about the role that expectations have on influencing health behaviours practices. Therefore, this study attempted to elicit the role that treatment expectations had on the health perceptions and health behaviour practices of elective ad-hoc PCI patients.

Structural Variables

Within the context of the proposed study structural variables are largely related to the PCI hospital experience and care provided post-procedure. The structural components of knowledge level, procedural pain, and length of stay are important aspects of cardiac care and are particularly relevant for the elective ad-hoc PCI patient. In order to provide optimal care, health care providers must be aware of how the patient’s knowledge level and hospital experience contributes to their perception of disease threat and consequent likelihood of action.

Knowledge level. Knowledge is a core component to understanding one’s disease susceptibility and severity. For example, in a cross-sectional comparative study (N=208), Redfern, Ellis, Briffa, and Freedman (2007) found that patients who did not participate in cardiac rehabilitation after a cardiac event (i.e., acute coronary syndrome) had worse risk profiles and poorer understanding of risk factors than those about to

commence a rehabilitation program. The authors concluded that knowledge of risk factors was a key factor in the initiation of a CRP.

Cardiac patients in general tend to also have limited knowledge or misconceptions regarding the cause of their CAD (Darr, Astin, & Atkin, 2008; Momtahan, Berkman, Sellick, Kearns, & Lauzon, 2004; Redfern et al. 2007; Tod et al., 2000; van Steenkiste et al., 2004; Zerwic, King, & Wlasowicz, 1997). van Steenkiste and associates found that some patient's understanding of CVD was incorrect; for example: "if your cholesterol is elevated, it means some blood vessel is blocked" (p. 303). Because health is a direct sensory experience of the body, many patients have difficulty envisioning and conceptualizing heart disease, as it is not a visible entity (Angus et al., 2005). Angus and associates described a very disembodiment reaction that patients have to their disease process. Because these patients have difficulty conceptualizing what is happening within their bodies, accurate knowledge and understanding of the disease trajectory becomes critically important.

In the nursing literature, there is a growing awareness that PCI patients have misconceptions about CVD; demonstrate a lack of awareness regarding risk factors; and have limited understanding of the disease process (Astin & Jones, 2004; Campbell & Torrance, 2005; Fernandez et al., 2006; Lauck et al., 2009). For example, based on interviews with elective PCI patients (N= 140) prior to their procedure, Astin and Jones (2004) found that 56% of men were hypertensive, based on the physician's assessment; however, only 3% of the men viewed hypertension as a health problem. Women demonstrated a similar disconnect between risk factors and disease awareness; physicians diagnosed hypercholesterolemia in 88% of the women, but only 28% of these women

believed this contributed to their CAD (Astin & Jones). Unfortunately, knowledge of risk factors is not significantly improved post-procedure (Fernandez et al.; Fernandez, Salamonson, Griffiths, Juergens, & Davidson, 2008; Lauck et al.). In a recent study, Lauck and associates found that 43% of the elective PCI patients surveyed (N=98) indicated that they did not understand the cause of their heart disease. As knowledge is generally viewed as a prerequisite for change, recognizing the gaps in patients' understanding of CVD is required to gain insight into the rationale for their health behavior practices.

The deficit in CVD knowledge in many elective PCI patients is believed to contribute to their low enrollment in CRPs, as well as their lack of initiation of lifestyle changes (Fernandez et al.; Gaw-Ens & Laing, 1994; Gulanick et al., 1998). Interestingly, Alm-Roijer, Stagmo, Uden, & Erhardt (2004) surveyed patients with CAD (N=347) and found that general knowledge of risk factors increased preventative health behaviours. They later reanalyzed this sample and found that knowledge of personal risk factors significantly improved self-reported lifestyle changes (Alm-Roijer, Fridlund, Stagmo, & Erhardt, 2006). Clearly, knowledge of risk factors has a role in the initiation of lifestyle modifications.

Although elective PCI patients may not be unique in their lack of understanding of CV risk factors, their lack of knowledge and misconceptions compounds our inability to effectively promote healthy lifestyle behaviours. If elective PCI patients do not know about the causes of their CVD, they will not understand why their behaviors need to be changed. This research study explored the relationship between knowledge level and lifestyle choices following elective ad-hoc PCI procedures.

Lack of procedural pain. The pain or discomfort associated with a disease or illness is a contributing factor in perceived disease severity. It is a generally accepted that CABG surgeries and MIs are associated with considerable pain. A recent qualitative study of primary PCI patients (N= 29) found that many participants were surprised by the lack of procedural discomfort, and this lack of pain was often used as an indicator of less disease severity (Astin et al., 2009). Astin and associates interviewed a participant who described the experience as “I expected a bit more, bit more pain more pain and a lot more (short pause) a bit more blood....it’s a lot like nothing’s happened” (p. 77). These participant reactions highlight the disembodiment of this treatment process, which is why they perceive that “nothing has happened”. This sentiment is reflective of an inaccurate perception of disease severity even in primary PCI patients, who undergo their procedure during an acute MI. Because elective ad-hoc PCI patients undergo their procedure on an outpatient basis, health care providers must realize how much more disembodies and difficult it must be for them to understand their disease threat given the lack of procedural pain and urgency around their treatment.

The lack of pain post-procedure may explain the lack of lifestyle changes initiated by PCI patients as compared to other cardiac patients (Fernandez et al., 2006; Gaw-Ens & Laing, 1994; Gulanick et al., 1998). Gaw-Ens and Laing compared risk reduction behaviors of MI patients (n=258) and elective PCI patients (n=210). They found that although the PCI patients were as knowledgeable regarding risk factors, the MI patients were more inclined to initiate the necessary lifestyles changes; they contended that this was largely due to the anginal pain and hospitalization experience of MI patients. Thus, the nature of the PCI event (i.e., acute versus elective) and symptoms of CAD may carry

considerable influence on the patient's perception of CVD threat. Currently, there is a gap in the research related to how lack of pain or urgency contribute to the lifestyle choices made post procedure. Therefore, this study investigated the role of lack of pain and the minimally invasive elective ad-hoc PCI procedure had on the perception of disease threat.

Abbreviated hospitalizations. Individuals undergoing elective PCI procedures experience very short hospital stays in which the emphasis is on the procedure, immediate recovery, and quick discharge. These hospitalizations can be as short as 10 hours post-PCI and are generally less than 24 hours in duration. As a result of the shortened hospital stay, PCI patients do not receive phase I of cardiac rehabilitation (CR). Phase I CR is initiated while the patient is in hospital and focuses on early mobilization, education regarding risk factor control, and physical activity instruction (Suaya et al., 2007). For example, CABG surgery or MI patients are generally hospitalized for 3-5 days and are therefore more likely to receive this information. Given the limited time for information exchange while the elective ad-hoc PCI patient is in hospital, these encounters tend to focus on safety issues, such as discharge instructions and how to monitor for chest pain and bleeding.

Abbreviated hospitalizations not only impact on the quantity of information, but may also affect the quality of that information. Research evidence supports the notion that time to provide ample, targeted information that addresses the patient's needs is critical to the patient's understanding of CVD (Fernandez et al., 2006; Gaw-Ens & Laing 1994; Gulanick et al., 1998; Pearson & Peters, 1997; Riley, et al., 2007). Astin and associates (2009) and Radcliffe et al., (2009) found that the shortened hospital stay for

primary PCI patients presented fewer opportunities to provide patient education and support; however, the hospitalization time for the elective ad-hoc PCI patients is even less, resulting in a further reduction of time dedicated to the education and support of these patients. Consequently, elective ad-hoc PCI patients tend to receive a brief generic script of information, which is provided to all patients without tailoring the information to their specific understanding or needs.

As short hospitalizations are unlikely to change, health care providers must gain an understanding of how these brief encounters affect the elective ad-hoc PCI patient's perception of disease threat. Thus, this research study begins to explore the relationships and patterns between the hospital experience, the patient's perception, and subsequent health behaviour practices.

Cues to Action

Cues to action include such factors as media campaigns, advice from others, reminders from health care providers, and the illness of a family member or friend. Advice from others is a critical cue to action for health prevention strategies. In particular, the role of health care professionals in supporting and encouraging the adoption of healthy lifestyles is a significant component in CVD management and prevention strategies. This support can be provided through planned follow-up, continuity of care, and effective communication.

Follow-up care. Follow-up programs are a cornerstone of quality chronic care management and are vital for health promotion and disease prevention. These programs provide the opportunity to reinforce health teaching, elaborate on information, answer patient questions, reinforce compliance with medical treatments, and tailor advice on risk

factor modifications that are needed to prevent disease progression. Follow-up care also provides support and encouragement for patients trying to make difficult lifestyle changes. Therefore, planned follow-up care should be an integral component of chronic disease management to ensure that patients will understand and be able to manage their disease and treatment plan.

In a patient survey (N=24,200) completed by the Picker Institute in 1999 (as cited in IOM, 2001), patients stated that they were treated with respect; they received attention for their basic medical needs; and doctors, nurses, and medical staff were generally courteous. However, the hospital discharge often resulted in an abrupt transition without information on how they should care for themselves, when to resume activities, what medication side effects should be monitored, or how to have their questions answered. Post angioplasty patients have echoed similar concerns (Gentz, 2000; Gulanick et al., 1998; Radcliffe et al. 2009; Sampson et al., 2009). In some centers, the elective PCI patient receives minimal follow-up care (Gaw-Ens, & Laing, 1994; Gulanick et al.; Radcliffe et al.), which may have detrimental consequences for the promotion of healthy lifestyle behaviours. For example, in a qualitative study of PCI patients (N=45), Gulanick and associates found that many participants felt “cut off after they left the hospital and would have appreciated follow-up phone calls to check progress” (p. 259). Participants expressed frustration over lack of discharge information; and described being “left in the dark about what tablets, or what you’re meant to do. Its just ridiculous really” (Radcliffe et al., p. 220). However, despite consistent evidence regarding this negative approach, the health care system continues to devote little planning and effort toward follow-up care.

The gap in information and care created by lack of follow-up may not only be problematic for the patients' understanding of their role in disease management and prevention but may also impact on patient safety. In the absence of clear directions, some post-PCI patients have been found to be exercising inappropriately at home – creating significant safety issues (Astin et al., 2009; Gulanick et al., 1998). For example, Astin and associates found that some post-PCI patients participated in unwise levels of physical activity; one participant indicated that he walked six miles the day after his hospitalization. Patient follow-up affords the opportunity to provide patient education directed towards improving their safety.

Many follow-up services have also lacked a clear delineation of provider responsibility. Consequently, these services have been plagued by gaps and inconsistencies in follow-up care (Henriksen & Rosenqvist, 2003; Riley et al., 2007). In a multimethod study consisting of questionnaires, surveys, and interviews (N=309), Henriksen and Rosenqvist (2003) found that follow-up care for patients with CVD was often viewed as the responsibility of another sector of health care. Patients were often surprised by the lack of communication between the hospital specialists and their family physicians. In some instances, specialist had not informed the family physician of the care plan, so they were not aware until advised by the patient (Riley et al., 2007). This lack of teamwork between primary and specialist care results in poor disease management and tertiary prevention. In the absence of a well-defined care plan, patients may lack direction and support for initiating difficult lifestyle changes.

In addition, follow-up programs are not always been driven by the goals of the patients, resulting in programs that are not necessarily meeting their specific needs. For

example, in their study on the follow-up care of MI, angina, heart failure, and CABG surgical patients, Henriksen and Rosenqvist (2003) noted that physicians were mostly concerned with carrying out physiological check-ups in relation to cardiac risk factors, whereas patients expressed a desire to discuss their new life situation. Patients expressed the feeling “that health care professionals, whether in hospital or in primary health care, lacked knowledge, interest, and above all, time to discuss these issues [life situation] with them and their family” (Henriksen, & Rosenqvist, p. 98). Although physical assessments are important measures they are only the biological markers of treatment, it is also vital to have an understanding of the psychological and social impact of treatment on the patient. These assessments can only be made through planned follow-up care. Given the limited follow-up services provided to the elective ad-hoc PCI patient population, this research project explored the possible role of follow-up care to their perceptions of disease threat.

Continuity of care. Continuity of care refers to the ongoing management of a patient’s care over time and across practitioners, and the patient’s experience of coherent and consistent care that is based on their medical needs and context (Riley et al., 2007). Continuity of care is important to the individual’s understanding of disease threat because it requires that all health care providers and the individual are involved in the care plan, this facilitates consistent attention to the individual’s medical, educational, and psychological needs. Although follow-up care is a factor in the continuity of care patients receive, it is also dependent upon multiple health care providers delivering the same message and working towards the same goals. Unfortunately, with the increase in specialization, patients often experience highly fragmented care (IOM, 2001; Morgan et al., 2007). This has had a direct impact on the continuity of care for cardiac patients.

Although improving the continuity of care for patients is critical to their safety, as well as their understanding of CVD disease, significant care gaps still exist for some cardiac patients, particularly those patients who do not attend CRPs (Paquet et al., 2005; Riley et al., 2007). Cardiac rehabilitation programs have become the primary provider of this important health information and an integral component in the provision of continuity of care to cardiac patients. However, as discussed in Chapter 1, too few cardiac patients participate in these programs.

Since individuals with CAD are a diverse population from various ethnic, social and cultural backgrounds, participation in traditional CRPs, which are generally conceptualized as standardized programs, do not appeal to everyone (Clark, MacIntyre, & Cruickshank, 2007). The current strategies for continuity of care for the cardiac population are not effective for the vast majority of this population. In fact, many patients believe that their CRP should fit their lives rather than their lives fitting the CRP (Paquet et al., 2005; Wingham, Dalal, Sweeney, & Evans 2006). Therefore, the delivery of information through this mode may be counterintuitive to the diverse learning and information needs of the cardiac population and alternative strategies need to be explored.

As the elective PCI population is poorly represented in CRPs (Bethell et al., 2006; King et al., 1999; Hamilton & Haennel, 2004), the valuable information, support, and continuity of care afforded by these programs are lacking for this population. Through telephone interviews (N=198), Higgins et al. (2005) found that three-quarters of the elective PCI patients surveyed preferred information sources and formats other than traditional CRPs. Thus, affirming the importance of other models for the delivery of

tertiary prevention and ensuring the continuity of cardiac care for these patients. Riley and associates (2007) contend that improvements in the continuity of care received by cardiac patients could lead to improved participation in prevention strategies. However, research has not yet established a clear relationship between continuity of care and engagement in tertiary prevention strategies. This study provided several insights into the relationship between continuity of care and the health behaviour practices of elective ad-hoc PCI patients.

Effective communication. Effective communication plays a key role as a cue to action and is critical to the individual's understanding of disease threat and importance of health preventative behaviours. According to Curtin, Mapes, Schatell, and Burrows-Hudson (2005), "the ultimate endpoint of effective communication is 'concordance' – an agreement between a patient and a health care professional that respects the patient's wishes and beliefs and assures that the patient has had a proactive role in treatment decisions" (p. 390). In a qualitative study, Barry, Stevenson, Britten, Barber, and Bradely 2001, found that lack of concordance between patient and provider resulted in patients having their 'life issues' ignored while the doctors focused solely on the physical problem. This resulted in frustrations and uncertainty about the treatment plan. Therefore, without good communication, the ability to engage patients in disease management and tertiary prevention will be hindered.

Good communication between provider and patient results in higher patient satisfaction and increased adherence to advice or treatment (Teutsch, 2003; Weinman, 1997). Effective health communication is critical to enhancing quality of life and supporting self-care management in patients with chronic illnesses (Barry et al., 2001;

Sutcliffe, Lewton, & Rosenthal, 2004; Thorne, Con, McGuinness, McPherson, & Harris, 2004; Thorne, Harris, Mahoney, Con, & McGuinness, 2004). For example, in qualitative study involving interviews and focus groups of cancer care patients (N=82), Thorne, Hislop, Armstrong, and Oglov (2008) found that some patients believed their cancer outcomes were influenced by the quality of the communication they had with their health care providers. According to Fischhoff (1997), poor communication may have greater public health impact than the risks that health care providers are attempting to describe because of their potential to prompt wrong decisions, create confusion, or cause undue alarm or complacency. Thus, effective patient and provider communication appears to play a critical role in the cue to action and health decision-making process for individuals.

Effective communication of health risks to patients is a very challenging task even under ideal circumstances. The scientific nature of CVD is often difficult for individuals to translate into the practical and physical ways of knowing one's body (Angus et al., 2005). Patients often emerge from consultations having retained very little of what they have been told, particularly when those encounters have been driven by the caregivers agenda (Weinman, 1997). Therefore, the quality of communication between patients and their providers is also an important factor in an individual's response to CVD. In interviews with acute coronary syndrome patients (N=171), Perkins-Porras, Whitehead, and Steptoe (2006), reported that causal beliefs associated with CAD are strongly influenced by the quality of communication and its ability to convey information regarding risk factors. Thus, communication is the mode by which health care

professionals can accurately convey health information and provide the cues to patients for altering unhealthy behaviours.

The abbreviated hospitalization of the elective PCI patient has a direct impact on the discourse between health care providers and their patients. As there is limited time for the health care provider to spend with elective ad-hoc PCI patients, the primary focus is on safety. Thronson and Sawatzky (2009) contend that these brief encounters are driven by the need to provide specific directions related to post-procedure complications and safety, rather than the opportunity to engage in discussions regarding long-term secondary prevention strategies. This contention is supported by research evidence. For example, King and associates found that only 35% of women undergoing a coronary angiogram recalled being told that they were at risk for CVD, despite the fact that 84% had three or more risk factors. Similarly, in a descriptive survey (N=98), Lauck et al., found that 50% of elective PCI patients did not know what lifestyle changes were required to prevent their CAD from worsening. It may be erroneous to assume that these patients were all not informed of their risk factors for CVD or the need for lifestyle changes. However, the timing of this health information, as well as limited time to ensure their understanding, may be contributing factors in their lack of awareness of risk factors or need for lifestyle changes.

The findings of several studies suggest that brief information sessions are insufficient for lasting improvements to risk perception because recall related to CVD and risk factors fades over time (Christian et al., 2005; van Steenkiste et al., 2004; Williams, Lindsell, Rue, & Blomklands, 2007). For example, van Steenkiste and associates found that some cardiac patients could not recall the specific information

provided in consultation: “he explained all that, but, I can not remember now” (p. 303). What participants often recalled was the key component of the message such as the “test result was good” (van Steenkiste et al., p. 303). The emotional relief of an ‘effective treatment’ may be the only salient feature of that exchange for some patients.

Furthermore, it is common practice for cardiac interventionalists to speak to their patients briefly post-procedure to relay test results. This may be inappropriate timing as numerous research studies have reported that patients have limited recall post-procedure because they are in shock or under the effects of narcotics or sedatives (Astin et al. 2009; Lunden, Bengtson, & Lundgren, 2006; Radcliffe et al. 2009; Whittle et al. 2007). This current communication practice may have a profound effect on the realization and interpretation of disease threat within the elective ad-hoc PCI population. Therefore, this study explored the relationship between post-PCI communication, and the perceptions and behaviours of elective ad-hoc PCI patients post-procedure.

Likelihood of Action

Changing health behaviours is a challenging task. Individuals will engage in preventative health behaviours based on a number of factors, including the perceived benefits and barriers for a particular health behaviour action. For the individual to be successful in adopting new health behaviours they must believe that the benefits outweigh the barriers (Becker, 1974). The individual’s assessment of the benefits of action is dependant upon the belief that a course of action will be effective in reducing the disease threat (Becker, 1974). Conversely, the individual’s perception of the barriers to action represents the negative aspects of pursuing a particular course of action. These negative associations may include such things as difficulty of the task, financial cost, and

time. In particular, health care providers must understand the patients' perceptions of the benefits and barriers to health prevention strategies. As current tertiary prevention strategies for the cardiac population are primarily provided in CRPs, the individual's evaluation of the benefits, and barriers of such a program are of paramount importance and need to be explored in order to improve the likelihood of preventative health action.

Cardiac Rehabilitation Programs

The goal of cardiac rehabilitation is to improve the health behaviours of individuals with cardiac disease. As well, these programs attempt to build self-efficacy - a core component to changing one's health behaviour. Numerous studies support the health benefits of CRPs (Clark et al., 2005; Jolliffe, Riss, Taylor, Thompson, Oldridge, & Ebrahim, 2001; Jolly, et al., 2008; O'Farrell, Murray, Huston, LeGrand, & Adamo, 2000; Pasquali, Alexander, Coombs, Lytle, & Peterson, 2003). For example, in a systematic review comparing exercise only to comprehensive CRPs (N=7683), Jolliffe and associates found that total cardiac mortality was reduced by 26% (OR: 0.74; 95% confidence interval: 0.57-0.96) in the comprehensive rehabilitation group. Few would dispute the benefits of CRPs, but those benefits can only be realized if the patient attends the program. Unfortunately, many cardiac patients cannot or do not attend traditional CRPs.

In general, patients who are less than 70 years of age (King et al., 1999; Suaya et al., 2007; Worcester et al., 2004), live inside a city, speak English, have fewer comorbidities (King et al., 1999; Suaya et al., 2007), are male (Bjarnason-Wehrens et al., 2007; O'Farrell, et al., 2000; Suaya et al., 2007), are not indigenous peoples (Shepherd, Battye, & Chalmers, 2003), and are of higher socioeconomic status (Alter et al., 2004;

Suaya et al., 2007), are more likely to attend CRPs. Unfortunately, there is a higher risk of developing CVD in lower socioeconomic groups (Skodova et al., 2008) and indigenous peoples (Hoy, Baker, Kelly, & Wang, 2000). Consequently, a substantial barrier to CRPs is the exclusion of a growing segment of the cardiac population. Tertiary prevention strategies, therefore, must begin to adapt to a changing CVD demographic. The success of such strategies will become increasingly important in the years to come.

Benefits of Preventative Health Action

In a qualitative study exploring incentives for behaviour change in patients with CAD (N=207), Karner and associates (2005) found that cooperative behaviour for lifestyle changes were motivated by the need to control symptoms and the desire to increase their sense of well-being. Similarly, in their qualitative study of PCI patients, Gulanick and associates (1998) found that successful lifestyle modifications are motivated by the desire to improve and control one's health. Therefore, the perceived health benefits of preventative health behaviours may be a strong motivating factor in the likelihood of action.

Numerous health benefits have been reported in PCI patients participating in tertiary prevention strategies (Dendale et al., 2005; Higgins, Hayes, & McKenna, 2001; Lisspers et al., 1999; Lisspers et al., 2005; Stewart, Badenhop, Brubaker, Keteyian, & King, 2003). For example, in a retrospective comparative study (N=223), Dendale and associates found that after 15 months, PCI patients participating in a CRP had lower incidences of major adverse cardiac events compared to non-participants (24% versus 42%, respectively). However, despite the advantages to tertiary prevention, engaging patients in these difficult lifestyle changes remains a challenge.

In addition to the health benefits, HRQoL also increases in those who engage in preventative health behaviours (Brugemann et al., 2007; Pasquali et al., 2003; Schulz et al., 2008;). In a prospective study of revascularization patients (i.e., PCI or CABG; N=862), Pasquali and associates found a significantly increased HRQoL in CRP participants. Specific to the elective PCI patient population, the relationship seems to be less clear. Back, Wennerblom, Wittboldt, and Cider (2008) and Higgins and associates (2001) found no significant difference in HRQoL between the control groups and the participants involved in health behaviour interventions. However, both studies had small sample sizes (N=37 & 99, respectively) and therefore may not have had sufficient power to detect any significant changes in HRQoL. At present the relationship between HRQoL and preventative health strategies is unclear and constitutes another area where future research is needed.

Barriers to Preventative Health Action

Chronic disease management and tertiary prevention strategies are extremely challenging for many cardiac patients. Several studies have reported that, prescribed plans for lifestyle modifications are often inconsistent with patients' values, personally defined senses of self, or particular needs, and are therefore difficult to follow (Fleury, & Sedikides, 2007; Gaw, 1992; Gregory et al., 2006; Gulanick et al., 1998; Paquet et al., 2005). Specific to PCI patients, the qualitative study by Gulanick and associates found that these patients expressed frustration with adopting lifestyle changes; one participant stated "anything that tastes good to you, its no good. That's the message they are giving. If it tastes good throw it away and get something that doesn't taste good" (p. 257). Therefore, given the difficulty of these lifestyle changes, it is important to understand the

patients' priorities, what they value, how they view themselves, and what they feel they need, so that health care providers can promote better disease management and tertiary prevention.

Limited time to engage in prevention strategies may also be a significant barrier to behavioural change (Eastwood 2001; Evenson & Fleury, 2000; Gregory et al., 2006; Karner et al., 2005). In a qualitative study exploring incentives for behaviour change in patients with CAD (N=207), Karner and associates found that increased demands related to family and work were described as constraining. The shorter convalescence associated with PCI procedures results in a very quick return to work (Fernandez et al., 2006; Reid et al., 2006). Unlike CABG surgery or MI patients, elective PCI patients may not receive sick benefits that entitle them to extended time away from work. Generally, the allotted time given to recover from an elective PCI is about fourteen days, depending on the nature of their employment and physician practice. Consequently, many patients return to work while still recovering from their procedure. This leaves little time or opportunity to initiate a prevention program or to attend structured CRPs and may be a significant barrier to the likelihood they will take preventative health action.

Environmental factors are also often reported as problematic for individuals trying to engage in healthy lifestyles. Safety, affordability, and easy access to exercise facilities or CRPs in the immediate neighborhood increase the feasibility of participating in prevention strategies (Eastwood, 2001; Evenson & Fleury, 2000; King et al., 1999; Karner et al., 2005). In a survey of cardiac patients (N=61), Evenson and Fleury found that the most common barrier reported to participation in CRP was financial. Therefore, there are also very practical, concrete, and contextual considerations for individuals

attempting to modify their health behaviours. As well, social support, which was previously discussed, can function as either a benefit or barrier to the likelihood one will engage in preventative health behaviours.

Lack of physician support for tertiary prevention programs appears to be an important barrier to the patient's adoption of a healthy lifestyle (Evenson & Fleury, 2000; Gurewich, Prottas, Bhalotra, Suaya, & Shepard, 2008; King et al., 1999 Smith, Harkness, & Aurhur, 2006). In an earlier study that used a retrospective chart review (N=1245), King and associates found that only 23% of the eligible cardiac patients had a referral to a CRP. As participation in CRP is often dependent on physician referral the use of automatic referrals was found to increase participation in CRPs (Gurewich et al.; Smith et al); however, initiation and maintenance of a CRP is still a challenge (Bethell et al., 2006; Suaya et al., 2007). Patient support for CRPs and tertiary prevention strategies are likely to entail far more than simply a physician referral.

Finally, several researchers have reported stress as a barrier to lifestyle changes (Fernandez et al., 2006; Gregory et al., 2006; Gulanick et al., 1998). Specific to the elective PCI population, Gulanick and associates found that patients frequently identified stress as a significant barrier to risk reduction behaviours. In their study, it was unclear whether the stress was directly related to the difficulty of the task or a result of juggling health concerns with work and family obligations, and therefore, requires further investigation.

Given the philosophy of free markets to maximize choices available to individuals, it is surprising that this same philosophy has not been embraced in an attempt to improve prevention strategies (Cheek, 2008). Greater attention needs to be paid to the

benefits and barriers that individuals face when trying to adopt healthy lifestyles so that alternative approaches or prevention strategies can be developed. A chronic under representation in CRPs would not be as much of an issue if there were alternative options and strategies to reach these patients. Therefore, this research study explored the benefits and barriers to preventative health behaviours that face elective ad-hoc PCI patients. The goal is to use this evidence to inform the development of alternative tertiary prevention programs.

Perceived Threat of Disease

According to the HBM, disease threat is directly influenced by disease susceptibility, and severity, while modifying variables and cues to action indirectly influence this perception (Becker, 1974). Self-efficacy is another modifying variable, which is central to the confidence, and competence one has for a particular course of action. The likelihood that an individual will adopt healthy behaviours is also dependent upon the barriers and benefits that the individual attributes to those behaviours. Therefore, for the elective ad-hoc PCI patients to be motivated towards pursuing preventative health actions they must believe they are susceptible to CVD; believe that the consequences of heart disease are severe; be knowledgeable about their risks for CVD; believe there is a benefit to adopting a healthy lifestyle; perceive limited barriers to that course of action; and have the necessary confidence to change those behaviours. Within the context of the proposed study, the elective ad-hoc patient is vulnerable to an inaccurate disease threat, which results in a decreased likelihood of engagement in tertiary prevention strategies, inadequate chronic disease management, and deleterious health consequences.

Chapter Summary

Based on the review of the related literature, the elective ad-hoc PCI patient's likelihood of taking preventative health action is affected by their individual perceptions, modifying variables, and their perceived benefits and barriers (see Figure 3). The individual perceptions, which appear most problematic for engagement in preventative health behaviours, are: the belief one is cured, and an inaccurate risk perception. The modifying variables that may contribute to a decreased likelihood of action are: lack of social support, low self-efficacy, unrealistic treatment expectations, limited knowledge, lack of procedural pain, short hospitalizations, limited follow-up care, lack of continuity in care, and ineffective communication. The benefits and barriers to preventative health action are individually evaluated based on the perceived value of the action, weighed against the difficulty of the task. Benefits appear to be related to improving one's health and sense of well-being, while some of the barriers include: the difficulty of the task, time, environmental factors, and stress. The summation of these perceptions results in the likelihood one will pursue a particular course of action.

Many factors appear to influence the perception of disease threat and affect one's ability to adopt healthy lifestyle behaviours. More importantly, there is a lack of understanding of how these factors influence the health behaviours of the elective ad-hoc PCI patient population. Therefore, the goal of this research study was to identify the experiences, perceptions, expectations, and beliefs of these patients because "as long as we lack such knowledge [illness experiences and meanings], the development of new paradigms of practice and effective treatment strategies will be delayed and the research

enterprise will remain enormously unbalanced toward disease questions” (Kleinman, 1988, p. 266).

Chapter 4: Methodology

The health behavior practices of the elective ad-hoc PCI patient population were explored using the qualitative approach of Interpretive Description. Knowledge that is derived from qualitative methods, such as Interpretive Description, is known as interactive knowledge (Thorne, 2008). The focus of interactive knowledge is on the meanings and interpretations that individuals attach to events (Raphael, 2000). Interpretive description was used to explore the relationships between the elective ad-hoc PCI patients' perceptions and their health behaviours.

Interpretive description has been used to understand clinical phenomena of interest for a broad range of health care inquiries. The qualitative interview questions utilized in this research study were based on the core components of the HBM and were aimed at uncovering the relationships between the patients' perceptions and their health behaviour practices following an elective ad-hoc PCI. This approach captured the perceptions, thoughts, expectations, and experiences leading up to the diagnosis, the PCI procedure and hospitalization, and their recovery. This chapter provides an overview of my philosophical position, the methodology, research procedures, ethical considerations, and interpretive process.

Philosophical Approach

The philosophical stance that seems most appropriate to my understanding of human behaviour is symbolic interactionism. Symbolic interactionism is based on three basic premises including: individuals act toward things based on the meanings that those things have for them; meanings are derived from the social interactions; and these meanings are handled and modified through an interpretative process (Blumer, 2004).

Thus, behaviour is not solely the result of environmental pressures, stimuli, motives, or attitudes, but also incorporates how the individual notes, assesses, interprets, and handles these experiences. Morrione (as cited in Blumer, 2004, p. xii) states “this approach [symbolic interactionism] views social interactions as primarily a communicative process in which ... a person responds not only to what another individuals says or does, but also to the meaning of what he says or does.” Consequently, to understand meanings one must insert a middle term of *interpretation* into the stimulus response couplet so that it becomes stimulus – interpretation – response (Blumer, 2004). This concept is pivotal to one’s understanding that all human behaviours are manifestations of their interpretations and meanings. Therefore, to understand human behaviour we must come to know their world and the interpretations and meanings that guide their actions. It is this interpretive process that I find most fascinating; as it captures the individuality and broad range of responses that one sees in human behaviour.

Interpretive Description

The methodology that guided the research study is Interpretive Description (Thorne, Kirkham, & O’Flynn-Magee, 2004). This research method shares a philosophical alignment with interpretive naturalistic orientations and fits well with the philosophical position of symbolic interactionism. Interpretive description contends that reality is complex, contextual and ultimately subjective (Thorne, Kirkham, & O’Flynn-Magee, 2004). The foundation of interpretive description is the investigation of clinical phenomena. The purpose of this type of investigation is to capture the themes and patterns within subjective perceptions and to generate interpretive descriptions capable of guiding and illuminating clinical practice (Thorne, 2008).

According to Thorne (2008), the clinical mind is not satisfied with pure description, but rather seeks to discover associations and patterns within the phenomena. It was for this explicit reason that Interpretive Description was chosen as the methodology for this study. The intent of the researcher was to move beyond the subjective description of the elective ad-hoc PCI experience (i.e., clinical phenomena), to gain an understanding of the interpretations and meanings between these experiences and the subsequent health behavior practices of elective ad-hoc PCI patients. Ideally, the insights gleaned from this study will facilitate the process of informed clinical practice.

Methods

Research Design

This research study used a retrospective qualitative research design. Qualitative interviews using semi-structured questions were employed to answer the research questions. Participant interviews took place between December 8, 2009 and May 26, 2010. On average the participant interviews occurred 22 days (range = 11- 35) following their elective ad-hoc PCI procedure. Interviews lasted an average of 67 minutes (range = 29 – 101). The retrospective approach was chosen to gain an appreciation of the salient features that the participants recalled following their elective ad-hoc PCI. It was their experiences, interpretations, and meanings that were of interest and vital to comprehending their subsequent health behaviour choices.

Study subjects. The sample included 10 first-time elective ad-hoc PCI patients. The participants were recruited from the cardiac catheterization laboratory at the Health Science Centre in Winnipeg, Manitoba. The original intent was to use a maximum variation sampling technique in order to purposefully pick a wide range of variation on

dimensions of interest; however, due to recruitment circumstances a convenience sample was utilized. Participants who met the eligibility criteria were approached for participation in this research study.

Patient criteria for inclusion in the study were as follows:

- The ability to speak and understand English.
- A recent diagnosis of CAD.
- Between 18 and 65 years of age.

Patients were deemed ineligible if they have had any of the following:

- Previous cardiac surgery, PCI, or MI.
- Prior attendance in a cardiac rehabilitation program.
- Significant co-morbidities such as cancer or heart failure.
- Individuals with severe cognitive impairment, who were unable to sign their own consent or individuals with significant psychiatric histories including such diagnoses as schizophrenia or dementia

These subjects were not deemed as a vulnerable population and therefore did not require extra precautions beyond those of informed consent and strict adherence to the Tri-Council Policy Statement regarding the “Ethical Conduct for Research Involving Humans”.

Procedures. The following is an overview of the research study procedures. The staff in the cardiac catheterization laboratory and on B3 (pre-post PCI ward) at Health Sciences Centre were informed of the study through informational sessions (see Appendix A: Staff Information). Only staff members in the cardiac catheterization laboratory were asked to identify and recruit eligible participants; however, it was

important for the staff on B3 to be aware of the study in the event that potential participants had any questions post-procedure. Study information posters (see Appendix B: Study Poster), which outlined the nature and purpose of the study, were located in patient care areas including the catheterization laboratory and on B3. The cardiac catheterization laboratory staff (i.e., cardiac interventionalists and/or the catheterization laboratory nurses) were asked to assist with identification and recruitment of eligible patients. Staff participation was voluntary and they were free to choose whether they wished to participate in the recruitment process. As I was not on site, the staff did not need to feel coerced into participation. For those staff members who chose to participate, I was readily available by telephone if they had any questions or concerns.

Staff members were asked to provide study information packages to eligible participants. These packages included an invitation to participate sheet (see Appendix C: Invitation to Patients to Participate in a Research Study), a reply form (see Appendix D: Reply Form), and a self-addressed/stamped envelope. When staff identified an eligible patient they would provide a study information package and ask if the researcher could briefly speak to them later on the ward. If the patient agreed to be seen, the staff would call the researcher and inform her of the patient's interest. The researcher would then briefly meet with the patient to explain the research project and answer any questions (see Appendix E: In-patient Conversation). Patients were reminded that their participation was voluntary and no consents were signed at this time. The participants were encouraged to go home read the information package and call if they had questions. The reply form provided the contact information by which the researcher could be contacted to answer questions or address concerns. The participants were given the options of:

giving the reply form to the researcher following their meeting, emailing her at a later date, or mailing the reply form after their return home. Any of these three responses would confirm their interest in study participation.

For participants who gave the reply form to the researcher, arrangements were made to contact the participant, via the telephone, in a week to verify their interest. Those participants, who mailed their forms or emailed the researcher confirming their interest, were contacted upon receipt of their form or email (see Appendix F: Telephone Conversation). Once participants had expressed their interest in participating in the study, arrangements were made for a time and place to meet for the interview. A consent form (see Appendix G: Consent Form) was mailed to the participants prior to the interview to allow for sufficient time for the individual to read and understand the consent, as well as to allow them an opportunity to ask questions prior to the actual interview. Participants were also offered the choice of being interviewed in their own homes or at an office in the Thorlakson building at the Health Sciences Centre.

Prior to the scheduled interview, participants were contacted via telephone to confirm the interview time and location. At the interview meeting the consent forms were signed and participants were asked to complete a demographic information form (see Appendix H: Demographic Information). The researcher ensured that two copies of the consent were signed; one of which was left with the participant. As part of the written consent, participants were also given the opportunity to receive a brief report of the study findings.

Interviews were recorded on a tape recording device; the researcher or a hired transcriptionist later transcribed the taped data for analysis. Field notes (see Appendix I:

Field notes) were taken to supplement interview information, including: any significant community or personal events around time of interview, relevant media campaigns, recent treatment advances, or simply as a reminder to have participants clarifying questions or expand on information provided. The field notes were also used by the researcher to critique the interview questions and process.

Research tools. The research tools that were used in this study included: an interview guide (see Appendix J: Interview Guide), demographic information form (see Appendix H: Demographic Information), field notes (see Appendix I: Field Notes), telephone conversation script (see Appendix F: Telephone Conversation), and In-patient contact script (see Appendix E: In-Patient Conversation). The interview guide followed the linear progression of pre-procedure PCI events, the PCI procedure, and post-procedure recovery. The interview guide was used as a working guide by the graduate student (principal investigator) during the interviewing process and was not given to the participants. The research questions were designed to reflect the components of the Health Belief Model (see Table 2) and were used to explore the perceptions, expectations, and beliefs that elective ad-hoc PCI have around their PCI experience and how this may have influenced their subsequent health behavior practices. Although these questions represent the core components to the information gathered from the research participants; questions were at times reworded, clarified, or rephrased. In addition, probing for further explanation of responses was often utilized to facilitate the understanding of participant responses in order to expand and enhance the depth and scope of the interview data collected.

The participant's demographic information was elicited prior to the interview and included their code number, age, sex, ethnicity, educational level, employment status, private health insurance status, and date of PCI procedure. As well, field notes were taken to supplement interview information and to follow-up or clarify any questions.

Table 2. Semi-structured Qualitative Interview Questions

Health Belief Model	Research Questions
Individual Perceptions	<p>How worried are you about having a problem with your heart arteries again? Possible probes: Do you think there are things you can do to help reduce your risk of having problems again? What are those things – please tell me about those. How confident are you in your ability to reduce your risks for future cardiac problems?</p> <p>Please tell me about your health prior to and leading up to your angioplasty procedure. Possible probes: When did you first start noticing symptoms? Please describe to me the symptoms that you were noticing. When did you decide to see a doctor about your symptoms? What made you decide to see a doctor did something change at that particular time? Did you discuss your decision to seek medical advice with anyone? Did you adjust your lifestyle in any way because of your health problem?</p> <p>Please tell me about your recovering from the procedure. Possible probes: How long did it take you to return to your “normal” routine? Please describe for me what your normal routine would be?</p> <p>In your perception how has the angioplasty affected your health? Possible probes: Tell me how your health has been since your angioplasty? Are you now able to do things you were previously unable to? What sorts of activities are those? Any other changes to tell me about?</p>

<p>Modifying Variables</p>	<p>Please tell me why you think you developed blockages in your heart? Possible probes: Has anyone in your family had similar problems? Can you think of any other factors that may have contributed to this problem? How do you think those factors affected your heart arteries?</p> <p>Please tell me about your angioplasty. Possible probes: I know you attend a teaching clinic prior to the procedures did the information you received there prepare you for the procedure? Did what happened during your procedure match your expectations of what would happen? What was the hospital experience like for you? What do you remember about your time in hospital?</p> <p>Please tell me about the health care providers involved in your care. Possible probes: Does anything stand out about one or all of them? Did you have questions for these health care providers? Were your questions answered satisfactorily?</p> <p>Please tell me about the discharge planning you received. Possible probes: Anything that stands out for you about being prepared to return home? How was the discharge process? Were you ready and prepared to return home? As you think about discharge planning now, is there anything missing?</p> <p>Have you seen your doctor since your procedure? Possible probes: What did you discuss at your appointment? What sources of information do you use when you have questions about your health? Have you ever heard of cardiac rehabilitation programs? Have you sought or received advice from someone else? If yes, from who and what was the advice?</p>
<p>Likelihood of action</p>	<p>Can we talk for a few minutes about your lifestyle? Possible probes: Has your lifestyle played a role in developing heart problems? Are you attempting to change any aspects of your lifestyle? Have you had any success with making lifestyle changes? What factors have helped? What factors have proved challenging? How do you manage those challenges? How motivated are you to make those changes? What has been the strongest motivation for you? When you look ahead, in a year or two, what do you envision for health? Do you have a plan</p>

	on how you might achieve/avoid that?
Perceived threat	<p>Can you tell me about your feelings around having to have an angioplasty?</p> <p>Possible probes: What does having an angioplasty mean for your future health?</p>

Ethical Considerations

Informed consent. The information package outlined the research study, as well as the requirements for participation (see Appendix C & D: Invitation to Patients Participate in a Research Study Reply Form). The informed consent (see Appendix G: Consent) was mailed to interested participants prior to the interview; contact information for the researcher was included on the consent form so that participants could contact the researcher with any questions or concerns prior to the interview meeting. At the interview meeting the consent form was reviewed and the formal written documentation was obtained prior to commencement of the interview. Two copies of the consent were signed, one for the researcher and one for the participant to keep. The participant interviews were conducted in a private space either in the participants' homes or at an office at the Health Sciences Centre.

The patients' hospital records were not accessed in this research study; any personal or medical information was obtained directly from the participants. As this

study investigated the beliefs, perceptions, and experiences following elective ad-hoc PCI, all patient information was elicited from the participants themselves.

Anonymity and confidentiality. Careful attention was paid to the privacy, confidentiality, and anonymity of all participants' information during the interviewing process, the data analysis, and the dissemination of results. The information provided was held in the strictest confidence and was/is protected in several ways using the following strategies:

1. All interviewees were identified by pseudonyms (no proper names were attached).
2. The participants (and individuals referred to during the interview) were not identified in any records or in written reports from this project.
3. All records were securely stored in a password secured computer file. All files will be destroyed after seven years via confidential waste procedures.
4. Only the identified researcher had or will have access to the records. The researcher has received PHIA certification. Research findings were discussed with the thesis advisors; however, names were not linked to any information discussed.
5. Findings will be presented in aggregate form. There will be no individual identifiers linked to any quotes, so it will not be possible to link the identification of individual participants to presented findings either in written or oral formats.
6. Only the graduate student (principal investigator) had access to the participants' contact information. This was used only for purposes of mailing a consent form, arranging interviews, and providing a research summary to interested participants.

Voluntary participation. Participation in this study was voluntary and participants were made aware that they could withdraw from this study at any time without risk of compromising their future care.

Deception. Deception was not used in this study; participants were informed of the intent, duration, and requirements of the research project. They were also advised of their ability to withdraw from the research project at any point in time.

Feedback/debriefing. All participants were provided with the opportunity to have a brief copy of the research report mailed to them following the analysis and synthesis of data. Information regarding their desire for this information was included on the consent form (see Appendix G: Consent). Participants were asked to provide a mailing address or email contact information to the graduate student (principal investigator) indicating where they would like the results sent. The graduate student was the only individual with access to the participants' names and mailing addresses and was responsible for dissemination of all study related information.

Risks and benefits. There were no anticipated risks to the subjects as a result of participating in this study. Although participants described feels of anxiety and depression, associated with their PCI, none experienced emotional distress related to the questions posed during the interview. However, provisions were in place in case participants became distressed during the interview. If this situation arose the researcher would have stopped the tape recorder, halted the interview, and allowed the participant time to collect themselves. If the participant wanted to continue, the interviewer would turn the tape recorder back on and proceed with the interview. Alternatively, if the participant did not wish to continue the interview would have been terminated and the

interviewer would offer support and a referral to a counselor to assist with the emotional distress experienced.

A potential benefit of participation in this study was the opportunity to share their understanding, beliefs, and perspectives around the experiences of having an elective ad-hoc PCI. The study findings did not directly benefit the participants; however, the information gained through these interviews allowed health care professionals to gain a deeper understanding of these patients and their needs. Ideally, this will positively influence the future care of other elective ad-hoc PCI patients.

Compensation. A small honorarium of \$20.00 was provided to compensate participants for their time. In addition, reimbursement of parking expenses was given to those participants who chose to be interviewed at the Health Sciences Centre.

Summary of ethical considerations. This research study adhered to the Tri-Council Policy Statement regarding the “Ethical Conduct for Research Involving Humans.” Prior to the study’s commencement, ethical approval was obtained from the Education and Nursing Research Ethics Board (ENREB) at the University of Manitoba. As well, permission for access to patients from Health Sciences Centre was secured. Informed consent was obtained prior to interviewing participants. Careful attention was paid to the privacy, confidentiality, and anonymity of all participants’ information during the interviewing process, the data analysis, and the dissemination of results.

Participants were made aware that participation in the study was voluntary and that they could withdraw from the study without compromising their care. Anonymity of the participants was ensured throughout the research project. All information collected was kept strictly confidential. Only the graduate student (principal investigator) and her

thesis committee had access to the non-coded, raw data. Subjects were assigned a code number and their names did not appear on any transcripts, documents, or reports about the study. In addition, their identities will remain anonymous in any future publications. Study findings will be reported by in-group format to ensure that there are no individual identifiers linked to any quotes, so it will be impossible to link the identification of individual participants to presented findings. The data is stored in a password secured computer file at the home of the graduate student. As well, the consent forms are in a locked drawer in the office of the graduate student. All files will be destroyed after seven years via confidential waste procedures.

Data Analysis

The data analysis involved a non-linear and iterative process. As the qualitative data was collected, it was transcribed and managed using a computer qualitative data management program. Transcripts were reviewed and reflective thoughts, questions, and perceptions were tracked through memos. As well, there were ongoing comparisons between different participant transcripts to draw out similarities and differences in perspectives. Eventually, through the generation of memos and dialogue with my committee members, an inductively generated initial list of codes was generated to reduce the transcripts into relevant passages. Initial data coding was followed by the refinement of codes, where some codes were collapsed and new ones considered. As data in each code was reviewed, patterns were identified that best described the details portrayed from the different perspectives. The end result was the generation of a profile concerning the health behavior practices of elective ad-hoc PCI patients. Once this profile was developed, the conceptual framework that guided the study was used to

inform our understanding of the strengths and limitations in the provision of health care so that we could identify our achievements and begin to address the gaps.

Chapter Summary

Interpretive description is the methodology that was be employed to gain in-depth in-sight into the underlying subjective experience of individuals who have undergone an elective ad-hoc PCI. A retrospective qualitative approach was used to determine the saliency of the experience and its impact on subsequent health practices. The research questions were derived from the conceptual framework, the Heath Belief Model, and reflect the core concepts of this model. Careful attention was made to accurately reflect the thoughts, beliefs, perceptions, and experiences of these participants. The ethical consideration for these participants was strictly followed as outlined. The participant's information was held in the strictest confidence and every effort made to ensure their anonymity and confidentiality.

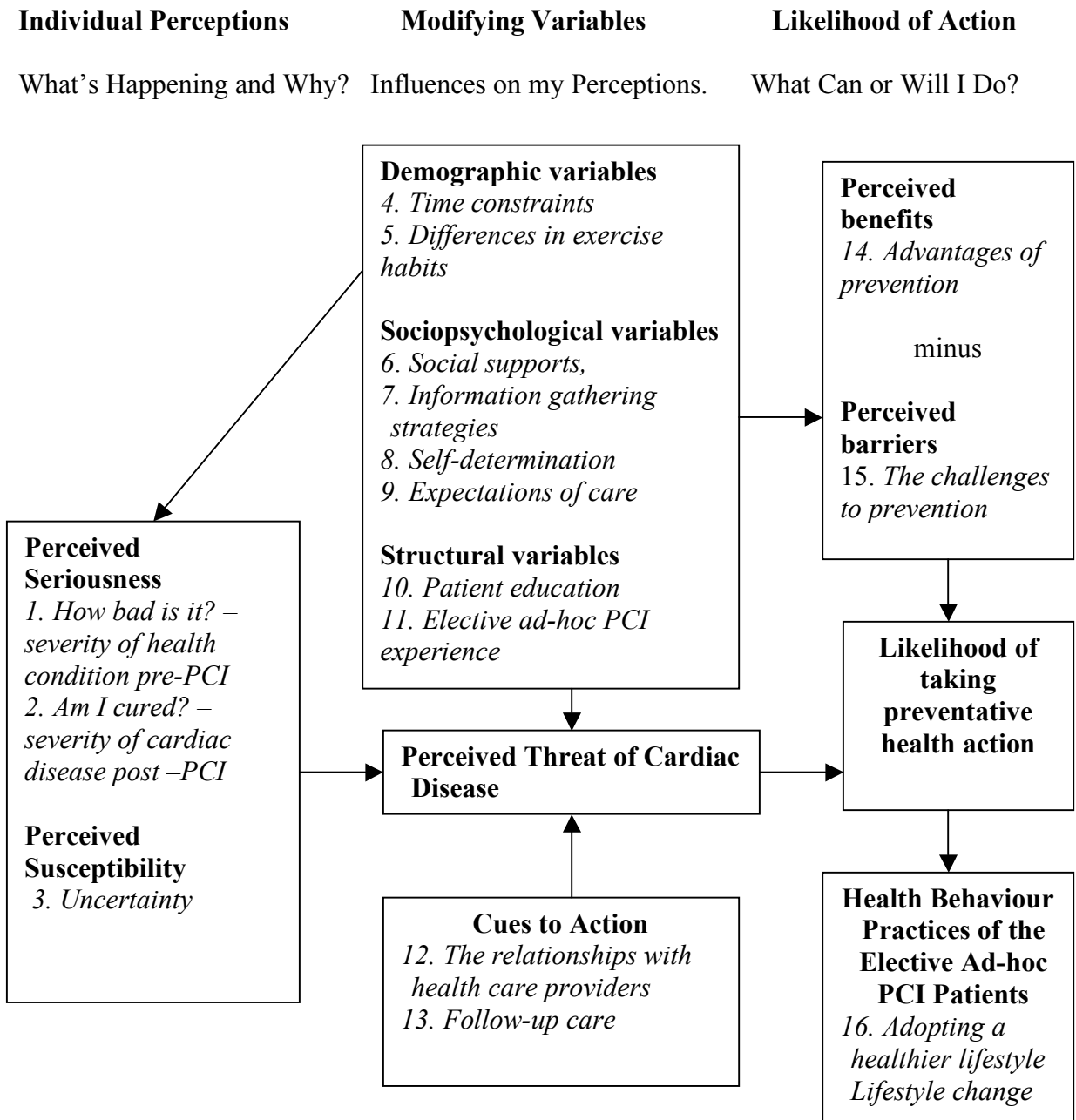
Chapter 5: Participant Thematic Findings

This chapter presents the findings of an interpretive description study that explored the experiences of elective ad-hoc PCI patients in the early stage of coronary artery disease (CAD). The questions posed during the interviews followed the sequence of events leading up to their diagnosis, the PCI procedure, and their recovery. Although each participant's PCI story was unique, what emerged in this chapter are the shared themes of the experience of having an elective ad-hoc PCI.

The Health Belief Model (HBM) provided the study framework, guided the literature review, and directed the interview questions. To review, the HBM has three major components that influence a person's perception of disease threat including: individual perceptions, modifying factors, and cues to action (Becker, 1974). Individual perceptions pertain to one's belief of disease severity and susceptibility (Becker, 1974). Thus, it reflected the participant's understanding of *what's happening and why* within the context of the disease process and treatment experience. The modifying variables have an indirect effect on the likelihood of taking preventative health action by influencing the perception of disease severity, susceptibility, and threat, as well as perceived benefits and barriers (Strecher & Rosenstock, 1997). Accordingly, modifying variables were heavily dependant on factors that *influence perceptions*, particularly as they related to the participant's understanding of the disease process and their probability of adopting lifestyle changes. Finally, the likelihood of taking action was dependant upon the perceived benefits and barriers of a particular course of action. Quite simply, this component of the HBM reflected the probability that the participants would take preventative health action according to their evaluation of *what can or will I do*. The

findings from the participant interviews have been incorporated into themes and placed within the organizational framework of the HBM (see Figure 4).

Figure 4: Study themes/findings adapted to the Health Belief Model: Public domain material adapted from www.google.ca/images, 2011.



Description of the Participant Sample

Of the fourteen individuals approached for this study only ten agreed to participate (see Table 3). The main reasons cited for not participating was lack of time. All ten individuals were newly diagnosed with CAD and treated with an elective ad-hoc PCI. Although the ten individuals who were recruited were fairly young, the women were slightly older than their male counterparts, which is reflective of the older age at which women typically develop CAD. The majority of participants were still in full-time employment. Although there were 5 rural participants they were still within 60 km of Winnipeg and therefore able to access the resources of a larger urban center. Despite variations noted in the education level this did not appear to translate in economic diversity.

Table 3. The Sample - Elective Ad-hoc PCI Participant Demographics

Characteristic	Number (N=10)
<u>Age</u> Age range Mean age Mean female age Mean male age	44-65 years 57.9 years 64 years 56.4 years
<u>Gender</u> Female Male	2 8
<u>Place of residence</u> Urban - inside city limits Rural <60 km from city perimeter	5 5
<u>Marital Status</u> Married Common-law Single Divorced Widowed	8 2 0 0 0
<u>Highest educational level completed</u> Junior High school Senior High school College University	1 3 3 3
<u>Employment status</u> Full-time employment Semi-retired Retired	6 1 3
<u>Ethnic background</u> Metis Caucasian	1 9

The Participants' Stories

When participants spoke of their elective ad-hoc PCI experience they often included vivid descriptions of their symptoms, treatment, hospitalization, and recovery. In addition, the importance of their relationships with significant others and health care providers were featured throughout their stories. Each participant provided a distinct and rich description of their PCI experience, which together revealed insights into common themes along with differences between their experiences.

Although there were ten participants, I have included three exemplars. I will share passages from a typical male participant, a typical female participant, and an atypical male participant. The sole two female participants were very similar, thus I am unable to share an atypical female participant story.

A typical male participant: Peter's story.

Peter is a 62-year-old male, who works in the construction industry. He resides outside of Winnipeg with his wife. His children are grown and he prides himself on being an active grandparent who enjoys playing with his grandchildren. He lives in a beautiful home, which he built. Peter describes himself as a highly motivated, energetic person. His pre-PCI symptoms include shortness of breath, and a lack of energy.

At the time of the interview, 34 days post-PCI, Peter was still not back to work. His family doctor wanted to reassess his health at the end of the month to determine his ability to return to work. Peter was finding this indecision and lack of direction very difficult and reported feelings of anxiety associated with his uncertain future. He stated:

"Like every time you meet the doctor, well we'll let you go now until the end of January and then we'll reassess. I'm not sure what that means to reassess."

Peter expressed frustration over the lack of information about what was “normal” and what to expect post-PCI. This high degree of uncertainty left him feeling quite susceptible to future problems. For example:

“I bust my shoulder years ago, well lots of years ago and it was good to know that after a while I could throw the ball again OK, I can play hockey again wait I must be getting better right. So you could kind of judge that much better than something like this where you don’t know what’s going on inside here (points to his chest). You have no idea.”

The lack of change in Peter’s symptoms post PCI contributed the disembodiment of this experience and resulted in an increased need for information. The resulting lack of follow-up and insufficient post-PCI information contributed to his uncertainty, which was a predominant theme throughout Peter’s interview.

Not only did this lack of information and direction from health care providers contribute to Peter’s uncertainty but it also failed to provide the direction or support he needed to adopt a healthier lifestyle. He expressed skepticism that he would find the support he needed within his home community:

“So you need to find some kind of support [for lifestyle change] that will help you with that, and I don’t know that picture yet but I know for me that has to happen because otherwise I know that I’ll be right back.”

Although Peter recognized his need to change his lifestyle, he understood the challenges he faced.

The diagnosis of CAD, PCI treatment, and recovery were significant events in Peter’s life. He described himself as looking at his life “in a whole new way” and was trying to make changes to reduce the threat of CAD. The lack of support and information available to him were significant barriers to the adoption of a healthier lifestyle and contributed to feelings of uncertainty.

The typical female participant: Angela's story

Angela is a 63-year-old female who resides just outside of Winnipeg with her husband. She is retired but keeps active by attending the sporting events of her grandchildren and shopping with her daughter and friends. Her CAD was diagnosed following a few brief episodes of decreased heart rate; throughout the diagnostic testing she was convinced that there was nothing wrong with her heart. At the time of the interview, 29 days post-PCI, she indicated that she was back to her normal routine and in fact went shopping at the mall on the day she was discharged from hospital.

Angela expressed a profound disconnect from the angioplasty procedure, frequently stating how great it was and how she slept right through the procedure. It almost seems like a non-event in her life, highlighted by the fact that she went shopping the following morning. She stated:

"As soon as I left the hospital, I stopped at the nurses' desk and asked the doctor if I could go to the mall for a while, he said 'as long as you go sit down if you don't feel good'. I said no I feel fine."

Not surprisingly Angela rated the severity of her CAD very low.

The diagnosis of CAD came as a complete shock to her; although she recognized some of her risk factors she didn't have a firm grasp on how they had influenced her current health situation. In particular, she had a strong family history on her father's side but expressed a high degree of uncertainty over how this affected her health:

"He [father] died at 59 of a coronary thrombosis and my sister died of an aneurysm and two of my brothers died of a heart attack... but my cardiologist said this is not related at all to my father's condition."

Clearly, Angela's misconception of her cardiac risk factors is influenced by the information she received from her physician and emphasized the role that health care providers had in assisting the participants' to understand their risks.

Not only was her knowledge of risk factors influenced by the physician but so too was her understanding of the importance of making lifestyle changes. At her follow-up appointment Angela asked her cardiologist specifically about making lifestyle changes. She recalled his response:

"No he [the cardiologist] just said to continue on to do whatever you were doing."

This lack of direction provided for making or promoting lifestyle changes was a barrier to her adoption of a healthier lifestyle. Angela left her appointment with no new information or guidance on lifestyle interventions that could help prevent the future reoccurrence of CAD.

Atypical male participant: Michael's story

Michael is a 44-year-old articulate and intelligent male. He resides in the city with his partner and two children in a spacious, well-kept older home. He works in the health care industry and is quite knowledgeable about the health care system. His symptoms prior to his elective PCI included shortness of breath, a generally feeling of unwell, and chest discomfort that he did not associate with his heart. One week after his elective ad-hoc PCI he was re-hospitalized for pneumonia and post-PCI angina. At the time of the interview, 19 days post-PCI, Michael was not coping well.

Michael was highly anxious about his health status and rated both his disease severity and his susceptibility to future CAD very high. He was skeptical that he will be able to achieve a positive health outcome and is fearful of the future. He stated:

“Absolutely, I’m feeling like I’m a time bomb waiting to go off and I’ve never thought that in my life. So I’m not living I’m making it through day to day right now and at some point I will get back to living, and if I go off, I go off and that’s the reality of it but I don’t like the idea.”

Contributing to Michael’s anxiety was the overall lack of information and direction from his health care providers. For example:

“Well I knew there was a problem when they turned the camera, well the TV away from me and they started talking all over in a corner which really pissed me off... The process itself to me became scary when people stopped talking to me.”

Michael’s fear and anxiety created strain within his personal relationships and affected his mental health. He was fearful of dying in his sleep, and in his own words says he had “an unrealistic fear” that his arteries were going to blow up.

Michael also expressed a great deal of frustration around making lifestyle changes. He was very motivated to adopt a healthier lifestyle and planned to attend a cardiac rehabilitation program. However, he was angry that he could not join immediately and had to wait for an opening:

“It’s this waiting in-between, like why I couldn’t have gone the next day somewhere and had somebody do a baseline with me and this waiting; it could be another 2 weeks before I get into the Wellness Centre; which is another 2 weeks that I can’t go to the gym.”

Michael’s motivation for lifestyle change was rooted in his desire to be around for his young children. However, he was fearful of his failing health and frustrated with the lack of information and direction from his health care providers. He was angry, anxious, and dissatisfied with the limited assistance offered by the health care system.

The excerpts from these three participants provide some insight into the experiences and challenges the participants faced following their elective ad-hoc PCI. Interestingly, even between the typical and atypical participants one can see the

importance of communication, relationships, and information to their understanding and ability to adopt healthier lifestyles. The following sections of this chapter will provide greater detail into the themes identified through the participant interviews.

Individual Perceptions – What’s Happening and Why

According to the Health Belief Model, the perceived threat of a disease is influenced by one’s perception of disease susceptibility and severity (Becker, 1974). Accordingly, there appeared to be a strong relationship between the participants’ perceptions of coronary artery disease (CAD) severity and susceptibility and it’s perceived health threat.

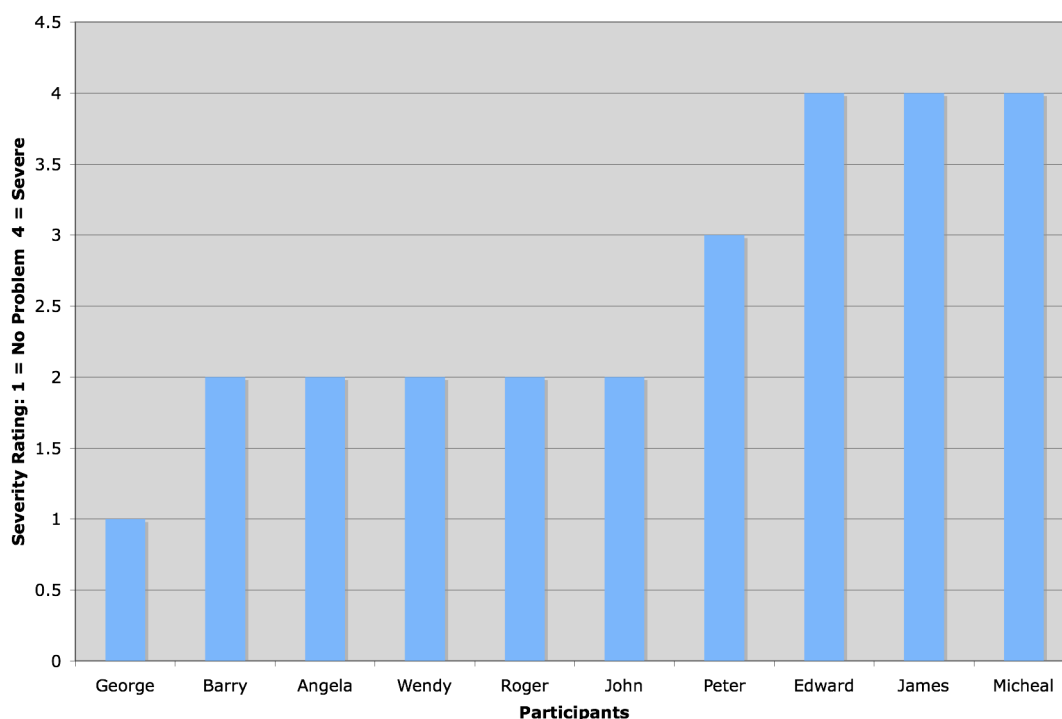
Perceived Seriousness

The relationship between the perception of disease seriousness and the threat of the disease are variable among individuals (Becker 1974). Similarly, there was a wide range of perceived CAD severity among the elective ad-hoc PCI participants. All participants were asked to reflect on their health status at two time points: prior to and following their PCI procedure. They were then invited to rate the severity of their perceived health threat using a scale of 1- 4; where 1= no problem, 2 = mild, 3 = moderate, or 4 = severe. Participants were also asked to provide the rationale for this rating. The participants’ perceptions of CAD severity will be discussed in the context of *“how bad is it?” – severity of health condition pre-PCI* and *“am I cured?” – severity of CAD post-PCI*.

Theme # 1: How bad is it? - Severity of health condition pre-PCI. All participants described themselves as being in good health prior to symptom onset. Therefore, the development of a health problem was often alarming and cause for

concern. The participants described this initial phase as a time of indecision as many did not know how to respond or what to think about the symptoms they were experiencing. Consequently, ratings of disease severity fell along a continuum; however the majority of participants described their health threat as mild to moderate (see Figure 5).

Figure 5: Perceived Severity of Health Problem Pre-Elective Ad-Hoc PCI



Central to the participants' understanding of the severity of their health problem were the interpretation of the symptoms potential causes. They engaged in a symptom interpretation process, which directed their health seeking actions. This process provided the rationale for their perception of the seriousness of their health problem. Other important components in this evaluation were the speed at which they were scheduled for diagnostic testing, and lay stories about CAD from those within their communities. These factors - *symptom interpretation*, the *speed of diagnostic testing*, and *lay stories* - provided the rationale behind their initial perceptions of disease severity.

Symptom interpretation refers to the participants' perceptions of symptoms origin. Often the apparent lack of interference with daily activities appeared to mask the severity of their health problem. For example, George rated his disease severity the lowest of all participants, stating:

"Because I could do everything I, I was doing except the jogging."

Even though he had chest pain while jogging, his ability to live an otherwise normal life persuaded him to believe the seriousness of his health condition was minimal.

In addition, many participants did not think their symptoms were cardiac-related, either because they did not have "typical" chest pain or they were in denial about their condition. Barry typifies this viewpoint:

"Most of the time this sort of pressure took place after I'd eaten something and then gone out and done something so I assumed the two were related. So it was sort of you know don't do too much right after you've eaten, you know related from my perspective more to gas or internal stuff like that so no I really wasn't that concerned."

Conversely, John described very typical cardiac symptoms; however he appeared to fail to recognize or act on them. The following anecdote is the retelling of his symptom experience:

"I was comin' down stairs from the bedroom to the living room and all of a sudden, my chest started to hurt, and my arms from the wrist across the chest and down the other arm to the wrist... and I wondered what the heck was going on at that point and I went and sat down on the sofa there, just sat quietly for about five minutes. It went away in a little bit and I figured... I wasn't sure what happened, I didn't know what had happened, but it wasn't ... it didn't fit my preconceived notion of like a heart attack." –John

It is unclear whether John's lack of recognition of the seriousness of his condition is related to deficient knowledge or denial. However, this example serves to illustrate how

even fairly convincing symptoms were ignored or attributed to less severe health problems by a few participants. Participants who did not relate their symptoms to a serious health condition rated their health more favorably and described less anxiety.

In contrast, the three participants who rated their health problem as severe conveyed a greater degree of symptom involvement, which they attributed to a serious health concern. These three all commented on the increasing severity of symptoms in relation to how the symptoms impacted their activities of daily living. For example:

"We had to walk up the block to the restaurant because we go to the restaurant first before, before the game. And I noticed within about 100 yards sort of a tightness in my chest and that was the first time it happened. [I was] scared because I didn't know what it was and then ever since then it would come on and off... it just got progressively worse and worse and worse. I could do less and less and less to the point where I would walk to the back yard and I had, had difficulty even scraping the windows on the car." - James.

The increase in disease severity corresponded to an increased perception of disease threat, which resulted in these participants reporting higher levels of anxiety. As James recalled:

"I was very anxious about what it is and what it was and I just wanted to know."

These participants also appeared to have more insight into the cause of their symptoms, as two of the three believed the origin of their symptoms were cardiac.

Not only were the participants' interpretations of symptoms critical components in their evaluations of disease severity, but this also influenced their consequent health actions. Attributing symptoms to minor health problems was associated with a decreased health threat and less urgency to seek care. For example:

"I said I will tell the doctor about it [chest pain while shoveling snow]; so that was in November, so I didn't tell him about it until January." - Barry

While those participants who rated the severity of their disease higher perceived an increased threat to their health and actively sought health care. James stated:

It's really scary you know and uh... [family physician] telling me it was in my head... No but I know something's wrong with me."

His sense of the seriousness of his health condition drove him to switch providers because he was unhappy with the care and answers he was receiving.

The *speed of diagnostic testing* pertains to how quickly the participants were scheduled for diagnostic testing. This also provided a measure by which participants evaluated the seriousness of their health problem. In general, most spoke positively about how quickly they were scheduled for tests and procedures. However, participants who perceived their testing to be scheduled sooner than anticipated took that as an indication of increased severity. As Edward recalled:

"I think because how fast they got me into, into the Health Science Centre here... cause you know I was, I talked to other people and other people say it was a lot longer waiting period and I thought the time frame might have indicated it was very serious."

The urgency of preliminary diagnostic testing was interpreted as an indication of disease threat; whether this was an accurate indication based on their risk stratification is unclear and cannot be addressed. What is evident is that participants associated speed of testing with disease severity.

The final component, *lay stories*, also heavily influenced the participants' perceptions of disease severity and health threat. The stories that were shared comprised the personal accounts of family and friends who experienced similar health problems and testing for CAD. The outcomes described in these stories heavily influenced the participants' feelings regarding their own health status and potential outcome. The

participants who shared stories that had negative health outcomes rated their disease severity higher and described a higher degree of health threat. This is reflected in Peter's account:

"Yeah, we've had a few guys around here that we have known personally, my age, that have died recently of heart attacks; so I think that anxiety thing was there constantly thinking you know what, it could be me."

Conversely, the participants who rated their disease threat as less serious often shared examples of others whose positive health outcomes enabled them to dispel their fears and anxieties. For example:

"my dad just died this past January and he was 92 and very healthy except for a little bit of arthritis and the one heart attack, which was 30 years before that. So he was very healthy yeah." - Wendy

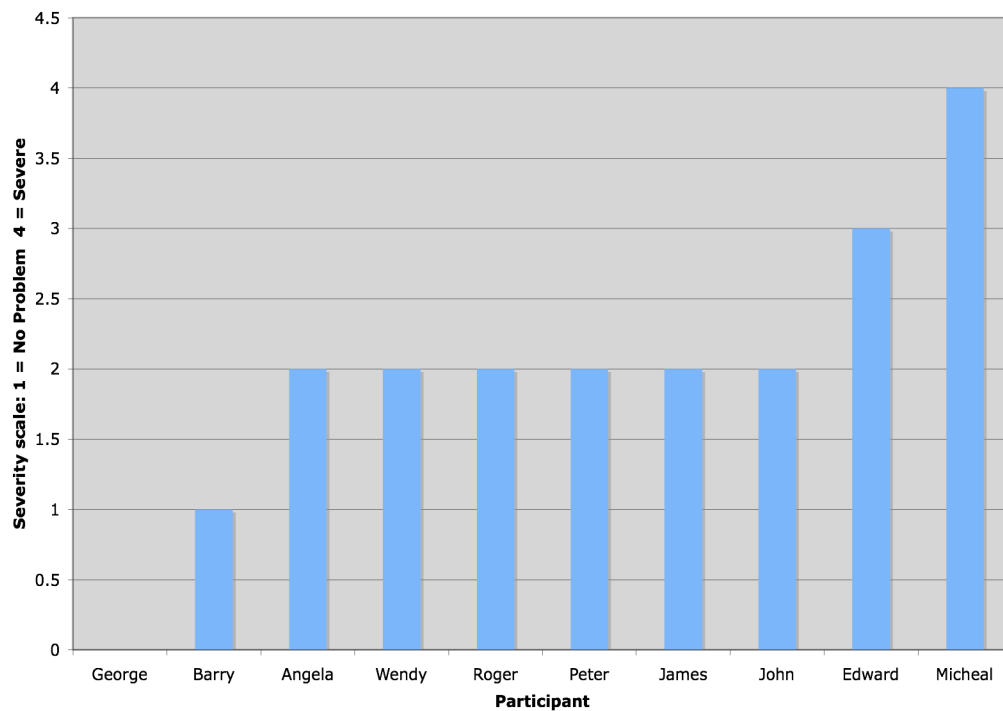
The impact of these lay stories was evident in the participants' ratings of the seriousness of their health problem and reflected the degree of health threat. The experiences of others with similar health issues provided powerful real life examples of health outcomes.

Symptom interpretation, speed of diagnostic testing, and lay stories were critical components in the participants' perception of disease severity prior to their PCI. Their understanding of *how bad is it* was dependant on the complex relationship between these factors, which influenced the participants' belief of disease threat.

Theme #2: Am I cured? - Severity of cardiac disease post-PCI. For many participants the post-PCI phase was described as a time of shock and disbelief. The confirmation of a diagnosis of CAD was often regarded as a surprise despite the results of preliminary testing and the need to proceed to an angiogram. In general, the confirmation of CAD did not translate into increased ratings of disease severity. In fact, the ratings of

disease severity decreased post-PCI for the majority of participants (see Figure 6). Therefore, treatment by PCI was often associated with a decrease in the perceived severity and threat of CAD.

Figure 6: Perceived Severity of Heart Problem Post-Elective Ad-Hoc PCI



Critical to the participants' perception of am I cured were the *management of symptoms* as well as the *physician's evaluation* post-PCI. Although the evaluation of symptoms was difficult for a few participants, most could clearly identify either a benefit or detriment as a result of treatment following their PCI. The physician's evaluation provided another critical element to their post-PCI evaluation of disease severity and CAD threat.

The *management of symptoms* was a crucial element in the participants' evaluation of their health and treatment success. Most participants reported improved

health following their PCI procedure. This was often the direct result of symptom relief, which was evaluated based on improvements noted in their activities of daily living.

Participants reported:

“Oh immensely, its really, really helped a lot an awful lot. Yeah, I can walk, I can scrape the windows on my car I mean you know my goodness.”- James

“I golfed 18 on Sunday so, so, it hasn’t made my game any better I mean but I feel better doing it so.”- Roger

Conversely, the only participant to rate his post-PCI disease severity as high was the individual who developed post-PCI chest pain. Michael reported experiencing symptoms shortly after returning home. He stated:

“The pain wasn’t staying away. I was using my nitro I think the day after I came home.”

Thus, the relief of symptoms was an important component in the decreased ratings of disease severity post-PCI, while a return of symptoms signified an increase in CAD severity and disease threat.

The *physician’s evaluation* was strongly associated with the participants’ understanding of disease severity and threat. “You’re cured” was the message received by those participants who believed their cardiac problems were over. Although only two participants described themselves as cured after their PCI procedure, their belief was firmly based on their physician’s evaluation. As Barry stated:

“I’m thinking it’s cured, it’s good, it’s just like it is brand new again; it had a little tune-up.... So it’s just based on sort of the 2 most important people involved the doctor who did the procedure and my cardiologist who recommended it.”

Similarly, one participant indicated he would know how serious his heart problem was once he had a chance to talk to his cardiologist:

“Well I’d probably say something else after Friday, I have a follow-up with my cardiologist there on Friday so... right now I think its about a 2 you know.” - Roger

Not only did physicians’ evaluations and statements appear to influence the belief of cure, they also swayed the belief of disease severity. Michael, the participant with post-PCI chest pain, recalled this conversation:

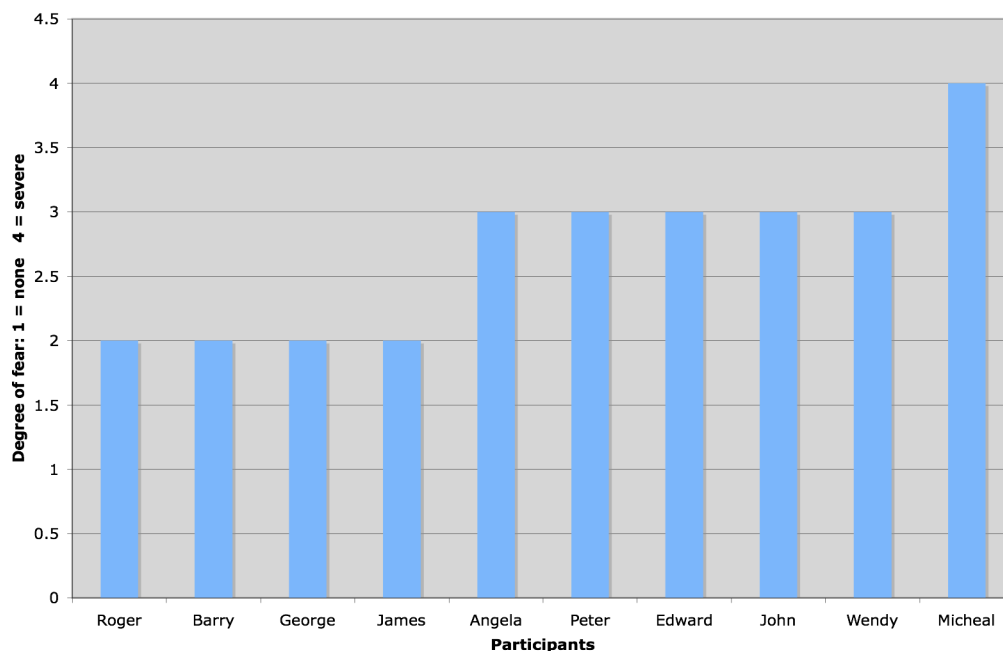
“[the doctor] tells me that my arteries are really fragile and that really I’m a walking time bomb and there’s not much they can do. They can’t even do a bypass.”

Therefore, the physicians evaluation appeared to play a central role in the participants understanding of disease severity and perceived threat.

Symptom management, and the *physicians’ evaluations* were integral components to the participants’ perception of disease severity post-PCI. Their understanding of *am I cured* was dependant on the complex relationship between these factors, which influenced the participants’ belief of disease severity and threat.

Perceived Susceptibility

According to the HBM, an individual’s risk perception is an important factor which influences the perceived threat of disease and the likelihood one will take preventative health action (Becker, 1974). Although participants reported a wide range of perceived severity post-PCI, there appeared to be much more consensus in the participants’ ratings of disease susceptibility. All participants were asked if they were afraid of having problems with their heart in the future; their responses are reflected in Figure 7. The majority of participants rated their fear of having future heart problems as moderate. None of the participants reported they had no fear of future CAD. The rationale for their ratings will be discussed in the theme *uncertainty*.

Figure 7: Perceived Fear of Future Heart Problems

Theme # 3: Uncertainty – Am I going to be OK? Feelings of uncertainty

dominated the participants' post-PCI experiences, in particular the recovery phase was described as a time of great uncertainty. The participants' descriptions of uncertainty will be discussed in the context of: *fear of disease reoccurrence*, the difficulty in *evaluating treatment success*, and the challenge of trying to determine *what is normal after PCI*.

The source of the participants' uncertainty was largely grounded in a *lack of information* from their health care providers and health care system. Thus, the lack of information post-PCI appeared to sow the seeds of uncertainty.

A *fear of disease reoccurrence* was common among all participants. They openly shared their concerns about their potential for developing CAD again and the uncertainty that posed to their future health. For example:

“My biggest worry is that other ones might get clogged, but like I said that’s going to be up to me.” – Angela

"I expect at some point I'm going to have some kind of problem somewhere, uh...I don't dwell on it all the time its just I think it's a possibility."- John

Even the two participants who thought they were cured expressed feelings of susceptibility towards future CAD. They stated:

"I guess what I really believe is in time it [60% blockage] will build up." – George

It has to be some concern because there has been a recognized problem." - Barry

Consequently, all participants felt vulnerable to the threat of future problems with CAD.

Moreover, for most participants the perceived threat of disease appeared to provide the impetus for adopting a healthier lifestyle.

The uncertainty associated with *evaluating treatment success* and fear of reoccurrence was particularly problematic for those participants with minimal symptoms. For example:

"I bust my shoulder years ago, well lots of years ago and it was good to know that after a while I could throw the ball again OK, I can play hockey again wait I must be getting better right. So you could kind of judge that much better than something like this where you don't know what's going on inside here (points to his chest). You have no idea."- Peter

"My little sign was hardly nothing I just thought well OK I'm getting older... And how do you know that it's gone?"- Angela

The accurate evaluation of treatment success in the absence of symptoms left the participants feeling uncertain that they were better. These participants expressed fear in their ability to not only evaluate their current health status but also their ability to identify future problems. This sense of vulnerability was associated with higher perceptions of disease susceptibility and threat.

Additionally, participants were uncertain about *what is normal after PCI*, and what to expect during their recovery. Peter best exemplified this uncertainty when he stated:

*“What is **normal** after... not knowing OK will I be able to do that again, will I ever be able to do that again, will I be able to you know run with my grandkids, will I be able to you know do those kind of things. So for me that’s more important than pain, I can work through pain. I almost wish there would have been some pain.”*

The participants described these life questions as their important questions and the ones they needed help answering.

The uncertainty that participants reported appeared to be based in a *lack of information*. Insufficient health information was endemic and highly problematic for participants who were trying to understand their CAD and make important lifestyle changes. Participants expressed a strong desire and need for more information throughout the PCI process. As Michael stated:

“I went in there thinking I had something and I have 5 pieces of metal stuck in my heart now and I don’t know what that’s all about.”

All participants commented on insufficient health information at some point during their PCI experience, which limited their understanding of the disease, treatment, or management process. These barriers to understanding this complex disease contributed to the uncertainty expressed by all participants.

The participants’ perceived susceptibility of disease was heavily influenced by uncertainty. The uncertainty they described was related to: *the fear of reoccurrence*, the difficulty in *evaluating treatment success*, understanding *what is normal after PCI*, and a

lack of information. These factors contributed to the relatively high rates of disease susceptibility and threat reported by the participants.

In summary, the participants' ratings of perceived severity and perceived susceptibility revealed some interesting perspectives. Although disease severity decreased post-PCI, ratings of susceptibility remained fairly high. Treatment of CAD with a PCI apparently offers some reassurance that their CAD is now less serious and the threat to their health has decreased. Conversely, disease susceptibility was high and reflected the participants' uncertainty of the disease process and impact on their future health. This uncertainty and fear of CAD reoccurrence appeared to provide a strong incentive to adopt healthier lifestyles.

Modifying Variables – Influences on my Perceptions

According to the HBM, modifying factors indirectly affect the likelihood that an individual will take preventative health action by influencing the individuals' perception, their perceived threat of cardiac disease, and the benefits and barriers associated with that health behaviour (Strecher & Rosenstock, 1997). These factors include an array of demographic, sociopsychological, and structural components. As well, cues to action may alter the perceived threat of disease and consequent health behaviour practices. Modifying variables appeared to influence the participants' perceptions of disease severity, susceptibility, and threat. As well the modifying variables seemed to be associated with health behaviours; however, the strength of these apparent associations or the direction of influence could not be determined.

Demographic Variables

Demographic variables include factors such as age, sex, ethnicity, income, and education. The participants involved in this study (N=10) were a fairly homogenous group. They were of comparable age and from similar ethnic, and economic backgrounds, however key demographic differences were noted. The factors that appeared to be associated with the likelihood of making lifestyle changes are captured in the following themes: *time constraints*, and *differences in exercise habits*.

Theme #4: Time constraints. Time demands were particularly significant for the younger participants who had dual responsibilities at work and home. Participants who were employed full-time spoke of the difficulty in implementing lifestyle changes or attending cardiac rehabilitation programs (CRPs) because of time constraints related to their already busy schedules. For example:

“Exercise, if I get back into the, the work program it might be a little bit harder, I might have to discontinue stuff.” - Peter

Even greater challenges faced the participants who also had childrearing responsibilities at home.

“It’s like I have no available time for myself.” – Edward

Thus, work and family demands meant there was little time or energy left for the participants to engage in healthy behaviours.

Theme #5: Differences in exercise habits. There appeared to be a difference in how men and women viewed prevention strategies, such as exercise. All participants were asked about the lifestyle changes and their participation in exercise programs since their PCI. Although the two women interviewed described themselves as physically active, they did not view their activities as exercise. For example:

“I hate exercising, I love walking... I can spend 3 or 4 hours walking in the mall” - Angela

Conversely, the men spoke specifically of exercise as a part of the lifestyle changes they needed to adopt.

“What I’m lacking right now is exercise.” – Edward

Peter appeared to have the most insight into the importance of exercise. He stated:

“I really don’t think that my heart, like I can work all day and I don’t think my heart rate will go up.”

However, it is unclear whether the women failed to recognize walking as exercise or whether their mall walking failed to constitute exercise. Given that the women described themselves as not participating in exercise, and spoke of their mall walking as a social event with family or friends, it was difficult to evaluate the cardiac benefit of this endeavor. What became apparent was that the male and female participants engaged in and talked differently about physical activities and exercise.

Time constraints, and differences in exercise habits were influenced by work, home, and gender differences between the participants. Thus, demographic variables appeared to be associated with the likelihood participants would make lifestyle changes.

Sociopsychological Variables

Sociopsychological variables include aspects of one’s personality, as well as the influence of others on a person’s thoughts, feelings, and behaviours (Becker, 1974).

These variables can also relate to the perceptions that are manifested by a group or association, such as societal expectations of medical treatment. The participants described a variety of resources that they used to try to understand and manage their CAD. Accordingly, the sociopsychological variables that were central to the

participants' stories were: *social supports, information gathering strategies, self-determination, and expectations of care*. These themes were associated with the participants' beliefs about their coronary artery disease (CAD) and health behaviour practices.

Theme # 6: Social supports. All participants spoke of the importance of the support provided by family and friends throughout their PCI experience. However, participants indicated that social supports were most critical at two specific times. The first was the assistance provided with engaging the health care system. The other occurred post-PCI and involved the support needed to adopt a healthier lifestyle.

A few participants spoke of how instrumental the support of family and friends was in their decision to pursue medical care. For example:

"I really started thinking it was time for me to maybe think about something but it was just one evening where I just decided, well actually it was my wife who decided for me that I needed to go into a walk-in clinic just to see, and of course they sent me to emergency." – Peter

Others found that family or friends with connections in the health care field were influential in securing health services. As reflected by James' experience:

"And thank God for my godson he, cause she [family doctor] said it would be at least 6 months before I got in and I thought oh my god, and he got me in right away in 2 weeks, he sells stents."

Whether the participants' support systems acted as surrogate decision makers for initiating care seeking or 'pulled strings' to obtain timely care, their contribution was greatly valued.

Support systems were also identified as critical in the adoption of healthier

lifestyles. As is reflected in the following anecdote:

“I’ve got somebody in my life that actually really wants to make that [lifestyle changes] happen.” – Peter

All participants recognized the important role of family and friends in assisting with lifestyle changes and ongoing health surveillance and encouragement.

The importance of support from family and friends was evident in the participants’ stories and reflected an awareness of their dependence on that support. All participants realized the value in the support they were given to engage, and navigate the health care system. The support to adopt a healthier lifestyle was critical for participants to change their lifestyles.

Theme # 7: Gathering information – the power of others’ accounts. The participants used a variety of information sources to understand their CAD and the angioplasty experience. Although physicians and other health care providers were viewed as the most credible sources of information, they were not always readily accessible. Thus, participants described alternative sources to meet their informational needs, such as lay stories, Dr Google, and overheard conversations between other patients and their providers.

The majority of participants viewed their physicians as the most important and credible sources of health information; however, their doctors were not always readily accessible. Most participants did not want to disturb them with minor questions and described their physicians as being too busy to answer their questions. They stated:

“I got a big knot in the, in the vein and I found that on Thursday so, but I didn’t really want to bother anybody about it so I just kind of watched it, it seemed to get a little bit bigger.” - George

“If I need some [information] I’m not going to bother the doctor with little things like that you know. I’d look that up or ask somebody.” – Wendy

Because physicians and health care providers were not perceived to be readily available, the participants primarily sought information from individuals within their community and on the Internet.

Lay stories included the personal accounts of CAD or PCI from family, friends, and those within their community. The participants described these personal stories as important sources of information throughout their PCI experience. They stated:

“I have a friend who’s a bit older than me that’s pretty active... I you know described sort of the symptom I had and he opined that it was, he just had a valve job done on his heart and that’s what he thought it was. So after that that’s what I thought it was, I thought it was a valve.” - George

“I was talking about my godson earlier, he was talking about it and I had talked to other fellows that have had it. And if anything it calmed me right down you know I wasn’t, I wasn’t worried in the slightest about it.” - James

As is evident from these anecdotes, personal accounts were highly influential in how the participants viewed the seriousness of their CAD and the degree of health threat.

The participants also sought information on the Internet. “Dr. Google” or Internet sources figured prominently in the participants’ information gathering strategies. Unlike their physicians, this information was described as readily accessible. Participants accessed this information to answer a multitude of questions that spanned the PCI trajectory. Their reliance on Internet sources for information was endemic. For example:

“He told me he figured it was angina so I went and looked it up on the internet, got definitions ...and all kinds of stuff.” – John

“And we actually got some of that information [discharge information] on the Internet.” - Peter

Thus, the internet was used to help participants better understand the diagnosis and treatment, as well as to answer many of their post-PCI questions, such as how to treat constipation and implement dietary modifications.

Despite the participants' apparent reliance on the Internet as a resource for health information, they were also quite skeptical of the accuracy of that information. Edward described:

“Yeah but I don't know if I would always believe the Internet because it's, you don't really know what your looking at right.” – Edward

The participants appeared to be caught between their need for readily accessible information and credible information. While the Internet was accessible, the information was associated with skepticism. Conversely, health care providers were viewed as credible but not accessible.

Particularly concerning was the trend toward participants consulting the Internet regarding safety concerns, such as bleeding post-PCI. James used the Internet to determine how serious his bruising was before contacting his physician. He stated:

“I had a huge bruise on my upper thigh ... and I wasn't quite sure about it but I went on the internet again and I heard some guys had it right down to their ankles...and they had lots of problems so I phoned him [cardiologist] and he explained it right away.”

Thus, participants viewed the Internet as a feasible approach to evaluating the seriousness of their health problem and degree of threat prior to contacting a health professional.

Unexpected sources of health information described by several participants were the overheard conversations between other patients and their health care providers. In the hospital, patients are generally admitted to units where there are other patients with similar health problems. As a consequence of the hospital's physical environment patients are often in close proximity to each other. The result is that patients often overhear conversations that are not meant for them to hear. Although this proximity may have a positive affect on the patients' perceptions, the stories conveyed during the interviews reflected negative experiences. John recalled overhearing the following conversation:

"They [the nurses] wheeled this woman out and she was in the next bay there and the same doctor came out and talked to her after...he told her...they were going to have to consult with a cardiac surgeon about what they were going to do. And I'm thinking oh, oh I hope mine goes better than that."

Other participants talked of their unease with witnessing another patient's recovery from the PCI procedure. Peter shared these reservations of his treatment after witnessing his roommate's experience:

"Like we had somebody else that was in the same room and... I saw a little bit of his experience and... it made me really uncomfortable because he wasn't well at all."

Although overheard conversations are not recognized as a formal source of health information the participants described them as powerful examples of real life experiences with CAD that they encountered while in the hospital.

Clearly, the participants utilized sources other than health care providers to gauge the seriousness of their health problem. Lay stories appeared to be the most readily accessible and influential sources of information for the participants. These experiences

were powerful accounts, which swayed the participants' perceptions of CAD severity. Although health care providers were generally viewed as the most credible sources of information, their knowledge was not readily accessible to the participants. The participants frequently used the Internet to gain information related to all aspects of their PCI experience.

Theme # 8: Self-determination – the will to change. Many participants described their PCI experience as a turning point, which had them looking at their life through an altered perspective. They reported a desire to live longer and healthier. For example:

“I want to live a lot longer yet. I don't want to, you know, be gone at this point in my life. You know, I mean I've had a good, good life but I feel that there's, now is where I am coming into an area where I should actually be relaxing and enjoying some of the things that I like doing.” – Peter

The participants described self-determination as confidence in their ability to make changes. Consequently, the participants spoke of their self-determination for making lifestyle changes.

Most participants talked of having confidence in their ability to make the necessary lifestyle changes. They stated:

“That's actually one area that I'm very confident... I've done this before when I've had injuries and I'm, I'm pretty stuck on that.” - Peter

“I'm pretty confident in what I want to do. I'm sort of strong willed.” - James

Whether their confidence was based on prior experiences, commitment to change, or personality traits, the participants generally felt that they could successfully adopt a healthier lifestyle.

Many participants spoke of family responsibilities as their primary motivation for making lifestyle changes. In particular, the parents of younger children expressed a strong desire and need to stay around for their dependants. They stated:

“Well I don’t want to see my kids go without a dad right so I think that, that sort of maybe changed my eating habits quite a bit.” – Edward

“I didn’t have a hope of getting past 60. I hope, my plan had always been to, to make it through to the time the kids graduated and, and I got to see that I didn’t work my ass off all those years for nothing...” – Michael

Grandparents also conveyed a desire to watch their grandchildren grow-up. Angela clearly expressed her motivation for making lifestyles changes. She stated:

“To live longer, to see my grandkids grow up.”

Self-confidence and external motivating factors appeared to be important elements in the participants’ self-determination to achieve a healthier lifestyle.

Theme # 9: Expectations of PCI. The majority of participants rated their PCI experience favorably. Interestingly, even those participants who did not have a clear symptom benefit from treatment rated their experience positively, which reflected the high expectations of the procedure. As Angela stated:

“I don’t feel any different but of course it has, its unblocked clogged arteries.”

The participants were optimistic about their PCI treatment and they had high expectations for recovery. For example:

“I believe that it [the PCI] should make the heart work much more efficiently so I’m not going to be so tired and I’ll have more energy so I can get more things done that I want to get done.” - John

“I don’t have my normal energy back yet but I feel a lot better than when I came home. So I think maybe it is just going to take time to.” – Wendy

Consequently, even if participants hadn't noticed any immediate improvement in their health they believed they would in time. There also appeared to be a relationship between the participants' expectations of the PCI treatment and their rating of disease severity post-PCI.

In summary, sociopsychological variables played an important role in the participants' understanding of CAD severity, susceptibility, and threat. There was also a relationship between these sociopsychological variables and the adoption of a healthier lifestyle. In particular, participants identified the importance of support systems, gathering health information, the self-determination for lifestyle change, and their expectations of treatment as important components in their perceptions of CAD, treatment, and management.

Structural Variables

Structural variables, such as knowledge level, treatment, and prior experience with disease, also interacted with how the participants perceived their disease threat. The participants described essential elements to understanding their CAD, such as patient education and treatment. These structural elements were dependant on time spent with providers in order to set the stage for the treatment and management of CAD. The structural variables identified in the participant interviews were: *patient education, and the elective ad-hoc PCI experience.*

Theme # 10: Patient education – the challenge of getting the information I need. Health education is critical for meeting the informational needs of patients. Similarly, participants identified education as an important element to their understanding of CAD. Their need for education spanned the entire PCI experience and was captured in

the three sub themes: *what's the diagnosis, understanding my risk factors, and getting set for discharge.*

What's the diagnosis? The majority of participants expressed gratitude for the health information and educational opportunity provided by the nurses at the pre-PCI teaching clinic. They valued the opportunity to talk to these nurses about their health and pending PCI treatment. They described this as one of the few occasions where credible health professionals could answer their questions. These educational sessions were not only informative but also allayed much of their anxiety. For example:

"I was wondering and you know we had heard reports of people actually not making these procedures you know... so you deal with that emotional thing. So having somebody there, she did a great job to teach us and there was enough information I thought that it helped us through but not over, overly much and that's good too. I think for me to digest all of that would have just kind of gone (indicates over his head), so it was I thought done really well." – Peter

However, several participants commented that because this was their first angiogram, they did not know what questions to ask and could not make maximal use of this educational opportunity. George recalled:

"The nurse at St. Boniface who explained a lot of stuff that I didn't understand and would have explained a lot more if I knew what I wanted to know; I just didn't know so..."

Although the participants described the pre-PCI teaching clinic as a highly valuable learning opportunity, they did not describe an encounter that prepared them for a diagnosis of CAD. This was portrayed as the forum for gaining treatment information and obtaining the necessary blood work and tests prior to their PCI procedure.

In spite of the education provided by the pre-PCI clinic many participants spoke of feeling ill prepared for their CAD diagnosis. The result of a *poorly set stage* was that

several participants expressed confusion and anxiety over the meaning of preliminary test results. This sentiment was best reflected in John's statement:

"I mean your wired for sound on that thing there... and to me it didn't feel like my heart rate got up, there was no chest pain nothing like that, like I would have expected... when they're purposefully stressing your heart. I didn't get that which, then when he said well you - you didn't make it your going for an angiogram. Its like what part didn't I pass you know but"

KT – "Right, did he explain that to you?"

John – "He didn't explain if there was any particular part... probably he was reading something there that he didn't like, where that actually fit in with what I felt I have no idea."

In addition, a few participants recalled conversations prior to their angiogram in which the interventionalist expressed surprise that they had been referred for a PCI and offered reassurance they would probably not find anything wrong. Michael recalled the following conversation:

"So the doctor [interventionalist] just went through the procedure and what was going to happen at the procedure and how that was going to happen and he said I think its going to be pretty simple there is not real indication that it's the heart, you'll be out in ½ hour to 45 minutes."

Michael described a long and painful procedure – something for which he felt ill prepared.

"I think as he was putting in the 2nd or the 3rd stent a selfish part of me said I wish this would just blow up and it because it was, it hurt more than I've been hurt before and it felt like somebody was going inside my chest and just pushing it apart and at some point it was going to blow anyway."

This lack of preparation through physician visits and preliminary testing resulted in many participants being astonished that they required a PCI. For example:

"Well when I went for the angiogram, I thought I would have it and go home. I thought that would be the end of it because I had no idea that anything was wrong with my heart"- Wendy

The lack of explanation and education around preliminary test results and reassurances from the interventionalists appeared to affect the participants' preparation and their understanding of the severity of their CAD

There appeared to be relationship between the *quality of cardiac information* participants' received and their ability to make sense of their diagnosis and PCI experience. Participants described varying levels of understanding regarding their CAD particularly in relation heart function and cardiac risk factors. As this study did not involve a chart review, all information relating to their CAD was based on participant recall. The participants' understanding of heart function and treatment results is reflected in Table 4. Risk factor awareness varied greatly among the participants and most were unaware of many of their risk factors.

Table 4. Participants' recall of elective ad-hoc PCI results

Procedure results	Number of participants (N=10)
<u>Vessels treated</u>	
3 vessel PCI	1
2 vessel PCI	1
1 vessel PCI	8
<u>Ejection fraction</u>	
Normal	5
Unknown	5

Interestingly, most participants were able to recall how many arteries were stented and the names of the stented arteries. Whether this was evidence of a clear understanding of cardiac anatomy or their ability to accurately regurgitate information was unclear. However, participants who had only one stent tended to view this as a sign of less severe CAD. John stated:

“I think probably they caught it early enough which is why there’s only the one stent in there, I think they caught it early enough to... for it to be really successful and that.” – John

In addition, five participants knew that their ejection fraction was normal; they found this information reassuring and evidence of less severe cardiac disease. For example:

“He [the family physician] said basically sort of the rest of the heart is very healthy and I’ve got a, you learn all sorts of neat new terms, I’ve got an ejection factor of 75 percent which he said is excellent.” – George

Conversely, participants who did not receive information on their ejection fraction reported increased uncertainty about their heart function. Angela stated:

“I just wish I had of asked what kind of shape my heart is in, I can’t believe I didn’t ask that or someone didn’t tell me. Just cause your arteries are clogged doesn’t mean to say that your heart is not functioning right does it? I don’t think so.”

Thus, information about the extent of CAD (i.e., number of stents) and the hearts function (i.e., ejection fraction) contributed to the participants’ perception of disease severity and degree of health threat.

Understanding my risk factors. Most participants had limited knowledge of their cardiac risk factors. When asked why they thought they had developed CAD, their immediate responses included lack of exercise, an unhealthy diet, or stress. However, when probed further it was evident that their understanding of these factors was very limited. Wendy stated that she needed to alter her diet and increase her exercise in order to get on the ‘right track,’ but when asked if these factors contributed to her current heart problem she stated:

“I don’t think so, I don’t know but I don’t think so. Like I don’t know what I could have done to avoid it. I really don’t.”

The participants' awareness of the role of risk factors in the development of CAD was often superficial.

Similarly, several participants had difficulty identifying genetics, hypertension, and elevated cholesterol as one of their cardiac risk factors. Although Angela had a significant family history, she was unaware how her family history related to her risk for CAD. She stated:

"There's nothing in your genetics that would make your arteries clog other than your lifestyle is there? Do you know that? Or that would be another question I'll ask. Like I don't think that's genetic, that has to do with your lifestyle, eating not eating properly but I do wonder if there is anything."

Participants also expressed confusion around the contribution of risks factors identified by the medical profession, such as elevated blood pressure and cholesterol. For example:

Barry's Wife - "A couple of years ago though you had high blood pressure, I don't know whether that's an indicating factor."

Barry - "Nobody said it was, so..."

"He said my cholesterol was 250, which I didn't, I don't understand what that really means." - Edward

Failure to understand how genetics, cholesterol, and high blood pressure affect the development of CAD was evident in the participants' stories.

There was also a relationship between the lack of understanding regarding risk factors for CAD and the incentive to make lifestyle changes, as Barry shared:

"So we don't know what the actual cause is so we're guessing at the fix."

Generally, the participants who did not understand their risk factors expressed hesitation as to where to target their preventative health actions.

Set for discharge. The discharge process for post PCI patients with CAD should include patient preparation for a safe discharge home. Participants spoke of a need for *information to help me move forward* with disease management and prevention. The participants seemed to be fairly evenly split in their views on whether or not they had received sufficient discharge information. In general, the issues participants identified around discharge included: the process, safety issues, and lack of awareness around bodily sensations or functions.

Several participants referred to discharge documents and pamphlets, rather than nurses providing the majority of their discharge instructions. Barry recalled:

“It was the nurse, she came in with the documents and said ‘here’s this document, that document’ and basically it’s the documents themselves that have the instructions on them.”

However, five of the participants reported inadequate discharge information, despite the documents and pamphlets provided.

A few participants related a discharge time that coincided with shift change as potentially hindering the nurse’s incentive to provide discharge information. For example:

“My discharge time is crossing over with the shift change too so one of them is anxious to get out and the others not anxious to get started so it was pretty cursory.”

However, for one participant the lack of information provided at discharge created a potentially unsafe situation. Michael stated:

“I just asked if I could go home they [the nurses] said sure shift change is going to happen in an hour, why don’t you go before shift change. There was no refusal I wasn’t being nasty with anybody and so he [the ER doctor] was a little appalled that they would take that risk that I could bleed to death in the taxi cab. Um by not

telling me what I should be doing and what to feel for so he told me if you feel these lumps and so on and so forth do this, this, and this but.” – Michael

Although there is a risk of bleeding post-PCI, Michael described a lack of awareness of this risk. The ER physician provided this information a week later. Though Michael described little discharge teaching from his nurse, it is unclear whether he read the brochures provided post-PCI.

Similarly, other participants also claimed to be unprepared for their post procedural occurrences. For example:

“As far as discharge information... I wasn’t prepared for a few things... And so that was one thing I though maybe could have been done, were they could have maybe talked about things like that you know and we actually got some of that information on, on the internet.” - Peter

Participants often described using the Internet in these situations to help them understand or deal with their post-procedural questions and issues.

The participants who were pleased with the discharge process could have either experienced an event-free post-PCI phase or received more information. However, the five participants who encountered problems or issues post-PCI were critical of the discharge process and felt they needed additional information.

While patient education is a key component to understanding CAD, the participants expressed frustration over not getting the information they needed from health care providers. The lack of information provided around preliminary test results, cardiac impairment, and risk factors influenced their perception of cardiac disease severity, susceptibility, and threat. Patient education during the discharge process was also an issue for participants in terms of getting the information they needed. The

participants expressed a need for improved education to assist them to safely move forward with disease management and prevention.

Theme # 11: Elective ad-hoc PCI - a disembodied experience. An elective ad-hoc PCI involves having a diagnostic angiogram, identifying a treatable coronary artery lesion, and then proceeding directly to PCI. Thus, the participants received their diagnosis and treatment during the same procedure and often described their treatment as a quick and easy fix. The ability to immediately treat arterial blockages was viewed positively by all participants; however, this may have also contributed to their inaccurate perceptions of disease severity and threat. The participants described their PCI experience as a disembodied experience in which they felt detached from what was happening around them. They related this sensation to the speed of treatment, and the medications given for the procedure. Unfortunately, these factors also influenced their ability to interact with others and limited their understanding of information.

Having an ad-hoc PCI meant that the coronary artery blockages were treated quickly. All participants expressed gratitude for ‘getting it all over’ at once; however, this expedited process had some believing that their CAD was less severe. John exemplified this belief best:

“The stent was... always a possibility, you may have that done and that but they didn’t say that’s what your going in for, they were going in to take a look and see what they could see and the whole bit and if they’re already in there and they figure a stent will do it, they’ll do it right then and there rather than come back and do it all over again, which makes sense. If they did send you back and you had to come back for a second time that would probably indicate there is something more serious going on there.”

Not only did the speed of treatment appear to indicate a less serious cardiac condition but it also contributed to the notion that the problem was an easy fix. For example:

“It’s nice to know that something that easy and that simple can be done to fix... which is really something that’s life threatening. There’s really nothing to it you know it was a piece of cake. I mean, I mean I fell asleep for goodness sake that’s how boring it was.” – James

Most participants expressed relief and gratitude that their cardiac condition could be treated by such an easy, quick and relatively pain-free procedure. There was an association between the apparent ease of treatment and the understanding of disease threat.

One of the most noteworthy findings included how their PCI procedure was such a disembodied experience. Participants had fragmented memories of their PCI experience, which was probably the result of medications given during their procedure. For example:

“I didn’t really know what all had happened because it was hard to remember, I remember them taking me back to the room and that’s about all I, I really remember about it, you know sort of in a daze. Because I guess of the sedative.” Wendy

A few participants spoke of wanting to be more awake so they could know what was going on with their body. For example:

“It would have been ok with me if I would have been a little more awake so that I could listen to them talking and get more of an understanding of what they’re doing.” - George

Thus, the participants’ limited recall of this experience also affected their understanding of the CAD threat.

Sedation given for the PCI procedure may have influenced the retention of health information, which further contributed to the disembodied nature of this experience. The interventional cardiologists and nurses discussed treatment results and recommendations immediately following the procedure, when the participants were still drowsy.

Consequently, the participants spoke of the difficulty focusing on and retaining health information during this time. As George stated:

“He came and talked to me and my wife was there but, I barely remember I was very nauseous and... I don’t remember a single thing that he, he said at post-op. If my wife hadn’t have been there you know, I wouldn’t have know so its all a big blur.”

The participants relied on family members to ‘fill them in’ on the information provided by the interventionalists and nurses. However, family members also had problems concentrating on the information. As Barry’s wife recalled:

“Yeah, aaah well I was assuming Barry was listening too. He was kind of focused on the pressure on his leg, that I was a little bit distracted also. I’m thinking like oh my goodness like what’s happening with the leg, I could see it was swollen, they’re pushing down, they’re saying they’re trying to stop the bleeding, and the doctors trying to talk and so it was a little confusing.”

Most participants felt that if their family members hadn’t provided some of this post-PCI information they would have received very little of the health information provided post-procedure.

The participants described their PCI procedure as a fast and easy process with limited time, ability, or opportunity to ask questions. As is best exemplified in John’s statement:

“Well it’s like an assembly line... so he really couldn’t spend a whole lot of time with every patient and I can understand that.”

In addition, the participants’ lack of bodily engagement further limited their awareness and understanding of what was happening. These factors were associated with a decreased perception of disease threat and increased dependence on family members to provide treatment results, explanations, and post PCI directions.

In summary, the structural variables *patient education and the elective ad-hoc PCI experience* were influential to the participants' understanding of CAD. The participants faced many challenges in getting the information they needed about CAD treatment, management, and prevention. As well, the PCI process contributed to a disembodied experience that resulted in a lack of an embodied reality related to CAD. The very nature of this disembodiment experience appeared to contribute to the perception that CAD was an easy fix.

Cues to Action

Cues to action are factors that influence the behaviours of individuals, such as reminders from health care providers or media campaigns. These factors may act singularly, or in combination and may be internal or external to the individual. The influence of the health care system through *the relationships with health care providers* and *follow-up care* were predominant themes in the participant interviews. These factors were strongly influenced and dependent upon the quality of communication. There appeared to be an association between these components and the participants' perceptions of disease threat, as well as the likelihood that they would take preventative health action.

Theme # 12: The relationships with health care providers. Patient-provider relationships refer to the participants' descriptions of their interactions with members of the health care team. These interactions not only shaped how they felt about their experiences but also influenced their understanding of CAD. The participants' relationships with their providers were strongly associated with the quality of communication, which fostered or hindered their trust and confidence.

The participants described good communication as being central to their

understanding of CAD and their treatment. As James stated:

“He [interventionalist] was very calming, very calming, very informative, very matter of fact, you know he pointed stuff out, did diagrams, did pictures, you know whatever it took to get, get everything across to me. He was very good, I was very impressed.” – James

Consequently, the participants who described good communication with their health care providers also expressed feelings of trust and confidence in those caring for them. For example:

“I think its nice to know too that we have a cardiologist who’s so in tune to what’s going on and that you know he’s [James] so well taken care of and that he will be well taken care of in the future as long as he’s [the cardiologist] in Winnipeg you know that we always can rely on him because he was really good.”- James wife

Good communication appeared to be critical to the participants’ satisfaction, comfort, and understanding of CAD. As well trust and confidence in the provider increased the participants’ confidence and trust in their providers medical decisions.

Conversely, when communication was less than ideal participants described poorer relations with their health care providers. Examples of poor communication with health care providers included receiving insufficient and conflicting health information. Participants also identified a lack of patient-centered care as being detrimental to their relationships with their health care providers. This resulted in frustration, anger, and decreased trust in their ability to adequately meet their health care needs. For example:

“That caused some anxiety because they didn’t give us a reason why we were switched... that caused us some anxiety oh there could be a little glitch in this procedure that we’re not really prepared for.”- Barry’s wife

When participants described poor communication, they identified gaps in the information provided, which influenced their understanding and resulted in a lack of confidence in the

ability of their health care providers.

The participants who received conflicting health information described problems in trying to sort out who was right, whose directions to follow, or what information to believe. For example:

"I went for the stress test, he read the stress test, he told me I had the heart of a 14 year old girl, lose some weight, stay on the Crestor, Lipitor at the time I was on, and everything would be fine... he [the cardiologist] called back saying that he didn't feel good about his diagnosis... So he sent me to another fellow, who's a cardiologist, and that cardiologist was very clear that I did extremely poor on the, on the stress test and that my EKG's weren't OK as people were telling me, and that he wanted to send me, as soon as possible, if I was agreeable, for a angiogram." - Michael

In Michael's case the conflicting health information he received resulted in panic over his health status. He stated:

"Oh no it [panic] was directly related to what the doctors were telling me. Um your healthy as a 14 year old and then you are going to go on the table and you might die."

This also contributed to his decreased confidence in his health care providers:

"So I'm a little frustrated with it and you know doctors if you even remotely sound like your challenging them, they're shutting down anyway and becoming defensive. They've got probably law suits running through their head rather than honest answers and trying to put your mind at ease so."

As a result of this conflicting health information Michael had a negative appraisal of his treatment experience and an increased perception of his CAD threat.

Several participants also described a lack of patient centered care. This resulted in feelings of not having their health concerns taken seriously. For example:

"It's really scary you know and... telling me it was in my head and, and just the look that she [family physician] gave me was like saying - its all in your head you know stop worrying about it blah, blah, blah, blah, blah I know what to do, I know what I'm doing. No but I know something's wrong with me." - James

Often this left participants feeling vulnerable about their health care providers' ability to provide quality health care services. As James stated:

"No, I just, I just don't have any confidence in her [family doctor] anymore, telling me it's in my head and just keep doing what you doing. I, I'd be on a slab right now if I would have done that you know."

These feeling were associated with the perceptions of increased disease severity and threat.

Clearly, the participants needed good communication with their providers in order to establish trust and confidence in the information and treatment provided. The participants' perceptions of disease threat were dependant on their confidence and trust, as well as quality communication with their health care providers.

Theme # 13: Follow-up care. Follow- up care pertains to the care provided in the community following discharge from hospital. The participants described incredible variation regarding their post-PCI follow-up care. They described their visits to family physicians or referring cardiologists as ranging from a simple discussion of the test results to a full comprehensive exam. For example:

"Well at that appointment he [the cardiologist] just basically went through, basically he just, just looked at the chart and just basically said there was no other abnormalities seen in the angiogram beside the one blockage and that was basically about it..." – Edward

Interestingly, the quality of follow-up care did not appear to be dependant on whether it was provided by a family physician or a cardiologist.

These follow- up appointments most often included physical evaluations, such as blood pressure and groin inspections. However, even this was not always

standard practice at some follow-up appointments. For example:

“I thought it was strange that he never did do the, you know, check the blood pressure or listen to the heart.” – Edward

In addition, the physicians rarely included lifestyle recommendations and referrals to cardiac rehabilitation. This was evident when I asked Barry if anyone had ever mentioned the benefits to joining a cardiac rehabilitation program. He responded:

“I would look at it [Cardiac Rehabilitation Program]. But no nobody’s talked about it, mentioned it, didn’t come in any brochures, didn’t even see it in any of the pamphlets so.” – Barry

Furthermore, repeat appointments were not always scheduled and often participants had little direction as to when or if to see their physicians again. For example:

“No one has ever said to come back or nothing. I guess if I wanted to see him [the cardiologist] I would have to make the appointment and I might make one just to find out about my heart”- Angela

Given this lack of consistency or standards followed when providing post-PCI follow-up care, George’s assessment of the health care system is not surprising. He stated:

“I think you make a lot of assumptions that you think people know or understand when they don’t you know and especially a first time patient. Now I think too if I wasn’t the walking wounded, if I’d have had a heart attack I’d have got a lot more information.” – George

Participants described a haphazard follow-up with their health care providers post-PCI. Follow-up care appeared to be left to the discretion of the referring family physician or cardiologist so that standards of care were very physician dependant.

Cues to action focused on external factors, which influenced the participants’ understanding of CAD and their health behaviour practices. These included: *the relationships with health care providers and follow-up care*, which appeared to be

strongly dependant on the quality of communication with health care providers. In addition, the variability of follow-up care also influenced the participants' understanding of CAD, and access to outpatient services. These factors were associated with the participants' perceptions of disease threat, as well as the probability that they would take preventative health action.

The modifying variables discussed herein reflect the import role that time, supports, information, self-determination, expectations of care, patients education, the PCI procedure, the relationships with health care providers, and follow-up care had on the participants' perceptions, beliefs, and knowledge of CAD. There was a strong relationship between these factors and the participants' perceptions of disease severity, susceptibility, threat, and their likelihood of taking action.

Likelihood of Action – What I Can or Will I Do

According to the HBM, perceived benefits and perceived barriers affect the probability an individual will take preventative health action (Becker, 1974). Perceived benefits are based on the belief that the action will be effective in reducing the risk or seriousness of the condition. Conversely, perceived barriers are based on one's opinion that the action will be costly or have additional negative aspects that deter action. Thus, health behaviours are dependant upon whether one views the various options as beneficial or unfavorable. The participants were asked to share their experiences with making lifestyle changes including the *advantages of prevention, the challenges to prevention* and their success with *adopting a healthier lifestyle*.

Theme # 14: Advantages of prevention. Becker (1974) found that the individual's assessment of the benefits of adopting a lifestyle change and taking

preventative health action, including medications, is dependant upon the belief that this course of action will be effective in reducing the threat of disease. Participants shared their perceptions about the benefits of lifestyle change and the role of medications to their future health.

All participants spoke of the importance of making lifestyle changes and identified target behaviours as part of their lifestyle plan, such as diet and exercise. For example:

“What I’m lacking right now is exercise.” – Edward

“Yeah, lots of exercise, eat healthier although I am really trying to eat healthy.” – Angela

However, most participants were unaware of the role outside resources such as nutritionists and cardiac rehabilitation specialists could play in easing the challenges that they faced and facilitating lifestyle changes. As expected, those who were aware of these resources had a much more comprehensive approach to adopting a healthier lifestyle.

Michael described his plan to attend a CRP, he stated:

“I’ve got a referral in with the Wellness Centre cardiac clinic which I think is 16 weeks, 3 times a week, so I’m going to be going to that.”

Although all participants identified the importance of making lifestyle changes, the degree of investment in those changes was variable. This was often the result of failure of the health care providers to supply this information and directions.

While many participants did not understand the role lifestyle choices played in the development of their CAD, all participants recognized their responsibility in adopting a healthier lifestyle. For example:

“Oh its got to be done no ifs and buts or maybes about it that’s ... if I don’t make any of the lifestyle changes or whatever that are required then that whole angioplasty thing was a waste of time. Time, effort, and money and everything else so they kind of go hand in hand you know, if you do one you’ve got to do the other, otherwise there’s no point in doing it. Um it’s a good first step is what it is, a big one and just go from there.” - John

All participants acknowledged the benefit to their health of adopting a healthier lifestyle.

Regardless of how severe the participants rated their disease, they all appeared to recognize their susceptibility to the development of future CAD. Fear of future disease appeared to be the main impetus for the adoption of a healthier lifestyle. Therefore, they all planned to make lifestyle changes; most often these changes focused on diet and exercise.

Theme # 15: The challenges to prevention. Changing health behaviours is a challenging task. According to Becker (1974) the individual’s perception of the barriers to action represents the negative aspects of pursuing a particular course of action. The participants described numerous challenges to adopting a healthier lifestyle which included: *practical considerations, medication side effects, long wait times for cardiac rehabilitation programming (CRP), and lack of support.*

Participants faced *practical considerations* when they attempted to change their lifestyle. The time, energy, and focus required to adopt a healthier lifestyle were challenges that most participants experienced. For example:

“We did buy a treadmill a number of years ago and I have used it occasionally but when I’m working, I come home and I am exhausted.” – Peter

“Staying focused I guess... The problem I find is you get going on these things and your expecting results [weight loss] and you don’t get them. I mean after 3 weeks or a month you figure you should be here but your only here and...You know it gets frustrating.” - John

Time and energy constraints were often imposed by work and family obligations. For two of the participants in particular, work scheduling was seen as their biggest challenge and had them contemplating early retirement in order to accommodate activities such as cardiac rehabilitation programming. John stated:

“They’re pretty good and if they don’t like it, I only have to give them 2 weeks notice and I’m retired, so... I don’t want to retire yet but... no I had planned on retiring in about 5 years. So we’ll see what happens. If it gets to be too much then hey, 2 weeks notice. That’s all it will take.”

Although early retirement would allow for the time needed to adopt a healthier lifestyle, financial ramifications were also a consideration for these individuals. Peter shared his thoughts:

“I’m concerned about that. I’m not financially set that I can just say oh well it doesn’t matter.”

Although these participants were contemplating early retirement in order to participate in preventative health strategies, not all individuals may have the financial security to choose lifestyle changes over work obligations.

Medications are an important component of disease management and secondary prevention. While the majority of participants were unsure of the role that *medication compliance* played in the prevention of future CAD, they realized this was a necessary part of their treatment. However, several participants complained of severe medication side effects, which influenced their compliance, for example:

“The um blood thinner wasn’t bothering me, um but the metoprolol was, it was just making me throw-up and it was knocking me out, and there was no way I could go to work and sit through a meeting and start falling asleep at the table... So I just took myself off them.” – Michael

Michael's decision to stop his medications may have contributed to a significant deterioration in his health. He recalled:

"I won't take them [medications]... That may have landed me in the hospital the second time." - Michael

Thus, severe side effects that are not appropriately managed can be a barrier to medication compliance, which appeared to influence the health outcome of one participant.

Cardiac rehabilitation programs (CRPs) focus on patient education, nutritional counseling, and supervised exercise programs. The participants who knew about CRPs clearly identified the benefits of these programs. In this sample, three participants received a formal CRP referral from their cardiologist or family physician. Two participants referred themselves to a CRP on the advice of family and friends. Of these five participants who enrolled in a CRP, they waited an average of 72.2 days (48 – 112 days) to begin the program. The participants expressed frustration at the long wait times stating:

"I went to Reh-fit centre on the [Jan] 22nd a week after I had it [PCI] done. I wanted to take a look at the place and check it out... they gave me an appointment for March 30th, which I thought was, wasn't very good." – John

This also left several participants questioning the importance of a CRP. John stated:

"Motivated - I'd be more motivated if I could get into the Reh-Fit center right away or something I'd be like, lets go, gung ho, let's do it. But when you got to wait, you kind of, uh, maybe it's not really that important. They don't seem to think so."

Participants also expressed frustration over why they could not be evaluated sooner, so that they could begin a taking preventative health action. For example:

“It’s this waiting in-between, like why I couldn’t have gone the next day somewhere and had somebody do a baseline with me and this waiting it could be another 2 weeks before I get into the Wellness Centre which is another 2 weeks that I can’t go to the gym because if I go to the gym and do something.” - Michael

Thus, these long wait times were viewed as barriers to the initiation of lifestyle changes.

However, as problematic as CRP wait times were, the participants who knew nothing of these programs were further disadvantaged, such as Barry:

“Have you ever heard of the Cardiac Rehabilitation Programs?” - KT
“I don’t think we have.” – Barry’s wife
“I don’t think so, no.” – Barry

These participants missed this opportunity because their health care providers had not engaged them in a discussion about the options available for preventative health strategies.

The participants spoke of the crucial role that family support had to the adoption of a lifestyle change; however, the *lack of support* from the health care system was a barrier to making those changes. For example:

“Well yeah basically the internet and I read a bunch of articles and sort of take a little bit from here and there, just figure out what’s good and what’s not and take it at that. But I still think I need to speak to somebody that’s very knowledgeable [about nutrition].” – Edward

“Oh no you get told what to do there’s just no help, and I, I work in the field and I don’t know how to do this so.” - Michael

Michael in particular expressed frustration at the lack of assistance provided by the health care system stating:

“There wasn’t a support system out there, that wasn’t, that wasn’t naturally built in so. And I’m not saying anybody did anything wrong, I just don’t know that the system is set up to help people through something unknown.”

One participant saw such a great need for additional support outside of his family that he

felt a support group, such as alcoholics anonymous, was required to help him initiate and sustain lifestyle changes. He stated:

“I think guys like me actually need a support group. I really think its like somebody who wants to quit drinking or smoking or whatever if you don’t have that lifestyle for me to change that, that’s not going to happen on my own.” - Peter

The participants described very supportive spouses and families but there was a perceived need for improved support from the health care system.

Theme # 16: Adopting a healthier lifestyle. Many participants described the PCI procedure as simple and easy; however, it was evident that this was a significant event in their lives; one that had the potential to alter their health behaviours. For example:

“Its kind of scary but I guess one needs to have something to scare them to, to live better, to live healthier.”- Angela

All participants described a desire to make some changes to their former lifestyles as a result of their diagnosis and treatment; most often these were dietary changes (see Table 5).

Table 5. Lifestyle changes following elective ad-hoc PCI

Lifestyle change	# Participants with established lifestyle change pre-PCI	# Participants initiating lifestyle change post-PCI	# Participants not yet initiating lifestyle changes
Exercise Program	1	1	8
Dietary restrictions	3	7	0
Smoking cessation	2	2	0

All participants indicated they were trying to implement dietary changes. They described an awareness of portion sizes, salt intake, junk food, reading labels, increasing fruit and vegetable intake, reducing red meat consumption, and cooking with less fat or oil. For example:

“So my eating habits have changed quite a bit. I try to stay away from red meats... I eat a lot more fish and a lot more chicken with no fat on it, no skin.”- Edward

Conversely, the adoption of an exercise regime was met with considerable apprehension and fear around the safety of exercise post-PCI. They stated:

“Getting over my fear that I’m going to blow it somehow. That ah I’m you know going to push it to hard at the gym and something is going to happen.”- Michael

“Just sitting and not knowing what you can or can’t, can you go for a walk?” – Peter

Although many participants listed exercise as a strategy to prevent future CAD, they appeared apprehensive about the adoption of an unsupervised exercise regime.

Two participants were smokers (both had recently decided to quit), while another two were ex-smokers. Of the two participants who were smokers, one was participating in a smoking cessation program through work, and the other was taking Champex. At the time of the interview the participant taking Champex was smoke-free. He shared his view regarding his smoking cessation strategy:

“We had done some research and found out that the, that new pill that’s out, Champex, was quite successful with some people that we knew so we went and got a prescription and started in November and on November 28th that was our stop date.”- Michael

Thus, in the short term both participants had made progress toward the goal of smoking cessation.

All participants were trying to engage in some form of lifestyle change; however, in this study sample dietary changes appeared to be the most readily adopted. Lifestyle changes, though beneficial, are difficult and require effort and planning. At this stage participants appeared to be eager to make lifestyle changes. Although all participants recognized the benefit, they all described numerous barriers to adopting a healthier lifestyle. The removal of these barriers will be an important consideration if patients are to be successful at adopting a healthier lifestyle.

Chapter summary

This chapter presented the findings from the participant interviews. The participants' experiences, perceptions, and beliefs associated with their diagnosis and treatment of CAD were very dynamic, but common themes were evident in their stories. The participants' ratings of cardiac disease severity and susceptibility revealed interesting beliefs behind their rationale for those ratings. CAD susceptibility appeared to be an important factor in their decisions to adopt a healthier lifestyle. In addition, the themes identified as modifying variables were associated with the participants' perceptions of disease threat, including: time constraints, social supports, information gathering strategies, self determination, expectations of care, patient education, and the elective ad-hoc PCI experience. As well, the cues to action that appeared to strongly influence the participants' understanding of CAD and disease threat were the relationships with health care providers and follow-up care. Finally, the likelihood that participants would engage in preventative health behaviours was strongly influenced not only by perceptions of disease severity, susceptibility, and threat and the influences of modifying variables but also by the perceived benefits and barriers to adopting that behaviour.

Chapter 6: A Discussion of the Thematic Findings

My experience working in the cardiac catheterization laboratory from 2002 – 2006 provided the impetus for this study. I was concerned about the quality of care provided to the elective ad-hoc PCI patients because it appeared that the primary focus was getting these patients in for a procedure and not the long-term implications of the disease process. Of particular interest were previous study findings that indicated these patients were not engaged in lifestyle change because they felt they had been cured (Campbell & Torrance, 2005; Eastwood, 2002; Gaw, 1992; 2005, Lauck, et al., 2009). Although I had a sense we were missing some important elements in our understanding of their health behaviours and in the quality of care that was provided to them, I was not prepared for the magnitude of our oversight.

I am sure most qualitative researchers will recall key quotes from their studies that will remain with them forever. I too will remember many of the quotes that participants shared, particularly George's statement:

"If I hadn't have been the walking wounded, if I had a heart attack I would have gotten a lot more information"

Information, support and education about CAD disease should be dependant on a diagnosis - not the length of stay, treatment option, or their entrance presentation.

Exploring the personal experiences, behaviours, and beliefs of these elective ad-hoc PCI participants as they navigated our health care system provided numerous insights.

This chapter will discuss the research findings of this interpretive description study. These findings have illuminated the experiences of elective ad-hoc PCI patients

with newly diagnosed CAD. All participants were in the process of trying to make sense of what this disease, diagnosis, and treatment meant for their health and future.

The central themes of this research study reflect the critical elements that emerged throughout the entire PCI experience for these study participants. These factors appeared to shape not only the participants' knowledge and understanding of their CAD, but also their consequent health behaviours. These themes also addressed the study objectives posed in Chapter 1. To review, the objectives of this research study were: a) to understand the patients' perceptions of the ad-hoc PCI experience and their beliefs regarding the perceived threat of CVD; b) to identify the factors that underlie the perceived belief that one is cured; c) to explore the role health care professionals have on the health behaviour practices of the elective ad-hoc PCI patients; d) and finally, to understand the rationale for the health behaviour practices pursued by these patients. An overview of the research questions and participant's responses are provided in Table 6. The intent of this table was to provide a simple guide to these very complicated responses. These responses will be discussed in greater depth within the context of the central themes.

The central themes derived from participant interviews included: *what a relief – I'm better, uncertainty, the importance of relations, and barriers to lifestyle change*. As well, the research objectives will be addressed in relation to the identified themes. The study limitations and the strengths and weaknesses of the chosen models will also be discussed. Finally, recommendations will be made for nursing practice, education, and research.

Table 6. Research questions and responses

Research Question	Response
a) To understand the patients' perceptions of the ad-hoc PCI experience and their beliefs regarding the perceived threat of CVD.	<i>*The elective ad-hoc PCI procedure appeared to indicate less severe CAD even when compared to other elective PCI procedures by virtue of receiving a diagnosis and treatment for CAD all during the same procedure.</i>
b) To identify the factors that underlie the perceived belief that one is cured.	<p><i>*The participants in this study entered the health care system with an expectation that treatment would solve their health problem or symptoms.</i></p> <p><i>*The physicians' assessment post-PCI was highly influential on the participants' understanding of disease severity and contributed to their belief that they were cured.</i></p> <p><i>*The disembodied feeling participants described severely limited their comprehension of the events, negatively impacting their recall of treatment information and limited their understanding of disease threat.</i></p> <p><i>*The ease of treatment described by participants' comments such as: "I felt nothing, no pain", and "I slept through the whole procedure" contributed to low ratings of CAD severity and factored into their belief system around disease threat and cure.</i></p> <p><i>*When participant's lacked knowledge of their risk factors they were more prone to believe they were cured because they failed to recognize their underlying health problem.</i></p> <p><i>*Finally, poor follow-up sent the wrong message about the importance of initiating and maintaining risk factor management strategies.</i></p>
c) To explore the role health care professionals have on the health behaviour practices of the elective ad-hoc PCI patients.	<p><i>*Health care providers have not provided adequate education or support in assisting the participants to understand or manage their cardiac risk factors.</i></p> <p><i>*Poor post-PCI follow-up left the participants with minimal information and directions on how to implement lifestyle changes, limited understanding of the disease threat, and unsure of the next steps needed to prevent disease progression.</i></p> <p><i>*Poor communication with health care providers is a reflection of a lack of patient centered care which participants described as: difficulty getting health</i></p>

	<p><i>information throughout the treatment trajectory.</i></p> <p><i>*Exercise regimes were poorly integrated into post-PCI lifestyle changes because participants had little direction on how to implement them and they were concerned about their safety.</i></p> <p><i>*Health care providers under referred the participants to CRPs.</i></p> <p><i>*Health care providers failed to engage the participant in lifestyle modifications even when they expressed a desire to change.</i></p>
d) To understand the rationale for the health behaviour practices pursued by these patients	<p><i>*Uncertainty and fear regarding their future health appeared to provide strong motivation for the adoption of a healthier lifestyle.</i></p> <p><i>*A lack of information and direction on how to proceed with lifestyle changes inhibited the adoption of healthier lifestyles post-PCI.</i></p> <p><i>* An important influencing factor the participants described for participating in lifestyle changes was the desire to be around for their families.</i></p> <p><i>*The biggest deterrents to the participants' implementation of lifestyle changes included: limited time, the risks perceived with exercise, lack of referral to CRP, and long wait times for CRP.</i></p> <p><i>*The belief of cure was not found to be a barrier to the adoption of lifestyle changes.</i></p>

Central Themes

What a relief – I'm Better

The decrease in perceived disease severity and threat that participants reported post-PCI resulted not only in physical but also psychological relief. At the extreme this evaluation of improved health was expressed as a belief of being cured. Although on an individual level it appeared that the belief of cure was most dependant on symptom relief and physician evaluations, upon broader examination there are subtle nuances that are potentially underlying the belief that one is better. Factors that appeared to contribute to this belief included: *miscommunication, treatment expectations, a disembodied process,*

knowledge of risk factors, and lack of follow-up. These themes were heard in all the participants' stories; however, the degree of relief from CAD varied among the participants.

Miscommunication. This research study found that two of the ten participants held the belief that they were cured post-PCI. Although this represented a smaller proportion of participants compared to previous studies, this discrepancy could have been the result of a small and relatively well-educated sample or health care providers that have begun to address this belief. The findings of this study supports previous evidence that elective PCI patients' have an erroneous belief that they are cured (Astin & Jones 2006; Campbell & Torrance 2005; Eastwood 2001; Gaw 1992; Lauck et al. 2009). Although the number of elective PCI patients who believe they are cured post-PCI may be decreasing, this belief is still present and has been a long-standing perception in this patient population.

Interestingly, it appears that *the physicians' assessments post-PCI were highly influential on the participants' understanding of disease severity and contributed to their belief that they were cured* (participant answer to research question b). When participants were asked why they believed they were cured, their response was based not on symptom relief but rather on the information gathered through discussions with their health care providers, in particular their physicians and cardiologists. This dependence on the providers' assessment may be due to the fact that these participants were in the early stages of heart disease and many had not had significant symptoms by which to evaluate their health status. Consequently, patients in the early stages of CAD may be much more dependant on their providers to help them understand their disease threat.

Clearly, health care professionals, particularly physicians, have a vital role to play in assisting the elective ad-hoc PCI patient understand CAD threat and its implications for their long-term health. It is unlikely that telling the patient they were cured was the message that the physicians or health care providers intended for their patients, but it was the one that was heard. This discrepancy between what was intended and what was understood represents miscommunication and emphasizes the need for clear language and repetition to prevent this type of communication problem. Evidently, there is a need for strategies to ensure accurate and complete information is provided and understood post-PCI.

Treatment expectations. It is a societal expectation that the health care system will look after our health problems and provide a cure, so it was not surprising that *the participants in this study entered the health care system with an expectation that treatment would solve their health problem or alleviate symptoms* (part answer to research question b), and that they would return to normal living post-procedure. An anticipation of cure appears to be firmly ingrained in societies expectations of medical treatment (Cheek, 2008; Kleinman, 1988).

The anticipation of being cured or fixed through treatment was not only evident in this study; previous research studies have also found that cardiac patients expressed high expectations that a procedure or treatment would fix their health problem (Johansson, Swahn, & Stromberg, 2007; Hirani et al., 2006; Odell et al., 2006; Ozkan et al., 2008; Radcliffe et al., 2009; Sampson et al., 2009; Whittle et al. 2007). Moreover, the study participants rated their disease severity lower post-PCI which supports the findings of

others researchers who also found that ratings of disease severity, post PCI, decreased over time (Astin & Jones, 2006; Ozkan et al., 2008). It appears that merely being treated is often sufficient for a positive treatment evaluation even, in the absence of symptom relief and in spite of received a diagnosis of CAD.

Conversely, the participant who experienced the complication of post-PCI angina rated his cardiac disease severity high. Interestingly, he was not only disappointed and frustrated by his treatment results but also surprised by the limitations of health care, as exemplified in his statement: *“we can send somebody to the moon but we can’t fix, you know our arteries.”* Despite the fact that post-PCI chest pain is not an uncommon finding in this population, patients do not anticipate its recurrence post treatment. Many other researchers have also found that participants were surprised and lacked awareness of how to respond to the return of chest pain (Campbell, & Torrance, 2005; Cronin et al., 2000; Gallagher et al. 2008; Kini, et al., 2003; Lauck et al. 2009). Possible explanations for this lack of appropriate response are poor post-PCI education or denial, because a return of chest pain does not match their expectation of treatment.

As a society we have placed high hopes in medical technological advances, which contribute to the expectations about treatment success. One might ask if the belief of cure was an evaluation of their treatment outcome or rather an expectation of treatment outcome. It is probable that both these factors play a role in the belief system one holds regarding treatment success.

A disembodied process. The participants described their elective ad-hoc PCI procedure as simple, easy, and disembodied. The sedation given prior to their treatment and the speed of the procedure resulted in a psychological and physical detachment from

what was happening around them. Although most participants described this disembodied sensation favorably, they demonstrated limited understanding of events and conversations during and immediately following their treatment.

Participants expressed relief that they could be treated with such a quick and easy fix to their problem. Other researchers have also found that participants treated by PCI had the perception that this was a benign procedure and was reflective of less severe CAD (Gaw 1992; Odell et al., 2006; Peterson et al., 2010; Radcliffe et al. 2009; Sampson et al. 2009). In particular, the *elective ad-hoc PCI procedure appeared to indicate less severe CAD even when compared to other elective PCI procedures by virtue of being able to receive a diagnosis and treatment for CAD all during the same procedure* (answer to research question a). The prospect of having to return for further treatment was associated with more severe CAD.

Not only did the ad-hoc PCI procedure confer a less severe problem, but it also contributed to the notion that it could be easily fixed. Similarly, other studies have found that the participants expressed surprise by the ease of treatment (Peterson et al. 2010; Sampson et al. 2009), the lack of procedural pain, and the absence of a scar (Astin et al. 2009), all of which were supportive of less severe CAD. The *ease of treatment described by participants' comments such as: "I felt nothing, no pain", and "I slept through the whole procedure"* contributed to low ratings of CAD severity and factored into their *belief system around disease threat and cure* (part answer to research question b).

Although the speed and ease of treatment contributed to the participants' disembodiment, it appeared that the most detrimental factor to their participation in the treatment process was the direct result of procedural medications. Consequently, the

participants in this study described their elective ad-hoc PCI procedure as a highly fragmented and disconnected experience. They had difficulty recalling the specifics of the procedure and what was happening to their body during and immediately after the procedure. Other researchers have reported a similar lack of treatment recall post-PCI (Astin et al., 2009; Lunden et al., 2006; Radcliffe et al., 2009). However, whereas this study, as well as Lunden and associates, attributed this phenomenon to procedural medications, Astin and associates ascribed it to emotional shock related to treatment for a MI. Though the participants generally viewed this *disembodied feeling positively, it severely limited their comprehension of the events, which negatively impacted their recall of treatment information and limited their understanding of disease threat* (part answer to research question b).

A disembodied treatment process does little to engage the patients in their treatment or disease. It is quite probable that the participants who felt they did not get vital information regarding their health, treatment, or discharge were told this information at a time when they could not retain it. Providing important health information when the patient is both embodied and engaged would be ideal in order to facilitate increased knowledge and understanding.

Knowledge of coronary artery disease risk factors. Many of the participants interviewed were unsure of how their risk factors and lifestyle contributed to their current health status. This finding is consistent with those of other researchers who have found that PCI patients demonstrate a lack of awareness regarding risk factors and have limited understanding of the disease process (Astin et al. 2009; Astin & Jones 2006; Campbell & Torrance 2005; Fernandez et al. 2006; Gaw 1992; Gaw-Ens & Laing 1994; Gulanick et

al. 1998; Lauck et al. 2009). As knowledge is generally viewed as a prerequisite for change, it is unlikely that patients who lack knowledge will have a realistic view of their CAD nor will they be able to make the necessary lifestyle changes. Given that engaging in lifestyle change requires an awareness of how to halt CAD progression, it is concerning that only a few participants in this study knew what lifestyle changes were needed to prevent future CAD. In particular, one participant's statement, "*so we don't know what the actual cause is so we're guessing at the fix*" reinforces the findings of others who have also reported that PCI patients lack awareness of how to prevent disease progression (Eastwood 2001; Lauck et al., 2009). Evidently, *health care providers have not provided adequate education or support in assisting the participants understand or manage their cardiac risk factors* (part answer for research question c).

For patients to understand disease severity and the associated risks of CAD they need education and guidance regarding risk factor management. Therefore, health care providers have a responsibility to educate and participate actively in the management of those risk factors. Clearly, *knowledge of risk factors is important to the implementation of health behavior change. However, beyond knowledge of risk factors and its role in health behaviour change another question arose. Are patients who fail to recognize their risk factors more apt to believe they are cured* (part answer to research question b)?

Poor post-PCI follow-up. The participants described minimal follow-up with health care providers and a lack of consistency or coordination to the care that was provided after the procedure. Participants described wide variation in not only what physicians focused on at their follow-up appointments but also on how closely they were followed: "*No one has ever said to come back.*" It appears that there are no standards

for follow-up care so the care decisions are left solely to the discretion of individual practitioners. Preceding research studies have also reported poor follow-up procedures (Henriksen & Rosenqvist, 2003; Gaw-Ens & Laing, 1994; Radcliffe et al., 2009; Riley et al., 2007). The participants in these previous studies expressed disappointment in post-PCI care (Gulanick et al. 1998; Radcliffe et al. 2009) and the need for additional information pertaining to medications, post-discharge care, recovery, CAD, and their condition (Kattainen, Merilainen, & Jokela, 2004). As a consequence of poor follow-up procedures, many participants reported receiving minimal information or direction post-PCI. Thus, *poor post-PCI follow-up left the participants with limited understanding of the disease threat and unsure of the next steps needed to prevent disease progression* (part answer to research question c). *What message do we send patients when we do not make follow-up care a priority, is it that their CAD is not severe; that it is “cured”* (part answer to research question b)? Our unspoken messages may be just as important as the spoken ones.

According to the Chronic Care Model, planned follow-up care is a critical component to long-term disease management (Wagner et al., 1996). Previous research shows that planned follow-up is associated with fewer hospital admissions and improved quality of life, particularly in the elderly (Courtney et al., 2009; Rytter et al., 2010). However, many follow-up services have also lacked a clear delegation of provider responsibility. Consequently, follow-up care services have been plagued by gaps and inconsistencies (Henriksen & Rosenqvist, 2003; Riley et al., 2007). Unfortunately, poor follow-up is not a new problem for this patient population but one that still needs to be

addressed. Therefore, guidelines for post-PCI follow-up care which outline provider responsibilities may be useful to help standardize care and ensure patients are adequately monitored, and referred to CR. One possible solution is a post-PCI follow-up clinic that provides closer patient follow-up, tracks complications, provides education, and supports these patients with lifestyle changes and tertiary prevention.

Regardless of the degree in relief of cardiac symptoms that participants experienced post-PCI several elements were evident in all the participant interviews. The theme “*What a relief – I’m better*” captured the elements that were critical to the participants evaluation of their CAD. At its extreme this sense of improved health was manifest as a belief of cure. In this study, *the belief the participants held of being cured was influenced by: miscommunication, treatment expectations, the disembodied process, lack of knowledge regarding risk factors and their contribution to CAD, and lack of follow-up* (more comprehensive answer to research question b). These elements lead one to question whether the belief of cure, so often measured in surveys of this patient population, actually measures a belief system or is it capturing other indicators related to the experience such as treatment expectations, knowledge, or poor communication.

Uncertainty

Uncertainty is a dynamic state characterized by “a perception of being unable to assign possibilities of outcomes that prompts a discomforting, uneasy sensation that may be affected through cognitive, emotive, or behavioural reactions, or by the passage of time and changes in the perception of circumstances” (Penrod, 2001, p.241). In this study all participants, irrespective of how severe they perceived their CAD to be, expressed uncertainty regarding their future health. The participants conveyed concern about their

risks for future events despite having a limited understanding of their disease. It is important to note that although they may have some awareness of their risks, the accuracy of their risk assessment was not evaluated. However, previous researchers have indicated that PCI patients are prone to underestimate their risk for future cardiac events (Astin et al., 2009; Fernandez et al., 2006). Rather than focusing on the accuracy of risk evaluations, this research study attempted to reveal the factors that influence the participants' perceptions of their susceptibility to CAD. Some of the factors that appeared to influence their uncertainty about their future health included: *fear of reoccurrence, treatment success, life after PCI, receiving conflicting health information, and lack of information and direction*. However, the uncertainty related to reoccurrence of their symptoms also appeared to provide strong *motivation for lifestyle change*.

Fear of reoccurrence. Fear was a core element in the uncertainty participants described when they talked about their future health. All participants indicated that they were concerned about developing the signs and symptoms of CAD again. It was fascinating that even the participants who felt they were cured were still concerned about having heart blockages again. Similarly, previous research studies have also found that PCI patients expressed uncertainty associated with evaluating their future health status (Astin et al. 2009; Gulanick et al. 1998; Higgins, Dunn, & Theobald, 2000; Lunden et al. 2006; Odell et al. 2006; White, & Frasure-Smith, 1995). The fact that the participants had coronary artery blockages once appeared to provide very real and concrete evidence that there was the potential to develop them again. This resulted in participants' expressing feelings of uncertainty about their future health.

Treatment success – am I better? For some participants this fear of reoccurrence was compounded by the lack of symptoms that they had experienced. Several participants questioned that if coronary artery blockages could develop without them knowing, how would they know if the blockages reoccurred? Similarly, Kimble and King (1998) also found that participants had difficulty evaluating their health post-PCI. This inability for some participants to evaluate their health based on signs and symptoms, resulted in a desire to be retested so they could be sure the blockages were gone. In addition, a few participants spoke of yearly retesting to be sure that the blockages had not reoccurred. These descriptions reflect the high degree of uncertainty that participants felt about their current and future health status.

Life after PCI – what is normal? In this study several participants struggled as they tried to put this experience into the context of their life. In addition, to the practical questions regarding CAD, risk factors, and how to proceed with lifestyle changes; they had very existential questions about their life situation. Where do I go from here and what is “normal” where common questions but ones for which they often had no one to answer them. Previous research has also found that patients were frustrated with their health care providers because of the lack of attention they paid to their life questions (Henriksen & Rosenqvist, 2003; Barry et al., 2001). In this study the participants unanswered life questions resulted in feelings of uncertainty about what this experience meant to their health and future. Thus, health care providers must have increased awareness, sensitivity, and time to respond to their patients’ life questions.

Conflicting health information. The PCI process involved multiple providers such as family physicians, cardiologists, internists, interventional cardiologists, and

nurses. Although experts in their fields, the involvement of multiple providers resulted in differing medical opinions. Several participants described feeling caught and having to 'select' which information to follow. In particular, the participants who received conflicting health information reported high degrees of uncertainty related to confusion about what health information to believe and follow. These participants found they were second-guessing their decisions or the provider's information and reported increased psychological stress, such as anxiety and high degrees of uncertainty about their health. Although medical mishaps and patient safety associated with receiving conflicting health information were not investigated in this study, Sutcliffe and associates (2004) found that medical mishaps were often associated with poor communication between providers as a result of hierarchical differences. Thus, having multiple providers involved in one's care poses problems, such as receiving consistent health information.

The participants in this study who received conflicting health information described devastating consequences to their psychological well being and reported feelings of anxiety and uncertainty about their health. Clearly, health care providers need to offer consistent health information in order for patients to move forward with a plan for disease management and tertiary prevention.

Lack of information and direction. Limited information and direction post-PCI contributed to the frustration and ambiguity participants felt about their health. The lack of information and minimal direction left participants uncertain of what to expect during the recovery process. The participants frequently asked questions such as "what is normal", "what can I do", and "can I do harm"; these sentiments reveal the frustration and uncertainty participants felt about gauging their recovery. Despite a plethora of research

highlighting the need for improved information strategies for post-PCI patients (Astin et al., 2009; Gaw 1992; Higgins et al. 2005; Kattainen et al., 2004; White, & Frasure-Smith, 1995), all participants in this study voiced concern about the limited health information and direction they received following their PCI procedure. Consequently, participants were often uncertain of how to proceed with lifestyle changes during the recovery process.

Thus fear of reoccurrence, receiving conflicting health information, and lack of information and direction all contributed to uncertainty and the consequent emotional distress that participants reported. In particular, depression and anxiety were noted in a several participants, which supports similar findings in the post-PCI population (Astin et al., 2005; Barnason et al., 2006; Fernandez et al. 2006; Lauck et al. 2009; Le Grande et al., 2006). Therefore, the relationship between uncertainty and emotional distress warrants further investigation and highlights the need for increased supports post-PCI.

Motivation for lifestyle change. The participants' descriptions of *uncertainty and fear regarding their future health appeared to provide motivation to adopt a healthier lifestyle* (part answer for research question d). Interestingly, Peterson et al., (2010) also noted that the fear of reoccurrence provided strong motivation for the participants who successfully adopted a healthier lifestyle. *Although the participants' appeared motivated to engage in lifestyle change, many lacked the information and direction needed to proceed with those changes* (part answer for research question d).

To a large extent the uncertainty participants expressed appeared to be rooted in a *fear of reoccurrence, difficulty evaluating treatment success, coming to terms with life after PCI, receiving conflicting health information, and a lack of information and*

direction. Unfortunately, the motivation generated for lifestyle change from uncertainty and fear was lost when the participants lacked information and direction on how to proceed with those changes. Therefore, appropriate interventions aimed at alleviating uncertainty are required to prevent negative treatment outcomes, such as emotional distress and failure to adopt a healthier lifestyle.

The Importance of Relationships

Communication is the foundation on which all relationships are built and a key component to a trusting relationship. Trust appears to be enhanced when health care providers attempt to understand their patient's experiences and values, communicate clearly and completely, and share decision making (Fiscella et al., 2004). Thus, trust and confidence in one's health care provider are the products of good communication. The participants, in this study, spoke of communication, as integral to trusting relationships with their health care providers, while the support of families was particularly vital to their ability to adopt a healthier lifestyle. Although the importance of these relationships influenced their lives differently they were both critical elements throughout the treatment process.

With Health Care Providers. Good communication practices have long been recognized as the cornerstone of effective patient – provider relationships, and influence not only the patients' understanding of the disease (Curtin, Mapes, Schatell, & Burrows-Hudson, 2005; Perkins-Porras et al. 2006; Teutsch 2003; Weinman 1997; Weng 2008), but also their compliance with physician recommendations (Teutsch 2003; Thorne et al. 2008).

All participants in this study recognized the importance of good communication with their providers. Several participants spoke highly of their providers' professionalism, openness, and availability to answer questions. Statements such as "I was well looked after", "they took time with me", "he did whatever he had to get the message across" were high points for these participants. Previous researchers have found that good communication and trust in the health care provider contributed to positive PCI experiences (Lunden et al. 2006; Radcliffe et al., 2009; Sampson et al. 2009). Similarly, the participants in this study who felt they had good communication with their providers conveyed feelings of trust, had positive evaluations of their health care experience and demonstrated increased understanding of the procedure, results, and lifestyle changes needed. However, this was not every participant's experience; the interviews highlighted several areas that were particularly prone to poor communication. These areas spanned the PCI treatment experience and included: *getting health information, the diagnostic process, the timing of health information immediately post-PCI, and discharge preparation.*

Getting health information. The participants described information seeking behaviours that had shifted away from communication or consultations with their primary health care providers. Not wanting to disturb their physicians, the speed and ease of accessing information via the internet, access to family and friends with similar experiences within their community, and the prolonged time frame to get in to see their providers were among the reasons that participants provided as contributing factors to this shift. Momtahan et al., (2004) and Radcliffe et al. (2009) reported a similar trend toward increased use of the media sources for health information, such as the Internet,

television, radio, and magazines. Although these sources of information are easily accessible, they are not necessarily the most accurate. The use of these information sources to “fill in gaps” left by their health care providers opens the door to less credible information. Health care providers must engage patients by providing an opportunity for dialogue about their cardiac health status, to ensure the accuracy of information received for other sources, and to answer their health questions.

The diagnostic process. Many participants talked about the surprise and shock they felt at having had a PCI. They felt ill-prepared for this reality because they did not understand the implications of preliminary diagnostic test results. Some individuals recalled receiving their preliminary diagnostic test results at their follow-up appointment post-PCI. While other participants were unable to relate how their diagnostic test results corresponded to their symptoms because they were not told the results or the results of these tests were poorly explained. According to Angus and associates (2005) the diagnostic process is vital in assisting patient's come to terms with their disease. When health care providers did not adequately communicate preliminary diagnostic test results with the participants, they failed to help them make the crucial connection between their symptoms, the diagnostic test results, and the probability of having CAD. This oversight denied the participants the opportunity to prepare, understand, and ask questions about CAD.

The timing of health information immediately post-PCI. Most participants in this study could not remember what the interventional cardiologist or nurses told them immediately following their elective ad-hoc PCI. Pain, sedation, and nausea were the factors that appeared to affect the participants' ability to concentrate and resulted in poor

recall of this important information. Similarly, other researchers have also found that the timing of information was a critical factor to later recall (Astin et al. 2009; Lunden et al. 2006; Whittle et al. 2007). One cannot ignore the potential impact that communicating health information to a patient when they are least able to comprehend or ask questions pertinent to their health may have on their knowledge level, retention, or understanding of that information.

Discharge preparation. The discharge process is generally recognized as a critical component to patient education and safety following hospitalization. The goal of discharge preparation is to transition the patient safely from hospital to home. In this study half the participants described this as a relatively smooth process whereas the other five encountered many challenges on their return home.

The Picker Institute Report (1999) highlights many issues related to patient discharge. In this report patients stated the hospital discharge often meant an abrupt transition without information about how they should care for themselves, when to resume activities, what medication side effects should be monitored, or how to have their questions answered (IOM, 2001). Similarly, in this study participants reported limited contact and communication with their nurses, minimal post-procedure directions, and a lack of information around medications and their side effects. Consistent with the current study, Radcliffe et al., (2009) and Sampson et al., (2009) reported discharge issues in their primary PCI participants; in particular, Radcliffe and associates also found that participants spoke of documents rather than nurses communicating the discharge information. In this study participants still had unanswered questions once they returned

home, despite the discharge documents provided. Health care providers must take the time to review documents and answer questions because if we do not take the time to speak with patients we may be sending the message that the information doesn't really matter.

Adequate discharge information is also a critical component to ensuring patient safety post-procedure. The findings from this study revealed that the participant with post-PCI angina was inappropriately taking his nitro, and remained at home long after he should have sought medical attention. While another participant skied for almost 3 hours the day following his PCI and developed a femoral hematoma. Previous research has found that poor communication and lack of information contributed to post-PCI patients disregarding chest pain (Barnason et al., 2006; Campbell & Torrance, 2005; Cronin et al., 2000; Gallagher et al. 2008; Lauck et al., 2009). Lack of time for communication related to abbreviated hospitalization may be a contributing factor to the quality and amount of discharge information. Health care providers must ensure patients have access to this information in order to safely return home. Patients who receive limited discharge information may be vulnerable to post-PCI complications.

Communication is a key component in patient-centered care (Berwick, 2009; Fiscella et al., 2004). Berwick describes patient-centered care as “the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care” (p. w560). Lunden and associates (2006) found that one of the three most important interventions participants identified post-PCI was patient centered care. As several participants in this study

described providers who did not consult with them regarding a plan of care, failed to explain treatments or procedural results, or ignoring their symptoms; providing patient-centered care has not been well integrated into the PCI treatment protocol. Clearly, adopting a patient-centered care approach to care that incorporates good communication and treatment patterns that value the goals of the patient are needed for the elective ad-hoc PCI patient population.

Poor communication with health care providers is a reflection of a lack of patient centered care which participants described as: difficulty getting health information throughout the treatment trajectory, and limited understanding of the diagnosis, PCI treatment, and discharge process (part answer to research questions c). According to Fischhoff (1997), poor communication poses a health hazard because of its potential to prompt wrong decisions, create confusion, or cause undue alarm or complacency. Two participants in this study experienced poor health outcomes related to inadequate post PCI information and insufficient discharge instructions. In response to communication challenges associated with short hospitalizations, Astin and associates (2009) recommend pacing or staging health information in order to promote patient learning. Thus, patients would receive health information on more than one occasion, promoting increased understanding and recall. Such strategies provide greater opportunity to communicate with patients along the treatment path and disease trajectory.

With family. Family in this sense is used broadly to reflect relationships with significant others, family members, and friends. These relationships have long been recognized for their importance in the support of patients. This support has taken on many roles and in the current health care environment appears to be expanding. The

participants in this study identified their family as a source of information along with being a support for initiating and maintaining lifestyle changes.

Though the participants used multiple sources of information, the most influential components in their understanding of CAD, particularly prior to their elective ad-hoc PCI, were the experiences of family and friends. Similarly, Radcliffe and associates (2009) found the experiences of family and friends were valuable sources of treatment information for their participants. According to Henriksen and Rosenqvist, (2003), and van Steenkiste et al., (2004) a patient's understanding of cardiac disease is strongly influenced by emotions, prior experiences, families and friends, as well as their cultural beliefs. Because participants in the current study were newly diagnosed and treated for CAD and did not have prior hospitalizations for CAD, the experiences of family and friends became surrogate information sources. Thus, these interpretations and perceptions were subject to influences outside of the medical community and may have reflected personal biases.

An important influencing factor the participants described for participating in lifestyle changes was the desire to be around for their families (part answer to research question d). Peterson et al., (2010) also interviewed PCI patients and found them to be strongly motivated to improve their health in order to have time with family. In particular, this study found that the parents of young dependants were keen to improve their health so that they could see their children reach adulthood. Thus, families appear to play a vital role in the desire to adopt a healthier lifestyle.

Similar to previous research within the PCI population the participants in this study also identified strong social support networks as being vital in the adoption of

healthy lifestyles (Campbell & Torrance, 2005; Eastwood 2001; Gentz, 2000; Gulanick et al., 1998; Higgins et al., 2005; Lauck et al. 2009; Peterson et al. 2010). The participants in this study spoke of how reliant they were on the supports of family and friends to initiate and maintain lifestyle changes. In particular, participants reported that dietary adjustments and smoking cessation initiatives were most dependant on family support. Like Gulanick and associates, this study also found that lack of spousal support was a significant barrier in the adoption of these behaviour changes. They reported that the participants who had dietary restrictions, which were not followed by family members, reported greater difficulty adhering to those recommendations.

Undoubtedly, the family had additional roles in the support, care, and recovery of the elective ad-hoc PCI patients; however their role in providing health information and support for lifestyle changes were consistently expressed in all the interviews. The participants reported dependence on family particularly when support, care, and information from within the health care system were lacking. This finding also highlights the importance of family involvement throughout the treatment and recovery process and the need for greater support from health care providers.

Barriers to Lifestyle Changes

Lifestyle changes, though difficult, are critical to disease prevention. The participants expressed a strong desire to live longer and healthier; however, in order to pursue a healthier lifestyle they encountered many barriers. *The biggest deterrents to the participants' implementation of lifestyle changes included: limited time, the risks perceived with exercise, lack of referral to CRP, and long wait times for CRP* (answer to research questions d).

Although participants reported that being around for their children and family provided strong motivation for lifestyle change, this desire also created an interesting paradox. Changing their lifestyle required time and energy, which was often difficult to find given their child rearing and work responsibilities. Eastwood (2001) also found that the patients who had dependants expressed frustration at their lack of free time to engage in lifestyle changes. Limited free time related to work responsibilities and family life were significant barriers, particularly for the younger participants.

While dietary changes appeared to be fairly benign activities and easier to implement; exercise was generally very poorly adopted into the participants' post-PCI routine. This finding is congruent with those of other researchers who also found that dietary changes are the most readily adopted lifestyle change post-PCI (Campbell & Torrance, 2005; Gaw-Ens & Laing 1994; Gentz, 2000; Higgins et al. 2000). In contrast, participants in this study reported that a determining factor for participation in exercise was the perception of safety. Participants reported fear of 'doing harm' to the stent, or their heart. Although previous research also reported low exercise rates among the PCI population, the rationale for this finding was not explored (Campbell & Torrance 2005; Cronin et al., 2000; Fernandez et al. 2006; Higgins et al. 2000; Lauck et al. 2009).

However, in this study *exercise regimes appeared to be poorly integrated into post-PCI lifestyle changes because the participants felt they had little direction from their health care providers on how to implement them and were concerned about safety* (part answer to research question c). Several participants did not want to engage in unsupervised exercise programs; therefore, they were waiting for direction and support. Cronin and associates (2000) recommended that PCI patients need progressive exercise schedules in

order to integrate exercise more effectively into their post-PCI routine. However, this intervention is contingent upon improved follow-up and support services be provided to these patients.

The current practice of CRP referral for the elective ad-hoc PCI patients of Manitoba does not include automatic referral during their hospital admission. Family physicians, cardiologists, internists, family members, or self referral to CRPs are the current process. Therefore, the referral of this population often occurs haphazardly despite research evidence that supports the use of automatic referrals to significantly increase enrollment in CRPs (Grace et al., 2007; Smith, Harkness, & Arthur, 2006). Thus, without automatic referral from hospital it should not be surprising that previous research has consistently reported that only a small proportion of elective PCI patients attend CRPs (Bethell et al. 2006; Hamilton & Haennel 2004; King, Humen, & Teo 1999; Lauck et al., 2009). However, many participants in this study had not even heard of CRPs; therefore, *health care providers are not only under referring this population to CRPs but also under informing them of the health benefits of CRPs* (part answer to research question c).

Long wait times for access to CRPs were another issue related to engagement in tertiary prevention programs. Participants were asking for information now - **not** in two months. As well, the participants who intended to enroll in a CRP were frustrated by the process and openly questioned the importance of the program if the health care providers did not see it as a priority to get them in quickly. The lack of alternative options also created frustration, as they did not know where else to access information or direction.

Quicker and easier access to prevention programs, particularly when patients are expressing interest is needed. *The failure to engage the participants when they were ready may have been a contributing factor to their low enrollment rates in CRPs and failure to adopt healthier lifestyles* (part answer to research question c). In response to these concerns the CRPs in Manitoba have recently adopted a continuous entry process, which should address the long wait times for enrollment.

In contrast to previous research and much speculation in the research community, *this research study did not find the belief of cure to be a barrier to the adoption of lifestyle changes* (part answer to question d). Although Peterson and associates (2010) found that PCI patients who were unsuccessful with lifestyle changes held a belief of cure, the two participants in this study who expressed this belief were also the two most actively engaged in lifestyle changes. Interestingly, Radcliffe et al., (2009) also found that a belief of cure did not appear to interfere with lifestyle changes in their research with primary PCI patients. Clearly, more research is needed before we can clarify the role that a belief of cure has on the elective PCI patients' health behaviours.

The participants involved in this study constructed their behaviour based on a multitude of factors that interacted and influenced each other. Although participants had intentions of adopting a healthier lifestyle, there were numerous barriers to implementation. Notably, personal barriers such as time and energy posed challenges, however, more concerning were system issues such as: failure to educate the participants around the safety of exercise or benefits of CRPs; not using an automatic referral to CRPs; and long delays in accessing CRPs.

The central themes of *what a relief – I'm better, uncertainty, the importance of relations, and barriers to lifestyle change* have provided insight into the perceptions and behaviours of the elective ad-hoc PCI patient. Although I have attempted to answer the research query, questions still remain and more have yet to be answered. What is evident is that the participants' health behaviour practices were multi-factoral and dependent on a myriad of personal, environmental, and system factors.

Study limitations

The primary purpose of this study was to gain insight into the perceptions of the patients being treated by elective ad-hoc PCI in Manitoba. Although there were study limitations the information gleaned from the participant interviews has provided valuable information related to the experiences, perceptions, and beliefs of these patients.

However, several study limitations warrant consideration. First the sample size was small and quite homogeneous. Although the intent was to use maximum variation sampling, the participants were recruited as a convenience sample. Thus, women, ethnic minorities, and individuals of lower socioeconomic status were underrepresented.

As with most qualitative research, the findings of this study are not intended to be generalized to all individuals who have an elective ad-hoc PCI or to all centers that perform these procedures. The small sample size and homogeneity require particular attention to the generalizability of these findings; however, there was sufficient variation in experiences and perceptions, which resembled the range of experiences noted in other elective PCI research studies, such as post-PCI angina. In interpreting the findings of this study care must be taken to determine the similarities or differences between PCI patients or centers.

The retrospective approach of this study could raise questions about the accuracy of the participants' recall. However, this approach also highlights the salient features of this experience. As interpretive description studies are concerned with the participants' perceptions of this experience, the thematic analysis was constructed based on their recollections, beliefs, and experiences (Thorne, 2008). Thus, although some aspects of the experience may be lost with a retrospective approach, arguably the central elements have been retained and are useful for informing practice.

Another consideration is that the information was derived solely from the participants; the accuracy of risk factor knowledge or treatment results could not be verified. A chart review would have been helpful in evaluating the accuracy of the information participants provided and may have highlighted additional areas of knowledge deficits. It is also important to note that this study did not evaluate the success of lifestyle changes, but merely asked what initiatives had been undertaken. Although the evaluation of success with lifestyle changes was not the intent of this study, a more comprehensive approach would have been to assess the success of lifestyle changes undertaken.

Although there were several limitations, this study did illuminate the experiences and perceptions of an elective ad-hoc PCI patient population. The central themes identified can assist astute clinicians to glean insights into this experience from the participants' perceptions. Thus, offering a new path for providing quality patient care, improved education, and new directions for future research.

The Models

The Health Belief Model (HBM) provided a strong framework for structuring the literature review and guiding the development of the research questions. The HBM was instrumental in helping to identify many of the components that contributed to health behaviours of the elective PCI patient population. As a novice researcher, having such a strong framework gave structure not only to the investigation but also to the analysis of the findings. I think understanding the complexity of this experience would have been much more challenging if I had not chosen such a strong framework.

The strength of the HBM - a strong focus on the individual - also became a weakness. Focus on the individual resulted in an overemphasis on personal behaviours and less on the health system, or environmental factors which also influence health behaviours. In addition, the HBM was not a predictive model, as suggested by the directional flow of the model, the participants' perceptions were subject to individual interpretation and certain elements within the model held greater significance for some than others. This limitation allowed for only theoretical associations to be made between the variables. Thus, the elective ad-hoc PCI participant's perceptions and beliefs about disease threat and their subsequent health behaviours were variable and dependant upon multiple factors. However, there were also commonalities that the participants shared, which provided insights into this health care experience.

In contrast, the Chronic Care Model (CCM) is a model that looks at the health systems approach to providing chronic disease management. Thus, the CCM was used as a supplemental model to provide insight into the gaps in the chronic disease management of this patient population. As chronic disease management is dependent on a team

approach and the utilization of community resources, the lack of referral to CRPs provides a good example of the failure of the health care system to connect the participants with resources in the community.

Although the CCM was useful in identifying some of the health system gaps in the care of these elective PCI patients, it provided little insight into personal values or attitudes that are vital to the beliefs and perceptions one holds about their health. Thus, its inability to address individual factors minimized its usefulness for addressing many health behaviour issues.

Together both these models provided insights that each alone could not address. Although the interviews explored the personal experiences of these patients, what emerged were their perceptions, beliefs and some glaring system failures. Many of the system issues identified had serious consequences to their beliefs about their health status, and the health behaviour practices they pursued. What became very evident in the participants stories was the strong focus on the procedure **not** the individual. As one participant stated *“well it’s like an assembly line.”*

Consideration of a more global approach may have been helpful to address some of the societal issues and barriers that individuals face when trying to adopt healthier lifestyles. Although alternative models may have provided addition or slightly different perspectives, the chosen models were useful in highlighting many of the important components, factors, and issues that the participants faced throughout the diagnosis, treatment, and recovery from an elective ad-hoc PCI.

Recommendations for Professional Nursing Practice

The importance of the study findings will be highlighted in the following sections on recommendations. A discussion of the findings in relations to their implications for nursing practice and patient education, nursing administration, as well as directions for future research will be underscored.

Implications for Nursing Practice and Patient Education

Despite the fact that nurses care for elective ad-hoc PCI patients, their opportunity to understand the experiences of these individuals is limited. Moreover, the time to engage, educate and teach these patients is inadequate. Thus, one of the goals of this research study was to gain insight into the patients' perceptions so that health care providers can begin to understand their perceptions and health care needs. The findings of this study reveal a wealth of potential areas of interest to nursing practice and education.

Nurses and other health care professionals need to be familiar with the informational and support needs of these individuals both before and after the PCI procedure. This will require improved pre and post-PCI learning needs assessments. In particular, attention must be paid to the learning needs of patients following their procedure to: facilitate their understanding of the PCI results, understand the implications to their health, increase their awareness of risk factors, and improve uptake in prevention strategies.

Health care providers also need to provide health information at a time when the individual is best able to comprehend that information. This will require improved follow-up care, which allows an opportunity for these patients to ask questions pertinent

to their health. Pacing or staging information will be an important strategy to prevent information overload while ensuring the chance to receive information on multiple occasions. Ideally, follow-up care would be provided in a designated clinic devoted to the education and care of PCI patients.

Finally, nurses and other health care professionals need to provide more comprehensive directions about post procedure care, such as chest pain management, groin hemostasis, safe exercise regimes, and smoking cessation programs. It is also important to explore additional strategies for providing tertiary prevention programs to this patient population.

Implications for Nursing Administration

The implications for administration pertain to the enhancement of nursing education with respect to the experiences of the elective ad-hoc PCI patient population. In an evidence-based culture, nurses must understand the parameters of health, utilize research at the bedside, be advocates for their patients, and understand the role nursing research plays in the health of their patients.

The scope of nursing administration must continue to evolve to include a much broader parameter of health. We have increased our awareness of the social determinates of health, but we also need to understand the influences of our health system on the population's health. In particular, how does the way we manage and coordinate health care influence patients? This type of knowledge can help provide new direction towards improving patient care and challenge current practice.

Nurses and health care providers must become consumers of research-based

knowledge that is relevant to elective ad-hoc PCI patients and apply what they learn in practice. This requires educational supports be readily available to staff nurses and that they have assistance with integrating that knowledge into practice. Resource nurses, nurse educators, and clinical nurse specialists must all work collaboratively to increase the clinical knowledge of the staff. However, the support of administration is also vital to the longevity and success of these learning initiatives.

Administrations must support nurses by providing the opportunity for them to examine a wide variety of literature with respect to the patients they care for so that they can offer a more holistic patient perspective. Bringing a broader perspective to the clinical area will heighten the nurses' consciousness of this patient population. This will increase the awareness and understanding of the issues the elective ad-hoc PCI patient faces so that nurses can become vocal advocates for the services and supports needed.

Recommendations for Future Research

Upon reflection of the findings, several areas were identified as for future further investigation. Research into this understudied PCI patient population needs to be enhanced given the exponential increases seen in elective ad-hoc PCI procedures over the past few years. As well, quality initiatives must be developed to facilitate evaluation of patient outcomes.

An area for future research consideration is to explore differences related to encounters with health care services between ethnic groups, minorities, individuals of lower socioeconomic status, or gender. For example, there were few opportunities to recruit patients of lower economic status. This was unfortunate given that the literature

suggests heart disease is increasing at higher rates in these individuals. Could this be the result of differences in access to care, symptom recognition, or related to prior experiences with the health care system? Further, qualitative or quantitative studies that encompass a more diverse sample, particularly those of lower socioeconomic status could provide additional insight into some of these questions.

Many participants described themselves as uncertain and anxious about their future health and felt they needed additional information and direction. Future research should explore the relationship between information delivery, uncertainty, and rates of anxiety. Perhaps a randomized control trial that evaluates the effects of an educational intervention, aimed at improving information and direction, on anxiety rates.

Additionally, most participants expressed fear and anxiety about the safety of exercise post-PCI. An interventional study aimed at increasing direction and support for the adoption of an exercise regime post-PCI could decrease fear of exercising and increase uptake of this prevention strategy.

Although previous research has claimed that many elective PCI patients who believe they are cured do not engage in lifestyle change; this did not hold true for this study. The two participants who believed they were cured included one who was actively pursuing dietary recommendations, while the other was engaged in an exercise regime. Therefore, further investigation is required into the role this belief has on health behaviours and what the belief of cure means to the individual.

Finally, women appeared to view exercise and physical activity much differently than men. Research is needed that explores how women interpret and are involved in

physical activity and exercise post-PCI. This could promote the development of alternative modes and strategies for the delivery of tertiary prevention.

Chapter Summary

Despite the rapid growth and increase in elective ad-hoc PCI procedures; the health care system is failing to engage these patients in the adoption of healthier lifestyles post-PCI. This chapter presented the discussion of the findings in relations to the current literature. The participants' personal beliefs and perceptions, the influence of health care providers, and system failures that contributed to their lack of lifestyle change were all addressed in the key themes: *what a relief – I'm better, uncertainty, the importance of relations, and barriers to lifestyle change*. In addition, the specific research questions that were the focus of this study were also addressed and summarized in Table 6. Study limitations, and the appropriateness of the models were presented. Finally, several implications for nursing practice and patient education have been suggested to provide a more patient centered approach to these patients. Nursing administration must also be involved in order to promote an evidence-based practice environment and to address some of the system failures in the care of these patients. As well, areas for future research have been highlighted for further exploration.

Conclusion

This interpretive description study explored the perceptions of individuals who experienced newly diagnosed CAD and treatment by an elective ad-hoc PCI. The information gleaned from the participant interviews identified key areas of health service delivery that can be targeted for improvement. The current model of elective ad-hoc PCI care is very process-driven. Although this may reduce wait lists, it is apparent that this

approach does not serve the patient well. The adoption of a more patient-centered approach, which focuses on quality indicators of care, could substantially improve patient outcomes. Key areas for improvement include: improved patient-provider communication, as well as increased information and direction throughout the diagnosis, treatment and recovery process. In addition, better post-PCI education and follow-up programs that monitor outcomes could help evaluate care and improve practice. Finally, improved direction and support for lifestyle changes along with better access to cardiac rehabilitation programs and more options for tertiary prevention programs could substantially enhance the adoption of healthier lifestyles. Improving the health outcomes of these patients will depend on our commitment and progress towards achieving these goals.

Reflection

This research project has been a long journey, one that has been fraught with delays and struggles. However, it has also been one of the most meaningful experiences of my professional career. I have gained incredible insight, not only into the experiences of these participants, but also into my own nursing practice. This was perhaps the first time in 20 years of nursing that I actually gave the patients I cared for time and space to tell me their stories. In our busy day-to-day practice it is difficult, if not impossible, for nurses to spend quality time with their patients. We get and give information in a very prescriptive, deliberate manner so that we can move on to other duties. This realization has emphasized the importance of qualitative studies, which explore and highlight the patient's perceptions of disease, treatment, and health care.

In concluding this study I have an overwhelming sense of my responsibility to share the participants' perceptions. They have honored me by sharing their stories and now in turn it is my duty to advocate for improved health care services. Improving the care we provide to these patients is dependant on integrating these research findings into our daily practice.

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Appendix A: Staff Information

First of all I would like to thank you all for attending this information session. I am Karen Thronsdon a graduate student from the Faculty of Nursing at the University of Manitoba. I am also a nurse with the department of anesthesia and have been a Health Sciences Centre employee for the past 19 years. As part of my Master's degree I am doing my thesis project, which is a research study on the elective ad-hoc angioplasty patient population.

Through this research study I am interested in learning about the patient's angioplasty experience and how that may influence their subsequent health behaviours. The literature tells us that many of these patients believe they are cured after their angioplasty. But what we want to learn is why patients believe they are cured, as well as the lifestyle choices patients make based upon this belief. I will be using a qualitative research approach that will involve interviewing the participants to try to understand their experience, perceptions, and beliefs around angioplasty. The interviews will take place either in their own home or at the Health Sciences Centre depending on the patient's preference. During the interviews I will be recording their responses to my questions. The information provided will be analyzed with my thesis committee members to generate the study findings. Does anyone have any questions about the research study?

The reason I have asked you all to attend is that I am asking for your help in the identification and recruitment of participants. Your involvement in the recruitment of participants is completely voluntary; I do not want you to feel forced into helping with this project. I realize you all have busy work schedules and that there may be days that recruitment just does not happen, but I would greatly appreciate any assistance you are able to provide.

I would now like to review the eligibility criteria with you.

The inclusion criteria includes:

- The ability to speak and understand English.
- A recent diagnosis of CAD.
- Between 18 and 60 years of age.
- Reside within 60 km of Winnipeg, Manitoba.

Patients are deemed ineligible if they have had any of the following:

- Previous cardiac surgery, PCI, or MI.
- Prior attendance in a cardiac rehabilitation program.
- Significant co-morbidities such as cancer or heart failure
- Individuals with severe cognitive impairment, who are unable to sign their own consent or individuals with significant psychiatric histories including such diagnoses as schizophrenia or dementia.

Are there any questions about the eligibility criteria?

Once you have identified eligible patients, information packages will be available for you to give to them. The information packages include: A Invitation to Participate in a

Research Study, A Reply Form, and a self-addressed envelope. (I will hand out an information package to each staff member so they can look it over). Does anyone have any questions about the information packages?

Once the recruitment of participants proceeds and reply forms are returned I will begin to get a sense of the number and the type of individuals we have recruited. So, I will keep you all well informed on how enrollment is proceeding. I will be keeping track of who and who is not represented in our current sample and may ask you to begin to selectively recruit certain populations of patients such as ethnic minorities or women. This will involve selectively handing out information packages to those target groups. As I said I will keep you well informed throughout this process. The goal of this approach is to get a very diverse sample of participants. Does anyone have any questions about the recruitment process?

I will not be on site for the recruitment process but will be readily available via the telephone if you have any questions or concerns. I will ensure that you have my cellular phone number so that you can readily contact me; however, in the event that you can't reach me I have voice mail, leave a message and I will get back to you.

Please feel free to direct patient inquiries or questions directly to me, particularly if you are busy and don't have the time to answer their questions or if you are unsure of how to answer a particular question.

Thank you for attending this information session, if there are any additional questions that have not been addressed feel free to ask. Once the research is complete I would be happy to come back and share our research findings with you.

Thank-you for your time.

Appendix B: Study Poster



Post Angioplasty Patients



The University of Manitoba, Faculty of Nursing

Invites you to participate in a *research study*

The purpose of this research study is to understand the angioplasty experience and its affect on your health.

The study involves a face-to-face interview with a graduate student from the Faculty of Nursing (Karen Thronson) at either your own home or at an office in the Health Sciences Centre.

You can participate if you are :

- **Newly diagnosed with cardiac disease**
- **Speak and understand English**
- **Between 18 – 60 years old**
- **Live within 60 km of Winnipeg**
- **And do not have other significant health problems such as cancer or heart failure**

Eligible participants will receive a small honorarium of \$20.00.

If you would like to be involved

Or would like additional information

Contact Karen Thronson at 981-0423 or umthron@cc.umanitoba.ca

Appendix C: Invitation to Participate in a Research Study



Dear Participant,

My name is Karen Thronson and I am a registered nurse (RN) and a student in the Master of Nursing Program at the University of Manitoba. This letter is given to you on my behalf from the staff in the cardiac catheterization laboratory (I do not know your name or have any information about you). The staff identified you as a suitable participant for my research study.

As part of the requirements to complete my Master of Nursing Program, I am doing a research study aimed at understanding your experience of the angioplasty procedure. Dr. Jo-Ann Sawatzky RN, PhD from the Faculty of Nursing, University of Manitoba is supervising this research study. Dr. Annette Schultz RN, PhD from the Faculty of Nursing, University of Manitoba and Dr. Joseph Kaufert, PhD from the Faculty of Medicine, University of Manitoba are the other two members of my thesis committee. The Education/Nursing Research Ethics Board at the University of Manitoba has approved this study.

The purpose of this study is to learn more about the factors that influence the health and lifestyle of angioplasty patients. It is my intention to interview patients who have undergone an angioplasty and stenting procedure immediately following their angiogram. The interview will take place approximately one to two months after this procedure. The interview will involve asking patients to tell me about the events leading up to angioplasty, the angioplasty procedure, and their recovery. In addition, participants will be asked to share their thoughts on the affect that angioplasty has had on their health and lifestyle. If you are interested in participating in the study, please fill out the attached reply form and mail it to Ms. Karen Thronson (self addressed stamped envelope is attached with this letter).

Any information that you share would be kept strictly confidential. As well, your decisions to participate or not to participate would in no way influence the health care you receive. Your participation is completely voluntary. You would be free to withdraw from the study at any time. A small honorarium (\$20.00) will be provided to those who chose to participate.

Your participation is very important for improving the care to future angioplasty patients. Thank you in advance for your time and cooperation. If you have any questions or need more details about the study, please call me at **981-0423 (C)** or email me at **umthron@umantioba.ca**. Alternatively, my thesis chair, Dr. Jo-Ann Sawatzky can be reached at 474-6684. We will be happy to answer your questions and concerns. I look forward to hearing from you.

Sincerely,
Karen Thronson, RN, BN, Graduate Student



Appendix D: Reply Form



Exploring Health Behaviour Practices of Angioplasty Patients

Are you interested in participating in this study and/or would like more information?

**** Fill in your contact details and
mail it to Karen Thronson, RN using the self-addressed stamped envelope provided.**

Print Name: _____ **Date:** _____

Phone number(s): _____

The best time to contact me is _____

If you have any questions or need more details about the study, please call me at **981-0423 (C)** or email me at **umthron@umanitoba.ca**

Appendix E: In-Patient Conversation

Hello..... I was informed by the angioplasty staff that you may be interested in this research study. Would you like me to tell you more about the study?

I am a nurse as well as a graduate student. This research project is my master's thesis that I am doing for my Master's of Nursing degree. This study is aimed at understanding your recent angioplasty experience. There are no right or wrong answers I am just interested in the events that led up to your angioplasty, your hospitalization experience, how you are currently feeling, and the affect that angioplasty has had on your health.

I would like to assure you that I am not employed in the angioplasty department and I have not intention of sharing your personal information with those involved in your care. The information you share with me will be presentation at conferences and written about in medical articles; however, your identity will not be revealed and all information will be presented as a group or through the use of code names.

Your participation involves a 60-90 minute interview with me, either in your own home or in an office at the Health Sciences Centre. Your involvement is voluntary so you do not need to feel you have to participate. Do you have any questions about the study that you would like to ask me?

After hearing this information are you interested in participating in this research study?

If you are interested you can contact me through the email address on the information package or by mailing your reply form. Once you contact me I will respond to verify your interest, answer questions, mail a consent form, and arrange a time and place to hold the interview. You also have the option of filling the reply form out and leaving it with me today. This does not mean you must participant but that I will contact you in a week once you are home and settled to discuss your interest in the study. If you are interested in participating I will mail a consent form, and arrange a time and place to hold the interview.

If you have any additional questions after reviewing the information package feel free to contact me, my contact information is included in that information.

I would like to thank-you for your time and interest in this research study. I look forward to speaking with you again.

Goodbye

Appendix F: Telephone Conversation

Hello..... This is Karen the research nurses you spoke to at the hospital and I recently received your reply form/email and would like to thank you for your interest in this research study.

Or

Hello... this is Karen the research nurse you spoke to at the hospital. You left a form with me and I am calling to see if you are still interested in participating in a research study.

As you may remember I am just interested in your recent angioplasty experience. In particular the events that led up to your angioplasty, your hospitalization experience, how you are currently feeling, and the affect that angioplasty has had on your health. Did you have a chance to read through the information package that was given to you by the nurses at the hospital. Do you have any questions that you would like to ask me about the study?

Your participation involves a 60-90 minute interview with me, either in your own home or in an office at the Health Sciences Centre. Your involvement is voluntary so you do not need to feel obligated to participate now or at any other time through the interview process.

Are you interested in participating in this research study?

I would like to mail a consent form to you so that you have time to read through it carefully. To what address would you like me to send the consent form to? If you have any additional questions after reviewing the consent feel free to contact me, my contact information will be on the consent form I send out to you.

Do you have any thoughts on where you would like to be interviewed? Could we schedule the interview now?

As a reminder of our appointment I will call you prior to our interview to confirm the time and location.

I will leave you with my telephone number 981-0423 in case you have additional questions. Please feel free to call me.

I would like to thank-you for your time and interest in this research study. I look forward to meeting you.

Goodbye

Appendix G: Consent



Research Project Title: Exploring the Health Behavior Practices of Elective Ad-hoc Percutaneous Coronary Intervention (PCI) Patients

Researcher/Principal Investigator: Karen L Thronson RN, BN (Graduate Student, Faculty of Nursing, University of Manitoba)

Note: Thesis Advisors: Jo-Ann Sawatzky RN, PhD (Thesis Chair, Faculty of Nursing, University of Manitoba); Annette SH Schultz RN, PhD (Internal Thesis Committee Member, Faculty of Nursing, University of Manitoba) and Joseph Kaufert, PhD (External Thesis Committee Member, Faculty of Medicine - Community Health Sciences, University of Manitoba).

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It will provide a basic idea of what the research project is about and what your participation will involve. If you would like more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

About This Project:

This research study is part of my master's of nursing thesis. The purpose of this study is to learn about the experiences of patients who have had angioplasty as a same day-surgical procedure. The researcher will be interviewing patients following their procedure and asking them to discuss the events leading up to angioplasty, the angioplasty procedure, and their recovery. In addition, participants will be asked to share their thoughts on the effect that the angioplasty has had on their health and lifestyle. Findings will be discussed with the thesis advisors, however names will not be linked to any information discussed. Research findings will be presented at conferences and published in scholarly journals; however, these findings will be presented in group form, with no names linked to any quotes. Therefore, it will be impossible to link the identification of individual participants to presented findings either in written or oral formats.

My understanding of the Research Activities:

You understand that if you agree to participate in the research project, you will be asked to participate in one open-ended, audio tape-recorded interview that will last about 60-90 minutes. During the interview you will be asked questions about your thoughts and experiences related to your angioplasty procedure, recovery, and lifestyle patterns. There are no right or wrong answers; it is your opinions and thoughts that are of interest to the researcher. You understand that the interview will be completed by a graduate student

(Karen Thronson) with the Faculty of Nursing at the University of Manitoba. As well the researcher will take field notes during the interview. The field notes will be used not only to help the researcher stay on track and focused during the interview process but also for such activities as: tracking new developments in angioplasty treatments or medications, identifying any heart health media campaigns that may be initiated during this time, and as a way of critiquing what the researcher is doing well or areas that need improvement. For example, are you comfortable answering the questions, are the questions easily understood or do they need to be clearer so that you better understand the question. The field notes will not be shared with you at the end of the interview but you are welcome to ask what has been documented.

Risks and Benefits:

There are no known risks to you if you participate in this project. Information gathered for this project will be held in the strictest confidence and will only be directly shared with the thesis advisors. Patient interviews are the primary way of collecting data in this study, however field notes will also be used. Data analysis will lead to descriptions of the effect angioplasty has had on participants' health and lifestyle. The information gained will NOT be used to evaluate specific persons actions, nor that of the cardiac catheterization laboratory. Finally there will be no way to identify participants (or individuals referred to during interviews) in any public documentation related to this project as noted above.

The benefit to participating will be to help health care providers understand angioplasty patients better so that we can develop programs that meet their specific needs. This information could lead to changes to the health care services offered to angioplasty patients. Finally, expenses incurred as a result of parking during the interview session will be reimbursed. As well a \$20.00 honorarium will be offered to participants upon completion (signing) the informed consent. This is a small token of our appreciation of your participation in this study. If you choose to withdraw your consent at any point during the interview or later, the honorarium is yours to keep.

Protecting Confidentiality:

The information you provide is strictly confidential and will be protected in several ways.

1. All interviews will be identifiable by a numerical code only (no names will be attached).
2. You (and individuals referred to during the interview) will not be identified in any records or in written reports from this project.
3. All records will be securely stored in a locked filing cabinet and/or password secured computer files. All files will be destroyed after seven years.
4. Only the graduate student, thesis advisor, and the internal and external thesis committee members will have access to the information provided during the interview. After the interview the graduate student will type out the interviews and remove any proper names. Then these typed copies of the interview will be provided to the thesis committee members so that the committee members will not know any proper names but will still have access to the interview information. This will allow all the members of the committee to discuss the interview findings without revealing your identity.

5. Findings will be presented/published in-group form so as not to identify individual participants.

Voluntary Consent:

You understand that your participation in this project is voluntary. You are free to withdraw from the study at any time, and /or refrain from answering any questions, without prejudice or consequence. Your decision to participate, withdrawal at any time, or refusal to participate will NOT influence or affect your health care. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation in the project.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the project and agree to participate in one interview. However, in no way does this waive your legal rights nor release the researchers, or involved institutions from their legal and professional responsibilities. In addition, you understand that you may contact Karen Thronson **981-0423 (C)**; or email **umthron@umantioba.ca**) if you have any concerns, questions, or need additional information.

This research project has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail margaret_bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Participant's Signature

Date

Principal Investigators Signature

Date

I would like to receive a copy of the brief report.

Yes _____

No _____

Please send the report to:

Name: _____

Address: _____

Postal Code: _____

Alternatively, you can provide an email address.

Email: _____

Appendix H: Demographic Information

Participant's code number _____

Age _____

Sex _____

Ethnicity _____

Marital Status _____

Educational level _____

Employment _____

Sick/health benefits _____

Date of PCI _____

Appendix I: Field Notes

Have there been any significant community or personal events that may be influencing this interview?

Does the participant understand and appear comfortable answering my questions?

Are there any relevant media campaigns that may influence the participant's behaviors or responses to my questions?

Have there been treatment advances that I should be aware of and consider for this participant?

Do I need to have the participant clarify that response or expand on their comment?

How was the interview, were there distraction during the interview process? How did I handle them and how did the participant handle them?

What went well during the interview?

What do I need to work on or change for the next interview?

Appendix J: Interview Guide

Warm-up

1. I thought before we get started I will just briefly recap the nature and purpose of the study. As you may recall I am interested in your experiences and perceptions related to your recent angioplasty procedure. I will be asking you a number of questions related to several different topic areas that are designed to help me understand this experience better. Please be assured that there are no right or wrong answers, I am simply interested in your experiences, ideas, and opinions. Some of these questions may appear silly or dumb because I am trying to put aside any assumptions about this experience. **Do you have any questions or concerns about the study or interview? If not can we begin the interview?**

Pre Angioplasty – I would like you to think back in time to before your angioplasty and reflect on what was happening with your health, how you were feeling, and where you turned for advice about your health. PAUSE- give time to reflect.

2. Please tell me about your health prior to and leading up to your angioplasty procedure.

Possible probes: When did you first start noticing symptoms? Please describe to me the symptoms that you were noticing. When did you decide to see a doctor about your symptoms? What made you decide to see a doctor? Did something change at that particular time? Did you discuss your decision to seek medical advice with anyone? What did your doctor advise at that time? Did you adjust your lifestyle in any way because of your health problem?

3. Please tell me why you think you developed blockages in your heart?

Possible probes: Has anyone in your family had similar problems? Can you think of any other factors that may have contributed to this problem? How do you think those factors affected your heart arteries?

Angioplasty – Now I would like you to focus on your time in hospital. I am really interested in understanding what this experience was like for you.

4. Please tell me about your angioplasty.

Possible probes: I know you attended a teaching clinic prior to the procedures; did the information you received there prepare you for the procedure? Did what happened during your procedure match what you thought would happen? What was the hospital experience like for you? What do you remember about your time in hospital?

5. What was your expectation of the angioplasty?

Possible probes: Did your angioplasty experience meet your expectation? How was it similar, how was it different.

6. Please tell me about the health care providers involved in your care.

Possible probes: Does anything stand out about one or all of them? Did you have questions for these health care providers? Were your questions answered satisfactorily? Did a doctor or nurse speak to you after the procedure to discuss your heart arteries? What did they say?

7. Please tell me about the discharge planning you received.

Possible probes: Does anything stand out for you about being prepared to return home? How was the discharge process? Were you ready and prepared to return home? As you think about discharge planning now, was anything missing? Can you think of any additional information or support that would have been helpful?

8. Please tell me about your recovery from the procedure.

Possible probes: How long did it take you to return to your “normal” routine? When did you return to work? Were you ready to go back to work? Please describe for me what your normal routine would be?

Post Angioplasty – I would now like you to reflect on your health since the angioplasty.

9. In your perception how has the angioplasty affected your health? Tell me more about that.....explain what you mean by that....

Possible probes: Tell me how your health has been since your angioplasty? Are you now able to do things you were previously unable to? What sorts of activities are those? Any other changes to tell me about?

10. Have you seen your doctor since your procedure?

Possible probes: What did you discuss at your appointment? Did you discuss your heart problems, what did he/she recommend. What sources of information do you use when you have questions about your health? Have you sought or received advice from someone else? If yes, from who and what was the advice?

11. How worried are you about having a problem with your heart arteries again?

Possible probes: Do you think there are things you can do to help reduce your risk of having problems again? What are those things – please tell me about those. How confident are you in your ability to reduce your risks for future cardiac problems?

12. Can you tell me about your feelings around having to have an angioplasty.

Possible probes: What does having an angioplasty mean for your future health?

13. Can we talk for a few minutes about your lifestyle?

Possible probes: Do you think your lifestyle played a role in developing heart problems? Are you attempting to change any aspects of your lifestyle? Have you had any success with making lifestyle changes? What factors have helped? What factors have proved challenging? How do you manage those challenges? How motivated are you to make those changes? What has been the strongest motivation for you? When you look ahead, in a year or two, what do you envision for health?

Do you have a plan on how you might achieve/avoid that? Have you ever heard of cardiac rehabilitation programs? Do you attend or have plans to attend one?

Closing

14. Can you think of anything else you would like to share with me about your experiences with angioplasty? The recovery? or trying to make lifestyle changes?

Thank you for sharing your insights related to your experiences with your heart health and being treated for an angioplasty. If you think of anything else in the next few days, you could contact me at.....