PATIENTS' AND FAMILIES' PERCEPTIONS OF FACTORS THAT AFFECT RECOVERY FROM CARDIAC DISEASE:
A RURAL COMMUNITY PERSPECTIVE

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Abstract

PATIENTS' AND FAMILIES' PERCEPTIONS OF FACTORS THAT AFFECT RECOVERY FROM CARDIAC DISEASE: A RURAL COMMUNITY PERSPECTIVE

This study used focus groups as a research method to elicit cardiac patients' and families' perspectives of the factors that affect recovery from cardiac disease in a rural community. The purpose of studying these perceptions was to gain an understanding of the behavioral characteristics, environmental indicators and educational factors that affect their recovery from heart disease. It was proposed that the behavioral and environmental forces and educational factors impacting on the cardiac patients' health and recovery needed to be understood before patients could be encouraged to participate actively in decision making that affects their health. A health promotion model was used as a conceptual framework.

Eight males and three females participated in one of two focus groups and three males and one female were interviewed individually as key informants. The ages of the participants ranged from 45 to 79 years. From analysis of the data, themes were identified and significant statements were used to describe the phenomenon under study.

The findings of this study suggest that although in-hospital cardiac education programs can provide general information to patients and families, there is a need to give specific information regarding the first few weeks at home and to provide early home support by health care professionals to reinforce this information and to provide emotional support. Knowledge of the available resources in the rural community is essential.
A group setting for educational, psychosocial and physical exercise is beneficial. However, families and physicians need to be educated to the benefits of these programs. Alternative resources may be required for people who cannot or will not attend these groups.
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Three Sets of Causal Factors Influence Behavior

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Chapter 1

Introduction

Background to the Problem

Heart disease kills more individuals than any other cause. Cardiovascular disease accounted for 38% of deaths in Canada in 1992 (Heart and Stroke Foundation of Canada, 1995). Evidence of heart disease often surfaces in the 45-64 year age group with mortality rates at 23% of the population of British Columbia (Division of Vital Statistics, 1989). In addition many individuals are at risk for developing heart disease. The Heart Health Survey (Ministry of Health, Province of British Columbia and Health and Welfare Canada, 1990) found that two out of three British Columbians aged 18-74 have one or more of the major cardiovascular disease risk factors.

Heart disease has repercussions beyond the health of the individual. For example, the entire family is affected by the health problem of a family member. The need to include spouses and other family members as important players in the recovery and rehabilitation of the individual with cardiac disease is well recognized (Newton & Killian, 1988). Newton and Killian (1988) state that one of the greatest areas of conflict in families is differences of opinion about medical advice and instructions. Spouses of individuals recovering from a myocardial infarction (MI) may feel responsible and over-protective and it has been found that their learning needs are similar to those of patients (Newton & Killian, 1988).

Part of the problem of providing quality health care today is that health care professionals and government representatives expend much time and health care dollars debating strategies to improve health care, yet rarely do they solicit the opinions of the consumers of that care (Gerteis et al., 1993). However, Canadian society in recent years has shifted its focus from one of government and professional driven initiatives to one that
involves the community. It is at the community level that the desired change, both personal and environmental, must take place. Gaps still exist in what we need to know "about assessing community needs and strengths, managing resource networks, participatory community planning and problem solving, organizational development, and skill-building in consultation and conflict management" (Health & Welfare Canada, 1992, p. 3).

The multidimensional methods of Green and Kreuter's (1991) health promotion planning model provide a thorough approach to addressing the gaps identified in the 1992 Health and Welfare Canada document and will be used as a framework for this study. The two components of the model are a diagnostic phase called PRECEDE and a developmental phase called PROCEED. The diagnostic steps involved in the PRECEDE phase of the model help the planner to focus on outcomes rather than inputs. In this way the planner asks why before how and subsequently identifies factors important to an outcome before designing the intervention.

Integral to the model is the concept of collaboration and to involve the people who will be most affected. Some research has focused on what patients' and families' perceive their needs to be (Avis, 1994; Campbell, 1993; Gerteis et al., 1993; Jaarsma, Kastermans, Dassen & Philipsen, 1995; Rukholm, Bailey, & Coutu-Wakulczyk, 1992). Perceptions of needs are derived from the individual's personal experiences and will vary from community to community. For the purposes of this study it will be assumed that people in the community to be studied are concerned about heart disease and recovery.

The epidemiology of heart disease is well documented (Division of Vital Statistics, 1989; Heart Health Survey, 1990; Health & Welfare Canada, 1992; Ministry of Health and Ministry Responsible for Seniors, 1994;) and will not be repeated but rather the focus will be on the behavioral, environmental and educational diagnosis of heart disease. Specific
behavioral and environmental factors related to health problems can be identified and linked to quality of life and health (Green & Kreuter, 1991). Hundreds of factors can be identified that can potentially influence a health behavior or conditions of living. These factors can be grouped together according to educational strategies that may be used to positively influence behaviors and environments. Factors are identified as those that predispose, reinforce or enable behaviors. Predisposing factors include "knowledge, attitudes, beliefs, values, and perceptions that facilitate or hinder motivation for change" (Green & Kreuter, 1991, p. 28). Skills, resources, or barriers that contribute to or impede change in behavior or the environment are considered enabling factors. Reinforcing factors are feedback and rewards that the person receives in response to a change in behavior. All these types of factors are considered by their relative importance in impacting the target behavior as well as the resources available to influence the factors.

The process of health promotion is aimed at enabling people to increase their control over determinants of health resulting in the outcome of improved health (Green & Kreuter, 1991). Green and Kreuter describe change in behavior as critical to the success of health promotion programs and professional interventions. People's ability to change behavior and to make healthy choices depends on knowledge, attitudes, a supportive environment and skills to adopt the necessary behaviors. In support of the health promotion approach, the Provincial Health Officer recommends that community-based initiatives be undertaken that encourage and support people to adopt healthy behaviors and skills. Typically however, health care professionals import health promotion programs developed in large urban centres rather than exploring the particular characteristics of the target population and the barriers to change found in that community.
The impetus for this study arose from the concern that a community cardiac rehabilitation program did not address the factors affecting the health and recovery of cardiac patients and the impact on their families living in a rural community. One particular community hospital in the Fraser Valley admits more than 430 patients per year to the ICU/CCU for cardiac-related illnesses. Approximately 90 individuals each year are referred to the in-house cardiac rehabilitation program (Chilliwack General Hospital, 1994-95). These individuals are then encouraged by the health care team members to attend Heart to Heart, a community-based cardiac education/support program promoted by the Heart and Stroke Foundation of British Columbia and Yukon. However, the facilitators of the Heart to Heart program have experienced an ongoing problem with insufficient enrolment to be able to offer the program in a timely manner to individuals and family members who are interested in attending. The perception of the nurses involved with cardiac rehabilitation at this hospital is that patients do not perceive a need to attend the Heart to Heart Program following discharge from the hospital although patients and family members are informed of the benefits of the program and are strongly encouraged to attend by the health care professionals involved in their care.

Problem Statement

The literature reviewed abounds with studies that describe the positive outcomes of cardiac rehabilitation programs by measuring knowledge levels of cardiac patients and in some cases, the knowledge levels of their families. The majority of programs are developed by experts in the field and the content is focused on what the experts believe patients and families should learn. Consequently the result is that one program is designed to fit all individuals' needs. Few researchers have considered the relationship between the barriers to recovery of cardiac patients and the impact on their families, particularly focusing on a rural
community environment and the intended outcomes of the cardiac rehabilitation program.

Purpose

The purpose of this qualitative study is to elicit cardiac patients' and their families' perceptions of the behavioral characteristics of people living in a rural community and the environmental indicators that affect their recovery from heart disease. Factors that predispose, enable and reinforce behaviors that influence health will be identified. The perceptions of these individuals is crucial to identifying the necessary supports conducive for actions and conditions of healthy living.

Summary

This chapter has introduced the problem and purpose to be addressed in this study. The literature reviewed does not address the cardiac patients' and families' perceptions of the behavioral and environmental indicators of a rural community that impact the recovery of cardiac patients and their families. The relevance of heart health planning and programming will only be sustained if researchers and health professionals work closely with the community on practical research initiatives. The Behavioral and Environmental Diagnostic Phase and the Educational Diagnostic Phase of Green and Kreuter's (1991) PRECEDE-PROCEED Model of Health Promotion Planning supports the exploration of these differing perspectives to ensure that programs at the community level are relevant and appropriate.

The remainder of this thesis is organized in the following manner; in Chapter Two a review of the literature on specific aspects of cardiac rehabilitation in relation to the behavioral, environmental and educational factors affecting the health behaviors of individuals with heart disease is discussed; and Chapter Three includes a description of the research methodology, the design used, sampling procedure, data collection procedure, data analysis, and ethical considerations. The data collected is presented in Chapter Four with a discussion and summary of the findings in Chapter Five.
Chapter Six presents the implications for nursing practice, education and research.
Introduction

There have been numerous studies done evaluating the effectiveness of in-hospital and out-patient cardiac rehabilitation programs. Outcomes may include for example, physiological benefits, patients' learning needs, patients' level of knowledge, psychosocial factors, motivational factors, self-efficacy and quality of life indicators. A few studies have included family members. The available material for review is massive and so for the purposes of this study, the literature review was limited to the years 1992 through 1996. The key terms of the literature search were health promotion, perceived needs, and cardiac rehabilitation programs.

The majority of cardiac rehabilitation programs are developed by experts and the content is focused on what the experts believe the cardiac patient and family should learn (Mirka, 1994). However, there is limited research available on the perceptions of patients recovering from heart disease. We lack an understanding of the behavioral and environmental factors that affect their health behaviors. In particular we lack an understanding of the needs and perspectives of patients and families who live in rural communities.

In this chapter, the concepts of the Behavioral and Environmental Diagnosis Phase of the PRECEDE-PROCEED Model (Green & Kreuter, 1991) will be used as a framework to present the literature reviewed regarding the indicators of behavioral and environmental factors and their relationship to the cardiac patient's recovery and health. As well the three categories of the factors identified in the Educational Diagnosis Phase of the model will be used to frame a description of the impact of these factors on health related behaviors.
Behavioral, Environmental and Educational Factors

Health promotion program planning involves the assessment of the specific behaviors that could be linked to the identified health problem or goals and the social and physical environmental factors that could be causally linked to these behaviors (Green & Kreuter, 1991).

These behaviors and environmental factors must be specifically identified and ranked because these are what the interventions of a health promotion program will be geared towards positively affecting. Behavioral and environmental factors are directly linked to health and quality of life (Green & Kreuter, 1991). Indicators described by Green and Kreuter that may be used to identify behavioral risk factors are compliance, consumption patterns, coping, preventive actions, self-care and utilization. Economic, physical, services and social indicators are among the environmental factors.

The population of interest in this study is individuals with coronary artery disease (CAD). As noted in the introductory chapter, heart disease remains the leading cause of death in Canada and in British Columbia 59% of the population between the ages of 18 and 74 have at least one of the major risk factors for developing CAD (Heart Disease and Stroke Foundation of Canada, 1995). Prevalent risk factors that contribute to the development of heart disease cited in the British Columbia Provincial Health Officer's Annual Report (Ministry of Health and Ministry Responsible for Seniors, 1994) are common lifestyle and behavioral factors such as smoking, poor diet, and sedentary lifestyle. It is also recognized that lifestyle choices are affected by socio-economic factors such as income, employment and education (Ministry of Health and Ministry Responsible for Seniors, 1994). For example, people who have very low incomes are more likely to smoke and are less likely to know the causes of heart disease.
An understanding of why people behave the way they do is critical to interpreting the current research in relation to rehabilitation of patients with CAD. Although health promotion programs today are state-of-the-art, interactive and often offer incentives if offered in the workplace, the participation rates are still disappointingly low (Prochaska, 1995). Prochaska describes six stages of change that people experience when changing high risk behaviors such as smoking cessation. The stages are "precontemplation, contemplation, preparation, action, maintenance, and termination" (Prochaska, 1995, p. 20A). Professionals need to be sensitive to the stage of change that individuals are in and match health promotion strategies to the stage to achieve much higher rates of participation than traditional programs. Prochaska states that variables such as decisional balance, self-efficacy, and processes of change can be controlled by the individual rather than imposed on the individual. Health professionals can potentially control these causal factors as well and help individuals to progress through the stages of change by matching change principles and processes to each stage the individual is in.

The principal educative strategies utilized to date have been to educate the public about the risk factors for developing heart disease. Significant gaps exist in the evidence of actual changes in societal attitudes, knowledge, understanding and subsequently changes in behavior in relation to these strategies (Pipe, 1995). Pipe believes that the concept of health promotion is not fully understood by many health professionals who tend to focus on risk factor identification and disease process modification rather than emphasizing the prevention of disease through understanding and attitudinal changes that result in modification of lifestyle and health related behaviors. Although statistics show that the incidence and mortality of CAD has decreased over the past three decades, Pipe remarks that many Canadians still cannot identify many of the major risk factors associated with heart
disease. Health promotion and disease prevention strategies have played a significant role in this positive change however increased efforts are necessary to continue to have an impact on a disease which is largely preventable.

O'Connor (1995) describes the principles of the Victoria Declaration developed by the Advisory Board to the 1992 International Heart Health Conference and emphasizes that we already know what is needed to prevent most heart disease. The declaration calls for promotion of a heart healthy diet, no smoking, regular exercise, and a supportive psychosocial environment as the four key areas that health promotion strategies should be aimed towards. Behavior will only be influenced if community program development involves the community in assessing the needs, planning, implementing and evaluating the health promotion program. O'Connor emphasizes the need for evaluation of existing programs as well as for new programs. Research priorities are specifically outlined in the declaration in the areas of "community interventions; demonstration projects to develop intervention knowledge and experience; epidemiology and cost-effectiveness of interventions; heart health education; evaluation methodology; policy research and research into the etiology and management of disease" (O'Connor, 1995, p. 13A).

An example of research that supports the evidence that health care professionals' perceptions of patients' needs differ from patients' perceptions of their needs is that done by Avis (1994) who investigated the perspectives of patients about participating in decision making about their health care. The study involved non-participant observation of 12 patients in a pre-surgery assessment unit to help in the development of the interviews. Avis then facilitated open unstructured interviews with 10 patients in their homes post-surgery. All of the patients expressed opinions of being the "work object" of the health care professionals. Avis suggests that this is a safe position for patients who are self-conscious
about their lack of knowledge about hospital routines, disease and illness. Also contributing to this deference to professional opinion are the unequal relationship between the patient and health care professional, poor communication and centralized health policies. Avis concludes that these enabling and reinforcing factors need to be understood before patients can be encouraged to be active participants in decision making that affects their health. These conclusions can logically be applied to the care of any patients and to the care of patients with CAD.

Gerteis et al. (1993) explored the concerns and needs of patients as defined by the patients themselves. The investigators conducted focus groups with patients and families, reviewed literature and consulted other health care professionals. From the information that was gathered, they identified seven broad categories of care that patients described as most affecting their illness experience. A survey instrument was then designed and more than 6,000 patients who had been recently hospitalized in 62 randomly selected hospitals were interviewed. As well, 2,000 friends or family members were interviewed. Numerous times the investigators found that there were dramatic differences between what the health care professionals could or would provide and what the patients identified as needs or wants.

The major concern for all types of patients was the transition from hospital to home. Twenty per cent of patients expressed concern about difficulties that they may experience at home, 30 per cent did not have medication side effects explained to them, 22 per cent stated that their doctor spent less than five minutes talking about activity at home and 37 per cent reported that nurses spent less than five minutes reviewing home activity. The interviews with friends or family members involved in the care of the patient revealed that the sicker the patient, the more serious were the worries of these caregivers about caring for the patient at home. However, these caregivers reported that they were less likely to receive help from
health care professionals with these worries and that they experienced more problems in getting information about the patient's condition and treatment than caregivers of patients who were healthier. From these findings, the researchers proposed that hospitals need to redefine their operations in ways that will effectively meet patients' needs, that the function of primary care needs to be redefined in generalist terms to decrease the fragmentation in health care, and that health professionals need to explore ways to understand patients' needs and experiences so that they can more effectively provide their professional services.

Factors that affect health behavior can be classified in a manner that makes it possible to group educational strategies that are likely to be used in a health promotion program. Possessing the necessary skills and resources and eliminating the barriers to change are important in changing health related behaviors. Education of patients is one of the vehicles to providing people with the skills that they need.

Several researchers have focused on the learning needs of myocardial infarction patients and the efficacy of cardiac rehabilitation programs (Duryee, 1992; Mirka, 1994; Todd, Dzifa, Stewart, & Wild, 1992; Wang, 1994). Mirka (1994) completed an extensive review of literature that spanned a decade and found that the majority of studies evaluated an increase in knowledge as a major outcome variable with the underlying assumption that knowledge gain will lead to change in behavior. Mirka points out that in most cardiac rehabilitation programs the individual as an adult learner is not an active participant in the identification of the key components of the program. According to Knowles' adult learning principles (as cited in Tornyay & Thompson, 1987), the content for instruction must have meaning to the individual before the individual will be willing to learn. As well, the more the individual is involved in the planning of educational activities, the more likely it is that learning will occur. Knowles also identified that it is important to consider the individual's
previous experiences in similar circumstances and the individual's perceptions in these situations to facilitate the learning process. Mirka concludes that current programs are ineffective in meeting the MI patient's learning needs because the programs are teacher focused and the content is determined by health experts. However Mirka's recommendations for a collaborative adult learning theory based approach to patient education is extrapolated from the literature that she reviewed and is not as a result of empirical research that she has completed utilizing this approach.

Pommier (1992) conducted a study with 100 male patients admitted with the diagnosis of CAD. The purpose of the study was to determine if patients' knowledge of CAD increased significantly from attendance at the CAD classes and what factors affected learning and knowledge retention. The study included a pre-test and demographic data collection, attendance at a one hour CAD rehabilitation class, followed by an identical post-test with one additional open ended question added, one month after the class. The only significant relationship between learning and any of the variables in the study was with marital status. Learning and retention of material was better for married patients than unmarried patients perhaps due to positive reinforcement from their spouses and families. This finding may suggest that spousal and family support are important social factors to be considered in cardiac rehabilitation. However, this study measures knowledge gain only and not observable changes in behavior that might indicate that learning had occurred. Also, since the post-test was conducted only one month after admission to the hospital, no conclusions can be made about long-term benefits of attendance at one 60 minute class.

Campbell (1993) utilized a questionnaire to guide a structured interview with 50 post-MI patients admitted to hospital. Two interviews were conducted with each patient, the first at four to five days post-MI in the hospital and the second interview was conducted at six to
seven weeks in the patients' homes. Questionnaires addressed level of knowledge, profile of mood and activities of daily living. The main findings of the study indicated that all MI patients needed more information about their heart disease and how this would affect their future; many patients did not understand the anatomy and physiology of the heart or the processes that occur during a heart attack; many patients did not understand the explanations given to them; many patients had a fatalistic attitude about their future with heart disease; patients and their families needed more specific advice about physical and sexual activity; many patients and their families experienced more difficulties than they had anticipated in the first few days post-discharge; and only one doctor had given any information about heart disease. Campbell concluded that consideration needs to be given to the person as a whole, including sex, age, culture, socio-economic situation and previous life experience because these factors influence the person's ability and motivation to learn. Effective communication, including eliciting the person's view of their illness, is beneficial to both the patient and the health professional. Also noted is the benefit of self-support groups that provide the opportunity for patients to discuss mutual problems and family attitudes that health care professionals cannot provide.

The PRECEDE-PROCEED model demonstrates the relationship of the causal factors of behavior and the relationship of behavioral and environmental indicators to health and quality of life (see Figure 1). One of the behavioral indicators identified by Green and Kreuter (1991) is self-care. A study that focused on long-term effects of cardiac rehabilitation was conducted by Conn, Taylor and Casey (1992) who studied 197 men and women who had a confirmed diagnosis of MI one to two years previous to the study. The purpose of their study was to explore the relationship between attendance at an outpatient cardiac rehabilitation program and subsequent long-term effects on mood disturbance, quality
Three sets of causal factors influence behavior. Behavioral and environmental factors can be modified to support the behavior, health or quality of life of an individual or others affected by that individual's behavior. Solid lines imply contributing influence. Dashed lines imply secondary effects.

of life, health, and self-care behavior performance such as exercise, diet, medication, ceasing to smoke, and stress modification. Data collection tools utilized were the Perceived Quality of Life (PQOL) scale, Rosenberg Self-Esteem (RSE) scale, Profile of Mood States (POMS), and Health Behavior Scale (HBS). A significant positive association was found between rehabilitation participation and the self-care behaviors of exercise, diet and medications. No significant association was found between attendance at the rehabilitation program and stress modification or smoking cessation.

Conn et al. recommend that cardiac rehabilitation nurses should modify programs to include opportunities for stress management activities and smoking cessation. They also suggest further study of the factors that affect MI survivors' decisions to attend cardiac rehabilitation programs as well as the outcomes of these programs. However, a limitation of this study is that Conn et al. focus on modification of the rehabilitation program content rather than on the individual characteristics of the clients which is essential to influencing behavioral change according to Green and Kreuter (1991).

Daumer and Miller (1992) used the Modified Sickness Behavior Model to study the effects of two types of cardiac rehabilitation programs on CAD patients with respect to the variables of psychosocial functioning and life satisfaction. The indicators identified in the data collection tools used to measure these variables are similar to Green and Kreuter's behavioral and environmental indicators. Ferrans and Powers' study (as cited in Daumer & Miller, 1992) included indicators such as socio-economic status, physical health, friendships, family, spouse, coping skills, psychological defense mechanisms, and community resources to evaluate life satisfaction.

The sample for the Daumer and Miller (1992) study included CAD patients; 21 participated in an outpatient rehabilitation (OR) program and 26 participated in a home
rehabilitation (HR) program. The OR program was a formal weekly program that included exercise, education and counselling. The HR program was a physician-directed plan for the individual with infrequent follow up visits to the physician for general information. The Sickness Impact Profile (SIP) and the Quality of Life Index (QLI) were used to measure the two variables and the data was collected in the subjects' homes six to eight weeks after the coronary event. Spouses also reported on the patients' psychosocial functioning to add validity to the patients' responses.

According to the Modified Sickness Behavior Model, psychosocial functioning and life satisfaction are continually influencing each other. The individual with CAD experiences signs and symptoms of this chronic illness and forms a self-perception of illness. The individual then decides to take action and seeks health care or decides to take no action. Results of the study showed that both groups reported similar psychosocial functioning and levels of life satisfaction. The OR group reported slightly lower psychosocial dysfunction in the domains of social interaction and the psychosocial dimension. The researchers thought that this may have been due to an increase in the participants' expectations as a result of the outpatient experience whereas the HR group did not experience this influence and therefore did not report any changes in these domains. From anecdotal notes, the researchers also concluded that both groups may have wished to impress the researchers and therefore reported a higher level of functioning. Higher scores in both groups for life satisfaction may be attributed to surviving a critical illness event since the study was conducted only six to eight weeks following the coronary event. Both groups reported a high level of satisfaction in the family subscale and the researchers again attributed this to the initial phase of recovery from a critical event. The absence of similar studies limited the comparability of these results and further study was suggested by the researchers. The generalizability of the results of this
Robertson and Keller (1992) selected variables from the Health Belief Model (HBM) and self-efficacy theory to examine the relationships among health beliefs, self-efficacy, and exercise adherence in patients with CAD. The variables of the HBM are used to explain adherence to medical recommendations by explaining health behavior at the individual decision making level. A convenience sample of 51 men and women who had experienced PTCA or CABG in the previous four to eight months participated in Robertson and Keller's study. Eighty-eight per cent of the participants had not attended a cardiac rehabilitation program. Perceived barriers contributed the most amount of variance, followed by self-efficacy and type of surgery. However, only 31% of the variance in exercise adherence could be explained by the variables used in this study. Robertson and Keller caution practitioners in the use of these results because of the complexity of compliance behavior and the complexity of the barriers dimension. Another limitation of this study is that only compliance to an exercise regime was studied. There are other critical compliance behaviors such as smoking, diet and medication intake that have an impact on an individual's health and recovery. Further study is necessary to gain an understanding of patients' perceptions and how these perceptions influence health related behaviors. Patients will not invest the effort into changing their behaviors if they have little commitment to the change.

Health is also affected by many social and environmental influences that are non-behavioral yet are beyond the control of the individual. "The factors which support health include a strong economy, physical safety, a stable income, meaningful work, positive conditions in our schools and workplaces, supportive family and friends, quality care in early childhood, and social justice" (Ministry of Health and Ministry Responsible for Seniors, 1994, p. 25). This report also states that higher incomes and social status are strongly indicative of
better health. This is due in part to the ability to purchase adequate housing, food and to meet other basic needs. Often there is greater security for these individuals, supportive social connections and more control in decision making. In contrast with the socially and economically stable population are the unemployed who experience significantly more health problems and hospitalization. People's ability to change behavior and to make healthy choices depends on knowledge, attitudes, a supportive environment and skills to adopt the necessary behaviors. The Provincial Health Officer recommends that community-based initiatives be undertaken that encourage and support people to adopt healthy behaviors and skills.

Although the research reviewed for this proposal included socio-demographic information, some of which could be identified as environmental indicators, this information was used by the researchers to describe the sample populations studied but few researchers included these indicators as a meaningful part of their analysis of the factors affecting the health and recovery of CAD clients. Only Pommier's (1992) discussion included the positive influence of the social indicator of marital status on the factors being studied.

According to Green and Kreuter (1991), environmental or technological factors constitute most of the modifiable nonbehavioral causes of health problems. They state that priority should be given to those factors that are identified as being strongly related to the health or quality of life goal or problem and also to those factors that are the most likely to result in change in response to interventions. In other words, the target community or population must subjectively agree with the importance of changing the environmental factors and the objective evidence must indicate high potential for change.
Summary

A review of the literature suggests that cardiac rehabilitation programs need to be focused on the individualized needs of cardiac patients and their families and what the patients and families perceive as important to their health and recovery. The behavioral and environmental forces impacting on CAD patients' health and recovery need to be understood before patients can be encouraged to participate actively in decision making that affects their health. Health care professionals need to explore ways to achieve an understanding of the patients' perceived needs and experiences. Although these concerns have been identified by researchers, health professionals and politicians, there has been limited research on the patients' and families' perceptions of the behavioral and environmental indicators and educational factors in a rural community that affect the health and recovery of the CAD patient. A gap exists in the available research about how people want to be involved in their health care. This study is proposed to explore these issues and a description of the methodology to be used is presented in the next chapter.
Chapter 3

Methodology

Introduction

Chapter three will describe the conceptual framework for the study and the use of focus groups as a qualitative research method. Also described in this chapter will be the methodology, assumptions, a description of the methods of participant selection, ethical considerations, data collection and data analysis procedures, and considerations of validity, reliability and limitations of the study.

Conceptual Framework

Green and Kreuter define health promotion as "the combination of educational and environmental supports for actions and conditions of living conducive to health" (1991, p.4). Individuals, groups, or communities may take action or behave in a manner that influences determinants of health. Health promotion is aimed at enabling people to exert greater control over the determinants of their own health. Ideally the individual exerts personal control over their own determinants of health yet there are complex issues affecting the health of others, that are more effectively controlled through community decisions and actions. For example, an individual may choose not to smoke but the community may not support banning smoking in public places such as restaurants.

The most effective centre of activity for health promotion is the community. Green and Kreuter (1991) emphasize that social change, especially with respect to the more complex lifestyle issues, needs to be decided at a level as close as possible to those people most affected. People are more likely to be committed to change when it is relevant to their own purposes or circumstances. Health promotion at the community level assures that programs are relevant and appropriate to the people affected as well as providing people
with an opportunity to be actively involved in the planning process.

The PRECEDE-PROCEED Model developed by Green and Kreuter (1991) involves six basic phases. This process may extend up to nine phases if evaluation of program impact and outcomes is to take place. The PRECEDE framework focuses on outcomes rather than inputs. This focus encourages the planner to ask why before how and subsequently to identify the factors important to an outcome before designing the intervention. The PROCEED framework was later developed to extend the administrative diagnosis step of PRECEDE. The phases of PROCEED involve planning, policy, evaluation, and implementation. The PRECEDE-PROCEED Model offers a procedure for comprehensive planning in a variety of situations. The concepts of the Behavioral and Environmental Diagnosis Phase and the Educational Diagnosis Phase of this model will be used as a framework for this study. Behavioral and environmental factors that link to health related problems are identified in Phase Three of the model and interventions of health promotion plans are aimed at influencing these factors. Phase Four, the Educational and Organizational diagnosis, provides a framework for grouping causal factors of behavior according to educational strategies.

Methodology

Group interviews in social science research originated in 1926 when Emory Bogardus tested a social distance scale (Frey & Fontana, 1993, chap. 2). Focus groups are group interviews that provide data that is more than simply having participants answer the researcher's questions. Focus groups as a qualitative research method are distinguished by the process of interaction within the group discussing a topic of interest to them which is fundamental to providing the researcher with data in the form of transcripts of these group discussions. The predominant area of application of focus groups as a qualitative research
method has been in marketing research. More recently focus groups have been used to help design and evaluate health education and health promotion programs (Anderson et al., 1996; Maillet, Melkus, & Spollett, 1996).

Morgan and Krueger (1993) are committed to advancing focus groups as a legitimate method in social science research. Although much of their knowledge comes from marketing researchers, their personal experiences with focus groups in a wide range of applications over the past several years has led them to the conviction that focus groups are a valuable qualitative research method in social science and evaluation research (Morgan & Krueger, 1993, chap. 1).

Morgan and Krueger (1993, chap. 1) provide meaningful explanations of the assumptions underlying many of the myths surrounding the advantages and disadvantages of the use of focus groups so that the reader can make informed decisions regarding how these assumptions may apply to a particular research project. Morgan and Krueger (1993, chap. 1) have derived from their experiences that many of the "rules" of research from other fields were not applicable to the use of focus groups in social science and evaluation research (p.3). They avoid directing readers to the appropriate or inappropriate use of focus groups because they believe that this would limit innovative research procedures but rather they encourage researchers to make a critical choice of which method or methods are best to use.

Focus groups may be used as the sole means of collecting data or in combination with other methods of qualitative or quantitative research. The typical argument that stems from marketing research is that focus groups are a preliminary tool that require substantiation by quantitative methods. In social science research "there is no a priori reason to assume that focus groups, or any other qualitative techniques, require supplementation or validation with quantitative techniques" (Morgan, 1988, p. 11). Morgan (1988) describes the utility of focus
groups as being valuable for orientation to a new subject, utilization of informants' insights to generate hypotheses, evaluation of different aspects of research studies, development of schedules and questionnaires for interviewing, and obtainment of participants' interpretations of previous study results. Morgan and Krueger (1993, chap. 1) state that focus groups may be preferred to quantitative methods when specification is desired or when the goal of the research project is to generate explanations or theories.

Focus groups combine the elements of individual interviews and participant observation in groups. The strength of focus groups is "the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group" (Morgan, 1988, p.12). The strength of focus groups as a qualitative method is the observation of group interaction on a topic in a limited time period. Practically, focus groups are easy to conduct and are relatively inexpensive and quick compared with other methods. Procedurally, focus groups offer the ability to explore topics and generate hypotheses without a lot of direct researcher influence. The results of research conducted using focus groups can stand alone and be assembled quickly. Focus groups may also contribute to triangulation methods of data collection. However, appropriate planning, recruiting and careful data collection and analysis are essential for achieving meaningful research results (Anderson et al., 1996).

Previously it was thought that a possible weakness of focus groups was that a naturalistic setting was not provided and therefore there was some uncertainty about the accuracy of the data collected. Morgan and Krueger (1993, chap. 1) believe that there is a range of naturalness among techniques for data gathering and that focus groups are more or less naturalistic when compared to other techniques, for example surveys (less natural) or participant observation (more natural). It is often more important according to Morgan and
Krueger, that the researcher matches the participants to the topic of discussion and asks appropriate questions rather than the characteristics of the setting where the research occurs.

Frey and Fontana (1993, chap. 2) describe the advantages and disadvantages of group interviewing, of which focus groups is one type. Some of the advantages of group interviews as a research technique are that the process takes advantage of group dynamics, brings the researcher closer to the social situation, provides insight into the relationships in the social setting, may reduce total cost, may stimulate new ideas, serves as a situation for testing hypotheses, and can contribute to the depth and variation in response to relevant social events. To avoid the disadvantages that may result from group interviews the researcher needs to be aware that the skills required for group interviews are different than for individual interviews. The interviewer must be sensitive to group dynamics and how these dynamics can negatively influence responses within the group. The size of the group can also affect the responses as well as the interviewer's influence. If posturing within the group occurs then false data may be collected. However, with careful planning and interviewer preparedness, these potential disadvantages can be controlled.

In the context of this study, focus groups provided a method of data collection complementary to Green and Kreuter's Health Promotion Model (1988). The focus group method meets the objectives of health promotion planning and education by engaging the community or client as active partners in the process, determining the subjective concerns with quality of life or conditions of living in the target population, verifying and clarifying these concerns with existing available data, documenting the status of the target community in relation to these concerns, and making explicit the rationale for selection of priority problems.
Assumptions

For the purposes of this study, the following assumptions were made:

1) a patient, having experienced an episode of illness related to coronary artery disease, would be able to speak to that experience;

2) family members, having experienced a loved one becoming ill with coronary artery disease, would be able to speak to that experience; and

3) individuals involved in this study want to and can influence the determinants of their health.

Sample and Selection Criteria

Focus groups, due to their limited size, are not representative of a large population and findings should not be used to make inferences to a larger population (Krueger, 1993, chap. 5). Knodel (1993, chap. 3) believes that participants who share common characteristics such as living in the same geographical area, socio-economic status or religious beliefs, are able to relate to each other's experiences and therefore would be able to provide more indepth information than a heterogenous group would.

This study required individuals who had been diagnosed with CAD or who had a family member who had been diagnosed with CAD. These individuals were able to speak to the experience of living with CAD in the selected rural community. A definitive sample size was not predetermined since the data gathered may have driven the need for more focus groups. Concurrent review of the data collected as the research progressed revealed sensitive issues or key informants that required follow up by the researcher.

The following criteria was also used for sample selection:

(1) participants were aged 35 years and older to add breadth to the data,

(2) participants were able to speak and comprehend the English language as the focus
groups were conducted in English,

(3) participants had the physical and mental capacity to participate, i.e. no hearing deficits, and

(4) participants were residents of the District of Chilliwack or the Fraser Valley Region to be representative of the target population.

Selection Procedure

Subjects were recruited by placing advertisements in the local newspapers and by placing posters in the heart support group meeting room, local Family YMCA and Physicians' offices (see Appendix A).

Information letters were given to prospective participants explaining the purpose of the study (see Appendix B) and a written consent was obtained indicating the individual's willingness to participate in the study (see Appendix C). The participants had an opportunity to ask questions about the study before the focus group or interviews began and were asked to sign the consent at that time.

Ethical Considerations

Following acceptance of the research proposal by the University of British Columbia Screening Committee for Research and Other Studies Involving Human Subjects, the investigator presented the information letter and consent form to potential participants. Written consent was obtained from all participants and all participants received a copy of the information letter and consent form. Potential participants were informed that their participation in the study was strictly voluntary. They were also informed that there were no foreseeable risks to them by participating in the study and that sharing their ideas may help nurses to improve care for CAD patients and their families in the future. Participants were notified of the intent to audiotape the discussions during the focus groups and the individual
interviews and that their anonymity would be protected and the audiotapes would be
destroyed following completion of the thesis. The participants were also notified of the
intention to publish the findings of this study and that they would not be identified in any
publication.

Data Collection Procedures

Collection of data in this study involved audiotaped group interviews held at the
community hospital which was centrally located. The interviews lasted 1 to 1-1/2 hours. The
individual interviews were held at the participants' homes and lasted 30 to 45 minutes.

At the beginning of the focus group meeting and individual interviews demographic
data was collected on each participant by asking the participants to complete a short form
(see Appendix D). The demographic data provided information in relation to characteristics
that would be unknown to the researcher prior to the focus group sessions and interviews but
that might have been valuable in the analysis of data collected to compare and contrast
participants' views. Opening remarks made clear that the purpose of the meeting was to gain
insight into what participants themselves think, what people in their community think, and
what influences their thoughts and behaviors.

A trigger question was used to stimulate the opening of discussion (see Appendix E).
Participants of the focus groups were asked to write down ideas that came to their mind in
response to the trigger question. The notes were to help participants to organize some
thoughts before an open discussion got started and may have helped them to remember
important points that they wished to include. The researcher also kept field notes regarding
general observations of the participants such as body language to augment the data gathered
by audiotape.
Data Analysis

The audiotapes were transcribed verbatim by the researcher. The data was comprised of both transcripts and field notes, and was analyzed concurrently as the data collection process proceeded. Data analysis involved identification of themes from significant statements in the verbatim transcripts. New trigger questions were identified for the subsequent focus group and individual interviews from this analysis as themes emerged. These themes provided a description of the phenomenon under study. The researcher returned to the data in each step of the analysis to ensure that the meanings remained true to the original data and that no data was ignored.

Validity, Reliability and Limitations

Traditional methods of establishing reliability and validity used in quantitative research do not apply because of sufficient differences in approaches to the various qualitative methods (Sandelowski, 1986). Guba and Lincoln (1991) describe four factors relating to the criteria of trustworthiness in naturalistic inquiry. The factors are how true, applicable, consistent and neutral the reflection of the research data is.

The truth value of the research is evaluated by the credibility or "... that the reconstructions ... that have been arrived at via the inquiry are credible to the constructors of the original multiple realities" (Guba & Lincoln, 1991, p. 296).

External validity in relation to applicability is less threatened in qualitative research than in quantitative research because of the naturalistic setting and fewer conditions that require controlling. Generalizability is not seen as a concern in qualitative research because the researcher, the subject and the context are particular to each research situation (Sandelowski, 1986). Along with generalizability of quantitative research are sampling procedures to ensure statistical significance. However in qualitative research the sample sizes
are generally small and represent the phenomenon to be studied yet a great deal of verbal data is collected and analyzed.

In qualitative research the researcher should strive to achieve the following according to Sandelowski (1986): first, auditability by making clear the decisions that were made throughout the study; and second, credibility and fittingness by checking data for representativeness and congruence as well as validation from the subjects themselves.

To ensure the rigor of the research being proposed, the researcher was aware of potential problems that may affect the validity of the data. For example, the subjects volunteering for the focus group may be the most articulate or accessible, subject's stories may not be told in the proper perspective, or the researcher's conclusions may not accurately represent all of the data (Sandelowski, 1986).

Reliability and repeatability in the quantitative sense are not applicable to qualitative research because of the uniqueness of human experiences. Rather Guba and Lincoln (1991) propose that rigor related to consistency of qualitative findings should be auditable such that another researcher should be able to follow the decisions made by the primary researcher and come to the same or similar conclusions. The inquiry auditor examines both process and product of the inquiry. Acceptance by the auditor establishes the dependability and confirmability of the inquiry. Using Sandelowski's (1986) strategies, the researcher strove to achieve the criteria of auditability by explaining how the researcher became interested in the study and how she viewed the study; by describing the purpose of the study and how she recruited subjects; by describing how the data was collected, over what time period and in what setting; by describing how the data was analyzed and interpreted and the techniques used to determine the truth value and applicability of the data.
Neutrality is achieved by confirmability according to Guba and Lincoln (1991). It is the neutrality of the findings that is critical in qualitative research not the neutrality of the researcher. When the criteria of truth, auditability and applicability are met then Guba and Lincoln say confirmability of the findings is met. Strategies that the researcher used to achieve confirmability were to check the data as a whole and coding categories and examples used for representativeness; to triangulate across data sources; to check for typical and atypical elements of data in any descriptions or explanations; to try and disprove any conclusions that the researcher drew from the data; and to validate the data with the subjects during the focus groups.

Krueger (1993, chap. 5) describes ten factors that the researcher considered in this study to ensure that the focus groups provided quality data. The first factor considered was that the purpose of the focus group was clear. Focus groups are used to collect information and not for decision-making. Focus groups should not be used to make inferences to a population. The second factor was to choose an appropriate environment that was neutral, easily located and comfortable for the participants. Thirdly, the quality of research could be adversely affected by underestimating the cost in time or money. Focus groups require time to recruit, develop the questions and to complete the analysis. Fourth, Krueger explains that it is important to recruit the right participants who represent the individuals you intend to study. The fifth factor to consider for a quality focus group is to have a skillful facilitator who is sincere, flexible, has a sense of humour and possesses excellent listening skills. Effective questions, the sixth factor, are ones that are sufficiently specific to the topic and an appropriate number to elicit the information needed. Factor seven was to consider the quality of handling data, for example, complete field notes, good quality electronic equipment, and attention to detail. The eighth factor of quality was to have a sequence of analysis that is
systematic and a verifiable process that another researcher could follow and come to the same or similar conclusions. The final report of the research findings must be presented appropriately to satisfy the ninth factor of quality. The final quality factor was to be respectful of the participants, of the clients who requested the research and of the research method itself by being aware of the advantages and disadvantages of the focus group method.

The limitations of this study are the following: the subjects and context of the research are particular to this research situation; participation was restricted to individuals who spoke English fluently for effective communication; and the sample size was limited by the time and resources of the student researcher.

Summary

Focus groups and individual interviews were conducted to collect data regarding the phenomenon to be studied. Participant accounts were constructed by using data collected at the focus groups and interviews. The data included field notes and verbatim transcripts from the audiotapes of these meetings. The data was concurrently reviewed during the data collection and analysis phases of the study. Strategies were utilized to meet criteria for rigor of the research. The limitations of this study were presented.
Chapter 4
Findings

Introduction

The accounts of cardiac patients' and families' perceptions of factors that affect recovery from cardiac disease will be presented in this chapter. The characteristics of the participants will first be described. Following the themes that emerged from the analysis will be discussed. These themes and contrasts were used as a framework to present the data in this chapter. The data presented under the first three themes reflect the participants' reflections of their illness experience: experiential responses to heart disease, the bottom line, and learning to say no. The last three themes are relevant to the purpose of the study of identifying factors that influence health behavior: socializing and support, groups aren't for everyone and the perceived priorities for heart health.

Characteristics of Participants

The community in which this study was undertaken can be described as a retirement community and has a population of approximately 60,000 people. The Chilliwack/Kent/Harrison Community Health Council Health Plan (1995) lists ischemic heart disease as the major cause of death for males (188 per 10,000 population for all ages) and second leading cause of death for females (106 per 10,000 population for all ages). The health plan also includes a statement that from the available data, this area is below the provincial average for most health status indices (p. 14). This region is ranked 12th on a scale of 1 to 21 with 21 being the worst regional rate for premature death. The participants in this study are a small representative group of this community whose lives have been impacted by the illness experience of cardiac disease.
Eight males and three females participated in one of two focus groups. Three males and one female were interviewed individually. One of the males was unable to attend a focus group but was keen to be interviewed. The other three individuals were willing to be interviewed individually but they did not feel comfortable speaking in a group. One woman in the focus group and one male in the individual interview were spouses of an individual with cardiac disease. The males’ ages ranged from 45 to 79 years and the females’ ages ranged from 55 to 69 years. Two males were widowed while the other thirteen participants were married. Two of the male participants were French Canadian and the remaining participants cited English as their primary language. One female was born in England.

Elementary school was the highest level of education for two females and one male, high school level for two females and seven males, university/college level for two males, and one male listed a post-graduate level of education. Ten of the males were retired and one was employed with a security firm at the time of the study. Three of the females described themselves as retired and one described herself as a homemaker. The average annual income ranges for the participants were one at 10,100 to 15,000 dollars, three at 15,100 to 20,000 dollars, seven at 20,100 to 30,000 dollars, two at over 30,100 and two participants did not answer.

Seven of the participants had undergone coronary bypass surgery, one female had congenital heart disease requiring several valve replacements, four participants had myocardial infarctions, and one participant was diagnosed with angina. Three males identified other health concerns such as diabetes and colitis and two females identified hypertension and migraines, and other vascular health problems.

All but one of the participants, including the spouses, had received some form of cardiac education that ranged from watching videos and reading books to comprehensive
formal education programs conducted by physicians and other health professionals. Only one of the participants was not aware of any of the heart support groups such as the Heart to Heart Program, Heart Support Group or the Family YMCA Healthy Heart Exercise Program.

**Experiential Responses to Heart Disease**

The participants' outlook on what the future held for them was aptly expressed by the phrase coined by one of the participants as "walking on borrowed time." The diagnosis of CAD was perceived by the participants as life changing because of the uncertainty about their future and the realization of their own mortality. They recognized that surgical or medical interventions could prolong their lives but no one could guarantee for how long.

The expressions of uncertainty about their future and the fear of dying was verbalized by one participant in his statement that "I know the first day that I walked out of X hospital, I thought I was walkin' on borrowed time, maybe. I was scared to move too fast, that I would, you know ...." Coping with heart disease on a daily basis was another common theme, "...heart disease is with you for the rest of your life so [you] don't feel too safe, you know."

The feelings expressed by participants in relation to the surgical intervention for their cardiac problems were predominately different than the participants who experienced MI's. Four of the males who had coronary bypass surgery denied feeling anxious or worried about their surgery.

The gentleman that was with me, he said 'I don't know how you feel but I'm just scared stiff about this surgery tomorrow' and I said 'I'm not at all scared, I'm just waiting to get in there and get it over' and I wasn't a bit concerned about it.

One participant said he coped with the surgical experience by giving himself a mental block. "Don't you think you can close your mind to what's coming? I think I could and I think that's why I wasn't concerned either, but I think you can give yourself a mental block."
Another factor that contributed to decreased anxiety for a participant was the short time period between being booked for the surgery and having the surgery performed. I had a triple bypass. I didn't really have time to be concerned about it. Like I wasn't worried about it, I wasn't scared about it because I didn't really have time. I got there on a Friday and on Sunday I went to the X and Monday I had the operation.

These men had all received instruction about the surgery and what to expect during pre- and post-operative care. They expressed feeling well informed and prepared for what was to occur.

...they came and told you what they were going to do, you know, in fact, the first guy came in, he says 'before you go in for surgery you'll probably hear the same thing three, four times over'...

These participants also felt there was good communication between the doctors and themselves. "I never felt that the doctors were withholding information because everything I asked, they always explained everything, good as can be."

The importance of including the family in education was recognized as well. "X hospital ran a clinic for about three or four hours and explained to the family, as well as to the member, what was going to happen before, during and after."

However when presented with the possibility of having another open heart surgery when he recently became ill, one participant did express a great deal of fear about more surgery and being transferred to another hospital.

...they shipped me in by ambulance in to X but I was just scared out of my mind that I was going to have another operation and they took the angiogram and they found that two of my old bypasses had collapsed and they said well, they could fix it up by angioplasty, but boy, was I relieved but oh, up until that time I was just right out of
my tree. I didn't know what was going to happen because I was so frightened of having another open heart surgery that it took me a long time to go to the first one. In contrast to the participants who were well prepared for heart surgery, the individuals who were hospitalized unexpectedly with angina or an MI expressed different feelings. These participants expressed strong feelings of fear in relation to the MI event and the real possibility of dying. The younger male who exercised regularly described feeling shocked when he was told he had heart disease. "Well, I think we're all so shocked. I know what happened to me, the doctor from X called Y, couldn't believe it was me. You know you run ten miles every second day and very active ..."

Resentment was another feeling expressed by a participant. "A lot of resentment, you know, people that have heart attacks they resent having it."

The fear of dying was aptly expressed as the realization of one's mortality, "...you suddenly realize you are in Intensive Care and they are looking at you every twenty minutes, suddenly the realization that I was mortal, I was not here forever."

The individuals who had MI's and angina also expressed feelings of being uninformed because they were not always told or did not understand what was happening in their care. Although they could rationalize that there were probably good reasons for why they were not told everything that was happening, their anxiety was heightened because of this loss of control over their circumstances.

I found one thing when you are in the cardiac ward initially, ah, they leave you in the dark for a while because I realize they have to get a lot of tests done quickly on ya and guess we are all human. We always want to know what are they doing this for and all that but they always sometime don't have the time to tell you.
One participant was angered by the lack of information and support while he was in the Intensive Care Unit.

When I was at the ICU here I never had - nobody told me anything. No counselling and what I should do or nothing. They were just bringing me pills in the morning and that's it. Then a doctor said 'you are ready to go today', that's it. So I never learned anything from them and I had to motivate myself, more or less. I didn't have any motivation whatsoever from the nurses. They didn't give me zip. I came home with absolutely nothing.

Experiencing an MI or heart surgery is a life changing experience for the individual with CAD because of the realization of one's own mortality and dealing with the fear of dying on a day to day basis. The first two weeks of recovery, either from surgery or an MI, were identified as critical time periods by informants. These reactions were reportedly shared by their spouses and families as being a stressful time for them as well. Their recovery during this time period was affected by physical limitations, constraints put on them by their spouses and families as well as the emotional constraints of the fear that they and their spouses were experiencing because of the unknowns that they were confronted with. One husband was worried about how his wife would cope with his dressings.

My poor wife had to change all my dressings. When I was in hospital for the bypasses, when I came out of the operation my leg haemorrhaged and it just came up like a balloon. I had to go back in the operating room and opened up again. I was kind of a mess when I went home but she looked after it.

A wife who had had heart surgery herself described feeling scared and worried about looking after her husband after his surgery.
Well myself, I have heart problems too and then X had his surgery done and I was so worried as to how I was going to look after him. How I was going to get through it. I did it. Scared as to what is going to happen next. You are scared to sneeze or cough.

One participant was frustrated by the limitations put on him by his wife.

My wife wanted to wrap me in cotton batting and I wasn't going to do anything. If I wanted something or if I was going to do something, she'd do it. She wouldn't let me do anything until finally I got hold of my doctor and told him what was happening and he had a talk with my wife and told her to 'get him out walking- start walking around the block.'

Patients and spouses expressed that a lack of knowledge regarding what to expect physically and emotionally during the recovery period was an important aspect that negatively impacted the cardiac patient's recovery. As well a lack of health professional support in the home was identified as one of the barriers to recovery.

...after I had my operation I was sent home from the hospital and nobody came to talk to me about how I was getting along or anything else. The only way I could do it is if I went to my own family doctor but he was just a GP and he didn't know exactly what, but that's all. I was left on my own.

One of the wives identified that she had learning needs that were not met prior to her husband coming home and this contributed to her anxiety. "I didn't have a clue. I thought he was going to keel over before I got him in the house.... As the caretaker she (wife) has to know what she is doing."

There are physical and mental effects experienced by the cardiac patient due to a lack of knowledge of what to expect after discharge from the hospital.
Course you worry, then I can't sleep. I couldn't sleep for the first two weeks. You figure if you go to sleep, you're never going to wake up, you really feel that, eh.... Well, I would like to know how I am going to feel. I had no idea I would feel like that. Nobody sort of warned me that I was gonna probably feel nervous and worried about yourself and every little twinge or every little pain is not your heart going bad again, but you feel it is.

After the initial recovery period, spouses and family members described misunderstandings about the individual's capabilities. These misunderstandings hampered the individual's return to a normal lifestyle as well as adding stress in their relationships. One woman tried to encourage her husband to decrease his stress:

I say to him you shouldn't be doing that but he takes it the wrong way and he thinks I mean don't do anything. That's not what I mean at all. Just take the stress out. Do what you're comfortable at. Don't stress yourself 'cause I get stressed out.

In contrast, some heart patients indicated that they were concerned that their families would assume that everything was "back to normal."

I think this is where your family members perhaps are after you've had the surgery and you feel good, like I do right now. Then they forget you're still a heart person and that you do get tired. It just looks like I'm right back to where I used to be, but I'm not. It's a fixup, a bandaid. That's all it is, really.

For some individuals being treated as an invalid was very problematic.

I'm ready and raring to go but everyone around you thinks that all of a sudden you're fragile and they won't let you do certain things, even when you say there is nothing wrong with that, I can do this and they say nope, you have a bad heart. I'm not letting
you do this, you can't do this and even employers say 'well I'm not going to hire you. What happens if you drop dead?'

Other participants felt they received all the support they needed after discharge from the hospital. These individuals experienced less anxiety and more confidence in their recovery as a result of the support they received at home.

...my daughter had got in touch with the nurses' group in Vancouver and, what do you call them? They in turn got in touch with nurses here and there was someone there right now when I came home, and every day for several days and then they would space it out and finally I was okay. I didn't need the care but I certainly had every attention when I came home.

In summary, the participants who perceived that they received adequate information and preparation prior to heart surgery and discharge to home and who received follow up at home appeared to experience less anxiety and more confidence that they would recover from the coronary event. However most participants did acknowledge that they lived daily with the knowledge that there was no guarantee that they would not experience further cardiac problems or even die prematurely.

The Bottom Line

The impact the heart disease event had on the personal lives of the participants depended on how they viewed the illness experience. Some participants described major lifestyle changes while others viewed themselves as having to make minor changes in their lifestyle. Regardless of the degree of change that the participants chose to undertake, the bottom line to them was feeling well and living day to day with the threat of further cardiac problems.
So yes I've had to change my life and alot of people who I sat in the Mess with, or go out with at parties, I can't go out with them now but I still do with other people. But, I can wake up in the morning, no heartburn, I feel good, so you know the bottom line for myself is I'm enjoying it and that's the road I'm going to take, I guess.

Having a positive attitude before his heart attack was seen as important to one participant's recovery.

I guess we have to listen to our body. That's I guess the real doctor is yourself then if you feel the pain then you know how to react to it, not get excited. Do not panic. I guess that's why I'm alive today. Being positive even before my heart attack. I still have some time I have pain but I don't panic.

Another participant stated that reducing stress in his life had a positive influence on his continued wellbeing. "My life is essentially free of stress now and you said it, you feel good and that's the bottom line."

Several informants felt it was important to "set your own pace" to sustain their health, although this was a continual challenge for many of them.

Well it has changed my life completely. Before I was quite active and at work I did everything almost at double time and then after I had my operation, I slowed right down to a crawl. I had to think twice about how fast I do things. I wanted to quit.

A common theme expressed by the participants and verbally identified by one of the focus group participants was stress. "One word I've heard here several times is the word stress ...." All of the participants in one focus group could identify stress as contributing to their ill health and impacting their recovery and continued well being. Stress was also identified by one of the participants interviewed individually. Stress, as described by the participants, is a
very subjective and individual experience that they must cope with on an ongoing basis.

One source of stress for an informant was being the primary caretaker for his wife. "Well, in my case my wife was struck with a stroke and I looked after her for a year and that put stress on my heart.

For another informant the stress of the terminal illness of his wife and the selling of his professional practice was described as contributing to his developing angina.

I can look back now and I could say well, by that time I was recognizing that she (wife) had a terminal cancer problem and I was trying to sell a practice, I was trying to sell a building, you know everything on the pot at one time.

A stressful job was described by an informant as one of the factors that contributed to his heart disease.

Well, I was, yeah it (job) was (stressful) and I put a lot in that.... I did all the construction work and also when the Gulf War was on, things were a lot more stressful during that time because was at a NATO base and the NATO base, we have every country that is involved with NATO stationed at that base. For instance during the war we didn't know who our enemy was ...

In summary, the participants acknowledged that they had to make lifestyle changes to decrease the risk of further cardiac problems. They recognized that heart disease is something they have to live with for the rest of their lives. The degree of change in their lifestyles ranged from minor to major adjustments depending on their personality and own circumstances. Stress was a common factor that the participants described as contributing to their cardiac event and that they continue to deal with to maintain their health.
Learning to Say No

As well as coping with stress, participants could identify other factors that affect their health and that could be managed in their lives. Making changes in their lives is a challenge daily and is very difficult for them. They acknowledged that they had to take responsibility for their health by learning to say no to certain things that they enjoyed. As one participant stated "I found that saying no to quite a few things has helped me. I love to be involved in things. I even have to say no to things I love doing and it's so hard."

One of the participants admitted to neglecting himself by not maintaining a regular walking program although he knew the deleterious consequences of this choice.

I have to admit I've been neglecting myself. I don't walk near enough, and now when I do start walking if I start out too fast then gradually speed up then I'm okay but in the last year and a half I've noticed, with the neglect, that I'm going to have to be careful. It's seldom I take a walk now that I don't have to take one (nitroglycerin) especially this cold weather and the thing is, smarten up man!

Diet was another challenge for participants to maintain. "I think one of the hardest things that I have found is to change your diet. It's very hard, especially if you're cooking for two people and the other one can tolerate more of the fats and stuff like that. I find it really hard."

Many of the participants found that the change in lifestyle that retirement brings to them was a challenge. "Challenges? Trying to retire. That's challenging."

In summary, there are day to day challenges of living with heart disease. Lifestyle changes are difficult to maintain for some individuals although the potential for illness is recognized as high.
Socializing and Support

All but three of the participants were involved in at least one of the local cardiac support or exercise groups. Socializing and support obtained in these groups were perceived benefits expressed by the participants.

Education and peer support were described as benefits for this participant:

If you go to the Heart to Heart first and then go into the Heart Support Group after, it's perfect because you go in right from the stage like you say, you don't know what you're doing, and there's also at the Y (YMCA), they have the exercise program, don't they?

The physical and emotional benefits of the exercise program were important to many of the informants.

I am not involved in any other support group other than the YMCA but as I say it's an addiction. If you miss a day or especially if you miss two days, next time you show up someone's asking you 'hey, I haven't see ya, you been okay?' and it's socializing and I think a support.

The education/support group that this informant attended was very important to her both for the information that she received but also for the ongoing socialization and support provided by the acquaintances that she has met.

The Heart to Heart is what saved me. I was going crazy. I just didn't know what to do. X had had surgery done and I had had surgery done and anyway I went to Z's heart support group, Heart to Heart and I learned a lot. I got alot of support from other people and we're still friends with people now that we met all those years ago at Heart to Heart ... I wish more people would go to it. It was definitely good.
During hospitalization the visit from a volunteer was very reassuring for this informant.

I was quite surprised when someone from your group [volunteer visitation group] came to see me before I ever went in for surgery and the first day I was in X I had a man from the group in there come to see me and he was there the day before I came home, again to see me. I thought it was quite wonderful.

Other supports identified by the participants that contributed to recovery were spouses and family members. For some informants adherence to the cardiac diet was important.

It has really been good for me. My wife is a real help to me though. She watches what I eat very carefully. Everything is baked, fish, chicken, turkey skinned, all that stuff, so I live by the sword - I never vary from my diet.

For other participants it was important to be able to communicate with their spouse so that they could deal with stressful situations together.

There is one thing I find though. If he is stressed out, I ask what's bothering you and he will do it for me, so it really helps in that way 'cause you understand the stress the other person feels.

In summary, cardiac education and support groups as well as the support of spouses and families were described as beneficial to the recovery and continued wellbeing of the participants.

Groups Aren't for Everyone

The impetus for this study arose from the concern that a community cardiac rehabilitation program did not meet the needs of some cardiac patients. The participants were asked to give feedback as to why they thought people did not participate in these groups. As mentioned previously all but three of the participants were involved in one or more of the local support groups.
One factor described by the informants was that people are reluctant to get involved. They don't want to get involved. Some people do, they'd like to go to talk to other people that have the same problem as they have, get some ideas from them how they're handling it and this is what happens. But a lot of people just don't want to or they just say well it's nobody else's business except for mine.

In contrast, some people are already involved in too many commitments.

Others get involved with too many other things that they have a hard time taking that time off, which I think we should you know. Probably schedule ourselves a little better.

Another factor is a lack of understanding about exercise after a heart attack or bypass surgery.

You know, there are a lot of families that think you're foolish if you make your heart work too hard. I think that is one of the reasons that people don't. You have trouble getting them into groups, I don't know.

For some people groups are not seen as problem oriented and therefore would not meet their needs.

I think the heart support group is a very good group too but I think we don't share enough about what are our problems. We're having meetings once a month but between ourselves I think we are missing there. Some, they come and you don't see them again, maybe for that reason.

People who "feel well" don't think that they need a support group.

I think people start feeling really well and then they say they don't need that club anymore, you know, but instead of getting active in it, maybe helping somebody else that is in trouble.
There is lack of reinforcement by the physicians to attend education and support groups.

How many physicians in town who support people if they have heart attacks? I heard over the years quite a few people I’ve talked to 'my doctor doesn't want me to do that.'

Some people are not comfortable in a group setting.

We [heart support group] think that people come in and get what they need. Sometimes they enter because they still need reassurance. They don't have confidence that they are going to survive... in fact we had one of our founding members was a person who was a civil servant at X and he was a real iconoclast. He attended two or three meetings and he says 'I just don't feel comfortable at these meetings. I feel that when I speak that everyone is looking at me.'

For some people, their needs may be short term and when these needs are met by the support group then they leave.

We [heart support group] give them what I think they need for a period of time and then other interests or maybe they think that they have outgrown us, and they move on and other people come in. I don't think it is necessarily their educational or their economic level that is determinate.

A lack of time was a factor described as well.

Let's take the productive years, from the twenties to the late thirties. You are married, you have a mortgage, you have a car payment, you have a furniture payment, you got three little rug eaters (children). You don't have a hell of a lot of time to come out and have the luxury of sitting around for a couple of hours listening to someone pontificate about what they have to deal with on a daily basis.
Younger adults think that these groups are for old people.

Even you see some of the oldtimers, they have this mall walking. A lot of people don't want to go to that because they say 'I'm too young to be in a group like that' but it might be an idea now and again. It all depends on how they are approached. You know, like anybody who has had the problem they would say it is not a bad idea but somebody who has a problem but who hasn't had it rectified yet, he might, that person might think it's for the older generation.

For some informants heart disease was viewed as a personal experience. During the recruitment process the researcher was told by three individuals that they did not like to participate in group settings. One of the participants who was interviewed individually did not want to attend the Heart to Heart group because he felt the MI was a personal experience just between himself and his wife.

Quite a ways to go (travel) you know and this Heart to Heart is tacky. I bet you don't get too many there because it is a personal thing, you know, and I think it is more personal than anything else. It's kind of, I think, there is a lot of people that won't talk about and I think that is one of them. Not too much anyways. It's always on your mind. Like I said, it's a little personal.

The individual who cited transportation and distance to travel to these support groups as deterrents for participation was interested in an education session if it was located closer to home.

I have that transportation problem. I think when you really need that [support group] is when you are getting out of hospital. When you have no idea that other people are going through the same thing, none whatsoever. You have no idea. You are thrown out of the hospital and that's it. You are on your own....It would be great here in X.
Of course we are away from a big hospital that deals with it and it would be kind of reassuring for a person to know that others are having the same thing as you are having and that you are not the only one.

Even though the MI event was viewed as a personal experience, it was acknowledged that education would be of benefit, however with the following stipulation:

Well, you know unless you're a professional, how are you going to understand it? Unless they can tone themselves down a little bit so they can talk the proper syllables or whatever, you know, so you can understand them.... Oh, I'm sure they [other people] would [be interested in an education group], because that would give socializing.

You see that is a big part. You know a group like that I think would work.

The informants in this study described many perceived barriers to participation in education and support groups. People may feel that they do not have the time to attend these groups or that group settings are not what they are comfortable with. Other factors may include distance to travel and transportation.

The Perceived Priorities for Heart Health

An important aspect of this study was to explore what the participants identified as needed resources in their community (for cardiac patients). When asked what their community needed to help people manage their heart disease, several of the participants responded by saying a cardiologist was needed.

I would like to see a cardiologist come into X. I find it very stressful and my husband has had surgery too. He has to drive us into Y, being there for a specific time. In one day I have to see a cardiologist, get an echogram, and I have to see a pacemaker clinic at the same time. I find it quite stressful. I feel it is needed.
As well as a cardiologist, another informant felt that the older population of this community should receive the services of a gerontologist.

There should be a cardiologist in a population centre this large. There should be also a medical doctor specializing in geriatrics and there isn't and you can't say they [local residents] are getting the same kind of care [as city residents].

Other participants felt that a health professional with special education about heart disease and cardiac surgery was needed for follow up after discharge from the hospital.

Well, I think that what we should have really is somebody with proper education to follow up after you come home from the hospital, so they can talk to you about your worries and problems. ...after I had my operation I was sent home from the hospital and nobody came to talk to me about how I was getting along or anything else. The only way I could do it is if I went to my own family doctor but he was just a G.P. and he didn't know exactly what, but that's all. I was left to my own.

Retention of nurses with cardiac experience was viewed as very important in the hospital setting.

We need the nursing people who have the expertise for cardiac to be retained in the cardiac ward ... who have a wealth of information sometimes surpassing in practical terms the actual physician.

Dietitians were viewed as an important member of the health care team.

Somethin' else too, like you're talking especially trained professionals and stuff like that, nurses. Something else I'd like to see in there is dietitians because everybody tells you what you can or what you can't do and stuff like that but how many times do you actually see a dietitian and say well, what can I do, what kind of food should I eat and I didn't know about like fat content.
A centre that would provide education, exercise facilities and professional support and monitoring was identified by one informant.

I think basically if you have a centre, like a rehab centre. I had my heart attack in X but after three months in there, you basically know what to do yourself ... the rehab centre took me from a point of distress where you feel the stress and everything about the bypass and all that stuff. Before you know it you're back on easy street again, yourself, so I think a rehab centre is a must.

More globally, one informant viewed funding in health care as inadequate. "You would like to see adequate funding and from adequate funding flows some of the things we have just been talking about..."

As mentioned previously, transportation was identified as a factor that impacts the cardiac patient's access to health resources. Transportation to the city for tests and doctor appointments was one issue identified.

I think it is not just transportation for [older people], you never know, we are talkin' about the heart here okay? If we got to continue goin' to X, you never know what kind of news you are going to receive at the other end. If the news is not good should you be driving? Okay, also when you know they just keep them in the hospital for seven days before they kick them out and send them home, there is no way that a person should or could be driving at that time.

Transportation to facilities within the community was another concern identified by the informants.

The transportation is inadequate. If one takes a look at the taxes a person pays, the amenities that are available to the X [city] resident versus the Y [local] resident, there are no comparisons other than the quality of life which is where you can get out to
look at nature's beauty. If you can get out. If you have transportation.

These participants felt strongly that their community needs a cardiologist, health professionals with knowledge of cardiac rehabilitation methods to follow up in the community and adequate transportation both locally and to the city.

Summary

In summary, the participants live daily with the uncertainty of their future and the fear of dying prematurely due to coronary artery disease. During hospitalization the participants who required surgical intervention did not experience the feelings of fear and anxiety that the participants did who experienced the sudden onset of an MI or hospitalization for angina. The participants who had coronary bypass surgery were well prepared by health care professionals about the surgical procedure and post-operative hospital care. In contrast, participants who experienced MI's or angina were not prepared for this event and expressed feelings of fear of dying and a sudden awareness of their mortality.

Spouses, as well as the cardiac patients, identified the first two weeks at home after hospitalization as critical times. Spouses expressed feelings of stress and worry about the individual and how to care for them. The cardiac patients expressed feelings of uncertainty about their recovery in terms of fear of another MI or even dying yet at the same time wanting to be active and return to their previous activity level. Some of these individuals were frustrated by the over-protectiveness of their spouses and family.

Several of the participants felt that they received all the support that they needed after discharge from the hospital. However a few of the participants did not receive follow up at home or felt that it was not timely for their needs in the first few weeks of their recovery. These participants felt they were not prepared adequately about what to expect physically and emotionally.
Many of the participants identified stress as contributing to their ill health and impacting their recovery. Spouses also identified stress related to their loved one's illness as having an impact on their role as caregivers, particularly in the early recovery period.

The impact that the illness event had on the participants varied from making minor lifestyle changes to a major impact on their lives. Participants could identify the factors that impacted their health and acknowledged that they had to take responsibility for their health.

All but one of the participants felt that cardiac education, support and/or exercise groups were beneficial. The one participant who stated that he was not comfortable in group settings did acknowledge that education and socializing were beneficial in the right milieu. All but three of the participants were strong advocates for these kinds of groups however they recognized that group settings are not for everyone and could offer reasons why they thought some people do not participate. They also identified the issues that they perceived as priorities for individuals with heart disease such as the need for a cardiologist in the community, improved transportation and health professional support in the early recovery phase.
Chapter 5

Discussion of the Findings

Introduction

In this chapter the findings of this study will be discussed in relation to the purpose of the study, the framework used to conceptualize the problem, and the literature reviewed in Chapter Two. The purpose of this study was to elicit cardiac patients' and their families' perceptions of the behavioral characteristics of people living in a rural community and the environmental indicators that affect their recovery from heart disease. Focus groups as a qualitative research method were used to collect an extensive amount of data from the participants' perspectives. As well, four participants were interviewed individually as key informants.

The data presented in Chapter Four included the factors that the participants identified as affecting the health and recovery of the cardiac individual. The discussion in this chapter will address the factors that predispose, enable and reinforce the behavioral characteristics and the environmental indicators that affect health and recovery from heart disease in relation to those identified by the participants. Educational factors that impact health related behaviors will also be discussed.

Behavioral and Environmental Factors

Health promotion program planning involves the assessment of the specific behaviors that could be linked to the identified health problem or goals and the social and physical environmental factors that could be causally linked to these behaviors (Green & Kreuter, 1991).

These behaviors and environmental factors must be specifically identified and ranked because these are what the interventions of a health promotion program will be geared
towards positively affecting. Behavioral and environmental factors are directly linked to health and quality of life (Green & Kreuter, 1991).

An understanding of why people behave the way they do is critical to interpreting the current research in relation to rehabilitation of patients with CAD. Although health promotion programs today are state-of-the-art and interactive, the participation rates are still disappointingly low (Prochaska, 1995). Integral to a health promotion model is the concept of collaboration and to involve the people who will be most affected. Perceptions of needs are derived from the individual's personal experiences.

The four key areas that health promotion strategies should be aimed towards as outlined in the Victoria Declaration (O'Connor, 1995) are promotion of a heart healthy diet, no smoking, regular exercise, and a supportive psycho-social environment. One or more of these key areas were identified by the participants in this study as causes of their heart disease as they discussed how stress, high fat diet, sedentary lifestyle and smoking contributed to their illness. The majority of the participants identified stress and a high paced lifestyle as the major contributors to their heart disease as well as having an impact on their continued wellbeing.

Beliefs, values, attitudes, knowledge and confidence are predisposing factors that provide the motivation for behavior (Green & Kreuter, 1991). The participants in this study shared the values of good health and valuing their life yet their beliefs, attitudes, confidence and knowledge in relation to heart disease influenced each individual personally. All but one of the participants held the belief that health care professionals were trustworthy and had faith in the professionals' abilities to provide them with appropriate care including the education that they required to cope with their heart disease. However their attitudes toward making behavioral changes varied. For example, one participant stated that he "lived by the sword"
and strictly followed the cardiac diet compared to other participants who stated that "life needs a few rewards" and that moderation was the key principle to be followed. Other changes in the personal lives of the participants varied from major changes such as ceasing to smoke, changes in social contacts, learning to slow down and setting their own pace, to the attitude that heart disease is with them for the rest of their life and that surgical or medical interventions just gives them another lease on life for a while. These attitudes provide the individual with the rationale or motivation for their behaviors. The example given demonstrates how knowledge alone may trigger motivation to act but does not always result in changes in behavior.

The behavior can be made possible by the use of resources in the environment called enabling factors. Accessibility to health resources, such as the hospital for acute care, are available to all of the participants. However, many of the participants, particularly the ones who were followed by a cardiologist in another city, described having to travel as a hardship for them both physically and emotionally. Also, accessibility to an educational program or support group was a barrier for the participants who lived outside of the immediate community. Specifically noted by these participants were transportation, distance to travel to attend a program and cost of programs as a deterrent for them as pensioners.

As noted previously, all but three of the participants were involved in at least one of the local cardiac support or exercise groups. These participants expounded upon the positive influences that participation in these groups provided for them. The support provided by family, peers and health care professionals in these groups are reinforcing factors that support both the cardiac patient and family. Participation in these groups also provided the patient and family with knowledge and confidence that can positively influence their behavior and lifestyle.
Participation in groups is not seen as beneficial or practical by all for a variety of reasons. Some of the potential participants who contacted the researcher declined to participate because they did not feel comfortable in the group setting. One of the participants who agreed to be interviewed individually also stated that the MI experience was too personal to share in a group. Other reasons proffered by the participants were that people don't want to get involved in groups; people are too busy with other commitments; people begin to feel well or think that they have received what they need and do not return; younger adults think these groups are for older people; or that their families and physicians do not support their attendance at these groups.

Educational Factors

The process of health promotion is aimed at enabling people to increase their control over determinants of health resulting in the outcome of improved health (Green & Kreuter, 1991). Green and Kreuter describe change in behavior as critical to the success of health promotion programs and professional interventions. People's ability to change behavior and to make healthy choices depends on knowledge, attitudes, a supportive environment and skills to adopt the necessary behaviors.

The principal educative strategies utilized to date have been to educate the public about the risk factors for developing heart disease. Significant gaps still exist in the evidence of actual changes in societal attitudes, knowledge, understanding and actual changes in behavior in relation to these strategies (Pipe, 1995). Pipe believes that the concept of health promotion is not fully understood by many health professionals who tend to focus on risk factor identification and disease process modification rather than emphasizing the prevention of disease through understanding and attitudinal changes that result in modification of lifestyle and health related behaviors.
The participants who had had surgical intervention for their cardiac problems received the traditional education strategy that focused on identification of risk factors and disease process modification. These participants felt that they were well prepared for the hospital experience because of the education that they had received prior to surgery. However the unanticipated hospitalization due to an MI or angina produced feelings among the informants that ranged from shock to resentfulness. These participants expressed strong feelings of fear of dying. They also expressed feelings of being uninformed because they were not always told or did not understand what was happening in their care. The experiences of the MI patients in this study are consistent with the main findings of Campbell's study (1993) in which all MI patients stated they needed more information about their heart disease and how this would affect their future; many patients did not understand the explanations given to them; many patients had a fatalistic attitude about their future; patients and their families needed more specific advice about physical and sexual activity; and many patients and families experienced more difficulties in the first few days post-discharge than they had anticipated.

The majority of cardiac rehabilitation programs are developed by experts and the content is focused on what the experts believe the cardiac patient and family should learn (Mirka, 1994). Newton and Killian (1988) state that one of the greatest areas of conflict in families is the differences of opinion about medical service and instructions. Spouses of individuals recovering from MI may feel responsible and over-protective and it has been found that their learning needs are similar to those of patients (Newton & Killian, 1988).

Newton and Killian's (1988) findings are consistent with what the participants in this study identified in that the first two weeks of recovery at home were the most critical time period for them. Spouses identified this time period as the most stressful for them. A lack of
information about the care of the heart patient, including activity, and signs and symptoms of impending problems were the common sources of stress for the patient and spouse. This is also consistent with the findings in Newton and Killian's (1988) study in which patients and spouses expressed the need for more information about activity, complications, signs and symptoms, stress management, and CPR. Other research that supports these findings is that done by Jaarsma et al. (1995) who found for both bypass and MI patients that areas of concern were emotional reactions, physical condition, side effects of treatment, and rehabilitation and convalescing. Jaarsma et al. (1995) also noted that in general the learning needs of the spouses were expressed earlier than the patients supporting the belief that the family needs to be included in education programs during hospitalization and in an outpatient setting. Patients and families interviewed by Gerteis et al. (1993) identified that the major concern for all types of patients was the transition from hospital to home, specifically worries about problems or difficulties that they might have at home and side effects of medications.

Many of the participants in this study had follow up by a Public Health Nurse for several visits and felt that they were very well supported. However the MI patients expressed the need for earlier visits immediately after discharge from hospital due to their anxiety related to lack of information in relation to their concerns. Duryee (1992) found in her review of the literature that in-hospital education programs partially met the learning objectives of these programs however the ability to increase patients' knowledge and promote lifestyle changes after discharge were inconsistent across programs and subject matter covered.

All but three of the participants were involved in at least one of the local education, support or exercise groups. The perceived benefits of these groups were education, regular monitored exercise, and socialization and emotional support from others with similar medical
conditions and associated concerns. These findings are consistent with what Jaarsma et al. (1995) found where patients wished additional information on organizations where they could seek help in case of problems, talk to fellow patients and participate in support groups. Campbell (1993) also noted the benefit of self-support groups in providing patients and families with an opportunity to discuss mutual problems and family attitudes.

Summary of Findings

In summary, three categories of factors affect a different type of influence on behavior. Factors are identified as those that predispose, reinforce or enable behaviors. Any behavior can be described as a function of these influences in a collective manner. The phenomenon of behavior is multifaceted and no one behavior is caused by one factor (Green & Kreuter, 1991). Health and quality of life are influenced by these behavioral and environmental factors.

The participants of this study were able to share their perceptions of the behavioral characteristics of people in their community and the environmental indicators that affected the cardiac individual's recovery from heart disease. All of the participants were able to identify the risk factors that they believed contributed to their or their spouses' heart disease. Stress was the major risk factor described by most participants yet stress is a personal experience and varies from individual to individual. Although the participants had knowledge of the risk factors for heart disease and valued life, not all of the participants shared the attitude of being willing to make major lifestyle changes. Attitudes provide the rationale or motivation for change in behaviors.

All but one of the participants were very satisfied with the care received in the acute care setting. For most, the follow up at home by the Public Health Nurse was seen as very supportive. However, the perceived need for a cardiologist rather than solely internists in the
community was noted by many of the participants. Transportation, distance to travel to
health resources, the physical and emotional stress related to travelling, and cost were seen as
factors not facilitating health or recovery for many in the immediate community and
community at large as well.

A group setting for education, support or exercise was perceived by the majority of
the participants as very beneficial to them or potentially beneficial if the group was accessible
to them. However, the participants did acknowledge that some people do not attend formal
programs for various reasons such as the time commitment, cost, the group setting itself or
non-support of families and physicians.

The majority of the participants had received some form of cardiac education while in
the hospital setting however the majority also commented that they would have liked more
information about what to expect upon discharge to home in the first few weeks, activity
level and warning signs to watch for. An earlier visit by the Public Health Nurse was seen as
beneficial support for the MI patient and family.

Conclusions

The participants in this study expressed many of the same concerns that subjects in
urban studies have stated. In contrast to the urban setting, the participants from this rural
community expressed needs for improved transportation both locally and to the city as well
as access to a cardiologist and gerontologist in their own community or region. Additionally,
the participants who lived outside of the immediate community expressed the need for an
educational program or support group closer to their home due to the barriers of distance to
travel and lack of transportation resources. For some of the participants who live on
pensions, the cost of programs was a deterrent to attending.
The beliefs, values, and knowledge level of heart disease of the participants in this study were fairly consistent yet the individuals' attitudes seemed to contribute to the variation in willingness or level of motivation to make changes in behavior and lifestyle. Although in-hospital cardiac education programs can provide general information to patients and families, there is a need to give specific information regarding the first few weeks at home and early home support by health care professionals to reinforce this information and to provide emotional support.

A group setting for educational, psychosocial and physical exercise is beneficial. However, families and physicians need to be educated to the benefits of these programs. Alternative resources may be required for people who cannot or will not attend these groups.

For some people in a rural community attending a support group was not a viable option for them because they felt their privacy was being invaded. An alternative resource for some participants may also be their strong connection to their religious community.

Summary

In this chapter the findings of this study were discussed in relation to the purpose of this study, the framework used to conceptualize the problem, and the literature reviewed. The findings were summarized and the conclusions presented.

In conclusion, the findings of this study suggest that although the cardiac patients in this community may have beliefs and values consistent with healthy lifestyle choices and a general knowledge of the risk factors for heart disease, these factors alone do not produce change in health related behaviors for these individuals. Attitudes as well must be understood as a key motivator for change. All of these factors must be considered collectively as key motivators or rationale for change.
To enable people to choose health related behavior and to reinforce the behavior, health care professionals need to promote the resources that are available to cardiac patients and their families. These resources may include educational programs, support groups, exercise programs, religious community, transportation resources and financial assistance programs.

Health care professionals need to involve the patient and family in assessing what their needs are for a healthy recovery and rehabilitation. Communication among the health care professionals across the care continuum is key to planning and coordinating care effectively for the cardiac patient and family.
Chapter 6

Implications of the Findings

Introduction

The implications for nursing practice, nursing education and nursing research will be presented in this chapter.

Implications for Nursing Practice

Nurses in acute care practice in a rural setting need to be cognizant of the fact that the patient and the family have needs for information and care planning specific to them. With decreased length of stay in hospital and workload demands on the nurse, the nurse has an obligation to her patients and their families to ensure that they are prepared for their discharge to home and the expectations of the first few weeks of recovery. As well, Public Health Nurses need to be aware of the need for psycho-social and educational support to these individuals and early prompt interventions to meet their needs.

In order to provide the psycho-social and educational support as well as the physical support to their patients and families, the nurse should complete an individualized assessment of the patient's and families' beliefs, values, attitudes and knowledge. The nurse should have knowledge of the resources available to the patient and family in the rural community to be able to inform the patient and family of these during the hospital stay and to reinforce this information during the early recovery period. These resources may include programs for education, exercise and financial assistance as well as support groups, religious connections and transportation resources.

Implications for Nursing Education

The promotion of the nurse as a coordinator of care for discharge planning and during the recovery period begins with each nurse's educational development. Students need to be
prepared to take on the role of coordinating their patient's care which includes the continuum of care in the home during recuperation and rehabilitation.

Nurse educators need to prepare their students to involve the patient and their family in planning for discharge including the identification of specific learning needs and resources available to them in a rural community. Individual assessment includes exploration of the beliefs, values, attitudes and knowledge of the patient and family.

Implications for Nursing Research

The sample size and specificity of the rural community in this study limits the amount of direction that can be taken from the findings. However, the findings suggest that further study in this area is required to better understand the factors that influence health behaviors and quality of life in rural and urban communities.

During the analysis of the data other areas of interest were raised that invite further research of the cardiac patients' and families' experiences. These include: (1) the maintaining of lifestyle adjustments over time; (2) the differences in gender and the experience of cardiac disease; (3) the experiences of the spouse or significant others during the early rehabilitation period; (4) the differences in perceptions of the cardiac experience in relation to the younger adult; and, (5) the influence of beliefs, values and attitude on changes in health related behaviors.

Summary

In summary, nurses involved in the care of cardiac patients and their families living in a rural community have a role in facilitating a patient's discharge from hospital and during the first few weeks of recovery by assessing the individual's and family's needs and providing them with the information about physical and emotional expectations during recovery as well as the resources available to patients and families in their community. Resources that nurses
should consider are education programs, support groups, exercise programs, religious
connections, financial assistance and transportation resources.
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Appendix B

Participant Information Letter

My name is Laurel Wichmann. I am a Registered Nurse and a student in the Master of Science in Nursing Program at the University of British Columbia. I am interested in learning about the experience of people who have heart disease including their families' experiences. My study is entitled "Patients' and Families' Perceptions of the Factors That Affect Recovery From Cardiac Disease: A Rural Community Perspective".

I am inviting anyone who has heart disease and any family members to participate in this study. Your participation is valuable as I believe that the people living with heart disease every day are the best able to provide health care professionals with information about what it is really like to have heart disease. Participation will involve attending a focus group at a central meeting location. I will conduct the interview which will take about 90 minutes and it will be tape recorded. Participation is not restricted to you as a family unit although I do ask that family members be at least 18 years of age.

Although your participation in this study may not benefit you directly, the sharing of your experience will help nurses better understand the factors that affect the health of individuals with heart disease in our community which will help to improve care for patients in the future.

Your participation in this study is strictly voluntary and if you do not wish to participate your decision will not affect any present or future medical or nursing care that you may require. You may withdraw from this study at any time.

The information received during this study will be used for the purpose of a master's thesis. The audiotapes will be destroyed immediately after the thesis is completed. The
Appendix D

Demographic Data Sheet

Please complete the following information with a check mark ( ) or hand printed answer.

(1) Are you ...?
   Male ____   Female ____

(2) What is your age?

   35-39 ____       60-64 ____
   40-44 ____       65-69 ____
   45-49 ____       70-74 ____
   50-54 ____       75-79 ____
   55-59 ____       80-84 ____

(3) What is your marital status?

   Single ____
   Married ____
   Divorced/Separated ____
   Widowed ____

(4) What is your first language?

   Example, Dutch _____________________

(5) What is your present occupation?

   Example, Retired _____________________

(6) What was your highest level of education?

   Elementary School ____ College/University ____ High School ____
   Post-Graduate ____
(7) What is your annual income range?

- 5,000-10,000 ____
- 10,100-15,000 ____
- 15,100-20,000 ____
- 20,100-30,000 ____
- 30,100 and over ____

(8) Do you have health concerns other than heart disease? Example, Diabetes.

Yes ____  No ____

If yes, please list: ___________________

____________________

____________________

____________________

Thank you for completing this information.
Appendix E

Focus Group Trigger Question

(1) What do you think our community needs to help people manage their heart disease?