

LIVES OF RURAL WOMEN AFTER MYOCARDIAL INFARCTION:

A CRITICAL ETHNOGRAPHY

By

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LIVES OF RURAL WOMEN AFTER MYOCARDIAL INFARCTION

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## Abstract

This study examined how rurality influenced the lives of twelve women who survived a myocardial infarction (MI). Using a critical ethnographic approach, in-depth interviews with women from southwestern Ontario were analyzed to uncover the ways in which social, political and cultural forces associated with rurality, influenced women's choices, challenges and experiences post-MI. Women were encouraged to filter their post-MI experiences through their "rural lens," to explicate their rural lives, and to reflect on the forces that shaped post-MI events and perceptions. Participant observation and interviews with nurses and physicians who provided post-MI care to rural women were also utilized to explore overt and covert influences in women's recovery.

Data analysis revealed four narrative themes. Reticence was evident in the tendencies of women to minimize articulation of their worries and to accept the course of their post-MI lives with few questions. Referral Games characterized the crucial role rural physicians played in strategizing to help women access specialty diagnostic and treatment in urban referral centers that were unavailable in rural communities. Resourcefulness was displayed by women in response to meeting their own needs for managing their recovery, so they did not have to depend on others, or if system resources were unavailable. Women placed great value on the support and advocacy they perceived in Relationships with rural health professionals and institutions, and viewed themselves as lucky to live in communities where such connections could be made.

The strength of the rurality influence(s) on the narrative themes could not be concluded. Women perceived themselves as different from urban women however, some

findings supported existing post- MI literature based on urban populations and previously identified rural health issues. Findings support the inclusion of rural people in policy and resource planning and supporting best practices of rural health professionals on whom women rely.

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## Chapter 1

### *Introduction*

I should have been aware of the possibility of a heart attack I guess-especially after what happened to my mother, but her life and mine were so different that I thought I was safe.

She had raised a family alone while working outside our home, whereas my husband and I look after everything together and I work at home. But I guess my mother and I were alike in both getting so caught up in looking after the needs of others, that we forgot to take better care of ourselves – forgot to listen to our own bodies. And I had also become concerned as I saw the years slipping away, that I might not have enough time to do all the things I still wanted to do in my life, so I worked faster and harder than ever. I was going full speed when this heart attack hit. No warning, nothing, but I was luckier than my mother- I lived to tell about it (Oost, 1999, p.16).

This research is based on the lives of twelve rural women who considered themselves ‘lucky’ in that they lived to tell their stories after surviving a heart attack, otherwise known as a myocardial infarction (MI). Like Oost (1999), a rural woman herself, these rural women were caught off-guard by their medical diagnosis and were individually challenged to absorb this experience and its implications into their life context. Specifically, this research aimed to explore, through the voices of the women participants, how rurality affected their lives after MI.

The critical ethnographic method chosen to elucidate the forces shaping women’s lives after MI offered a unique way to uncover the health challenges of a relatively silent

and invisible group of rural people who have been marginalized from dominant dialogues on many levels. The description of the method as a relevant approach for investigating marginalized populations is put forward by Thomas (1993):

Critical ethnography is a type of reflection that examines culture, knowledge, and action. It expands our horizons for choice and widens our experiential capacity to see, hear, and feel. It deepens and sharpens ethical commitments by forcing us to develop and act upon value commitments in the context of political agendas.

Critical ethnographers describe, analyze, and open to scrutiny otherwise hidden agendas, power centers, assumptions that inhibit, repress, and constrain. Critical scholarship requires that commonsense assumptions be questioned (p. 2-3).

The choices that rural women have available in their recovery following MI are based on a set of circumstances which women may or may not be aware of, but that arguably shape the course of their post-MI lives. This research was structured so that women's "knowing" voices shaped the construction of what would be "known" and offered a way for their previously silenced experience to be heard (Lincoln, 1993). The way in which "being rural" influences choices and subsequent life consequences for women after MI has not been a focus in the dominant research discourse, but is well-suited to critical ethnographic inquiry. Further discussion of the method will appear in Chapter 3.

This research articulates a rural perspective that is different from that taken in the traditional health and research paradigm. That rural-urban differences do exist and that rural people's needs and the rural context had not been well addressed by the current institutions, drove the establishment of the Canadian Society for Rural Health Research and the Office of Rural Health as a part of Health Canada. The purpose of this Office

was “to ensure that the views and concerns of rural Canadians are better reflected in national health policy and health system renewal strategies” (Health Canada, 2001). There is a need to maintain vigilance in promoting the unique rural health perspective by generating health research that illustrates the issues of importance for rural people, lest their voices be silenced by the increasing din of those who are focussed on urban health. (Dr. Nancy Ross, personal communication, October 25<sup>th</sup>, 2002). Additionally, there is a need to question the prescriptive approach to health care that can negate the individuality of patient’s lives, so that systems and their practitioners become more person-centered and sensitive to the influence of geographic place in health.

This chapter provides an introduction to the foundational contexts of the study by exploring my journey to this research, elements of the rural perspective, and general knowledge that framed understanding of the life world of post-MI rural women.

### *Background*

#### *Researcher Context: My Journey to Exploring the Post-MI Lives of Rural Women*

Butterfield (1990) notes that the critical approach by nurses helps them to “see beyond the perpetuation of status quo ideas and may be able to generate unique ideas that are unencumbered by previous stereotypes” (p.6). The application of this critical philosophical approach gave rise to the development of the research question and shaped the research process. In contrast to positivist traditions, critical nurse researchers have been counseled to explicate their “nursedness” (Leslie & McAllister, 2002, p.710) in the research process and “place in the public sphere that which has been insidiously erased: the role that nursing plays in extending social science knowledge” (Leslie & McAllister,

2002, p.710). The role that my nursing and background had in the evolution of this research is described to reveal that process.

Growing up as the eldest daughter of immigrant parents on a farm in the sixties and seventies in rural Ontario, I did not consciously define myself as a rural person although I did recognize differences between my life and that of a city friend. For instance, I can recall how strange it seemed that my summers were spent playing and helping out with the chores of farm life, while she went to a cottage where her family “escaped” from their city life. The separation of working and relaxing in two geographically different and distant spaces was foreign to me and I felt different, less sophisticated than she. Being rural became unconsciously equated in my young mind with having fewer options and like many rural young people, I left the community for post-secondary education and employment. After some years of nursing practice in urban settings, when I returned to live in rural Ontario, I moved to a farm property, regarded by urban friends as “the sticks.” I found escape in nature, was soothed by the silence and rejuvenated by the natural world around me. The rural life was a therapeutic one for me, although I recognized that I lived a somewhat privileged rural existence and because of my move into the neighbourhood from the city, may not be seen by those born there, as truly rural or belonging to that rural community.

Later, during a research project in which I interviewed rural people about their experience in returning home after surviving a life threatening event, potentially negative aspects of rural life were apparent when poor health was experienced (Caldwell, 1999). One woman’s story about her life after MI had special resonance and my interest in rural women and their experiences with health and illness gained direction. I wondered, how

did being rural affect health and recovery from illness? What did health care providers need to know in order that the health care needs of rural women were met? The notion of focussing women's post-MI experiences through a "rural lens" evolved and drove this study.

### *Research Context*

#### *The Rural Lens*

The idea of bringing a "rural lens" to health research, planning and policy was advocated by the Government of Canada (2002) in the Canadian Rural Partnership and the Federal Framework for Action in Rural Canada. The rural lens is

a way of viewing issues through the eyes of rural Canadians. The Rural Lens raises awareness of rural and remote issues across federal government organizations by asking them to assess the effect of new policies, programs and services on Canadians living in rural and remote areas (Government of Canada, 2002, p.1).

This research offers a view of post-MI life for rural women through their eyes and raises issues central to their recovery. The use of a rural lens in this research fits with the imperative in qualitative traditions to honour the emic (insider) perspective and acknowledge the etic (outsider) perspective. Outsiders have sometimes attributed aspects of quaintness and simplicity to rural life, whereby it assumes mythical qualities that evoke images of good health and wellbeing. Insiders, those who hold an emic perspective, know the intricacies, understand that rural life is complex and that local economies, weather and distance can challenge even the best laid plans for day to day existence. It could be argued that the idea of rural people surviving such adversity has

encouraged the view of rural people as tough and resilient, and that the uncritical acceptance of this ideology has intangibly influenced health policy and practice.

The adoption of the rural lens for this research immediately raised fundamental questions about the definition and dimensions of rural. Although the term is widely employed, the fact it has eluded certain definition may have contributed to challenges in the identification and resolution of issues relevant to rural people.

### *What is Rural?*

The debate about the definition of rural remains unresolved in the literature and within disciplinary circles (Humphreys, 1998; Weinert & Boik, 1995; Pitblado & Pong, 1999; du Plessis, Beshiri, Bollman, & Clemenson, 2001). There is no consensus on the Canadian definition of rural although the term is used frequently to describe segments of the Canadian population (Pitblado & Pong, 1999; Ramp, 1999, Kralj, 2000). This lack of consensus is problematic because different rural populations are generated by employing different definitions of rural, making comparisons and use of aggregate data difficult (du Plessis et al., 2001).

From a critical perspective, it is necessary to consider the possible ways in which adoption of a rural definition may influence research. Possible influences of the adopted definition on this research are discussed as limitations in Chapter 6. Although parameters of a rural definition are often undefined in studies and literature about rural people, conclusions about rural issues have been drawn (Weinert & Boik, 1995; Pitblado & Pong, 1999). These conclusions have decidedly social and political repercussions including those associated with funding and resource allocation (Humphreys, 1998). It is possible

that employed definitions of rural reflect political purposes that may not be in the best interest of rural residents.

Du Plessis et al. (2001, p.7) identify that rural may be viewed in terms of geographic boundaries or sociocultural factors, while others argue for rural to be viewed as a combination of those representations (Humphreys, 1998; Kralj, 2000). That people who are classified as rural may not classify themselves in that way, has also been raised as an issue affecting research and policy development (Dr. S. Dukeshire, personal communication, October 23<sup>rd</sup>, 2002). Alternatively, some communities that would not fit into existing definitions of rural have lobbied for definitions to be expanded in order they can access resources that have been made available to rural communities (S. Gardiner, personal communication, July 18, 2001).

Although there is a lack of consensus about the “best” definition of rural, it is clear that researchers must explicate the rural definition on which a study and its subsequent implications are based. For purposes of this study, the Organization for Economic Cooperation and Development (OECD) definition of rural cited by the Office of Rural Health was employed to determine the residence of study participants. Using this definition, an area is considered to be rural “if more than half the people there live in communities with a population density of fewer than 150 persons per square kilometer” (Health Canada, 2001). The process by which a woman’s rural residence was confirmed is outlined in Chapter 3. The adoption of this definition was based on the relative ease with which it could be applied and on the assumption that research findings placed in the definitional context of a government Office would have greater potential for influence. It should be noted the employed rural definition is one that has been imposed by a



government agency, may differ from people's views of themselves, and includes only one characteristic (population density) of the many aspects commonly equated with rurality.

### *Participant Context*

#### *Women Who Live in Rural Places*

The location or place where one lives, and the options that place confers, shapes choices and experiences in health and illness (Kearns, 1993; Moon, 1995; Raphael, 2001). Exploration of the linkages between place of residence and life choices and experiences related to health, has received relatively limited attention in the context of Canadian life (Ramp, 1999). This may be due to an assumption that all Canadians living under the terms of the Canada Health Act (Health Canada, n.d.) have equal access to all insured health services, wherever and whenever they are required. Alternatively, it may reflect an “urban-centric” approach to viewing the health of Canadians, whereby health research, which has arguably been an urban phenomenon, has tended to draw research problems and populations from urban environments and hence, even unintentionally, ignore those who live in rural, northern and remote communities. Urban bias in health policy frameworks and health service organizations has been previously identified as problematic for health care professionals who try to meet the needs of rural people (Ramp, 1999). Additionally, the low power accorded to women who live in rural places may further marginalize rural women in the dominant medical paradigm, leaving their issues and experiences unexamined.

Women as a sub-group of the non-urban population have historically struggled to have their voices heard, to be included and considered, in mainstream Canadian institutions and in the policy decisions that affect their lives (Health Canada, 1996). An

example of this phenomenon is made by Johnston (1998) who pointed out that when a national Canadian magazine advocated women's utilization of menopause clinics for specialty consultation, it ignored the fact that in rural Canada no such services existed, rendering the advice irrelevant for rural women. This example strengthened her argument that the life situations and health needs of rural women have been largely invisible to mainstream institutions, including the women's health movement (Johnston, 1998).

The examination of the post-MI experience of rural women thus becomes a decidedly political act, when it intends to raise awareness about a marginalized population living in a marginalized environment and from their perspective. Using the critical ethnographic process, this research aimed to increase the visibility of the meanings and realities of rural life, when the heart health of rural women was challenged.

#### *The Case for Studying Rural Women and MI*

Ischemic Heart Disease (ISD) which includes MI, is a leading cause of death in Canadian women (Heart and Stroke Foundation of Canada, 1999). Heart disease is increasingly recognized as a threat to women. It tends to affect women later in life than men and this may account for the increased mortality rates in women (Young & Kahana, 1993; Shin, Jaglal, Slaughter & Iron, 1999) especially in view of the associated age-related increases in comorbid conditions (Nohria, Vaccarino & Krumholz, 1998; Johanson, 1999). In spite of this major threat to the health of Canadian women, much of the knowledge that has guided the development of heart health care has been derived from the experience of men (Hamilton, 1990; Cochrane, 1992; Angus, 1996b) although some progress has been made in this regard (Charney, 1999). Women's clinical

presentation at the time of MI is often referred to as “atypical” because it differs from the “typical” MI pain that has derived from the experience of men (Zerwic, 1999).

Minimization of and/or misinterpretation of cardiac symptoms in women that caused delays in the diagnosis and treatment of MI, has been recorded in women (Beery, 1995; Dempsey, Dracup & Moser, 1995; Zerwic, 1999).

Recent Canadian data reflect that women, particularly the elderly, are less likely to be referred for coronary angiography after a MI, although once referred, women tend to undergo invasive treatment more quickly than men (Alter, Austin & Tu, 1999). In Ontario, concern has been raised about the rates of hospitalization for rural women related to cardiovascular diseases and the presence of poorly understood urban-rural differences in cardiovascular health (Naylor, 1999; Shin et al., 1999). In the Ontario Health Survey, self-reports of three or more cardiac risk factors were more likely to be identified by rural women in general, and by women with low income and education, than by women overall (Shin et al., 1999). Although numbers of women who sustain MI have been on the increase, mortality rates have been decreasing (Heart and Stroke Foundation of Canada, 1999). These trends have been attributed respectively to the greater number of aging women in the population and to advances in treatment (Chan & Young, 1999). Should these trends continue as expected, more women will return home to their communities for cardiac recovery and secondary prevention activities.

The need to place nursing knowledge within patient’s social, political and economic life-contexts has been advocated as necessary in the promotion of wellness (Moccia, 1986; Stevens, 1989; Reutter, 2000) and specifically in the facilitation of women’s recovery from cardiac events (Angus, 1996a; Angus, 1996b; Fleury &

Cameron-Go, 1997). Pong (2002) advises a similar holistic environmental focus for researchers, practitioners and policy makers in relation to fostering rural health in Canada. Hence, if health policy and the nursing knowledge base that informs equitable and culturally sensitive health care is to meet the needs of all Canadians, there is a need to understand the world of rural women who survive a heart attack and continue to live in rural communities. The call for researchers to contribute to the development of an evidence base for practice and policy related to women's heart health (Advisory Board of the International Women, Heart Disease and Stroke Conference, May 8-10, 2000; Health Canada, 1999) is an invitation and opportunity to examine and include rural women's cardiovascular health issues within the dominant discourse.

#### *Significance of the Study*

This study aimed to make visible the lives of women who have been marginalized from mainstream institutions on at least three counts, as women, as women with heart disease and as rural dwellers. Their stories have the potential to influence professional health practice, health research and policy-making.

The critical ethnographic approach taken for this research facilitated this nurse researcher's interpretation of women's descriptions about how rurality affected their post-MI lives. Rurality and its influence on women's post-infarction lives has not been part of the dominant discourse in cardiac care or related cardiac literature. Although urban-rural disparities in cardiac health have been recently recognized, there is a need to take that discussion further and understand the nature by which rurality affects people after life-threatening events such as MI. For health education and support for post-MI recovery to be relevant and adopted by rural women, nurses and other health care professionals who

counsel and care for rural women returning home after a heart attack must have an understanding of the client's life context. Understanding the impact of rurality on post-MI recovery has the potential to inform the development of future health education and support services for rural women. Health policy and practice related to cardiac care has traditionally been based on studies of urban populations or those who can access urban centers for care and be included in research studies. Different or additional opportunities that consider the uniqueness of the experience and challenges of rural life may be indicated for rural women who survive MI. The study has the potential to inform and facilitate nursing practice, regional cardiac programming and (rural) health policy that is relevant to the context of post-MI rural women's lives.

## Chapter 2

### *Review of the Literature*

The place of the literature review in qualitative studies has been debated in research circles but it is generally agreed that the approach to the review should be in keeping with the employed research tradition (Cresswell, 2003). Cresswell (2003) suggests that in the case of critical ethnographies, reviewed literature be presented near the beginning of the study to provide a framework for the ensuing inquiry. It is recognized that many qualitative studies evolve because of limited knowledge related to the subject of interest (Polit, Beck & Hungler, 2001) and true to the inductive approach, the relevance of other literature may become evident as the study evolves (Cresswell, 2003).

This literature review was organized to explore the following content areas; rurality, the context of rural women's lives, the recovery of women from MI, and rural cardiac issues. Consistent with the critical approach, the review was shaped by the fundamental imperative to challenge the ontological and epistemological foundations on which current understandings have been based (Thompson, 1987; Campbell & Bunting, 1991; Kincheloe & McLaren, 1994; Mill, Allen & Morrow, 2001). The review provided direction for question formulation and a basis on upon which I could reflect on overt and covert contextual influences related to rurality in women's post-MI lives.

#### *The Nature of Rurality*

The term "rurality" appears in the literature, but suffers from similar problems to the definition of rural in that it is seldom, if ever defined as a term in and of itself. The term rurality appears somewhat surreptitiously in the literature and its origins remain

unclear. While the terms rural and rurality are sometimes used interchangeably, it may be that semantic distinctions have arisen as a result of controversy about what constitutes the designation of a person or place as rural. The term rural reflects its use as a category in which one can be placed or not, whereas rurality implies there may be shades of “ruralness” (Weinert & Boik, 1995; Leduc, 1997; Humphreys, 1998; Kralj, 2000; du Plessis et al., 2001). The effort to quantify rurality is reflective of the struggle between positivist and post positivist traditions in which objective truth about the nature of rurality is thought to be attainable and useful in decision making about issues such as resource allocation. In this vein, some authors have advocated the use of rurality indexes to support categorizing people or places as rural (Weinert & Boik, 1995; Humphreys, 1998; Kralj, 2000).

Specific factors relevant to the exploration of rurality in general, and in relation to health care in particular, have been put forward as relevant by those who view the rurality as quantifiable. The factors include; distance from emergency care (Weinert & Boik, 1995), existence of and distance to local hospital, time and distance to referral center, access to family doctors and specialists, access to diagnostic testing and ambulance, weather conditions, access to social events and post-secondary education (Kralj, 2000). Central to many of the identified variables is the issue of access to health care and this reflects a common theme in the rural health discourse (Schreffler, 1996). In a review of health literature concerning access to health care for rural persons, Porter (1998) differentiated between the system and “person-centered” views of access. Systems access included affordability of transportation and for the health service, and management practices within the health care system (Porter, 1998). Person-centered

components of health care access included rural persons' perceptions of geographical distances and assessment of an individual's openness to actually seek out care (Porter, 1998). The person-centered approach reflects a rather novel valuing of the rural person as "knower" in relation to rurality measurement. Similar directions to quantify the "human" aspects of rurality were introduced by Humphreys (1998) who advocated the inclusion of measures of environmental esthetics, self sufficiency, problem solving, and relation to the community as part of a rurality index to facilitate health planning.

There are questions that must be raised about the quantification of rurality. Will its quantification serve to better the lives of rural people? Will there be advantages and disadvantages to being more or less rural? Why should rurality be defined by those "on the outside?"

An assumption underlying literature about rurality and which subsequently informed this research, was that the term has relevance for understanding issues facing rural people. The characteristics of rurality that have been proposed in the literature were used as the basis for development of interview questions. Given the lack of consensus about the definition of rurality, there was a need in this study to value women's "expert" insider knowledge and to create opportunities for women to ponder and articulate their own interpretations of rurality during the interview process.

For purposes of this research, rurality referred holistically to the quantitative and qualitative components reviewed, and included the subjective interpretations of "being rural". The inductive approach taken to capture the essence of rurality left open possibilities for further defining the term.



*Who Are Rural Women?*

There is a paucity of literature related to the lives of Canadian rural women in spite of the fact that this group comprises a significant proportion of the rural population (Statistics Canada, 1992). Using the OECD definition, 30.4% of Canadians lived in rural Canada in 2001 (Agriculture and Agri-food Canada, 2002). A report about Canadian women cited 21% as living in a rural area, only 3% of whom lived on farms (Statistics Canada, 2000). Rural women include farm women, women living and working in small towns, and women living outside of small towns (i.e., “in the country”) and who may work in town, as well as seniors who may reside inside or outside small town limits (Statistics Canada, 2000).

*The Context of Rural Women’s Lives*

Landscape can be deceptive. Sometimes a landscape seems to be less a setting for the life of its inhabitants than a curtain behind which their struggles, achievements and accidents take place. For those who, with the inhabitants, are behind the curtains, landmarks are no longer geographic but also biographical and personal (Beilin, 1998, p.166).

Part of the difficulty in defining the context of rural women’s lives is that they are not a homogenous group, making generalizations about their lives difficult (Bushy, 1993; Long, 1993). The commonly held misconception that “rural woman” means “farm woman” serves to stereotype rural women and thus subsequently ignore the context of the lives of non-farm women. Such stereotyping serves to silence the lives and experiences of the non-farm segment and minimize the context of farm women.

The diversity of the rural female population is reflected in the development of groups such as the Ontario Farm Women's Network (OFWN) and Women for Rural Economic Development (WRED) who serve different segments of the rural female population and who have strived to increase the visibility and autonomy of rural women (Teather, 1998). These organizations reflect a trend by some rural women to advocate for themselves in what have frequently been referred to as androcentric, conservative and "traditional" rural environments in which women have had little authority or decision-making power in spite of being essential to the viability of their families and livelihoods (Bushy, 1993; Teather, 1998). Although examination of power structures in rural communities, particularly as they relate to women's health care and available options, is necessary to understand the dynamics of their health experience, and subsequently, to ensure women's voices are heard, social taboos may discourage women from engaging in activities that may be construed as "feminist." When women are actively or passively discouraged from becoming part of activities that focus on their needs and circumstances, the status quo is maintained. Teather (1998) commented about the potential negative impact for rural women in Australia, Canada and New Zealand to align with what is viewed as a feminist agenda.

Many rural women see feminism as an urban movement. For rural women to espouse publicly the feminist agenda would bring problems for them in terms of social rejection...Many rural women feel either that feminism is irrelevant to them, or that their frank acknowledgement of a feminist agenda would damage their position in rural communities (Teather, 1998, p.212).

This possibility had specific relevance when entering the rural community specifically to interview women about their experience, in that a potential existed for the researcher to be seen as mobilizing a feminist agenda and negatively affect study participation.

### *American Literature*

In a review of literature about the lives of rural women that was intended to raise awareness for nursing practice, Bushy (1993) identified several themes relevant to rural women but cautioned the reader against generalizing the findings to all rural cultures. Although the themes are derived from some American literature that is now two decades old, their relevance continues to be reflected in the discussions in disciplinary circles and literature and they provide a marker against which the rural literature can be examined. Reviewed literature did not have a nursing focus and for a large part revolved around farm women. It was also noted that part of the invisibility of rural women in the literature was their inclusion in research as part of a family or spousal unit which served to minimize, if not conceal, their experiences. The benefit to studying rural women specifically is that it places the focus directly on them and their needs and experiences. Bushy's review identified that multiple role expectations were the basis of conflict in the lives of some rural women who juggled farm or other income-generating work with socialized female roles of mother, wife, and roles relating to the extended family. A variety of geographic and personal barriers to accessing health care services were identified as problematic for many, although distance was noted to be a relative concept that may not have the same effect in deterring travel as it might for urban dwellers. When families required help, women were seen as the ones who would initiate access for

others. There are suggestions that feelings of low self worth and depression were of particular concern and that women's insular support networks coupled with the value on self-reliance, discouraged women from seeking help for themselves.

A phenomenological study of six rural Caucasian women living in upstate New York explored how rural culture influenced health perceptions (Pierce, 2001). Women were 60-85 years of age, four were widows and none had major health problems or economic concerns related to health. Consistent with other literature about rural views of health (Long, 1993), women identified their ability to work and fulfill their traditional roles as equating with good health. Connections to the land and the community were cited as promoting good mental health. Distance to services and weather conditions were problems at times but the women accepted this as a fact of rural life. Self-sufficiency was valued and had a negative impact on the likelihood they would ask for help if needed. The women distinguished between "insiders" and "newcomers" and there were indications that for those who were perceived to be on the outside of a community, what insiders perceived as necessary connections within the community, may be absent. While this study reflects views of a very small sample, it suggests rural researchers must be aware of the potential for rural inhabitants to silence and isolate others who are perceived as outsiders, yet live within the rural community. It may be that "newcomers" have different needs and experiences in terms of accessing support than those who are "connected" on the inside.

The difference in experience and perspective between those who were considered "new" to a community and those who were not, was also an issue in a phenomenological study by Porter (1998) who explored health care access for eight

rural American widows. The women were 75 to 84 years of age; two women were new to the rural community. The experience of accessing health care was described in terms of women's desires to "stay close to shore." Those who were unfamiliar with urban environments and who had seldom ventured far from their home "shore" were more inclined to view travel for care as problematic. This finding reinforced suggestions that health care access may be as much about perception and attitude as about actual physical distance from a facility. This challenges the preferred objective view of distance and guides the discussion of access to include subjective perceptions of distance and affective components related to an individual's confidence in getting to a destination.

#### *Canadian Literature*

Canadian rural women lack visibility in the nursing literature. Some of the limited rural research available has tended to focus on issues related to the farm population, perhaps because it is an identifiable rural sub-group and they have distinct issues related to work-related and economic demands (Viens, 1997). A second focus has tended to relate to mental health issues in rural people.

Regional variations exist in the economic and social contexts of women in rural Canada (Best, n.d.), however some commonalities can be found (Health Canada, 1996). For instance, general threats to the rural societies in which women live and work have been noted as contributing to health issues in rural Canada. Troughton (1999) notes that

The redefinition of rural Canada that has occurred over the last 50 years has produced a fragmented, chaotic system. Many of the positive values that contributed to the identity and cohesion of the traditional rural system have been severely weakened...Rural areas have been virtually abandoned by central

governments, or at the very least, assumed to be merely extensions of the dominant urban systems (p.31).

Rural Canada, long regarded as a bastion of family values, close community ties and self-sufficiency has not escaped the pressures of the twenty-first century and is vulnerable to the effects of global economics, youth migration to urban centers and changes in family structures and function (Pong, 2002). These stressors place additional pressures on current resources and on women and their families when poor health is experienced. It has been argued that for rural communities to develop and sustain health and health care for its' citizens, rural people need to have "ownership " for resource development (Kulig, 1999) as imposed urban solutions may not be relevant or accepted.

A Canadian report compiled to explore and examine substance abuse in rural women provides a foundation to understand the challenges and realities of life for rural women in general (Health Canada, 1996). The report drew from a wide literature base including government documents, publications and rural research focussed on farm families and/or substance abuse. Limitations of the literature were not reported. Issues identified as germane to the discussion about the lives of rural women included a lack of a voice in the community, feelings of low-self confidence and self-esteem, and the challenge of trying to meet expectations around traditional female roles. The fragmented social system that has evolved in rural Canada, left some women feeling stressed and unsupported. Socioeconomic challenges and isolation were also cited as contributors to feelings of disempowerment in rural women. When poverty and / or unemployment were issues, women tended to focus on meeting others needs instead of their own. Social norms that discouraged seeking professional help and the absence of such resources in

communities exacerbated the plight of rural women with family violence and/ or substance abuse problems. Distance from services, transportation problems, weather and road conditions were factors affecting accessing supports and health service. Positive aspects of rural life that could be used to support change were not identified.

A telephone survey of key informants who were knowledgeable about health in the Waterloo Region in southwestern Ontario, identified several important issues related to health in that region (Zupko & Shearer, 2001). Participants noted accessibility problems existed due to lack of available transportation, distance to services and shortages of professional services such as physicians. It was noted that economic hardship was sometimes invisible in rural communities and that many farm families experienced great stress related to unstable economic conditions. Domestic violence was identified as an issue for rural women who were seen as less likely to seek support because of distance to and lack of shelters, and because they would rather stay in their community and access known support networks than go to an unknown community. Paradoxically, accessing support networks was identified as difficult because privacy and confidentiality could be threatened by letting others know of the need for help. The tendency for rural women to keep their problems to themselves and not use support systems beyond their immediate circle of family and friends has been reported elsewhere (Viens, 1997) and is an issue when considering the acceptability of new support initiatives that might be introduced into a community.

### *Summary*

Rural women have been marginalized in the literature, in and by their own communities and by the narrow and uninformed urban views about rural people. Social

forces within the rural culture have served to silence women's voices and discourage social change that could give women different life choices. When the knowledge base is lacking about the context of women's lives, imposed decisions that affect rural women are based on assumptions and stereotypes ("urban legend"). Women subsequently can be forced to fit with urbanized approaches to rural problems. There is risk in challenging accepted ways of being in rural communities and some women have perceived they stand to lose more than they gain when they step outside of those invisible but powerful boundaries.

#### *Women's Recovery From MI*

The need to increase the volume and scope of the research literature so that practitioners can understand and appropriately influence the recovery of women from MI was identified by Boogaard (1984) almost twenty years ago and has continued to be echoed (Angus, 1996a; Angus, 1996b; Fleury, Sedikides & Lunsford, 2001). There is a continued tendency by the world-at-large to view heart disease as a predominantly male health problem. This distorted image is reinforced by the large numbers of studies composed exclusively of males recovering from MI (Hamilton, 1990) and studies in which the small numbers of post-MI females preclude the drawing of firm conclusions about women (Cochrane, 1992; Beery, 1995).

The recovery of women following MI has been studied using quantitative and qualitative methods. Typically, quantitative studies about women's recovery have focussed on measured behaviours and outcomes in the recovery period. Conversely, qualitative research has focussed on recovery processes and experiences.



For purposes of this review, analysis of literature about women's post-MI lives is presented according to methodological divisions. Examination of quantitative literature appears first, followed by analysis of qualitative studies. Using CINAHL and Medline, studies were retrieved that focussed on women, myocardial infarction, recovery and/or psychosocial response. Further relevant studies were identified from references within retrieved literature. There are relatively few studies that focus exclusively on the female MI population. Subsequently, selected studies that informed quantitative and qualitative sections of this review included the following populations; those that drew strictly on female post-MI populations, studies of mixed (male-female) post-MI populations and studies that included post-MI women who were part of a broader cardiac diagnostic group with labels such as cardiac event, coronary heart disease (CHD) or ischemic heart disease (ISD). For literature that focussed on mixed male/ female or cardiac diagnostic groups, studies were included if they identified MI subgroups.

### *Quantitative Findings*

Literature that examined behaviours and outcomes for women in the period following their discharge from hospital after MI was the particular focus of this review.

### *Return to Activity*

A relatively early study by Mickus (1986) utilized a mailed survey to determine women's perceptions about differences in their activities between pre and post-MI time periods. A 16 item questionnaire was developed by the researcher and tested for content validity. Twenty-five urban women who were 5 to 12 months post-MI completed the survey from a pool of 58 women with uncomplicated MI. The mean age of respondents was 66 years. Self-reported data were analyzed using central tendency and variability

measures. On average, women decreased their paid work, housework and sexual activity from pre-infarction levels and increased time sitting at home. Eighty-four percent of the sample reported depression as a post-MI symptom although the parameters of this symptom were not defined and it cannot be considered a clinical diagnosis. The study limitations include a failure to test for reliability of the instrument, small sample size, the problems associated with recall in eliciting retrospective data and failure to consider variables that could influence response, such as other medical conditions and time post-MI.

Hamilton and Seidman (1993) compared return to work, sexual activity and participation in cardiac rehabilitation in 20 women and 42 men who had sustained a MI 2 to 18 months previously. Subjects were identified from a tertiary Coronary Care Unit database and asked to mail-in a completed survey. Content validity was reported at 100% based on expert assessment. Based on testing of 2 men and 2 women, test-retest reliability of the instrument was deemed “moderately reliable” by the authors, supporting the identified need to further refine the instrument for future use. Twenty of 54 women completed the survey in spite of a special call in the accompanying letter for women to participate and thereby increase the knowledge base specific to post-MI women. Mean age for women was 62 years, which was not significantly different than men, but women were more likely to live on their own. In the first four weeks post-MI, significantly more women than men participated in housekeeping chores such as sweeping, laundry, dusting and bed making. No sex difference was found with regards to return to paid employment. When sexual activity was resumed, women encountered significantly more angina and decreased frequency of sexual encounters than men. No significant difference

was found between numbers of men and women who enrolled in outpatient cardiac rehabilitation, although this amounted to only 42% of subjects. Small sample size and wide variation in time from MI to self-report limited generalizability of findings.

Cardiac rehabilitation is perhaps the most frequently studied aspect of the post-MI period, although most participants are men and rehabilitation programmes are not yet universally available in Ontario (Cardiac Care Network of Ontario [CCN], 1999). The need to learn more about women who are recovering from MI so rehabilitation programmes and practitioners can more fully meet women's needs in the post-MI recovery period has been documented in the literature over the past two decades (Boogaard, 1984; Arthur, Wright & Smith, 2001). A recent study compared referral to and compliance with cardiac rehabilitation programs for women and men in an urban American hospital (Halm, Penque, Doll & Beahrs, 1999). Of the 87 subjects, 46 were women and of these 89% had a MI; 41 were men, 78% had a MI. Other diagnoses were angina, coronary angioplasty and bypass. Chart audit, patient interviews and cardiac rehabilitation attendance records were used in data collection. Instrument validity and reliability were not reported. Descriptive statistical analysis identified that when outpatient cardiac rehabilitation was available, women were less likely to be referred and to complete a rehabilitation program. Transportation challenges, use of home exercise equipment, lack of insurance, other health problems and need for further care were identified as issues that prevented women's participation. In contrast, men did not identify transportation or other health needs as germane to their rehabilitation decisions. The study was limited by small sample size and by failure to identify results for

individual cardiac diagnostic groups. Results do offer direction in the exploration of cardiac rehabilitation opportunities for rural Canadian women.

### *Psychosocial Recovery*

To further understand women's adjustment to MI, Reigel and Gocka (1995) used a longitudinal survey design and data from a primary study in Southern California. Based on previous suggestions that worrying (neuroticism) and cardiac function influenced adjustment to MI, the investigators matched 32 women and men on neuroticism and cardiac dysfunction. Validity and reliability were reported for the Eysenck Personality Questionnaire [EPQ] (Eysenck & Eysenck, 1975) measuring neuroticism and the Coronary Prognostic Index [CPI] (Norris, Brandt, Caughey, Lee & Scott, 1969) that measured cardiac dysfunction. Subjects were then surveyed in their homes at 1 and 4 months using 5 tools that measured self-esteem, emotional distress, health perceptions, interpersonal dependency, and social support. Internal consistency and construct validity were reported for all scales. Results of the multivariate analysis suggest that the way in which adjustment occurs may be different for women and men although both groups showed comparable adjustment at 4 months post-MI. No differences between women and men were found in emotional distress, or self esteem. Significant increases were found in women's perceptions of their health over time and their emotional distress decreased significantly. Women wanted, gave and received more social support than men at 1 month and stress related to the support relationship was increased for women at 4 months post-MI. Spouses were identified as major supports by both groups but women also identified daughters as important sources of support. There is some suggestion that women may mobilize supports more effectively than men. Although sample size is

small, results support the need to be cognizant of different needs and processes that may occur for women in the recovery experience.

In response to indications that emotional distress affected women's post-MI roles, MacKenzie (1993) studied roles and emotional responses in a convenience sample using a descriptive correlational design. Nineteen women diagnosed with ISD from 3 urban and suburban coronary care units were interviewed prior to discharge. Thirteen participants were post-MI, five had unstable angina and one woman was diagnosed with coronary insufficiency. Mean age was 62.2 years. Two author-designed instruments intended to measure role enactment and physical symptoms were rated for content validity only. An adapted version of the General Well-Being Schedule [GWBS] (Brook et al., 1979) was used to measure emotional wellness; content validity, internal consistency and stability were reported for the instrument. Subjects were interviewed prior to discharge and again 4-6 weeks post-discharge. Statistically significant correlations between role enactment, physical symptoms and emotional responses were not achieved, however qualitative data was identified as insightful in describing post-MI life. Study results suggested there were different experiences for subjects who were post-MI and those who had other ISD diagnoses, supporting a need for studying post-MI women separately. After discharge, 9 women who were post-MI took on a new role of "heart patient" which included assuming new lifestyle behaviours. Thirteen women continued to invest most of their energy in domestic roles that included caring for family and housekeeping. Women described ways they modified activities, such as reducing their pace so that they could maintain responsibility for their traditional roles. For all subjects, stress in close emotional relationships occurred within the first two weeks of

discharge. No differences were found in the emotional responses of women with different ISD diagnoses. Fears related to loss of control and the unknown consequences of the cardiac illness were common. Small sample size, lack of rigor in instrument testing, failure to control for other medical conditions or parameters such as severity of illness, and inclusion of more than one diagnostic group limits application of findings to women post-MI.

Wingate (1995) surveyed 96 women 2 months to 20 years post-MI, to examine quality of life (QOL) and its relationship to social support, health locus of control and self esteem. Using an ex post facto one group correlational design, women were recruited from a pool of 407 women identified from cardiologists' office files. Following written consent, women were mailed a survey consisting of 4 tested instruments. Construct validity and internal consistency were reported for the Social Support Questionnaire (Sarason, Levine, Basham & Sarason, 1983), Health Locus of Control (Wallston, Wallston & DeVellis, 1978) and Self Esteem Inventory (Bedeian, Geagud & Zmud, 1977); criterion-related validity and internal consistency were reported for the Quality of Life Index (Ferrans & Powers, 1985). Women who returned to pre-MI employment, who were satisfied with their social support, and who had higher levels of self esteem had significantly greater QOL scores. QOL scores for post-MI women in this sample compared favourably with scores for well individuals. The score was not measured at a specific time or sequentially in the post-MI period, so measurements may have failed to capture changes in QOL over time. Failure to control for medically prescribed rehabilitative and surgical therapies after MI may also have influenced the findings.

Based on indications that depression was a problem for those recovering from MI, Frasure-Smith, Lesperance, Juneau, Talajic & Bourassa (1999) investigated the presence and impact of male/female differences one year post-MI. The study was a secondary analysis of data from two study populations in Montreal and area hospitals; one a prospective study to assess psychosocial risk after MI and the second, the control group of a randomized controlled trial that tested a psychosocial intervention. The combined study population for the secondary analysis was 896 people; 283 were women. The Beck Depression Inventory [BDI](Beck, Ward, Mendelson, Mock & Erbaugh, 1961) which assesses symptoms of depression, was completed by patients after they were transferred from Coronary Care to a medical unit. Validity and reliability for the BDI were not reported. One year follow-up data were collected from provincial health insurance data and from subjects and their families. Significantly more women than men had BDI's  $\geq 10$  which identified the presence of mild to moderate depressive symptoms. Multivariate regression analysis revealed that post-MI in-hospital depression was a significant predictor of one-year mortality for women and men. For both studies, women  $\geq 65$  years were significantly less likely to participate, raising questions about generalizability of results to elderly females. It is notable that the study sample excluded those who lived too far away for follow-up, raising questions about the occurrence and influence of depression in the recovery trajectory of women who may live in rural or remote settings.

### *Summary*

Objective outcome measurements in quantitative studies have tended to focus on physical activity, return to work, sexual activity, emotional responses and role challenges. Whether or not these are important and significant outcomes for the women is not known,

however the implied epistemological assumption is that as expert, the researcher is able to define the behavioural outcomes that should be relevant. Research questions aimed at understanding or explaining objective outcome measures is scant and in this respect the context of women's recovery experience is minimized. In spite of recognition that women's work includes that of nurturer and emotional caretaker , exploration of the effect of MI on this important role is limited. When such questions remain unasked, interpretation of women's post-MI experience is forced to fit within the context of the dominant male life patterns (Harding, 1991).

### *Qualitative Findings*

Nine studies were retrieved related to the experience or process of recovery in women post-MI. The terms recovery process or recovery processes were used to describe developmental tasks that have been identified as occurring over time after MI. Recovery experiences reflect themes that have been generated through MI survivors descriptions of post-MI events. The review will address studies of recovery experiences first, followed by studies of recovery processes.

### *Recovery Experiences*

A study by Boogaard (1984) signalled the need for practitioners and researchers to attend to possible differences in the experience of women and men recovering from MI. Using semi-structured interviews, the author compared return to physical activity, psychosocial influences and family relationships in 10 men and 10 women 3-6 months post-MI. Participants ranged from 25-55 years of age. Details about the interview instrument or process were not reported. Women reported returning to domestic unpaid work soon after discharge home although they did not consider activities such as dusting,



cleaning up or washing dishes as work. Women's increased activity came in the form of increased domestic duties whereas men tended to engage in more structured exercise such as walking programs. In comparison to the men, most women felt guilty in accepting help and resisted offers to help with traditional role functions. More men than women attended cardiac rehabilitation and more women did not return to pre-MI employment. Age-related differences in experience were not reported. The study was limited by the small sample size and lack of rigor in the study design.

A phenomenological study by Benson, Arthur and Rideout (1997) employed focus groups to explore the needs and experiences of 14 women, with a median age of 61 years, who were 1 to 6 months post-MI. Participants were recruited through invitations posted in community newspapers, poster boards and health care facilities. The focus group approach and data analysis procedures were clearly outlined. Striking in their findings was the expressed need for women to connect with others like themselves to validate the cardiac event, challenges faced and treatment experiences. Connections with physicians were perceived to be gender-biased as women cited examples that left them feeling minimized, different and under serviced by the health care system. The need for participants to continue to nurture and protect others limited their ability to ask for and accept help. The focus group approach to data collection may have encouraged the recognition by participants of their need to network, receive support and place their own experience in the context of other women's recovery trajectories. Participants' place of residence is not reported however, it is interesting to note that these women continued to have unmet needs in a Canadian medical community where tertiary cardiac care and a rehabilitation programme were available.

An exploratory Australian study based on feminist principles examined recovery experiences of 10 married urban women at three points in the first month following their first MI using semi-structured interviews (Jackson et al., 2000). The convenience sample was recruited from a large urban hospital. Women ranged in age from 43-77 years. Data collection and analysis procedures were described in detail and rigor in the processes was evident. Findings reflect that women initially had many fears and uncertainties about their futures and abilities that gradually began to fade over the 3 weeks post-discharge as they began to integrate the reality of the MI into their lives. Women were developing support networks consisting of family, friends, community organizations, telephone counselling and family doctors by the end of the first month post-MI. Implicit in this support building is that the women were left to initiate connections on their own. They voiced a profound unmet need for information related to lifestyle change and recovery and were uncertain if they had forgotten or ever received health teaching. Only one of ten woman had entered a cardiac rehabilitation program. Women in this study entered the second post-MI month with unresolved physiologic and psychoeducational needs: how or if women resolved these needs after the initial month would be a focus of further study. Findings may not be applicable to women who are not living in a stable married relationship as were the study participants or who are challenged to access support services.

Similar themes to those identified by Benson et al. (1997) were uncovered in an American study to investigate perceptions and lived experiences of women over age 45 who were diagnosed with CHD 3 months to 21 years previously (Lisk & Grau, 1999). The study used a grounded theory design and focus group approach. Women were

recruited by health care professionals when attending cardiac rehabilitation, community clinics or in hospital coronary clinics. Details of the interview instrument, research process and data analysis were adequately described. Interestingly, over half of the women failed to acknowledge the chronicity of heart disease, distancing themselves from their diagnosis by viewing it as an isolated event in their lives. This may partially explain the knowledge gaps about heart disease noted by the researchers. Whether or not this negatively impacted on women's health is not known. The stress of being seen as the "cared for" instead of the "caregiver" was noted across the sample, with women acting to minimize their needs and behave in ways that did not make them feel selfish. Acting in more assertive ways with physicians, seeking social support and reliance on God were identified by the majority of women as ways of coping with heart related stressors. Cardiac rehabilitation was viewed by those who participated as positively affecting self-confidence, stress management and physical wellbeing. Differences between those who received rehabilitation and those who did not are not explicated. Over fifty percent of the 41 participants were post-MI although their specific experiences are not distinguished from those women with other cardiac diagnoses.

#### *Recovery Processes*

The view of women's post-hospital recovery from MI as a process, as opposed to individual measured behaviours, was first described in a landmark study using grounded theory by Johnson & Morse (1990). To explore what the authors term "the post-MI adjustment process", 7 men and 7 women who were enrolled in a cardiac rehabilitation or cardiac self-help programme were interviewed 1 to 45 months after first MI. Participants were selected for study inclusion, however the selection criteria and process were not

described. Data collection and analysis procedures were adequately described. Age range was 43 to 68 years. Successful post-MI adjustment was characterized as a four stage, non-linear “struggle to regain control” over one’s life. The following stages were identified in the adjustment process; defending the self against the diagnosis, coming to terms, or accepting the diagnosis and its implications, learning how to move forward in life and living to ones fullest potential. Knowledge that enabled participants to anticipate outcomes of actions or decisions and the ability to subsequently make and act on those decisions, was cited as crucial to moving through the stages. Although common themes were identified between men and women, differences were noted in relation to their management of role transitions. Women had trouble giving up their usual housekeeping and care giving roles and so engaged in these activities earlier than recommended. Although study results enlighten understanding about adjustment post-MI, it is possible that the process may be different for women who do not have access to, or choose not to participate in formal rehabilitation programmes or self-help groups. No specific time was identified for the completion of the adjustment process and it was noted that for some participants, a sense of control and subsequent adjustment could not be established. The life process experienced for those who did not adjust is recommended as a focus for future study. The benefit of social support for study participants was evident however, the role of specific formal supportive interventions in facilitating the adjustment process for women was not clearly explicated and merited further investigation.

An American study generated results that built on and were consistent with, the finding of Johnson and Morse (1990). Using a cardiac support group of 13 women who met weekly over a 9 month period, Fleury, Kimbrell & Kruszewski (1995) aimed to

describe the recovery process for women following a cardiac event. Women had a mean age of 58 years and time from the acute event ranged from 8 weeks to 3 years. Recruited from advertisements, health care professionals and word of mouth, participants volunteered to be part of a support group for women with various cardiac diagnoses. Four women were post-MI, others had coronary bypass, angioplasty or had been diagnosed with coronary ischemia. Data collection and analysis was clearly described; issues arising from the decision not to tape group sessions were addressed and served to limit auditability. Differences, if any, that arose between cardiac diagnostic groups were not addressed. A three stage “healing process” emerged from descriptions by study participants. Initially, participants described the struggle to survive the upheaval in their everyday lives and reviewed the forces affecting an altered sense of self. The redefinition of self occurred in the second stage as women identified priorities, shedding the guilt that was first encountered in focussing on themselves. By creating their own support systems, women gained inner strength to move on to a third phase in which they felt able and open to meet the challenges for redefining self and health behaviours. The women involved in this study invested significant time and emotional energy in participating in the research/support group and this investment may be a challenge for some women living post-MI. The healing process described is one that relied heavily on women having insight, motivation and perceived support over time to take the risk to reflect. These results raise questions about the nature of the healing process women experience whose life circumstances are different from the study population.

Eight urban women between the ages of 61 and 87 years living in Eastern Canada, were interviewed 2 and 4 weeks after discharge following an MI, to identify and explore

the meaning elderly women attached to their cardiac illness, recovery and social support (Helpard & Meagher-Stewart, 1998). Data collection and analysis procedures were adequately described. Of those who chose to participate in this convenience sample, all women had experienced at least one MI; two had recently been discharged for unstable angina. No differences in findings were reported according to current discharge diagnosis. Interviews took place in the women's homes. A theoretical model evolved using a grounded theory approach to describe the processes that helped individual women "find a voice" (Helpard & Meagher-Stewart, 1998) and evolve to a new state of being in their worlds. Although not labelled as such, women expressed the need for experiencing components of mutuality as essential to finding their voices and achieving equilibrium. Traditional female household responsibilities and other socialized expectations of self and others were central to the unique struggle women described as they found ways to integrate their losses and experiences. These women did not find nursing intervention facilitated their individual recovery and the presence and type of ongoing support from other health resources was not clear. Implicit in these findings is that women took ownership for their recovery and persisted in finding their own social support and other ways to manage moving on in the first 4 weeks of their post-MI lives. Following participants longer into convalescence may uncover new challenges that arise for elderly women after the first month following MI.

A second sample of 11 urban women over age 70 and 8 weeks after first MI, explored elderly women's perceptions about their MI experience (Sutherland & Jensen, 2000). Cardiology nurse's recruited participants during their post-MI hospitalization. Three women who originally agreed to participate withdrew on return home due to poor

health or interview anxiety. The interview and data analysis processes were adequately described. Findings echoed many of the themes uncovered in the other reviewed studies. “Living with change” was identified as a five step, potentially nonsequential post-MI process. After the MI diagnosis was established, women described the challenges of comprehending the reality of the diagnosis and its implications, understanding the imposed changes, trying to stay in control, and adjusting to new realities. Of note is what is described as the women’s fighting spirit, not only to survive, but to live, within the changes. The MI was incorporated as another change that had to be faced in a life of changes. The women described taking ownership for maintaining their own and others wellbeing as they navigated the changes imposed by MI, in effect continuing to nurture others while sorting out their new realities. Five of the eleven women experienced supportive effects of rehabilitation programmes however it is not clear how or if their adjustment process differed from that of the six women who were not invited to attend these programs.

One study was retrieved that may have particular relevance for rural women post-MI. A study by Tobin (1996) which corroborated the findings of Johnson and Morse (1990) used a grounded theory design to describe the post-MI recovery process in a female population. Twelve participants were recruited in hospital following their MI and interviewed in their home 8 weeks following hospital discharge. Women ranged from 60 to 80 years of age. Data collection and analysis processes were described. A recovery process the women termed “getting back to normal” was generated through interview analysis. Participants’ descriptions of coming to terms with their diagnosis and then preparing to resume their lives and move forward, suggest that it was they who took

charge of the recovery process. Of significance in this study is that none of the women were in an outpatient support group or cardiac rehabilitation program and that participants did not consistently comply with or maintain lifestyle changes in the time the study took place. The women described their gradual resumption of life as a cautious testing of their abilities to engage in specific activities, and any support received was ascribed to family sources. Given these women appeared to recover with little professional help in the 8 weeks post-discharge period in which they were interviewed, it would be of interest to see if their perceived adjustment continued over a longer time period or if new challenges emerged. The fact that study participants lived within a 60 mile radius of a tertiary centre in Newfoundland, a province known for its rural and remote population and landscape, provokes questions about the impact of rurality on this study population. It may be that the experience of some rural women is embedded in the stories of study participants.

### *Summary*

Studies about women's recovery experiences identified that issues related to helping others, helping themselves and asking for help were important issues in their post-MI lives. Researchers placed women at the center of the process as experts in self-knowledge. There were indications of a therapeutic effect in the telling of stories and sharing of experience and while this was not the purpose of the reported studies, it draws attention to women's need for opportunities to express themselves about integrating the MI into their lives. Suggestions that post-MI life is a process may imply that MI is self-limiting and detract from the identification of MI as signalling the presence of chronic disease. Examination of the hegemonic structures and practices of health care institutions



from which women receive post-MI care, remain relatively unexplored in terms of their impact on women's experiences and recovery processes.

### *Rural Cardiac Issues*

Literature informing this review was retrieved from the Medline and CINAHL databases using search terms rural and/or rural health and/or cardiac and/or myocardial infarction. In addition, websites for the Heart and Stroke Foundation, Health Canada and Government of Canada were searched for relevant literature. No studies were found that focussed specifically on rural women and MI, hence the following review was intended to identify issues that have been raised related to rural cardiac care in general. Rigorous research about rural cardiac care and rural cardiac populations is sparse at best, although data recently compiled by the Institute for Clinical Evaluative Studies (ICES) supports the need to focus on differences found between rural and urban areas (Naylor & Slaughter, 1999). Evidence revealing urban-rural disparities in cardiovascular health in Ontario was based on data analysis from numerous sources such as the National Population Health Survey (NPHS) 1994/95, Canadian Institute for Health Information (CIHI), Ontario Health Insurance Plan (OHIP) and Ontario Myocardial Infarction Database Project (OMID) (Naylor & Slaughter, 1999). Modifiable risk factors such as smoking, sedentary life style, obesity and high fat diets were found to be more common in rural areas. This finding conflicts with commonly held beliefs that rural people are healthier because of their proximity to "the land" resulting in healthy diets and active outdoor lifestyles. Not surprisingly, an increased incidence of ischemic heart disease was found in many rural communities. Additionally, CIHI data from 1992/93 – 1996/97 show rural women had increased age/sex-specific hospitalization rates for MI

over their urban counterparts (Chan & Young, 1999). Inequity in access to angiography was identified for those living outside tertiary and teaching centers (Naylor, 1999). Secondary analytical methods and possible weaknesses in databases were outlined in detail and “interpretive cautions” were acknowledged in each part of the analysis, strengthening credibility of the findings. As discussed previously, definitions of ‘rural’ vary; ICES did identify the working definition of rural used for individual analyses. The practical research implications regarding a lack of consensus about the definition of rural are immediately evident when data are compiled from databases using different rural definitions. For instance, rural hospitals were classified according to the Ontario Ministry of Health/ Ontario Hospital Association criteria and place of residence for tracked patients were defined by (rural) postal code (Basinski, 1999). Primary and secondary prevention strategies and further investigation of the noted disparities was recommended (Naylor, 1999). However, prior to implementing prevention strategies, there is a need to further understand the environmental, geographic and social contexts influencing rural cardiovascular health. For instance, CIHI data point to lower income levels in rural regions in comparison to urban areas (Basinski, 1999). Understanding the dynamics at work in rural communities is essential for interventions to be relevant, acceptable and efficacious in the targeted rural population. Although comparisons cannot be readily made, similar calls for redress of what are perceived as urban-rural disparities, have been made in United States where rural women have been marginalized in terms of access to cardiovascular prevention at all levels (Taylor, Hughes & Garrison, 2002).

Meeting the challenges of delivering primary cardiac prevention to a rural community was the focus of an initiative in a sparsely populated agricultural area of

Saskatchewan (Ebbesen, Ramsden, Reeder & Hamilton, 1997). The programme was aimed reducing cardiovascular risk in women and men, however the majority of the participants were female. Of specific interest is the attention to rurality issues in the programme design and implementation in the effort to meet rural needs and foster participation. The modification of the program to the seasonal demands of the farming community and creative use of available community resources, such as use of the church and ice rink, were viewed as crucial to encouraging attendance. Challenges identified to programme sustainability included participation expectations of volunteers and participants, maintenance of confidentiality in the small community and difficulties in attracting men into the programme.

The unique context of rural cardiac care drove the Rural and Small Urban Committee of the Canadian Association of Emergency Physicians to develop a guideline for chest pain management in rural hospitals (Thompson et al., 1999). The guideline was generated to address some of the challenges rural hospitals face in meeting standards of care for acute MI. These challenges include physician and lab support being available on an on-call basis, nurses having responsibility for both in-patient and emergency patients and relatively low numbers of MI treated annually per rural physician (Thompson et al., 1999). The effectiveness of the guideline in addressing the specific rural issues is not reported and requires study. The authors also point to a need for further investigating communication breakdowns that sometimes occur between rural and urban hospitals that negatively affect the care of rural clients who return to the community.

An American commentary about challenges faced by nurses who provide in-hospital care to rural cardiac clients, reiterated that nurses working in rural hospitals may

juggle generalist and specialist cardiac care roles and have limited access to continuing education to prepare them for those roles (Winters & Mayer, 2002). MacLeod (1999) noted a similar theme in rural nurses working in British Columbia who summed up the nature of their practice by saying “we’re it” (p. 69). The implications of these challenging nursing roles on the experience of patients requires address.

It is known that full cardiac rehabilitation is not available to many Ontarians in spite of its increasingly recognized value as a therapeutic intervention post-MI (CCN, 1999). Recently, the Ontario Cardiac Rehabilitation Pilot Project (OCR) expanded the number of cardiac rehabilitation sites across Ontario in an attempt to increase access, although there are still many areas that remain unserved.

An American study focussed on the factors affecting 254 rural residents who were randomized to a 12 week cardiac rehabilitation program following discharge for MI, angioplasty or coronary bypass (Johnson, Weinert & Richardson, 1998). Thirty-three per cent of participants were women; only 17 % of all participants attended all or part of the program. Instruments tested for reliability and validity were used to identify predisposing, enabling and need factors from a health utilization framework and resulting data were subjected to regression analyses. The following factors were found to promote attendance; recommendation by a physician to attend, social support (source and nature were not discussed), being unemployed, viewing health as effectively managing change, perceived personal economic resources and close proximity to rehabilitation facilities. Failure to identify results for women participants and low overall participation rates in this study limit generalizability but do provide some direction for investigating women’s attendance in rehabilitation. Similar concerns about program attendance have been raised

in Canada and results from a recent study indicated rural residents were less likely to participate in a formal rehabilitation program although reasons were not identified (King, Humen, Smith, Phan & Teo, 2001).

### *Summary*

Issues have been identified at multiple prevention and delivery system levels related to the unique context of rural cardiac care. While rural women may be at increased at risk for MI over their urban counterparts, there are concerns about their access to acute diagnostic and rehabilitative care. Although alarm bells have been sounded, concentrated efforts to develop a research programme focussed on rural women were not in evidence.

### *Summative Themes*

The reviewed literature revealed gaps in the information base related to rural women, women who survive MI and the experience of recovering from MI within the rural environment. The summary is organized by themes generated from the review.

### *Rural Women in Post-MI Research: Absent at the Table*

There is agreement that women have not been the focus of traditional cardiac research and there is reason to question whether rural people have been well served by research and practice models generated by centralized tertiary urban institutions. Most study populations throughout the reviewed literature have been generated from recruitment activities in tertiary care centres. Some studies have specifically included only those women who resided within city limits, effectively marginalizing rural women from the knowledge generation controlled by dominant urban systems. Aboriginal women and women from rural, remote and northern environments have not been the

focus of, nor intentionally included in quantitative or qualitative research about post-MI life. Would practitioners be willing to base their care decisions for urban people on research generated from populations of rural women? While current findings about behavioural outcomes, experiences and processes offer some insight into the recovery of women, there is a need to intentionally widen the inquiry to include women who have been marginalized from the mainstream research populations for future care and health planning to be sensitive to their context.

*Access to Services: Roadblocks to Recovery*

Issues about limited access to services were frequently identified in relation to rural life, rural health and women's recovery from MI. Access issues were multi-faceted and related to health and rural infrastructure issues, in addition to patient's individual socioeconomic circumstances. Until these issues are explored to examine the ways in which their existence reinforces the social order and distribution of resources, women are likely to continue to experience challenges in accessing services. Some of the reviewed studies that focussed on the world of women who survived MI drew their samples from those women who accessed supports such as cardiac rehabilitation programs or support groups, failing to identify issues in the lives of women who did not participate or have such access. Subsequently, access issues for rural women recovering from MI have little chance of being named or examined and this silencing serves to protect the system from the strain of increased demand.

Exploration about what women do who do not access structured supports is missing in the literature and merits investigation. Knowledge of the ways in which rural women who do access supports are different from those who do not, would also broaden

the knowledge base for future policy and care decisions and potentially expose power imbalances that contribute to the situation. Understanding the dynamic influences from the rural perspective on the perceived choices and decisions rural women make as they try to resume their lives is necessary prior to introducing new or alternative solutions for facilitating access to recovery opportunities.

There is evidence to suggest the length of time a woman lives in a community may affect her health experience; issues for newcomers may be different than those who have been long established. This suggests that a social hierarchy may exist inside rural communities that could serve to limit women's inclusion in informal support systems. Alternatively, it may be that those women who have moved to a rural area may have previous urban connections that offer them "privileged" knowledge of post-MI possibilities. Examination of these social forces may reveal new understandings of how rural women resume their lives post-MI and how the rurality affects their choices and chances.

#### *Influence of Female Roles on Women Who Are Post-MI*

In general, the reviewed literature about women's recovery from MI reported studies that offered some evidence that women are more negatively affected than men after MI with regard to return to work, sexual activity and opportunities to participate in cardiac rehabilitation. This said, there has been some question raised as to whether it is appropriate to use similar behaviours to measure and compare the recovery of men and women (Cochrane, 1992, Angus, 1996a). Return to work has been used as a measure of recovery after MI, although issues about women and what constitutes women's work, complicate the findings (Hamilton, 1990; Hamilton and Seidman, 1993; Wingate, 1995).

It has been suggested that women's older average age at MI and the work involved in traditional female roles, frequently referred to as "women's work", make return to paid work a less relevant measure of recovery for women than men (Fleury and Cameron-Go, 1997). Exploration of women's recovery from MI and return to work need to take into account the work involved in role performance and not only place value on paid work. Why have the outcomes for women when they cannot or do not assume their roles as nurturers and caregivers after MI, remain unexamined?

Central to challenges women faced in the recovery period were the domestic task and nurturing roles to which women have been socialized, and that appear to limit asking for and receiving help. Women have described the struggle to resolve guilt related to changes in gender mediated roles and balance this with their recovery needs and guidelines. Given that traditional role expectations have also been identified as issues for rural women, how women who return to rural communities manage their post-MI recovery is of concern. Examination of systemic structures that have allowed this situation to perpetuate has been absent in the dominant discourse.

There is evidence to suggest some women engage in the construction of new identities post-MI and that support systems play a significant role in that remodelling. Further research is warranted to explore the ways in which women's environments and support systems affect the evolution of a new post-MI self. Knowledge of supports used by rural women post-MI does not exist in the current literature.

Depression has been identified as a significant factor in the recovery of women from MI and in rural women. Failure to define the term in some studies has resulted in 'depression' being used loosely as a subjective feeling rather than a medical diagnosis.



Other themes that have been identified relating to emotional status after MI include perceived loss of control, the effort to regain control and manage uncertainty. How rurality impacts on the emotional well-being of rural post-MI women is unexplored but merits attention given that access to diagnostic and treatment options may be problematic. Emotional wellbeing may also have an impact on role function, the seeking of support and the adoption of lifestyle modifications in the post-MI life phase. Research has tended to focus on the behavioural outcome instead of examining the possible environmental roots of behaviours. For instance, what contributes to (feelings of) depression in women? Are women who have difficulty accessing supports or care, or those who have increased demands as nurturers, more likely to be depressed? Post-MI quality of life discussions should be expanded to explore how women achieve or maintain self esteem, and to identify the dynamics underlying the seeking and receiving of social support in their recovery.

### *Research Perspectives*

Reviewed qualitative studies have included women two weeks to over twenty years post-MI, with the majority of research focussed within the first six months. However, based on the nature of the recovery described, evidence to suggest limiting the time period for studying post-MI processes and experiences is weak. Processes described in the literature reflect that post-MI developmental tasks do not necessarily occur in a linear fashion, rather they have cyclical and iterative characteristics and time frames for completion of recovery processes are inconclusive. Given that women who survive MI are actually living with a chronic health problem (ISD), it is interesting that women in the reviewed studies sometimes approached MI as an acute and self-limiting episode. This is

an enticing perspective although it is deceptive when it relates to MI. Studying women in the short term may risk minimizing the long-term impact of MI on women's lives and the chronic nature of heart disease. It is argued there is benefit to studying women's perspectives over a longer term so that, if issues related to chronicity exist, they may be revealed. Are there benefits to the dominant social systems when problems can be viewed as short term? Because the impact of rurality on post-MI women has not been studied, it is not known if there is a point at which rurality ceases to make a difference and hence time limits on studying post-MI rural women are difficult to support.

Research has tended to approach the study of rural women, cardiac care and women's recovery from MI from a deficit position, identifying what is lacking, and negative or not functional from the perspective of "knower" connected with urban institutions and/or agendas. While this perspective is obviously necessary, a shift in perspective to uncover strengths and resources in rural women and rural communities could be used to inform the care and policy related to post-MI needs. Offering rural women an opportunity to reflect on their experience, lives and thoughts from a post-MI vantage point is a way to build knowledge from the inside, out.

#### *Statement of the Problem*

The numbers of Canadian women who will have MI's in the future will increase and there is need to ensure that policy, services and care are available to meet their needs for optimum recovery. Although themes have been identified about women's post-MI recovery experiences, there are few data about rural women to support decision-making related to any of these facets of health care. If culturally sensitive care is to be available for rural women, there is no better place to look for guidance than to the women

themselves. The way in which being from a rural community influences the life choices, experiences and decisions of post-MI women is central to the discourse at all levels.

Thus there is need to study how rurality affects the lives of rural women who survive myocardial infarction.

The primary research question that guided this study was:

How does rurality influence the lives of women after myocardial infarction?

Secondary questions intended to help women articulate the meanings embedded in their post-MI rural lives were structured around the following broad questions:

- 1) How do women view their rural communities and themselves as rural dwellers?  
What meanings has their rural existence had for them?
- 2) What recovery and life choices were women aware they had after MI?
- 3) What choices did rural women make in their post-MI lives and what did they view as influencing those choices?
- 4) What formal and informal structures influenced the lives of rural women after MI and in what ways?

### Chapter 3

#### *Methodology*

The approach chosen to explore these questions was critical ethnography. This chapter begins by outlining ethnography as a methodological approach to describe the world of post-MI women, and then distinguishes how the critical perspective influenced the research process. Following this, I critically reflect on my role as the ethnographic researcher and discuss how I may have affected the research process. Participant recruitment, data collection and analysis, and attention to rigor in the research process are then discussed.

#### *Ethnography as a Research Tradition*

Ethnography has been valued as a methodology for describing and interpreting the life-worlds of groups of people who have some common connection or pattern in their lives (Cresswell, 1998). As a method, Aamodt (1991) observes that ethnography is a way of collecting, describing and analyzing the ways in which human beings categorize the meaning of their world. In other words, ethnography attempts to learn what knowledge people use to interpret experience and mold their behaviour within the context of their culturally constituted environment (p. 41).

The culture of a group is both constructed by and reflected in behavioural and linguistic patterns and in the meanings of associated cultural artifacts (Cresswell, 1998). The cultural group at the center of this study was women who had survived MI and returned home to rural communities. These women were in essence a “subculture” of the broader culture to which rural women belonged (Dietz, Prus & Shaffir, 1994; p.59). As a subculture these women had a common medical diagnosis (MI), were regarded as facing

common threats and challenges associated with MI, and lived in an environment known for its unique characteristics.

Ethnography is valued as a way of explicating the *emic* or insider perspective to reveal that way in which people view and take action in their world (Cresswell, 1998; Polit, Beck & Hungler, 2001). Prus (1994) advises that certain assumptions are central to understanding that world and he refers to the interactive/interpretive ethnographic tradition, as “the study of human lived experience” (p.18). Based on his writings, the following assumptions informed the ethnographic focus as I studied rural women’s post-MI lives:

1. Multiple realities formulate the social construction of a person’s existence as an individual and within the culture of a group.
2. People create meanings through self-reflection and interaction and act according to the meanings which objects or situations have for them.
3. The influence a person has on another affects interaction and is relevant to understanding a culture.
4. Human existence is socially constructed.
5. Human existence is a dynamic process and understanding these dynamics is essential to the research process (Prus, 1994).

#### *The Critical Perspective and the Ethnographic Tradition*

It has been argued that critical theory, which informs critical ethnography, is fundamental to a philosophical paradigm intended to generate nursing knowledge that is sensitive to the social, political and environmental influences on individuals as biopsychosocial beings (Mill et al.,2001). Critical theory originally arose from the

Frankfurt School and was influenced by the human tragedies related to the World Wars and the writings of philosophers like Kant, Hegel and Marx (Kincheloe & McLaren, 1994) and later, Habermas (Holter, 1988; Campbell & Bunting, 1991). It currently and more aptly refers to a group of critical theoretical constructs to which critical researchers variably ascribe (Thomas, 1993, p.31).

Morrow and Brown (as cited in Cresswell, 1998) say that the critical theoretical perspective taken “is defined by the particular configuration of the methodological posture it embraces” (p.81), in this case an ethnographic approach. Further, to this Agger (1991) identified substantive and methodological levels to which the critical perspective could be applied. In terms of the ethnographic tradition in this research about rural women, the critical approach was evident in the decision to study post-MI rural women, in (re)viewing the related literature and concepts, and in collecting and analyzing the data.

The assumptions guiding the critical process for this research were drawn from an eclectic critical perspective (Campbell & Bunting, 1991; Kincheloe & McLaren, 1994; Lindsey, Shields & Stajduhar, 1999).

1. Societal structures that have evolved over time and which may be invisible, influence the human experience .
2. Social exclusion has been created through the adoption of various ideologies by dominant forces, including those that intentionally oppress.
3. People may not be aware of the forces acting upon and shaping their life experience.
4. Knowledge, enlightenment and emancipation are possible and created through the critical dialogic process, to which the researched person, as “knower” is central.

Critical ethnography takes the researcher beyond conventional ethnography, beyond the mere description of people and events, and invites reflection on, and examination of, the status quo, with the goal of generating possibilities for change (Thomas, 1993). While the “ethnographer gathers artifacts and physical trace evidence, finds stories, rituals, and myths, and/or uncovers cultural themes” (Cresswell, 1998; p.59), the critical researcher is called to “describe, analyze, and open to scrutiny otherwise hidden agendas, power centers, and assumptions that inhibit, repress and constrain” (Thomas 1993, p.3). Critical ethnographies are intended to uncover the influence of “the other,” including people, institutions and practices that may be affecting human existence and in so doing, act to positively change the condition of marginalized populations. As a result, critical ethnographies invite what Friere (1970) referred to as a “conscientization process” in which an awareness evolves of “what could be” if the existing powers and influences were shifted. Habermas described the way in which the critical perspective enacts “a process of self-enlightenment of socialized individuals about what they would want if they knew what they could want” (Holter, 1988, p.227). Emancipation and enlightenment, become “products” of research grounded in the critical paradigm (Campbell & Bunting, 1991). The possible ethical dilemmas associated with the critical process are discussed later in the chapter.

### *Rurality and the Critical Perspective*

A major assumption underlying the stance that influenced the direction of my research was that rurality influenced women’s experience post-MI. Guided by the aspects of rurality identified in the literature, rurality and the ways in which it could

affect life was explored from the participants' perspectives. Rurality was the cultural lens through which meaning of women's post-MI experiences was filtered.

Women who returned home to rural communities post-MI were valued as expert “knowers” of their own experience and were encouraged through reflective dialogue to make that knowledge explicit. Polit et al. (2001) acknowledge this as a challenge, saying that ethnographers “strive to reveal tacit knowledge, information about the culture that is so deeply embedded in cultural experiences that members do not talk about it or may not even be consciously aware of it” (p.213). Through a process of critical dialogue, participants were encouraged to reflect on their perceptions of rurality, to become consciously aware of, and to articulate their lives as rural women who survived MI, and the influences that gave rise to their post-MI experiences.

#### *Participant Selection*

This study was based on a convenience sample that targeted recruitment from rural communities within driving distance of my home in rural southwestern Ontario. At the study inception, I had decided to limit the study to women up to one year post-MI, hypothesizing that by that time most post-MI issues would have been identified. Morse (2000) counsels qualitative researchers to constantly reflect on the research process, to “follow your nose” (p.579) and strategically modify the approach when necessary to fit with new understandings. As the data collection progressed, it became evident that the effects of rurality may not be gone at one year and that my initial time limits may have served to silence rural women who were living with effects of cardiac damage and who were over the one year benchmark. Subsequently, women who met the following inclusion criteria were eligible to participate in the study:



- 1) Diagnosed with a MI in the past year or more.
- 2) Lived in a rural community in south-western Ontario.
- 3) Able to speak English.
- 4) Agreed to one-to-one taped interview(s) with the researcher.

Based on the desire to get as much diversity in the sample as possible, no exclusion criteria such as number of MI's, age or psychological or functional status were designated.

There is no consensus regarding sample size within ethnographic research. While the issue of sample size was addressed, it could not be viewed in isolation from other study elements. Patton's (1990) approach was instructive in this regard: "The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size (p.185). Patton (1990) further recommends that a researcher target a minimum sample number, but remain sensitive to the emergent data and the possible need to increase or decrease numbers.

After twelve women were interviewed, when no new themes were being revealed, a decision was made to suspend further recruitment. At this point the women represented wide diversity in experience with MI, demographic details, "newcomer" / "long-established" rural status and place of rural residence. Additional cultural documents (identified under Data Collection), field observation and discussion with rural MI survivors, patient educators, a rural physician and an urban referral centre for rural residents provided rich data that served to facilitate reflection and analysis of the women's stories.

*Recruitment Strategies*

Berg (1989) advises ethnographers to be flexible, but strategic, in considering how they might gain entry to the participant group. A purposive sample was generated by targeting recruitment of post-MI rural women through snowball sampling and advertising in rural areas. In snowball or chain sampling, cases thought to be “information-rich” are identified by individuals who are known to have a wide contact base likely to lead to the target population (Miles & Huberman, 1994). These individuals are valued in the ethnographic approach and have been labelled as key informants and gatekeepers (Berg, 1989; Cresswell, 1998).

Letters outlining the research and giving my name and number were distributed to those identified as key informants and gatekeepers, which included physicians in selected regions of rural southwestern Ontario (see Appendix A). A poster with contact information was included in the letters for distribution (Appendix B). A toll free phone line was initiated so those interested in participating or in making a referral to the project could do so at no cost to themselves. Paying for long distance phone calls was seen as a potential deterrent to participation and is an issue for residents of rural areas. Word of mouth and information that was passed between participants, nurses involved in teaching programs related to cardiac risk factors and physicians were the major sources of participant referral. Nurses who taught heart health classes at three rural hospitals contacted me and subsequently they passed on my poster to women who had been diagnosed with MI with whom they had contact in or outside hospital. One woman was referred through a community contact.

In an interesting and supportive turn of events, the administrator of a rural hospital who were eager to increase the knowledge base about rural women and to promote nursing research, initiated a meeting with me to determine how they could facilitate the study. This resulted in a chart audit by that institution to identify potential participants and they subsequently mailed the poster and a letter of introduction about me, inviting participation by those identified women. In another endorsement, a woman who had contact with Women for Rural Economic Development (WRED) requested I email her my poster and it was subsequently distributed through that electronic network. This resulted in contact with me by two women who were not interviewed because they lived well over 200 kilometers outside the targeted area.

Eligibility for participation was determined at initial telephone contact with each potential participant. Participants contacted me by phone or gave permission and their number to a key informant to have me call them. Several women contacted me who wanted to participate but when questioned it was apparent they had not sustained a MI, but had Congestive Heart Failure and/or ISD that had resulted in angiogram and/or angioplasty or coronary artery bypass. This (non) finding is of interest in that it signifies there are rural women who may not understand their cardiovascular diagnosis. Another woman who contacted me advised me she had been scheduled for coronary artery bypass graft (CABG) surgery but had taken herself off all medications and was now taking an alternative oral therapy which she was selling to others in her community to save them from “unnecessary” traditional medical prescriptions. This woman had not infarcted but did have angina and hypertension. One woman outside the study area had published a reflection following MI and this was obtained as a cultural document. Email contact was

maintained with her. The second woman outside the area lived on a farm and emailed and phoned me to discuss her experience. Whether she actually infarcted could not be ascertained, although she claimed her physicians thought MI had occurred during an unexplained illness in another part of the province a few years previously. She was diagnosed with unstable angina and had a CABG. Her insights provided some context for understanding the plight of rural women with heart disease and were corroborated by many of the themes that emerged for women with confirmed MI's.

The diagnosis of MI was confirmed for all women who were referred through health care professionals. The participant who was referred through a community contact stated she had three MI's and had a family member who was a physician that confirmed the diagnosis. All stories recounted by the women were consistent with a MI diagnosis although there were variations within the sample as to when and how diagnosis was made.

During our initial phone conversation I described the study and the commitment I was asking for, and any questions were answered. The daughter of one elderly woman contacted me to discuss the study. A date, time and place were agreed to for the initial interview. All interviews, save one, were completed in the women's homes at their requests. One woman preferred to come to my house for the initial interview as she was embarrassed by the "mess" she claimed her home to be in.

Rural residency was confirmed for all women. Women's reported place of residence was plotted on a map of Southwest Central Ontario Restructured Communities (Association of Municipal Managers, Clerks & Treasurers of Ontario, 2001). The name of the municipality was then entered into the Profile of Canadian Communities website

(Statistics Canada, n.d.) which was based on 2001 census data. Population densities were calculated based on community data and compared to the OECD definition. All women lived in communities that fit the OECD rural definition.

### *Data Collection*

Prior to beginning each interview, participants reviewed and signed a written consent to participate that outlined the terms of the research (see Appendix C). In addition, a more concise and less intimidating information sheet was made available (Appendix D) and was also distributed to new key informants and gatekeepers when written information about the study was requested. The primary data collection technique was in-depth semi-structured interviews with individual participants. Interviews were audio-taped and transcribed verbatim. As Easton, McComish and Greenberg (2000) suggest, transcripts were read and re-read while tapes were played so that all words and phrases accurately represented the participants dialogue. The interview process took place over a seven month period in 2002.

The interview process is what Lincoln (1993) terms a “search for stories” (p.35). Lincoln counsels that the search “must involve active seeking, active listening, and patient probing since would-be narrators may have to find the shape and form of such stories, and a language and imagery for telling them” (p.34-5). An interview guide generated from the literature review provided general probes (Appendix E). In the spirit of the critical perspective, data were reflected on, apparent contradictions in the data noted and notations made for follow-up interviews if required (Thomas, 1993). Minimal notes were made during the interviews. Questions were reframed to probe issues and

new conceptualizations that developed during the interviews as a result of the critical process.

This interview process was new and somewhat intimidating for many women initially although when I made connection as a rural person, interviews seemed to flow more easily. Some expressed relief they did not have to travel to the city in which the university was located for the interview. In retrospect this may have discouraged participation by women and this should have been made clear on the poster.

As Berg (1989) advises, more detailed field notes were made immediately following the interviews. Following the interview, each interview was transcribed. In spite of extensive planning and rechecking, the quality of one interview was extremely poor and fortunately this was recognized as soon as the interview was over. For that interview, extensive field notes were made including remembered quotes. Following audio tape transcription, interviews were replayed, reviewed for accuracy and notations made for follow-up.

Women were contacted by telephone and arrangements made to review their transcripts, ask clarifying questions and to clarify emergent themes. It is through reflection and the critical dialogic process that participants are encouraged to increase awareness about their situations and new possibilities. As interviews unfolded and as analysis progressed, issues and possibilities were reflected upon with the women and again, observations were recorded.

Review of data and analysis occurred according to the women's wishes. In total, 2–4 hours of interview time occurred over two to three contacts for eleven of the twelve

participants. One woman died prior to follow-up, however review of the interview did occur with her daughter who was present at the initial interview.

Thomas (1993) advises critical ethnographers to “continually be alert for additional sources of information that reveal the details and nuances of cultural meaning and process (p.38). Morse (2000) also counsels the qualitative researcher in the art of self-reflection, encouraging the ethnographer, like the good detective to “follow your nose” (p.579), checking out hunches, reviewing approaches that are effective and those that are not, and subsequently make strategic decisions to generate a better study. The journey of inquiry undertaken to discover the world of post-MI rural women followed this guidance, resulting in strategic shifts that broadened the basis of the ethnography and enhanced the critical approach. Initial decisions to include only women in their first year post-MI were reviewed with the research committee and the timeline subsequently extended when it became apparent that issues related to rurality persisted, developed or were recognizable for some women when some distance from the acute MI event was achieved. “Distance” involved the passing of time and the feeling that a woman’s health was not in immediate danger and that she felt energetic enough to engage in discussion with a stranger. An additional factor in recruitment and data gathering was verbalized by some women and key informants who said that some women identified periods of time when they were emotionally vulnerable and did not want to explore their MI experience. Putting limits on who they spoke to and what feelings were revealed may illustrate how women assumed and maintained some control in their lives.

“Leads” were followed to broaden understanding of the story women were describing. To this end, I utilized additional fieldwork approaches that included the

following; accompanying a participant and her family in a fund-raising Mother-Daughter Walk organized by the a community Heart and Stroke Foundation, attendance at nurse directed post-MI outpatient educational sessions at two different rural sites, interviews with rural staff nurse patient educators involved with care of post-MI rural women, discussion with rural physicians and interview with a nurse in the cardiac catheterization lab from a referral center. For these additional observational data sources, consent was obtained following description of the study and review of the Participant Information Sheet. Field notes were made during and immediately following the interview or event. These observations and interviews resulted in approximately 40 hours of additional contact.

Cultural documents also informed the ethnography, lending insights about rural communities and rural issues and information about activities available to post-MI women. These included rural newspapers, written material given to post-MI women by health care professionals, a letter written to me by a participant, a reflective book written by a woman after her MI and emails to me from women with cardiac histories.

Templates were created to record the following information and kept in a secure file: Record of Participant Demographic Data (with instructions to get to the interview site), Cultural Document Record, Observation/Key Informant Discussion (for recording observations made, salient discussion points, questions for follow-up).

### *Data Analysis*

Becker (1996) advises us that qualitative researchers must “pick out” the relevant details of participants’ accounts to focus on answering the research question(s) and challenges whether the conceptual notion of “thick description” attributed to Geertz can



ever be accomplished (p.63-64). The discussion about the nature of data analysis by Miles and Huberman (1994) was helpful in what they allude to as the somewhat daunting task of managing, processing and analyzing qualitative data, while staying true to the intent of the study and maintaining rigor. Of particular assistance was advice that

data collection is inescapably a *selective* process, that you cannot and do not “get it all” even though you might think you can and are...What you “see” in a transcription is inescapably selective. A critical theorist sees different things than a deconstructivist or a symbolic interactionist does. The instrumentation, too, will selectively determine much of the data collected. Informants themselves are selective too, sometimes deliberately, sometimes unwittingly. They may gloss over important parts of their behaviours and perceptions and the researcher may not be aware of this (Miles & Huberman, 1994; p.55-56).

While recognizing the selective nature of analysis, my challenge was to be as cognizant as possible of that selectivity, while maintaining a critical stance. The way in which I approached this was guided by Thomas (1993), who provides helpful instruction for the critical ethnographer in the data analysis process.

The researcher decodes the ways that the symbols of culture create asymmetrical power relations, constraining ideology, beliefs, norms, and other forces that unequally distribute social rewards, keep some people disadvantaged to the advantage of others, and block fuller participation in or understanding of our social environs “” and “ identifies ways by which alternative interpretations of cultural symbols can be displayed. (p.43).

Data analysis was also informed by the procedures outlined by Miles and Huberman (1994). To some extent, preliminary data analysis began during the interviews as I constantly reflected on what was being said or not said, and then tried to pursue questions related to that and to uncover how rurality and its associated characteristics, may be influencing the narratives. The data analysis became a cyclical deconstruction/reconstruction of the women's narratives and this ultimately uncovered the study findings.

The coding proceeded following transcription of the interviews. The review of transcripts was guided by the primary and secondary research questions. Initially, some codes, such as distance and social networks, were derived from the research questions a priori to link into the “conceptual interests” as Miles and Huberman (1994) suggest. As the analysis continued, these initial codes were subject to revision and renaming to “fit” the data. As systematic review proceeded manually, inductive labelling of data “chunks” or themes evolved to create files using Microsoft Word. A list of codes was kept to keep track of the labelling system.

With each additional transcript, a search for cross-interview linkages was undertaken to identify pattern codes that reflected themes in the narratives. Memos were written to record possible linkages, explanations and/or issues to check out. A “conceptual web” (Miles & Huberman, 1994; p.63) was created to map linkages in the generated themes.

Data analysis is presented according to the thematic descriptions that unfolded. Decisions regarding analysis were recorded as part of the audit trail and included as relevant in the analysis.

*Attending to Rigor in the Research Process*

While there is need for the qualitative researcher to creatively pursue the research process, there is also need for attending to checks that ensure a systematic and sound discovery process (Marshall & Rossman, 1989; Sandelowski, 1993; Whittemore, Chase & Mandle, 2001). Thomas (1993) states that critical ethnographic research is not an objective endeavour, and that topic selection, data collection and analysis shape conclusions that are, and can be drawn. For instance, decisions by me invariably affected who I spoke to, when I spoke to them, the questions I asked, what counted as data, and how I chose to view relationships in the data. The influences affecting the study and the need for methodological rigor will be addressed in the following sections that attend to issues about the researcher as instrument and identify specific strategies used to enhance the quality of findings.

*The Researcher as Instrument: Who Was I To Do This?*

Clearly, the researcher is the instrument in ethnographic research (Polit et al., 2001). The role of the critical ethnographer in the research process must be examined at all phases of the research process and the researcher must respond to the query “who are you to do this research” (Agar, 1980). I will outline my relationship to the research and how that relationship was handled as the project developed.

Thomas (1993) described critical ethnography as “conventional ethnography with a political purpose” (p.4). I began this research with a political purpose. I believed there was a need for policy makers and health practitioners to understand the influences on the lives of post-MI rural women from the perspective of rural women, and that future practice and policy should reflect that understanding. In addition, I believed the social

norms, structures and assumptions that created these influences may in themselves need to be changed or at the very least, articulated and made visible.

“The ethnographer enters the field with an open mind, not an empty head” (Fetterman, 1991, p.90). It was important that, as the researcher, I recognized what influenced formation of my research questions and the influences on my thinking at all phases of the process. In my roles as a child of the farming community, a rural woman and nurse, I believed there was a story to be told, a story whose telling had not been invited and then not articulated by those to whom it made the most difference. Questions about rural women’s post-MI experience, needs and issues had not been asked and subsequently remained unknown or invisible to the institutions and professionals that influenced their lives. I came to this research not knowing the story that awaited, and not knowing what must be changed, but with ideas grounded in literature and life that told me inequity and muted voices existed in the rural female cardiac subculture. This is what Thomas (1993) termed an undoubtedly *value-laden* approach. Inherent in this was a moral imperative for me, the researcher to have awareness of my preconceptions and preferred interpretations, and to be clear about these in the research process. During all phases of the research process I examined my motives, biases, influences and inclinations to ask questions, pursue a line of thought or action and to arrive at analytical decisions and interpretations. These were chronicled in a journal, field notes and analysis memos.

My background in nursing and nursing education had prepared me to respond to people in therapeutic ways and, from limited past research experience in which the duality between nurse and researcher became evident, I had been concerned as to how this would shape my research. Lipson (1991) offered guidance to nurses undertaking

qualitative studies saying that “socialization into a helping profession before becoming an ethnographer cannot be erased” (p.82). She counselled that when confronted with dilemmas in which one felt compelled to enact the helping role, the nurse ethnographer had to “grapple” with the choices and their own value system. She further commented as to the way in which therapeutic intervention on the part of the researcher can sometimes shut down or change the direction of important dialogue, so that the need to intervene may be at odds with “rich” data collection. Conversely, Leslie and McAllister (2002) celebrated “nursedness” as a cultural construction to be exploited by critical social nurse researchers, and advised that communication skills and trust accorded to nurses by the public are assets that serve to break down hierarchies and facilitate the research process (p.700-701).

Anderson (1991) viewed information-giving on request by nurse researchers to participants as a way by which participants invite tangible reciprocity in the research process. She advises that “the onus is on the researcher to ensure that women’s concerns are heeded” (p.117). It was also postulated that giving information may enable women to see alternatives, thus enacting the emancipatory aspect of critical research.

That the critical ethnographic approach could sometimes elicit disturbing decision-making, self-reflection and change, was a reality of which I was mindful and vigilant. This was accomplished through continuous self-reflection, dialogue with my research supervisor and recording the reflexive process in written format at all phases of the study.

*Enhancing the Quality of Research Findings*

Lincoln and Guba (1985) identified the following issues as essential to establishing “trustworthiness” of qualitative research; credibility, transferability, dependability and confirmability. Using these constructs as a framework, I will outline the ways in which I addressed criteria to eliminate error and promote “truth” in my research.

The accuracy with which the findings can reflect the reality of the participant’s interpreted worlds has been the subject of some discussion in the methodological literature and some controversy as to the best approaches still exist (Sandelowski, 1993; Devers, 1999; Whitemore, et al., 2001). Given it was necessary to demonstrate use of measures to support research quality, I have selected several techniques advocated to promote research rigor.

*Credibility*

Patton (1999) identified three factors required in gauging the credibility of a study; the philosophical commitment to the qualitative process, researcher credibility, and rigorous data collection and analysis measures (p.1190). My belief in the critical ethnographic method and the philosophical tenets of qualitative inquiry are evident in discussions about the pursuit of this research endeavour and my credibility as a researcher has been addressed in previous sections. I employed three specific techniques to enhance rigor of data collection and analysis including member checking, triangulation of data sources, and the search for negative cases.

Sandelowski's (1993) advice to critically apply techniques such as member checking of participants' narratives, was instructive in employment of that technique in my research. Sandelowski (1993) challenged the technique in her claim that

the stories that members tell in interviews are themselves constantly changing. They represent members' efforts to order, find meaning in, and even live their lives at a particular moment in their lives....Stories are not simply vehicles for the communication of information that can be easily categorized and counted for consistency; rather they are time-bound, interpretive, political, and moral acts (p.5).

She argues that member checking may infer that reality is singular and concrete instead of multiple and constructed; that revised stories are in fact, new stories to be analyzed (Sandelowski, 1993, p.3). I subsequently used member checking discriminately and in consultation with advisors. Participants were offered the opportunity to review interview data and respond to follow-up questions, and their "checked" responses became new data. I also discussed with them, my insights from the emerging analysis and noted their responses.

Triangulation is a research technique used to refer to the reliance on more than one data source, researcher, method and/or theory (Patton, 1999; Streubert Speziale & Carpenter, 2003). Patton (1999) explains that contrary to common belief, triangulation may generate inconsistencies instead of sameness in results, and that this serves to deepen and broaden understanding of the study phenomenon and why differences may exist (p.1193). In this study of rural women, I used triangulation of data sources and ideological perspectives. The participants I interviewed displayed diversity in many

ways that contributed to the breadth of data, however, observation of cardiac groups, discussions with patient educators, physicians and a nurse in a referral center and review of cultural documents, served to deepen understanding of rurality and its effect on women's post-MI lives. As described earlier in the chapter, employment of the ethnographic and criticality perspectives helped to move the discussions beyond mere description of the studied phenomenon, and into a deeper understanding of the influences that created the current situation for rural women.

The search for participants who fit the eligibility criteria, but were more diverse than alike, was a technique used to increase the breadth of participant experience and insights upon which the findings were based. Additionally, a search for instances of “negative or outlier cases” was undertaken within and across interviews. This included checking out statements or indications that seemed at odds from what that participant or others had said previously, either at the time of an interview or as a result of transcript or other data analysis.

Miles and Huberman (1994) caution researchers to prevent bias in representing participants by 1) recognizing when there are actually no patterns in the data, 2) placing more weight on data from articulate “higher status” participants and 3) “going native,” whereby the researcher loses the ability to stand back from the data and question the process (p.263). I used several avenues to recruit women for this study and I was aware of a broad range in their abilities to reflect on and articulate their experiences and insights. Key informants were of great assistance in encouraging those who might not have responded, often out of feelings of low self-assurance, to agree to make contact with me. There were women who were interested in participating, but for various reasons,



such as feeling too unwell or having other significant family pressures did not. There is always the possibility that these women who were not interviewed would have shaped findings in other ways and the findings must be viewed with this in mind. During all levels of the analysis I was aware of the power of some participants to “speak” for what I was inclined to infer from other stories and thus influence the direction of the analysis and findings. The discussions with other data sources were particularly helpful for me to “hear” voices of other women who I did not interview.

#### *Transferability*

Transferability of qualitative research has raised questions in the research community and this research is no exception to that concern. Descriptions of the participants and study context will help others to decide the extent to which findings may be applicable to their populations. It is hoped that at the very least, this study will raise issues or questions that future researchers, health care providers and policy makers will consider in their deliberations about care of post-MI rural women.

#### *Dependability*

An “audit trail” is advocated as a means by which research steps and decision-making are evident at all points in the research process, making the process visible and open to scrutiny (Miles & Huberman, 1998). The research activities including contacts with key informants, participants and their interviews and other data sources were recorded and filed. Field notes were written immediately following contacts. During analysis, memos were made as coding proceeded. A record of the coding process was maintained.

### *Confirmability*

Confirmability refers to the freedom from bias, and, in addition to other strategies mentioned, the use of a reflexive journal by the researcher is considered essential (Miles & Huberman, 1998). Throughout the research process I maintained a journal that included reflections about many issues referred to in the previous section about the researcher. I also reflected on ways in which I tried to avoid or manage potential biases while remaining true to the critical perspective taken for the research.

### *Ethical Issues*

The proposal was reviewed and received approval from the McMaster University Research Ethics Board (MREB). As potential participants contacted me for inclusion in the study, the research was explained and questions encouraged and answered so they could decide whether or not they would be interviewed. At the time of initial interview, the project was again explained to the satisfaction of the participant and a formal consent to participate signed. A copy of the consent was left with participants that outlined the general nature of the research with a contact number to reach the researcher should a participant have questions or reconsider their role.

All letters of consent, interview audio tapes, transcripts and field notes were kept in a locked file to which only the researcher had access. Participant identity was protected through the use of an assigned pseudonym. No participants chose to withdraw from the study.

Some ethical issues related to the participant/researcher relationship were addressed previously in the section Researcher as Instrument: “Who Am I To Do This Research?” During the interview process, there were many occasions I felt sadness and

outrage at the turn of events that had transpired for individual women. At the time, I was aware of my desire not to frighten or worry them, nor did I want them to feel they had somehow been mismanaged. At the same time I wanted to hear their stories and hear their insights. At the outset, the pursuit of the critical approach seemed honourable, however in practice, I questioned if introducing women to other possibilities was an ethical action on my part. Nevertheless I gently explored issues, carefully constructing questions to have women reflect on what I sometimes perceived to be poor decisions on their part that could jeopardize their lives. I gave women who found the reflection emotionally wearing, time to cry, rest and regain their composure. None wished to terminate an interview and when I expressed concern for them, or asked if they wanted to stop, I was reassured and sometimes told that it was good for them to talk about it. I left all interviews feeling grateful for the effort made by each woman, for the time and emotion that was spent on a process that I had initiated. I had not been prepared beforehand to feel the tremendous responsibility to the women that permeated each interaction and I am grateful for their willingness to walk down a path they had been down before. I reflected on these thoughts and feelings in journaling and discussed the issues with advisors.

## Chapter 4

### *Data Sources*

This study centered on the experience of rural women who had survived a MI. True to the ethnographic tradition, I used additional data sources such as community newspapers, observation of the community-at-large and attendance at heart health talks to gain insight about the context of rural life, of rural health care and the world of each woman. Using the critical (rural) lens, I probed other data sources such as nurses and physicians to explore issues of power imbalances that came to light as the interviews and data analysis evolved. In the following chapter, introductions will be made to the women who gave of their time and energy, and a brief description of other significant data sources will be presented.

The women who volunteered to be part of this study all lived in Southwest Central Ontario communities that include Wellington, Bruce, and Grey counties. This area lies south of Lake Huron and Georgian Bay and is characterized by farmland, small towns and villages.

The women who volunteered to be part of this study reflect the varied personal backgrounds and residences of the rural people found in these communities. Four women lived in the countryside, six hailed from small towns or villages and two lived on the village “fringe.” All participants were cared for initially in one of four rural hospitals within the identified region.

The idea of participating in research was a novel one for most of the women who participated. Over the course of the study it became apparent that several were concerned they would have to go to the University in order to participate and this may have resulted

in discouraging contact by potential participants. The women came to be part of this project as a result of contact with key stakeholders who had knowledge of the study; two from physician contact, five from Registered Nurses who worked with post-MI patients; four participated following an invitation by a rural hospital to contact me, and one other woman was referred through word-of-mouth and was able to produce medical confirmation of her MI. At the time of the first interview, six women were in the first year post-MI, four were within two years, one infarcted four years previously and one woman was newly diagnosed although the exact time of infarction could not be established. All women described their motivation to participate in this study as a way they could possibly help other women in the future, although many expressed doubt their personal story could be of use. While it may be considered that those who volunteered to share their time, experiences, and emotions with me may be different than those who did not come forward, the diverse range represented in the participants' places of residence, age, and MI trajectory does offer breadth to the sample.

There was diversity in the ages of the participants. At the time of first interview, three women were in their forties, two in their fifties, three were in their sixties and four ranged in age from seventy-three to eighty years of age. Of the five women less than sixty years of age, two were on disability because of cardiac damage, one returned to homemaking and two had returned to work outside the home. Seven women were married or in common-law relationships; five were widows. One woman had a university education; six had not finished high school.

The following is a brief summary of each of the women who came forward to share their stories. I have chosen to present them in the order in which they became involved in the study.

*The Rural Women*

*Anna*

Anna was the first participant to contact me about participating in the study. She was 43 years old, married and living in a small town with her husband and two early teenage children. Anna had grown up in the surrounding community and her parents and other extended family still lived in the surrounding rural areas. Anna not only brought her experience as a rural “insider” to our discussions, but she also had “inside” knowledge of the health care system within her community because she had been employed in it for some time. She spoke as someone who was familiar with “how things got done” in the system and as one who had long established ties with her rural nurses and physicians prior to the MI. Anna was eager to tell her story and came to view her participation as therapeutic in her psychological healing.

I found Anna’s story powerful on a number of levels. Not only was she a relatively young woman, but she also experienced a cerebrovascular accident (CVA) at some point during the hospitalization for the subsequent bypass surgery. But even as an insider in the system, Anna could not access all resources that she saw as available to her urban counterparts nor did her connections enable her to have access to all the information to which she felt entitled. Anna’s connection in the community put her in touch with two other women in their forties who had experienced MI within the past year but Anna reported that both women felt too overwhelmed with their condition and their

struggle to recuperate to participate in interviews. Anna tried to represent these women as she reflected on the post-MI events and issues that had arisen for her. She felt her insider position within the medical community gave her an advantage in recovery these women did not have. Months after our first interview, Anna's previously healthy husband also experienced a sudden and unexpected MI. At that point, she had begun to use her experience and connections in the system to try to help him access the post-MI diagnostics and care she believed he required.

Anna contacted me following referral from her family doctor and thought her experience could help others.

*Beth*

Beth also lived in a small town and was the 53 year old foster mother of two school-aged children. Beth grew up on the East Coast and until the time she met her husband about ten years ago, she had been a single parent who had struggled with poverty and occasional depressive symptoms. Currently living in the most secure domestic and financial situation of her life, Beth felt that in spite of her MI, her life was very good. She felt very supported by her husband and the assumption of the role of foster parent had given her a sense of purpose. Her greatest concern at the time of the MI was that her foster parent role was threatened, that she would be viewed as unable to assume the role of parent and that the children would be taken from her. She continually expressed her relief this had not transpired. Although she struggled with anxiety related to fears of having another MI, Beth considered that she had a positive relationship with her family doctor and hospital. In the 23 months since her MI, Beth had maintained contact with the nurses who had run the post-MI education program from her local

hospital. She frequently verbalized great faith in, and gratitude for, her rural health caregivers, the care they provided, and their accessibility.

Beth heard about the study through nurses from the heart health program she attended and thought her experience might help others.

*Cassie*

Cassie, at 50 years of age, was the most isolated and marginalized of the women who participated in the interviews. She was eager for me to visit her and referred to feeling bored and lonely a lot of the time. Her social isolation and the idea that someone (the interviewer) was requesting her help, motivated her to ask a nurse who called her about follow-up classes, to have me contact her.

Cassie had a very “tough” exterior and she was uncomfortable when she became tearful during exploration of her experience. Our discussions were punctuated with long drags and puffs on Export A cigarettes which Cassie regarded as one of the few pleasures in her life. Her need to earn an income from the animal boarding business she had set up on her small farm was the priority in her life, and as such it affected her decision to reject the MI diagnosis and follow-up care. The demands of her rural life dictated that her body meet the requirements of hard manual labour and the MI diagnosis threatened this existence. At the time she contacted me, Cassie claimed she did not know if she had really had a heart attack because she had been told that her results were positive. She chose to view this terminology as meaning she had no problems. I did confirm the MI diagnosis, however, Cassie’s denial mechanisms were strong and she continued to choose to view herself as a healthy person who the doctors had mistakenly diagnosed with MI. She chose to cancel the initial appointment with a cardiologist that had been booked five



months post- MI. Cassie viewed the local health care professionals as nice people who understood her choice to turn down offers to attend heart health workshops and follow-up care.

*Doris*

Doris was a 69 year old widow who lived on the edge of a small town. She had moved into town from the farm and, until recently, been relatively well. At the time of our first contact she was awaiting mastectomy for a malignant breast lump and was more concerned over that diagnosis than the MI. Five weeks previously she presented in the local emergency room with what she thought was an allergic reaction but was told that she had a silent infarct prior to that day. Cardiovascular disease was prevalent in her family and because she had not experienced the acute MI symptoms that other family members had, she minimized the possibility that her MI was of much importance. She regarded its greatest impact on her life as perpetuating the ensuing rush of appointments to go out of town for further diagnostic tests, the need to attend cardiac education classes and the rebooking of her mastectomy in a city hospital because of her increased surgical risk.

Doris heard about the study in the cardiac classes she attended and, on the premise of helping other women with heart disease, she asked that a nurse pass her phone number to me so I could call her.

*Edna*

At 68 years of age, Edna was a widow and grandmother who lived on the edge of a village, having moved there from the farm following the death of her husband. My conversations with Edna were punctuated by her heavily accented but animated

descriptions and questions as she sought to understand her cardiac events and the options now available in her life. A WWII survivor, Edna had a very strong Christian faith, a joyful approach to life, and a spirited mistrust of the medical system that she readily shared with her medical practitioners and me. At the time of the first interview she was very excited about her discovery of “Heart Drops,” an herbal therapy for high cholesterol that she had accessed through a fellow churchgoer. The woman who sold her this product later contacted me and described a thriving herbal remedy business which she ran from her farm and described cancelling her own quadruple bypass surgery because of the success of this treatment. Armed with her faith and belief in self-sufficiency, Edna had been a strong advocate for herself in the medical system and in designing her own rehabilitation following two MI’s and bypass surgery sixteen months previously. She wanted to be able to help other women who might face similar problems and said she enjoyed talking to people.

*Fern*

Fern was a 76 year old widow who moved to a seniors building in a small town after she and her husband left the farm. She was 3 months post-MI when we first met. A previous CVA had compromised her physical mobility although she continued to drive herself, and others, in and around her community. At the time of our first contact she was a quiet and observant attendant at cardiac education classes. She liked the company the classes provided. Like some others, Fern had deferred going to the hospital during the acute MI, not wanting to make a fuss on a Sunday evening and instead, chose to wait for a scheduled doctor’s appointment the following day. Fern had a calm acceptance about life and its challenges, and viewed MI as one of many she had faced. She had some

trouble with feeling “down” and was tearful at times but claimed the little pill her doctor had given her helped to minimize that feeling substantially. She had been a long time member of the community and had worked in the hospital kitchen for many years, leading to a feeling when hospitalized that she was being cared for by friends. Follow-up discussions with Fern were delayed when she sustained a fractured ankle that resulted in surgery at a referral center and a subsequent 4 week stay in her local hospital.

*Gerry*

Gerry was a 49 year old who was married and living on a farm that had been the pride of her and her family’s lives. The disability resulting from Gerry’s MI had huge implications for the nature of their farm work and Gerry continued to grieve for the times past when she kept animals and worked closely on the land. Although Gerry had infarcted 4 years previously, she was living daily with the effects of massive cardiac damage. She contacted me after hearing about the study through her doctor, thinking it may help her to help others.

The post-MI time span meant that Gerry had time to thoughtfully reflect on the events associated with her MI, and the insights and experience were valuable to understanding the web of challenges faced by post-MI rural women. In spite of the time that had elapsed since her MI, in many ways Gerry was still searching to understand her experience, to process the issues, and to find new options that would increase her psychological and physical health. Sitting at her kitchen table, gazing at the view of her fields and bush, Gerry debated the pros and cons of rural life, of rural life when health was threatened, and the possibility that living in an urban setting would dispel some of her worries about requiring medical attention in the future. Gerry had an extremely close

and supportive husband and family who have played a central role in her recovery. She has had several hospitalizations for cardiac failure and at one point was considered for the transplant list. I have found myself returning often to her stories of trying to negotiate a recovery path. During the course of her post-MI life, Gerry has become increasingly aware of the need to raise issues and awareness in others about preventing MI and how to access resources to maximize recovery, although she has been frustrated at times in that pursuit. She had come to the point in her healing to want to advocate for herself and others in a more public way, although she was searching to find the way to do this. She contacted me about the study as an avenue to help others. As part of her evolving activism, I participated with her and her family in a Heart and Stroke Walk aimed at raising awareness and money for research about women and heart disease.

*Hanna*

At 73 years of age, and having survived her third MI almost 2 years previously, Hanna despaired over her precarious health and the increased demands on her maternal role with children and grandchildren who lived with her. Our interviews were rescheduled on several occasions because of her family responsibilities or because she felt unwell and/or fatigued. A move to the country many years previously had separated Hanna from her church, her friends and supports. Hanna was the only participant with a university education and she maintained that she was privileged in having more options than other rural women because of close family ties with the medical community. In spite of her feelings of “insider” privilege, Hanna’s palpable loneliness in her struggle to regain wellness blanketed our discussions with sadness and she clearly felt like an outsider in her rural community. She was convinced that if she had another MI, she

wanted to be cared for in the local rural hospital where she felt the care was excellent. Over the time of our interviews, Hanna's main focus was on finding out-of-country health insurance and the necessary medical support to obtain it, so that she could go for an extended period to live with a daughter in the United States. She viewed this as the only way in which she could obtain the necessary support for her own health and escape the increased demands of her domesticity. Her spiritual distress was significant and on one particular day that we met, she was driving to a nearby city to find a priest who she felt could help her. She agreed to speak with me out of an obligation to try to help other women and because she thought the idea of research was important.

*Ida*

Ida was an 80 year old widow who was the most debilitated of all participants. She became part of this study when contacted by a rural hospital about the research. I was contacted by her daughter Janice who, as a former nurse, wanted to promote research. She wondered if her mother was too debilitated to participate. Ida had infarcted 14 months previous to our interview and over the past three months had been hospitalized intermittently for cardiac failure. She had daily homecare visits as well as frequent help from her daughter with activities of daily living (ADL). I was eager to include her in the study because she represented an extreme on the wellness scale and her experience offered insight into the life of an elderly woman who was an "outsider" to the rural community, and who was dependent on family and health system assistance and advocacy to meet her ADL needs.

I interviewed Ida in her mobile home with her daughter. Ida's home was positioned immediately next to her daughter's farmhouse. She had moved there from

Toronto a few years ago to be close to her daughter and family as her need for support increased. Ida's dependence on her daughter as an advocate was reflected in her inclusion in the interview and in the reliance Ida placed on her daughter to initiate and/or implement decisions on a daily basis. Prior to a follow-up interview, Ida's condition deteriorated further. Janice described the incredible support she received at the time from the homecare agency and home visits from the family doctor. Ida died at home in the care of her daughter and son prior to the end of the study.

*Jean*

Jean, aged 62, lived with her chain-smoking husband on the edge of a small village. Eleven months prior to our interview, Jean and her husband were at a wedding in the United States when she became very ill, experiencing what she now knows was an acute MI. Certain that she had food poisoning, she and her husband opted to drive for almost 2 days to come home, stopping on the way at their rural hospital. Neither Jean nor her husband ever considered stopping in another community for care- familiar surroundings and their home community was where they wanted to be. Jean's subsequent lengthy stay in hospital raised questions for me as to whether her eventual return home may have been faster if she had stopped in an urban community on either side of the border. Jean has returned to pursuing volunteer work in her community and viewed her participation as a way that could possibly help another woman in the future. She contacted me following hearing about the study from her local hospital.

*Kate*

Kate, a widow, lived alone in a village and had been diagnosed with MI 8 months previously. The day of our first interview, her home was filled with cards and flowers in

celebration of her 80<sup>th</sup> birthday. She was the sole participant who had utilized the provincial telephone hotline to determine the course of action when she had awoken at night with chest pain. Refusing an ambulance because of concerns about disturbing others, Kate elected to have the triage nurse phone her daughter who then transported her to hospital. She felt she had had a good life, continued to enjoy the occasional cigarette, but was curious about which margarine she should be buying to cut down on her fat intake. As requested, I did supply Kate with some reading material about dietary fat. Following her diagnosis, Kate returned home and since then, saw no need to visit her physician or have follow-up care. She contacted me to become involved in the study after receiving information from the rural hospital where she had received care.

*Laura*

Laura was the most difficult of all participants to access because since her MI 18 months ago she has chosen to be on the road with her husband and was often out of the country. I spoke to her several times from thousands of kilometers away when her home phone would ring through to her mobile one. Laura had agreed to become involved in the study after hearing about it from the hospital nurses and had asked that her number be passed on to me.

Laura lived in a small town where she had grown up and where she had been employed in the health care system. Her MI left her unable to work.

Interviewing Laura left me with a feeling of overwhelming sadness – I could physically perceive her fear at reinfarcting or dying, her disappointment when certain doors were closed to her and trace her retreat under her husband's protective shell. She seemed to be just hanging on. I felt the most hopeless when I was with Laura. A

relatively young woman of 47, Laura had exhausted her own resources and understandably perceived there were no more available to her. She had no more energy to advocate for herself or challenge parts of the system that seemed unresponsive to her needs.

#### *Additional Data Sources*

##### *Rural Physicians*

During the data analysis it became evident that additional insights could be gained about issues that women were describing and commenting on in the interviews. Two rural physicians in two separate communities were referred through gatekeepers and subsequently agreed to discuss their perceptions about issues that had surfaced with study participants.

Dr. Lee was a female physician with a practice in internal medicine and had practiced in her present position in the rural community for 15 years. Prior experience in other rural communities meant she was well acquainted with the challenges of rural practice and the system issues, both past and present. Dr. Lee was highly valued by her community peers and patients and viewed as a gatekeeper to specialty service inside and outside the community. She was supportive of this study although initially she was somewhat guarded in her responses to questions that probed beyond the level of description. Her commitment to serving the rural population, both male and female was evident.

Dr. Green was a male physician who had practiced as a general practitioner in a farming area for the past 21 years. In his role, Dr. Green cares for all ages of people throughout the lifespan and this includes obstetrical and emergency practice. His “laid-



back” and conversational style was punctuated with anecdotes and colloquialisms that illustrated involvement with the community, positive regard and advocacy for the people he served.

### *Nurses*

Five Registered Nurses that represented all communities from which the study participants hailed, volunteered to speak with me as part of the study. Two were referred by a nurse (gatekeeper), one by a participant, and two contacted me based on knowledge about the recruitment, and on previous professional contact with me. All of these nurses had lived and practiced in their rural communities for a period of years. All had direct involvement with the in-hospital care of women post-MI; four of the five had involvement in outpatient educational activities for post-MI patients. Over the course of the study, we had many conversations that probed issues identified by the women, about their practice as rural nurses, and about being a rural woman. Their commitment to helping women find ways to move forward after MI within the limits of their nursing practice, was clear in all our interactions.

### *Heart Health Sessions*

I attended Heart Health sessions in two locations that served three of the four rural areas in which the study took place. Depending on the individual community, these were four or eight, two hour education sessions structured around the Heart and Stroke Foundation’s Recovery Road programme (Heart & Stroke Foundation, (n.d.)) and open to anyone in the community who had been diagnosed with CHD, MI or a cardiovascular risk factor. Groups ranged in size from 6-8 people per time, including those who accompanied the patient for support. Patients were encouraged to bring a significant

other and they were all warmly agreeable to, and curious about, my observation of their sessions. Men and women attended on a fairly regular basis and most were eager to connect with the nurse session leader. There was a clear sense of community in these sessions; nurses and patients were often connected in their community outside the hospital and both had some knowledge of others' family members, and lives. In one area, one of the nurses had established a reputation among cardiac patients as "Dr. Ruth" an internationally known personality and sex expert, and from the first session, group members joked about which session Dr. Ruth would be attending. The creativity nurses demonstrated in helping groups feel welcome and comfortable was evident.

Group members sat in a circular formation, or around a large table. Depending on the session topic, a guest speaker such as a local nutritionist or pharmacist was present and during such times the teaching session was didactic in nature. Questions were encouraged although most often, participants wanted to hear what the nurse thought was important. The information shared followed the written manual on which the programme was structured, and as such was not specific to individual needs. Participants were encouraged to make an appointment with any of the health professionals for individual counselling as required and some did follow-up, particularly if they were a diabetic.

In one of the areas I attended, nurses gave each participant a red rose at the end of each session and this gesture was positively received by group members and served to foster their relationship with the nurse.

## Chapter 5

### *Findings*

Throughout data collection and analysis I continually refocused my research lens on how rurality influenced the lives of the post-MI women. I have tried throughout to remain true to their tales, to hear what was being said and not said, to explore and examine what shaped their perceptions, actions and experiences following MI. Four central themes - Reticence, Resourcefulness, Referral Games and Relationships recurred in the narratives and created a central pattern around which I came to view the solitary lives of the twelve women.

### *Central Narrative Themes*

#### *Reticence*

I don't know what's wrong with me...I am just not used to talking about myself so much. We talk about other people, other things, but rarely myself. You don't worry about yourself, that's just part of life. You do what you have to do and go on (Cassie, 2002).

Early in the data collection process, I felt I was observing the “outside layer of the onion.” As I heard the stories and attempted to peel the narrative layers back from the superficial description of events, I became aware of reticence as a pervasive theme that was evident in participants and key informants. Reticence has been defined as “an inclination to be reserved in speech or behaviour” (Webster's Dictionary of the English Language, 1987). Labelling this theme proved to be critical in understanding the phenomenon I had set out to examine- the influence of rurality in the post-MI lives of

women. I began to recognize that reticence was a powerful filter on the rural lens through which I chosen to view women's post-MI lives. As a theme, Reticence created a cultural context within which women's Referral experiences, their Relationships and Resourcefulness could be understood.

*The Faces of Reticence in Women's Post-MI Lives*

Early in the data collection process, I became aware of women's tendencies to accept post-MI events and their resulting circumstances with few questions. They tended to minimize any concerns they might have or have had, through positive self-talk, avoidance or by focussing on their gratitude for surviving MI and for the health care professionals and institutions that were available to them. In their quest to feel secure in a world that had been rocked by the unexpected, these actions served to reinforce the much-desired notion they were coping, at least for the time being.

Reticence was noted in women's hesitancy and discomfort in focussing on themselves, even though they had survived an acute and potentially life-threatening blow to their health. During an interview in which Anna reflected on the events following her MI and bypass, she began to realize that she had questions and needs that she had never allowed to surface.

This (interview) has been a good thing for me- to get it (the emotions) out. I didn't realize that I...I think the main thing is I try to protect everybody around me, like maybe I need to talk to somebody on a regular basis, like get it out. Even after this realization, planned opportunities to reflect on a regular basis did not happen for Anna. She attributed this to the fact that her initial emotional interview with me had served her needs well, that she could not identify who she would seek out for

therapeutic discussion and that later when her husband became ill, she had less time to focus on her own worries.

For Cassie who lived within low economic means, reticence to focus on her health needs was tied to a need for her to earn money and a personal need to see herself as strong. She could not admit she had needs related to her cardiac status as this would make her vulnerable and threaten her subsistent existence.

I think that if a person doesn't have enough to do, their mind tells them that they are sick and if you listen to your mind and it says you're sick, you are going to be sick and you think that people are going to feel sorry for you and after a while people don't feel sorry for you they feel like you have a mental problem...If you are busy and you like doing what you are doing I don't think that you feel as sick as what most people are feeling. That's what I find anyway, like a lot of the women that are at home they have a lot of mental problems, they have a lot of physical problems, my knee hurts, my back hurts, this hurts, that hurts, they have too much time on their hands thinking about the pain. There's no point in that. Cassie's life experience had not encouraged her to expect the empathy or help of others. She voiced surprise when she became tearful after some time had passed during our initial interview.

I don't know what's wrong with me...I am just not used to talking about myself so much. We talk about other people, other things, but rarely myself. You don't worry about yourself, that's just part of life. You do what you have to do and go on.

Cassie did not view post-MI follow-up with health care professionals as something she had to do. She described her reasoning in turning down invitations to attend a patient education programme for cardiac patients.

I went there (to the cardiac education class) openly minded when I first went and that was just like the pre, prior to the classes to get you ready for the classes.

They weighed me, which I knew I was overweight anyhow. They took my blood pressure which is low like always, which is a good sign, it's not high, it's low. I contribute that to so many animals, always patting them.... but that's supposed to be good for your heart and for your blood pressure. I was very opened minded and she (the nurse) was asking me again like what did I know about my heart, like what was my major problem and the results of my tests and I said I don't know. I am not the kind of person who is going to demand to know. If there was a major problem they would phone me and he (the doctor) didn't. So they asked if it was all right to phone, and I said, sure no problem. So they phoned and found out that all my tests from Kitchener came back as positive.

Cassie interpreted this as meaning the results were good news, that she had not had a MI and that there were no problems with her heart. This in fact was not the case. She refused to go back to see the nurses or her family doctor and cancelled all subsequent appointments.

Laura reflected on how her inability to fulfill her role after MI only increased her reservations in asking for help.

I think rural women are uncomfortable asking for help. Because I think rural women are women who are very strong and able to stand on their own, you know what I

mean... They tend to do everything and I think after they've had a heart attack I think it really affects them. Speaking for myself, rural women are supposed to be the one there...I mean we are supposed to hold everything together...I think they feel inadequate after a heart attack. I know I felt inadequate after. I don't now but I did for a long time.

Experiences in which women were silenced, served to diminish their expectations about what was possible and muffle any further questions. For Laura, reticence to raise her voice resulted from a stifled attempt at finding mental health services to help manage post-MI depression. After being turned away from mental health professionals, she resigned herself to accepting the only care she could access- medication prescribed by her family Dr.

Well I was on Prozac for a while and it seemed to help a whole lot. Then I went off that. Now I'm on Zoloft. But then I still have my fear. I am fine if my husband is with me. I don't know if counselling would help or not because I know what my problem is. I am afraid to sleep at night. I don't think that is going to go away because that is when my heart attack happened. That is all something I am just going to have to deal with.

Laura's energy was also focussed on being grateful for the services she did have and as was true for all participants, this focus fertilized the development of a culture of silence around their experiences that did not disturb the current system.

Edna's empathy for nurses in shouldering a heavy workload lead to reticence in asking for information post-MI.

They are much too busy those nurses. I feel sorry for them. They go home and have a family too. They don't need more work (involved in replying to her questions). I can find out what I need by myself. They did give me a book.

The women who attended cardiac education classes often modelled reticence in articulating their individual concerns in the larger group. Some women described that they would talk to the nurse afterwards rather than focus on themselves in the larger group. Like Fern, Doris kept her worries and questions to herself and was uncomfortable voicing them.

It is very interesting (hearing from the nurses). You worry a lot more after a heart attack. I worry a lot about everything. If you have a worry, give it to me- I will worry for you. I don't like to ask questions but I like listening to the others. Some of them are so funny....I just don't like to say much.

Gerry's observation of an exchange at a rehabilitation group, in which she found women's life context to be ignored, helped her to make the decision not to return. She did not voice her concerns at the time, but simply chose to stay away from future sessions.

The doctor was saying it's better to exercise, drop everything else, exercise, exercise, exercise, but what this woman (in my class) was trying to say, but she went in the wrong way to get around it - what she was really trying to say is, how do I do that when I have three kids at home and teenagers that were running her ragged and she had a job and they were actually on a farm and she had all this stuff to do? And I thought, he doesn't understand. It's not easy for us (women) to say to our families, you know "What you are all making your supper for the next



month? I am going to do nothing but jog, jog, walk, walk,..." So that's where I think he ( the doctor) was frustrated. He was frustrated by how many questions she could have. The women behind me were going, oh for Pete's sake - another question! This is not what I would have expected...it didn't take much for me to not go (back to the rehab). It's so far over there anyway.

Hanna had tried to seek answers to questions she had about her cardiac status but did not want to appear demanding. Concerns about how she would be perceived by others gave rise to reticence and eventually, frustration.

Being married to someone in health care, my fear all my life was I don't want to look imposing to them (health care professionals). I try to keep away from that type of thing, I didn't want to have any feeling that I was putting people out by asking too many questions or making requests.

Hanna felt trapped in her role at home but after weighing her options felt she had to tolerate the expectations on her and not ask for the help she needed.

The family doesn't understand. I look well. They will criticize – how many pills do you take a day, that type of thing. As far as things I have to do around the house, it's worse than ever. I have more responsibilities. I know (the cardiologist in) London would say to me, cut this off, but how do you turn family away? I don't think I could live with myself. No, I'm not retired. No, it's worse than ever. I am a housewife and I have a routine, only I have children back. The golden years are not golden, so enjoy them while you can.

Ida had resigned herself to living in a state of dependency in her mobile home and relinquished most decision-making to her daughter. Her reflections betrayed a sense of hopelessness that she felt unable to overcome.

I have a good life out here. Well, come to think of it, I don't know what is good about it when I stop and think. Well, it is quiet. My daughter takes me everywhere I want to go. I don't really want to go anywhere anyway. I have lost all interest.

Kate, on the other hand was still interested in her life and in making the most of it, however this did not include seeking post-MI care. She could not be convinced that seeing a physician would make any difference to her. Her reticence to seek follow-up care was fuelled by the notion that her MI was like an episode with the flu- it was now over and she would go on.

What's the point in going to a doctor? I feel fine. What would he tell me? My daughter helps me; I read my magazines and watch some of the health shows. I still do my quilting and go to Bingo when I can. I am 80 you know and things are going to happen.

While Gerry was glad to have the opportunity to speak one on one during the interviews and raise the issues that had bothered her since her MI, she was reticent to advocate for herself in a larger forum. When a mother-daughter fundraising walk placed Gerry in a situation that posed a physical risk, she did not want to appear to complain or let others down, and so kept her worries to herself. Gerry had been asked to start off the mother-daughter walk for Heart and Stroke in a nearby rural community. She had been working up to the 3 kilometer trek on her own but when she saw the terrain, she became

concerned about whether she could do it or not. The entire route was hilly and had no rest points. I accompanied her and her family and we monitored her with trepidation for the duration of the walk. She expressed amazement when she was able to complete it. With encouragement, she was able to express concerns to the organizers afterwards about the challenge the terrain presented to her and the possibility it could deter others like her from participating. Her comments were met with surprise by the chief organizer but she later reported that this feedback had sparked discussion in the debriefing of event organizers. She noted that Gerry's concerns had raised awareness and plans had begun for ways in which women with heart ailments could be included in this initiative in future.

For the most part, women did not believe they could make a difference in how the system could meet their needs. Even when they recognized things could be different, the few ways in which women took action to challenge the status quo were singular acts within a system that absorbed their non-conformity and subsequently did not appear to change.

Anna tried to speak out and have practitioners recognize and investigate her concerns of neurological deficits after her bypass. Her CVA went undiagnosed until she returned home to her rural community. Her persistence in pursuing a diagnosis eventually got her the care she required but the route to validation was circuitous. Even when the CVA was diagnosed, practitioners acted in ways to minimize her concerns. She viewed herself as different from most other women in that she questioned practitioners, although this was only evident in the exchanges with physicians she knew in her community.

I do believe every patient has the right to know. I will say; well what does my diagnosis say? “Well, you’re not supposed to ask, they say.” I have had to do a lot of initiating. I mean I was the one that initiated the CT scan because I came to my family doctor and said, “I think I’ve had a stroke. I’m sure I have.” And I remember them saying “No, you look like shit but you know what, you’re doing really well.”

Even as one of the most vocal of the women, Anna had trouble seeing how taking issue with what happened to her will help in the future. She counselled her husband in not making waves, believing that any challenge to past events was unlikely to change the future for others.

I trust my doctor. He’s fully human. He makes mistakes. You know my husband said maybe they could have done something different. But I said, Jim, I’m not going to live like that. What’s done is done. And we’ve got to keep moving on.

Most women assumed a passive role in their post-MI interactions with health care professionals, seldom questioning the prescribed route of action. When I asked Beth about her involvement in treatment decisions she replied

Well, I didn’t put it in my mind to refuse anything he (the doctor) suggested. I just put my fate in the doctor’s hands and I never even thought of it the other way.

Although Edna advocated for herself quite aggressively regarding scheduling of the bypass surgery, she was later reticent to ask nurses for information related to secondary prevention. This was partially related to her belief that the bypass was more crucial to her survival than lifestyle change. When she knew the stakes were high, Edna spoke out on her own behalf, threatening a law suit. This tactic to quickly access the

surgical waiting list silenced her threats against the system, but it was unlikely to have changed practices for prioritizing patients for coronary bypass.

The idea that living in a rural community means that one had to accept that some services would not be available or close by, was reiterated and accepted by many women. Anna's conclusion that "We're just too small to get everything in these communities" laid the foundation for reticence in women generating possibilities for the future care and opportunities for women like themselves.

There were instances in which nurse key informants from all communities in which the research was based, displayed reticence in raising issues with the women and with me. During outpatient patient education sessions there were occasions when questions were asked about what women could expect to happen at a referral agency, where they could go for exercise rehabilitation and concerns were expressed about knowing the limits of and how to monitor activity. In all instances the nurses actively listened, offered recognition of how difficult life must be, and gave general replies which sometimes included seeking the opinion of their family doctor, cardiac consultant or local physiotherapist. The nurses described feeling "badly for the patients," helpless and inadequate in their responses, recognized the system had gaps, and then related how much better they were to respond to patient needs now than in years past when there were no outpatient education programmes available. The programmes had been initiated by nurses in response to perceived patient needs. Nurses commented that "we do what we can, there's not much else we can do, there's not anything else for them round here." In discussions, the nurses believed that they were powerless to do more and they were hesitant to talk to patients about programmes like exercise rehabilitation that were

unavailable. One physician described actively withholding information about exercise rehabilitation because he believed “they (the women) were at greater risk driving the distance to get to rehab than in staying home.” Reticence to supply alternatives that rural health professionals viewed as unattainable was intended as a protective intervention and it helped maintain the status quo.

*Overcoming Reticence: Finding a Voice*

For two women, the action to change their world could be perceived as small, however both perceived their decision to speak out as a “big” step in their personal growth and recovery. Following reflection on our discussions, Anna decided to raise questions about the lack of documentation and communication regarding the CVA she sustained that had significant negative repercussions in back to work negotiations with her employer. Pressured to quit, she declared

I will leave on my terms. I have got this far because I have been aggressive. I’m not going to sit back any more. I’m going to go over to my doctor and I’m going to sit down and say “I want to know why. I want something more. And if you don’t have it right now, I understand. But you get to London. We need to know this.”

In addition she has been a staunch advocate for her husband as he has recovered from his MI, using knowledge gained from her own experience to advocate for him.

For Gerry, the decision to reach outside of her situation and be a spokesperson for heart disease with the Heart and Stroke Foundation was stimulated by reflection on her abilities and her desire to make a difference for other women. Her pride, and the pride of her family was evident as she delivered her first a motivational speech about heart health

and overcoming her challenges with heart disease. Her desire to influence the future for others was clear as she carefully constructed and rehearsed her speech over many days. She called me on two occasions to voice doubts about her ability to speak out. She was not sure what to say. Eventually, she wrote her own script and the response was uplifting for her. Her joy was palpable.

Wow - I can't believe I did that! I've never spoken to a crowd like that before. I really wanted to let women know they need to look after themselves. That there is hope. Things like this (walk for research money) will make a difference. It was the hope of all women participants, that the telling and retelling of their stories could somehow make a difference for other rural women in the future.

#### *Referral Games*

“It's a game. **You** know what they have to do.” (Hanna, 2002).

#### *The Human Face of Referral*

For all women in this study, having a MI meant at some point they were referred to a place and practitioner away from their local community. It was evident from the first interview on that “referral” was far more than an administrative task of arranging transport and requesting that another institution or practitioner consult about and/or administer care to a referred woman. Referral was a lived experience for post-MI women and when the consultation was over administratively, it often had significant and lasting effects in their post-MI lives. The referral process was shown to be less than simple- in fact it was fraught with complexities that women viewed as beyond their control and outside of their “patient” roles.

Hanna's coinage of the referral "game" implied there were also game rules, game players and the possibility of winning or losing. Until the time Hanna identified this, I had not fully examined the dynamics of the referral process or the way in which the referral process supported the hegemony of tertiary urban centers.

*The Rural Route to Cardiac Diagnostic and Surgical Interventions*

The need to go "out of town" to a referral center to access what their local physician considered necessary after MI, was seldom questioned by the women. They recognized and accepted that living in a rural area meant that referral was part of medical treatment when significant illness existed. Being from a rural place meant that tertiary facilities were located at some distance and that not all cardiac services for post-MI patients were present within the rural communities. For the women participants, referral to a tertiary care center occurred for one or more reasons; acute management of the MI, diagnostic procedures such as angiogram, stress tests and echocardiograms, consultation with a cardiologist and / or to receive angioplasty or coronary artery bypass surgery. The women accepted that their situations warranted referral for diagnostic and treatment procedures away from their rural communities without question. There was no expectation on the part of any of the women that services, for which they were referred out, could be provided any differently. Raising questions about the processes was perceived as pointless. Families or friends dutifully drove women wherever and whenever they were asked. Jane, a nurse who was very familiar with the juggling for position within the referral system, explained that many patients and families would not challenge or negotiate referrals for fear it would have negative consequences such as not getting the consultation, testing or care that was required.



Patients and their families know there are waiting lists and they think if they make a fuss, they might not get what they need. They feel threatened by the system. They know it is jam-packed. So they just do what they are asked and don't complain.

*Power Plays: The Rural Cardiac Care Game*

Although women ascribed a vital role to rural health professionals in the management of their MI's, the power rural practitioners appeared to have in helping women access specialist care and cardiac interventions outside of their communities was variable. Waits for angiograms and appointments with cardiac specialists were perceived by women as being somewhat out of the control of their rural health providers. Hanna described referral as a "game" that local doctors sometimes had to play so that women got the treatment or referral they required. For the most part, women were silent players in the game. Like pawns awaiting a move, women waited for their turn in the line-up for specialty care. Some women were oblivious to the game that was played to position them in the referral tree – others recognized it and appreciated the work of their advocates. When she talked about the "game", Hanna looked at me and in a statement that implied that those in the system knew of what she spoke said – "You know what they have to do." Several women believed that their physicians had "pulled strings" or done something out-of-the-ordinary to get them what was necessary in accessing specialist care. Other women commented on being kept in hospital to accelerate their acceptance at referral centers. Ida's daughter remembered what her mother's physician, who was new to the area, said about learning the rules of the game to position patients in the system.

Her doctor said to me; the next time I have a patient who needs a lot of work up or an angiogram, I won't discharge them because you can get things done if you stay in (the local hospital).

This would suggest that referral is at least partially, a covert strategy game of learned advocacy behaviours, learned experientially by those in the system. Knowing the rules enabled physicians to make the necessary plays for their patients.

Most women tended to view their rural doctors as strategists who advocated for them in the health care system, and there were instances in which calculated strategies were employed as a way to accelerate access to tertiary centers. Rural health providers were allies on whom women depended for access to what they saw as scarce cardiac specialty resources.

Dr. Green supported this perspective and offered further insights when questioned about the referral process.

Our connection with the referral doctor is really important, there is no question, especially as the system gets bigger and bigger. Being accepted as a referral depends on how the (tertiary) centers see themselves. Toronto doesn't see themselves as supplying the countryside with access to care. But we have a good relationship with London and I attribute that to a secretary there- no- I mean that! When we call there it's not "how can I stop this avalanche from coming?" It's "how can we help deal with this avalanche?" He (the specialist) knows we don't send him crap.

Although Dr. Lee felt she was able to get critical care for her patients when they required it, Dr. Green described how he needed to make his case to the right person in order for an acute referral to be accepted.

We call down to a tertiary center and they say “what’s the wedge pressure? What does the CT scan show? Are you sure they haven’t had a stroke?” They just don’t understand that is not available here. Slipping the patient on a ventilator is not a choice here! The residents have been trained there (in urban centers)– they haven’t been practicing where these things are unavailable and are used to making decisions based on these criteria – and you can’t blame them. Consequently we try to bypass the Residents.

Discussions with a nurse in one community identified there were times when hospitals led referral centers to believe that the patient was still in hospital when in fact they had returned home to wait for the referral appointment. The premise was that in-hospital patients would be triaged as more urgent than outpatients. The covert nature of this strategy was a source of discomfort for some nurses who said they had great difficulty in maintaining this façade when the referral agency called to check on the patient. One nurse described that a written script of “what to say” was prepared by a physician for nurses to use in exchanges with the referral agency but that “we weren’t supposed to talk about it.”

Gerry’s description of her experience in waiting for an angiogram reflected her knowledge of the strategic practices used by rural professionals to obtain care for their patients.

They kept me in the (rural) hospital just to get me down (for the angiogram) because once you're released from hospital, there is a long wait.

Laura recounted the challenges encountered by physicians and nurses when they played by the rules but were frustrated in their attempts to get her into a tertiary center on an urgent basis. Her eventual acceptance at a tertiary center was the result of her physician taking an alternate tack in the referral game.

I was in intensive care that whole time at the (local) hospital and I was supposed to go to London and they couldn't get a bed down there. That was on a Sunday night, so on a Tuesday I saw (a visiting internist) at (my) hospital. He wanted me to go to London for this angiogram and so they called down there and they were supposed to call back with a bed and all this. Like this is what my friend (a RN) was telling me that they said. That they were like calling every day and the doctor was calling every day trying to get me down there into London and then kept saying they didn't have a bed, they didn't have a bed and then (the visiting internist came back) the next Tuesday, I was still there and so then he got on the horn and the next thing I knew I was going to Hamilton.

Subsequently, a week post-MI, Laura was transferred by ambulance to an alternate referral center. When she got there, she did not have a welcoming reception.

Like one of the them said to Sandra, (the accompanying nurse), "Well what are you doing here? And Sandra said, " well, she came here to have an angiogram. We are from (rural hospital). And the girl said, well you guys aren't supposed to come here. You are supposed to go to London. And Sandra said, "she is booked

to come here because there isn't a bed in London." But the girl that was talking to her, she was really, really rude.

This interchange was followed by a complicated angiogram that necessitated a longer than usual stay at the referral center.

I had an angiogram. Yeah, and so they went in and I had a collapsed artery and so then they put in a stent. Then during the first surgery my heart went into spasms and I had chest pains and everything and then they had to go back in and redo the angiogram just to check things out.

Laura was discharged home with her husband one day later and 10 months later has had no further contact with this referral center, but does see a visiting internist.

Beth also experienced a delay at getting in to a referral hospital following her life-threatening MI. She tried to reconcile her understanding of the urgency of her condition with the time it took to get tertiary care.

(The doctor) was shaking my foot and he was saying, come on, stay with us, don't die and I said Oh Christ sake I think I am dying and that was it and it took a couple of week before I got into (the referral center). I think the very next day after I got there they gave me that thing (the angiogram/angioplasty).

Gerry did not go to a tertiary center until after her discharge home following her MI. She described how, at that time, her husband kept asking if she should not be transferred out of the local hospital at the time she was having the MI. Although they did not understand it at the time, as a result of information she obtained from television, Gerry now believes that a transfer to a tertiary center would not have made a difference in her outcome.

My husband kept saying, shouldn't she go to London, shouldn't she be taken out of here and the doctor said, well there is nothing that they would be able to do either. I saw it on TV. and I didn't realize that with a massive heart attack there is nothing anybody can do and that's what the doctor meant, because all it was, was either I was going to make it or I was going to die. So it was, which way is she going? So if that's true, that you have to sit and wait, that's what they were doing (for me).

Since that time Gerry has been back and forth to the tertiary center many times and has been assessed for a heart transplant. Gerry has also had several hospitalizations for congestive heart failure since the MI and at one point was referred for an angiogram.

Jean was taken to a tertiary institution for an angiogram about 2 ½ weeks after she was admitted for MI at her community hospital. When she questioned her physician, it became clear to her that her physician had strategized to avoid potential obstacles to get her necessary care.

I'll tell you though; I was really frustrated with the wait. Another woman who was also in with a heart attack at the same time as me got sent to Kitchener for an angiogram the next day. I asked my doctor about that you know, because I couldn't understand why I had to wait for my angiogram and she got hers right away. The doctor explained that if my angiogram showed that I needed surgery, I couldn't get it in Kitchener. I would need to be referred somewhere else. My lungs had filled up with water and my friend who is a nurse told me my heart attack was a really bad one. That worried me. So I just waited.

She described her return back to the local hospital to await further tests and bypass.

The main artery you know the one, it was 95% blocked and it was you know, where there is a “V”. It was just at the “V” and if it had been a bit farther I wouldn’t be here. And he told me when I was there “ Do not get them to do the balloon-ever.” Anyway, we come back to (the local hospital) and he phoned my doctors and they scheduled me for a bypass and they didn’t say how long it would be. I had been talking to other people and I knew it would be quite a few weeks and they wanted me to stay in the hospital, so I stayed in the hospital

Jean’s stay in hospital to await her bypass turned lengthy and she felt well during that time period.

All told I was in (my local) hospital for five weeks and the reason the five weeks was because my doctor did not let me go home until they found exactly what was wrong and I had done the tests. Then if I had to have a bypass and if you stay in the hospital, you are first in line (for the bypass). There were some men waiting for bypass at the same time as me- we used to watch the ball games together. One waited in hospital for seven weeks.

Jean believed that if she had been sent home to await her surgery, others would take her place in the surgical waiting line and her surgery would be delayed. Jean explained the back and forth plays that resulted in an eventual end call to the process by the referral center.

Then (the tertiary centre) called and they said that they wanted me to go for a scan to (another hospital) but I couldn’t get into it, so they sent me back to (the original

center) and they did a test, and they gave me another ECG and they sent me back to (my local hospital). That was on the Thursday and then on the Friday my doctor was away and so they sent my result and then on Saturday they let me go home. The rest of my heart was okay ...and they thought that it would be fifty, fifty if they did the bypass.

Women viewed their physician's ability to convince the receiving institution that a patient warranted quick consultation as key to getting them "in." After her experience in awaiting care, Beth was convinced that "the (local) doctors have to put an emergency down on paper or otherwise it will take months to go there" (to the referral center).

Anna believed that it was her connections to the health care community in which she lived and worked, that were powerful in influencing her physician to transfer her to a tertiary care center early in her MI, and in the fact she only had to wait 5 weeks for a bypass. She compared herself to others who did not get referred out during the acute MI period.

I had medical connections. I think it's different for people who do not. I think it was pressure from the nurses on the doctor, saying I should be out of here. I have a girlfriend- she had become my friend since the heart attack – she had one (a MI) 3 months after me. She has never even seen a cardiologist. She has never been to London. She has had one echocardiogram and she had a stress test that's here. And I said to her, who's looking at the big picture?

Some women, like Cassie and Kate, had no expectations that referral agency personnel would need to know anything about them as individuals and assumed that communication between rural and tertiary agencies related to their results and care would



transpire. They sought no active role in this process were hesitant to question the process and simply awaited contact by the rural health providers.

Rural physicians or consultants, who came regularly to rural areas from other centers, were identified as the individuals who made the referral to the tertiary center. There were differences in the time women waited to actually go to the referral center after the referral was made. Anna was the only participant who was taken out of her rural hospital on the day of her MI. She was transferred via helicopter to the referral center and believes this was a life-saving intervention that accelerated her access to coronary bypass.

They ended up giving me the tPA (a thrombolytic) and everything went fine and then they airlifted me down to London right away. They said they wanted me to get the angiogram and all that done first. Why did they send me? Not everybody gets sent out. Actually, I found out afterwards that it was a very bad heart attack...If I wouldn't have been where I was, I wouldn't have made it. That's what they told me. About 2 hours later they did an angiogram and that's when they found out that my arteries were 85% blocked.

Edna was referred to a tertiary center for angiogram and went there after she had been discharged home following re-infarction while in hospital. Edna's angiogram results indicated that she needed bypass surgery. She found the wait after returning home difficult, particularly after what she was told when she resisted the idea of bypass.

The surgeon, very nice lady, she said I need bypass. I said to my son, I don't want to have operation, so he asked her. I won't have operation, how long I live? She

guarantees 40% in 2 years I am dead, and with the operation, 10 to 15 years. That we will take he said.

In spite of this compelling argument made by surgeon, Edna's surgery was cancelled three times before she took matters with the referral center into her own hands.

This was now the third time and I said to her (the person who was calling to cancel), "I told my son, should I have a heart attack, sue them." That was on a Friday and on the Monday she phoned and said, "Can she come in tomorrow morning?" Now.... That (threat) helped. I felt sorry, but each time my heart went bom, bom, bom, I worried...

Following her MI, a surgeon at the referral center gave Anna a similar ominous warning prior to her return home to wait for bypass. Although the message was delivered as a choice, Anna felt she really had no choice at all.

The surgeon said, "You have your choice. It's your decision. With 85% blockage you can go home and we can leave you." He said "I'll tell you right now, you have an attack and you are going to die." There was no decision. We did it (agreed to have the bypass).

When I asked her what it was like to come home from the referral center following her MI, Anna began to cry. She tried to reconcile feeling physically stable with the message that she was being sent away from the resources that were judged as critical to her survival. Being told that the key to her survival was the bypass and then having to wait for it at some distance and time away produced anxiety. Her confidence in reading her body was also undermined.

It was really scary coming home. Down there (in the referral center) they have everything. It was really hard to come back. I felt good though. But my cardiologist told me that was just part of my denial.

Following her MI, Cassie was referred to a city for non-invasive cardiac tests and an appointment with a cardiologist that was booked for her three months later. The delay in the appointment time served to reinforce Cassie's denial that she did not have any significant cardiac problems. She later cancelled the appointment and has had no further follow-up. Although she refused to acknowledge coronary problems, she believed she should have been seen earlier. She commented about the delay in seeing a cardiologist.

It sucks. If there was a major problem I would want to see him a lot sooner than I was going to.

Doris and Cassie were not referred for angiograms and believed that if they were necessary, their doctors would have ensured they were done. Women commonly relied on their physicians to know if and where they should go and none tried to negotiate or renegotiate the location of their referral.

#### *A Rural Route to Mental Health Care*

Concerns around the referral process were generally focussed around referral for medical intervention to diagnose and treat cardiac insufficiency. However, when Laura experienced severe anxiety and a possible depression in the months following her MI, she was referred for specialty mental health care. Laura had expectations that she would receive help that was not available in her community but was disappointed with the results.

I went down to Guelph and I got there on a Wednesday and I saw the doctor there. Then I saw him on the Thursday and then it was a holiday weekend and so everybody was closing up there. They were starting to leave Thursday at noon. A lot of them were leaving, like the counselors and staff like that, and so of course Friday, Saturday and Sunday there was nothing. I was there; I was admitted there, I had no choice but to stay. Sunday I went on a leave and I came home and had a bit of holiday time with the kids. The kids looked after the meal and everything and then I went back and Monday of course there was nothing. And so then Tuesday came and I went to a couple classes, one was anger management which I don't have a problem with. So that really didn't, you know help. It wasn't for me and then I went to see a couple of counselors for depression and that type of thing. The one counselor said to me that I didn't fit into their profile because my anxiety was real and there really was a (physical) problem, not something in my head. So then they said that I didn't fit their profile and so that the program that they were teaching really wasn't for me and so here I was. I spent all these days down there... So then the doctor came in Wednesday morning and after I had talked to these other counselors on Tuesday they discharged me.

Laura came home with no new mechanisms to help her cope with her mental health. She has resigned herself to relying on the medications her rural physician has prescribed and on time as a healer. The referral by her local physician would indicate there were expectations on his or her part that the referral center could meet Laura's mental health needs and yet this assumption proved to be untrue.

Of the interviewed women, Laura was the only one referred for mental health services although several women expressed feeling “sad” or being “down” and had never considered nor been invited to have a forum in which their affect could be investigated.

*The Rural Route to Rehabilitative Care*

When women felt well enough to attend, some had options to participate in what was sometimes termed cardiac rehabilitation, although in most cases this did not include individualized exercise programming. Only two of the twelve women interviewed accessed full cardiac rehabilitation that included exercise and neither woman continued this for a long period. Hanna considered herself lucky to get into such a program in the past 2 years and noted it was not the norm for women in her community. She was referred by her doctor, but felt that not everyone had her opportunity and she believed her connections in the medical community helped her gain this “privilege.” In spite of this opportunity, Hanna chose to stop attending shortly after beginning.

I was very fortunate to get into the heart exercise program. It was a group and you were lucky to get into it. They just had funding for so much. It was a bit of a drive and it was just too much- I just couldn't keep going.

Gerry understood that she was not well enough to participate in rehabilitation and she did not question her doctor about this.

I remember thinking, I was not recommended to anything because they didn't think I was going to make it the first year. I think it was a touch and go the first year because they say usually you have your next one (MI) then. I wasn't in the greatest shape but I was getting these vibes that I could do more and yet I didn't know what to do.

For reasons she could not identify, Gerry did not validate her assumption about being unable to be in rehabilitation. After her cardiac status improved 2 years ago she sought referral to a rehabilitation program based on a friend's advice.

I was really surprised when a friend of mine came home from work and she said “I have a phone number for you” That was for the Cardiac Rehabilitation Center in Kitchener. The only way I knew anything about it was through her.

Anna recalled that a physician from the referral center she attended wanted her to attend a full cardiac rehabilitation program but when he reviewed the distance she had to travel to a site, he did not pursue the issue.

He said, how am I going to get you up there? Because it's an hours drive. Back then I couldn't drive (because of the heart attack). It is just too far, especially in the winter.

During a session of cardiac education classes I observed, patients noted that physicians in referral centers sometimes had no knowledge of where their community was located. The lack of familiarity with the referral region served to build psychological distance between some patients from their urban caregivers. One participant described this phenomenon saying

So the doctor (in the tertiary center) said to me, just where is (your rural community) anyway? And then I told him. So he asked me a few questions like, well how far is that to London? How far is at to Hamilton? How far to Kitchener? Then he says well.... I guess that won't work then.... There isn't anything around you.

Referral to rehabilitative services of any type was inconsistent. Some rural hospitals had Registered Nurses who saw patients in hospital and then issued invitations to cardiac education classes. In all regions where women were interviewed, there were nurse administered educational programs that were structured on the Heart and Stroke Foundation Recovery Road manual (Heart & Stroke Foundation, n.d.). One institution included referral to the classes as part of their in-hospital care map for MI and the classes were held by a city hospital. When women received a referral, some women turned down the invitation to participate. Edna turned down the opportunity to attend the classes because she thought she knew as much as the nurses who would teach the classes.

I didn't want to go there. For what reason (would) I go? Exercise I know myself, diet I know better than they say. She would say, you can buy this and you can buy that. I never bought that stuff in the first place. I know just what they would say.

Cassie went to the first class but then quit because she said she could not afford to be away from home. Her comments play down her denial about her own health, and instead, focus on her worry that she may be offending the nurses.

I felt bad because I wasn't going to be taking the classes and they were trying to convince me into doing it and I thought well okay, I will come to them and that's just to find out if something else (other than her MI) happened. And then because my dog was due to have puppies and she is a rare breed and they are a lot of money and I can't afford to lose all that money I decided. No I wasn't going to go and that I was going to stay home and look after the babies and that's what I did. The nurses and doctors who have been on the farm or lived a farm routine, they

know the quality of money, they know what money means to people and how hard it is to get it up here.

Laura declined the referral to local cardiac classes because she felt she had been exposed to some of the information in a former job. She accepted the written materials but was not available to attend classes as she frequently accompanied her husband out of the region in an effort to allay her anxiety at being alone. Beth, Doris, Fern and Jean attended the classes to which they were referred and saw value in them, both from social and informational perspectives. Kate and Ida could not recall being referred to the outpatient cardiac classes.

#### *Riding the Rural Referral Route*

Once a referral was made, women described various means by which they physically arrived at the referral institution and were transported home. Considering that many referrals were some distance away from their homes, travelling was sometimes a stressful event.

Anna was the only one of the interviewed women to be transported by helicopter to a tertiary center. Five days after air evacuation following her MI, Anna returned home, driven by her husband in what was soon to be repeated 2 hour car ride. Anna was scheduled for quadruple bypass surgery and so, in the next four weeks she made the 4 hour round trip car ride four more times. Her recount of the post-MI, pre-surgical time period was busy.

We went down to see the cardiologist, then another day to the surgeon, then to a clinic for my surgery. As we're leaving, they said "we want you back here the next day. We're doing your surgery tomorrow."



Anna returned home to prepare herself and her children for her absence.

So, we go home and get everybody's clothes ready and back down again the next day. I was there from Thursday and I came home on a Tuesday. They kept me an extra day. So, five days after a quad bypass, two hour drive home.

Upon her arrival after a 2 hour ride, Beth became aware of differences in expectations about transportation of post-MI patients between the referring and receiving hospitals.

I went from here to London to get an angioplasty...It was a big screw up too.

They were supposed to send an ambulance there to transfer me there because I had a heart attack but then the (local) hospital said no, just get someone to drive you there. So George took a day off work and drove me to the hospital. He picked me up at this hospital and drove me to London. And then when I got to London, those people jumped all over my hospital because they said that I should have been in an ambulance not in a van.

Transportation to the referring hospital by family members was common in the women's stories. Women questioned how the decision about their transportation to a referral center was made. Nurses in rural communities were not certain as to how those decisions were made by referring physicians. Nurses in different practice settings voiced concern that some families were sometimes pressured into transporting their family member to referral centers but that families would do what doctors requested. During interviews, women described the role their families played in transportation, and all accepted that this was how their world worked, that there were no other reasonable options.

Kate's son dropped her off for the day at a referral center while she had an angiogram.

He came in the morning to pick me up at the hospital and then drove me to the other hospital. It worked out just fine. I got a ride back to the hospital later on, in an ambulance. It was a long day. I wasn't back to the hospital 'til after 9 at night. They did feed me there though, but I was tired.

Ida recounted that her daughter had picked her up each time when she was referred out of town. She expressed great faith in her daughter's ability to make travel arrangements and to get her where she needed to be. Her daughter, Janice, described her commitment to helping her mother but also voiced frustration over transportation and scheduling challenges. The appointment time was made for her but the logistics were left for the family to work out as best they could.

I of course had to take her as it costs less for a family member to take them...and then I brought her back – it was ok – once we stopped at Wendy's for a bite to eat. The first appointment for an angiogram was 9 am in Toronto, so my husband took the day off work because I don't like to drive in Toronto. A cousin who worked in hospital in Toronto got the appointment changed until noon so that made a big difference. I'm not sure if it had not been for her if I would have had the power to change it...Of course they don't tell you at the front door of this referral centre that there's a totally flat wheelchair accessible area around the other side, so I had to help her (Ida) up the stairs, then take the wheelchair up the stairs.

The stress of negotiating the physical environment and finding their way around referral centers was accepted by women as part of the referral package. Following her complicated stent insertion Laura's husband decided to stay near her and got a motel room near the hospital. Nurses in rural hospitals told me this was not uncommon and that

when patients had referral appointments in winter, they might book a room in the referral city the night before so they did not miss the appointment. One nurse said

They (families) are so worried about missing the appointment that might have been hard to get in the first place and hard to reschedule, so they do almost anything to keep it. They worry that if they complain too much, they might miss the opportunity all together.

The return home following the referral appointment could also be stressful. Laura described going home in the car following her stent insertion. Her comments echoed those of other women who did not feel that the distance they had to travel was of consequence to those who cared for them in the referral centers.

My husband drove me home. It was winter. It was a very long, trying ride home. It's about a couple of hours and I was still having a fair bit of pain where the catheter went through and actually for almost a week after I had pain there...I don't know if they knew how far we had to drive or not...It was winter, my husband was nervous and no one gave him information to make him feel better about being responsible for me.

Edna accepted the events regarding her transport to and from the referral center with no questions asked. After tiring diagnostic testing she was told she did not require a pacemaker and could go home. Bad weather delayed her return.

I was down in the ambulance Thursday till the next weekend. I could have come home on the Friday but that big snowstorm came and so my son couldn't come down and get me.

Jean was kept in her rural hospital for weeks post-MI and during that time was

twice sent out for referral. The first time Jean went in a car driven by her husband. Jean was reassured that her friend, who she described as a “heart nurse” volunteered to accompany them in the car. Her transport home was in an ambulance. Jean’s comments reflected her lack of clarity about transportation to and from the referral center.

They sent me home in an ambulance and it was the worst trip of my life, terrible, and I don’t know why. I don’t know why they sent me back in an ambulance.

Maybe because of the dye thing up my leg and I had to lie there for a few hours.

The next time I went down and back in a medical service taxi. It was great. They let my husband come with me in the taxi.

The taxi Jean referred to was used by an agency to transport those who did not require an ambulance but need a stretcher. This was a move designed to free the local ambulance for more urgent calls.

Gerry’s description of the demands of time and distance on family or other drivers in getting to referral appointments was echoed by other interviewed women.

We’d be about two and a half hours. If we leave here at 8:45 we are pretty well there by eleven, it’s a long drive . If you’re lucky you wait ten minutes and you go in and you come out. You go all day for that short time, because when you come out you have to eat, and then back 2 1/2 hours again. So it is five hours that you are wasting the whole day, it’s a long drive. In winter it’s not that great a trip sometimes. It’s hard enough being on a road you’re familiar with.

#### *After the Referral: What Now?*

Inconsistencies in follow-up practices after referral were evident in the women’s stories. Many women had questions about the ongoing role the physicians from the

referral center played in their lives. For some, this was unfinished business and over the time of the interviews, some women identified they needed answers about this and subsequently strategized as to how they would go about getting answers.

Laura was sent home via car following a complicated stent insertion 2 weeks post MI when she was still experiencing chest wall pain. The advice she and her husband got was somewhat vague and did not reassure them.

They just told me if I had any problems, I was just to go to emergency...They didn't really prepare me for coming home.

Laura lived a short distance from her local emergency department but she could not recall anyone asking her about that. Laura believed the focus of her care at the referral center was on the procedure and not on how she was coping or would cope when she went home. Because she had been transferred from the rural hospital for invasive procedures, she had not yet been discharged as a post-MI patient with specific instructions for her recovery.

My husband found that nobody really told him anything. I don't think they even explained anything to him...Because I was having trouble remembering things at the time. I don't remember anything from the time I had my heart attack until after the surgery. I think if he would have got more information he would have given it to me.

Laura and her husband returned home to their community exhausted, somewhat anxious and lacking in any specific direction that made them feel confident in being there. By that point Laura's fears, fatigue and need for some control fostered her retreat to the

familiarity of her own home. When we spoke, she questioned the soundness of her judgement at the time she came home.

I just feel they really rushed you out. They go in and do this surgery and they put this thing in ...normally people would go home the next day. I didn't feel rested at all when I came home. I was just really rushed and I didn't feel ready to be there. My family doctor wanted to readmit me but I just wanted to come home. My husband was very nervous when I came home. Like I think he would have preferred to take me back to our own hospital.

Laura has seen a visiting internist from another city and has also travelled to his practice setting for stress testing.

They never asked me to come for follow-up after the stent. They just send you back to your family physician. So I see the visiting internist and my family physician.

Laura continued to experience angina and limitations in her activities. Beth on the other hand returned for more than one follow-up appointment after her angioplasty and was more functional than Laura. Different practitioners and referral sites may help to explain the differences in practice for follow-up, but the follow-up process after referral was not transparent, nor was it always understood by the women or their families.

Anna had unanswered questions relating to the CVA (cerebrovascular accident) she suffered at some point during her time in hospital for the quadruple bypass. The CVA became a major focus in her recovery from MI. During our discussions, she raised issues about the communication channels between referral centers and rural hospitals.

(After the bypass) my family doctor got no (follow-up) letter saying anything about my stroke. He did get a letter from London but it just said about how wonderful I did all the way through (the bypass). Something happened there. But he didn't know. I want to sit down with him (my family doctor) and say, okay you two (doctors) confer so you both know what happened to me. Then – somebody talk to me here. My question always was- was the stroke because of the tPA so many weeks before? Did it happen at the time of surgery? When? I would have thought they would have called to do a follow-up.

Although Anna was grateful to have follow-up with a visiting internist in her community, she felt somewhat uncomfortable with the fact that she was not being followed by a cardiologist as she perceived others might have who lived in the city.

The biggest thing is I don't have a cardiologist. I have an internist who is wonderful but he is not a cardiologist. You have to drive ...It's a 2 hour drive to see him (the cardiologist). I've been very lucky I have never had to wait. But you've got 4 hours on the road for a 10 minute visit.

Hanna expressed frustration as to who was actually overseeing her cardiac health and whom she should be calling for follow-up appointments when she ran into problems. She had been treated at two referral centers. When she tried to sort out her concerns, the advice she got was invitational but confusing, and did not resolve her question.

Well this is what I am confused about, is that other than my family physician no one is looking after my heart. My cardiologist, or the one in Kitchener at least just says you know if you have any questions just let your family doctor know and I will be most happy to treat you. I called London where they are so busy and I

said, you know I am confused on this and the doctor says Hanna, we have not discharged you, you are always a patient in our heart system and any time you want to see me, you just get in here.

Jean also felt confused about the advice she received regarding how her need for follow-up would be managed between her rural and urban physicians.

I go to both of them. My local doctor says I should still go to Hamilton for 2 years. But in Hamilton, he said I just come back in 3 months. So I don't really know.

### *Silenced Voices in the Land*

There were inconsistencies in women's experiences of feeling heard by those who practiced in referral institutions. Women did not feel heard, nor were they able or willing to express their issues when prior communication had left them feeling devalued and unimportant. Anna experienced this following her bypass surgery when she felt something was wrong and no one would listen to her.

I don't know when the stroke happened. I remember the Saturday. That's when I started acting funny. That is when my hand really started bothering me. I had no strength in it. I could not pick up anything. We (Anna and her husband) kept talking to them and saying there is something wrong and the one doctor decided to keep me an extra day. So we drove back from London. I had quad by-pass, two hour drive.

In fact Anna had a CVA at some point in her bypass hospitalization, but this was not diagnosed until she returned home to her rural community. She persisted in having her concerns validated. The failure of the referral center to acknowledge Anna's concerns



and CVA, later had major implications for her return to work and rendered her voice silenced in having disability claims heard at the employment negotiation table.

My family doctor wanted me to stay home from work. I wanted to get back....My doctor read some of the letters from the surgeon and he said “How are they going to treat your disability?” Because everything here is “thank you for letting me see this lovely person or whatever. She is doing extremely well” But not once did the surgeon put in there that I had a stroke.

Gerry described how a comment at the referral agency reflected the invisibility of her life context and a minimization of her cardiac status.

They (at the referral center) gave me the impression I was fine. They said “You can go back to normal.” I thought, “I can? You can’t see the inside of me.” I mean this is supposed to be the biggest doctor there and he saw me because my other one was somewhere else and I remember he said, okay so you are doing everything you used to do. And I thought, everything I used to do? I wanted to say, what do you mean? How could he know what I used to do? He didn’t. I thought, have you ever worked all day and gone home and picked three or four acres of stones? Like has he ever done that, like does he have any idea what that would be like, because that threw me and it’s always stuck in my mind. I believe it’s assumed, I am a woman, I’m young, I don’t look like I am out in the field picking rocks, I don’t look like I live that kind of life...Somebody once said to me - a doctor said – “You look like you lead a pampered life” and I thought “Pampered? Pampered life, how do they figure that? I was stunned at that

comment, a pampered life. No nobody has asked me about my life....When I told my doctor here at home she said, “They should know better than that.”

Laura felt that she, her husband and her rural health care providers were judged negatively by some health care professionals at the referral center. This perceived lack of positive regard served to create roadblocks to useful and necessary dialogue that could have benefitted Laura.

They just felt we were country bumpkins, even my husband felt that way. He got treated that way. Even Sandra, (the rural nurse) felt that they think we are stupid or something because we come from the country and we don't comprehend what's going on. And meanwhile Sandra is one of the most knowledgeable nurses you can get. She has worked in emergency for years and then the O.R. and then here is this girl (receiving nurse at the referral center) talking to her like she was a farm wife and not a nurse.

Later on, Laura's experience with a mental health referral effectively silenced her call for help in dealing with fear, anxiety and depressive symptoms related to the MI. Her referral was to mental health services that did not exist in her community. The referral center identified she had a “real” problem, claimed she didn't fit the profile of their program then sent her home out of the earshot of mental health professionals, effectively driving her to self-sufficiency.

Gerry's frustrated attempts to access information from a specialist served to silence her self-advocacy and turn her away from further participation in a cardiac rehabilitation group.

I asked the question at the wrong time and he (the rehab doctor) got snappy and I never went back again. I thought I have been there all that time and said one thing, I wanted to know what my ejection fraction was, if he would know. And he said well why would I know that? And I said, well I asked my doctor, my family doctor and he said you have to find out in an ultrasound. So this rehab doctor said, okay didn't Dr. G. just do an ultrasound ? He would probably have it...

### *Resourcefulness*

“When you can fill your own bag of potatoes, don't wait for the Lord to do it for you.”  
(Edna, 2002)

Self-sufficiency is a trait that “urban legend” has attributed to rural people and I found many examples of women turning to themselves as resources to fill gaps created from living in a rural place. Very early in the interview process I became aware of women's tendencies to “make do” with what they had and to take initiative to problem-solve when faced with challenges imposed by their MI's. Patient educators gave examples from other rural communities in which lay persons had initiated a “Recovery Road” programme (Heart & Stroke Foundation, n.d.) to try to meet post-MI needs for information when no formal programmes existed.

### *Taking Matters Into Their Own Hands*

When Anna could not get those in the referral agency to hear her concerns about “feeling funny” in the postoperative period following coronary bypass, she dutifully returned home to her rural community where she knew she would be heard and where she could set the wheels in motion to get the answers that would address her worries.

I suspected I had a stroke. We drove home. My parents brought the kids home. I was very happy. After my parents left we didn't say nothing. After my parents left I said "I want to see Dr. M. because I think I've had a stroke. We called. He said "No" and I said "Yes I have. There is something wrong." We went right over to the doctor's office and he did a CT scan and there it was... So there is always something good from being rural (she laughed, inferring that she was diagnosed in rural Ontario, when her symptoms had been ignored in the urban center). The next day my family doctor called and asked us to come to the hospital and we went up and he said " I can confirm exactly what you diagnosed yourself with." It was quite extensive. It affected my speech, my memory and my hand.

That women were resourceful did not mean that their decisions would be the ones health care professionals would sanction. Kate had never returned to see any physician following hospital discharge post-MI. She seemed surprised when I asked about follow-up care.

No – I haven't been back. Why would I? I feel fine. I was supposed to have an appointment but then the doctor had an emergency and cancelled me. I never called back. My daughter is helping me with my diet. No red meat. No sugar. No white bread. So I am listening to her. But would you have anything about margarine? I'd like to know what I should be buying.

Cassie's financial needs weighed heavily in her decisions about taking medication and attending cardiac education classes to learn about activity and other lifestyle issues.

professionals for advice she thought she could easily get from knowledgeable friends or television. She referred to advice from CNN (a television station) several times.

I don't need any help. My operation for sure would cost a lot of money, so I don't want to take time away from others who need it. I am independent. I am a war child. I was always taught from little on, do it yourself. As a matter of fact, my aunt used to say, "When you can fill your bag of potatoes yourself, don't wait for the Lord to do it."

In an attempt to assume control over their health, some women stopped taking their medication and some did not discuss this with their physicians. Edna, was not tolerating her antihyperlipidemic and subsequently used her alternative community resources to try to resolve high cholesterol. She followed the advice of a church friend who was a firm advocate of an oral preparation called Heart Drops.

I heard about Heart Drops. The doctors don't like that but it saved my life I tell you. I take 15 drops under my tongue and I wait a minute and I swallow. Three times a day. I go through a bottle every 2 1/2 months. I get it from a friend. I got her name from a man in our church. He said, Edna get yourself these heart drops and I talk to this lady and she gave me the bottle and she said you take your medication and take the drops. So I said, will that help my dizziness? She didn't know. Anyway I did that then I thought that won't work, sometimes I took and sometimes I didn't take it and so this went on and on and on, until I had to go for an operation, triple by-pass, see my blood pressure was very high too. So these drops I started three times a day after my surgery.

Edna stopped all other prescribed medication. She did tell her doctors what she was doing and was triumphant when her cholesterol and blood pressure dropped near to desired ranges. During an interview a few months later a distressed Edna told me her cholesterol remained too high. She mobilized her informal community resources again, and a friend who had heard about the value of red wine for heart disease said she would bring Edna a bottle so she could add a drink to her daily medicinal regimen. Edna believed that she was able to look after herself and did not want to rely on the health care system more than she thought was necessary.

After Laura met with disappointment related to her mental health needs, she found a way that she could minimize her anxiety and fear. Her answer was to stay with her husband and accompany him in his international trucking business that required him to be “on the road” for extended periods. Laura left the country to maintain the caring and support she required daily. The suite in the back of their transport truck became Laura’s home away from home.

I started going with him in June (about 4 months) after the heart attack. I was having an awful time sleeping at night especially when I was alone because it happened at night, so that bothered me the most. I am afraid to stay by myself. I have always enjoyed going with him and he was feeling very uncomfortable leaving me at home. So – it worked out good. He wanted me there and I wanted to be there. We can be gone for a week and we would be home on the weekend, or sometimes we are gone for 2 weeks. Like we could be home on the weekend or every other weekend. But usually, at least every other weekend.

Being together helped Laura control her anxiety although it effectively removed her from her community and province. She did have out-of-country health insurance and told me she had never needed to use it.

My husband also likes me with him. He usually doesn't go to sleep until I have gone to sleep. He feels he can do something if he is there. Because when it (the MI) happened, he was on the road. So for him, he feels secure. We both do.

That's why it works.

Hanna also resorted to going out-of-country to access family members for support after each of her MI's. She encountered challenges in getting health insurance for those trips.

Beth was still plagued by feelings of insecurity as to whether the pains she experienced were another MI or not. When she experienced chest discomfort she sometimes sought help in her doctor's office or mobilized self-talk.

I don't know if it is just being scared because I had a heart attack and every time I got a pain here or something is not comfortable around this area I went to the doctor's. I don't know how many times it's been, but it feel like your heart skips a beat once in a while and I think I am getting angina back ...I used to smoke when I had anxiety ..but I quit 3 years ago – I blame that on getting a heart attack. I am getting better at controlling my nerves. I just tell myself to settle down. They won't give me no medication for it...I don't really know if I am recovered. I can't say that I feel comfortable because... maybe it's because of my hernia, I never know. It's always in the back of my mind and it never goes away. When I am worried, I tell my husband – I don't know how many times we get ready to go

to the hospital and I think oh gee, I got something. Is it heartburn? Lots of times I take a cup of water and it goes away and the doctor says well its not your heart, so I feel better about that.

*Working Out How to Work Out*

The absence of structured and individualized exercise programs for post-MI patients in the rural communities meant that women found their own ways to meet what they deemed to be their exercise requirement. For the most part women began tentatively, and experimented with increasing their activity with minimal guidance, although some women received little to no input about activity. Resourcefulness was the option for women when they were uncertain about what to do, who to ask, and what to ask for. When women did receive advice about exercise, they were often challenged to incorporate that into the context of their rural lives.

Beth learned to manage her own fears in resuming activity post-MI.

When I came home after the angioplasty I was scared, I was scared. I couldn't leave the house without my cell phone on ... When I drove I always thought it was going to happen again and I was scared to go up and down the stairs and I was scared to do anything basically. But then little by little you get used to it and you forget and now I go for a walk with my Nitro. I never used to.

Cassie described how she had trouble acting on the exercise advice she received because she needed to have a tangible purpose for taking a walk on her sideroads. She had difficulty reconciling how her prescription for activity could be consistent with a



diagnosis of impaired cardiac function.

The doctor said that I should walk briskly while I am in the country. If I am going to walk I have to have a reason. If I am walking, I am taking my dogs and if I am taking my dogs I have to hit every one of my neighbours and say, keep your damn dogs in or I will sue you if they come and bite me. I will sue you if they come out after my dogs. They now freshly paved our roads again and with the chips. I can't walk the dogs on it because it's too rough on their paws. Maybe I go for my twenty minute walk a day and maybe I don't, but I walk around the property with the goat and the dogs. As far as I'm concerned if he (the doctor) wants me to go for a 20 minute walk every day, then I have no limitations. I can do what I normally do, go back to my old pattern of living. Mind over matter.

Not knowing the type or extent of activity they should be engaging in left women like Gerry to their own devices to figure out what was okay for them. When I asked Gerry how she knew what activities she was able to do, she replied

Now isn't that funny. I was asked that by my sister. I said well, for one thing, when I go to do something and I get short of breath, I wear myself down, I really start breathing heavy.

Gerry described her frustration when she was told to "walk" by a doctor in a referral agency. In an area with sidewalks or indoor walking programme, walking may not present the logistical challenges that Gerry met on her farm. Although she loved living where she did, Gerry was fearful that if she experienced difficulties when walking, no one would know or be around to assist her. When she raised the issue with her doctor, there was no guidance forthcoming.

Walk? Where? Down there? (points to the lane that goes back through her fields). Like I was surprised when the doctor in London said that. They would say you get out and walk. Like they think it's so easy to just go out there and walk down a highway that's totally... like this road is becoming the main route to Toronto and then I think okay I have to question myself there. Am I being a chicken? To walk down the road or back the lane? I have never been afraid of anything. I mean I am still not afraid of a lot of stuff, but I think is it because I am afraid, and I think, well yeah I am afraid that somebody won't know that I am there. Like I don't want to lay there for a half or an hour ...and then I think why do I need to walk anyway?...I told them we are out in the country and he goes "Well.."

After her third MI Hanna was able to get into a rehabilitation programme in a nearby city. As her fatigue, arthritic symptoms and family responsibilities increased, the drive to get to rehabilitation proved too much and she dropped out.

My rheumatologist is saying if it hurts you, stop doing what you are doing. I come in here and you tell me that I have to get my heart up to so much of a level, and I said to them I don't know what to do because I cannot do the treadmill. It's making my heart go but it's a very uncomfortable go. There are days that just for me to get out of bed is a chore and I keep going ...I walk, I loved to walk. But where we live, the road is so busy now I am too afraid to walk up to the next side road. Someone mentioned the other day that I could drive to the next side road and walk there. I hadn't thought of that. I think that I am going to have to learn to accept things that I don't really do in my life.

Some women could not remember if they received specific instructions in hospital about acceptable activity once they returned home. Months after her MI and following her bypass surgery, Edna got a “book” from the surgical center which she read and then proceeded to develop her own exercise regimen.

They gave me another book that said don't walk when it's foggy, don't walk when it's cold, don't walk when it's too hot, don't walk up the hill. (Therefore) there are just a couple of days of the year when I can walk, so I said, good grief, good for me, I walk in the basement! The doctor in Hamilton phoned me once and asked how my exercises are. So I told him, I started ten minutes of walking when I came home after the operation...then I increased it. Walking is healthy!

Ten months after her MI, Kate has decided she should exercise and shared with me the Woman's Weekly magazine that had developed an exercise program for healthy women. Kate had chosen a few exercises that did not include walking and she was eager to lose “the fat” around her abdomen. At one interview, when winter had definitely arrived, Kate reiterated how difficult it was to walk outside and she hoped the exercises she had chosen would also help her to get her balance back so she did not fall when she did go out.

Three of the twelve women had bought a treadmill for home use in their efforts to get the exercise they thought they required. None consulted a health care professional about this before they bought it – it was simply their answer to the prescribed need for exercise. Beth bought her treadmill so she could get exercise in all types of weather but concluded it was difficult to maintain a program on her own.

I have a treadmill downstairs. I bought it last winter because I started to do some walking and then around here it's a small place. They don't clean the sidewalks very well so you don't want to walk on the road, its yucky to walk on and very uncomfortable so I bought it for the winter. I went to see the physiotherapist about using it because I didn't know how far I could push it. I started off good but you know when you start a programme, you are always hyped up for it and then it's like, yeah, right...

Anna decided to buy a treadmill and structure her own exercise programme when no reasonable options for exercise were generated.

It felt terrible not being able to do much. I don't know if it was because of my age. There is nothing here for us to go to. There is, you know, no gym unless we drive. But even there, it is a paid programme and there is no direction as to how much you should do. So I bought myself a treadmill. I haven't really had any advice about it. I began myself and did my own programme where I start 5 minutes and then I'd increase and I do about 30 minutes at tops and I do that twice a day. You know the weather last fall – well I just couldn't get out, so I just went and got on my treadmill.

Fern continued to use equipment she had bought for exercise after her stroke.

I have an exercise walker here tied to the balcony on the railing. It's like a walker and there is the arms things too and you are walking. I have been using it, but I haven't overdone it - I get tired if I overdo it. In the wintertime I can't get much exercise, except from walking from here to the car.

Some women consulted physiotherapists to guide them with their exercise.

Women self-monitored for the presence of palpitations and judged their ability to breathe easily as indicating whether exercise was okay or not. Left to their own resources, women often equated any physical activity as meeting the recommendations for exercise.

Jean viewed herself as a very active person although this more aptly referred to her community involvement and her interest in her community, than her exercise. Her views reflected those of most women in that they did not understand the therapeutic intent of an exercise program. Jean described the challenges of keeping up the activity she started five weeks post-MI.

After I came home I didn't really know what to do. I am a very active person. In Hamilton, they said, how long have you been active? I said well if I wasn't active I wouldn't be here and they said play it by ear and see how you feel. They told me to go walking and when I got home I went to the corner and every day I went farther. It went fine. Slow. I was frightened to put up a pace. I didn't keep that up very long- I would say about a month or so. It was in the winter time and they told me not to go out in extreme cold because it's bad for me but I will be honest, I will walk when I go window shoppin' and I will walk for hours, so I mean I don't go for per say a walk and if I go to Fergus, I will park my car here and I walk to the bank here and walk back.

The mall strolls that Jean and her husband will take from time to time are located in communities some distance away from their home. Like other communities in which women were interviewed, no malls or indoor walking programs exist that would be accessible and which could help overcome exercise barriers related to weather.

Laura got some advice from her family doctor about activity in the immediate post-MI time period. She did not enroll in an exercise program, nor had anyone spoken to her about one. She had been told that walking was good for her. She described how she incorporated advice for walking into her life which, for the most part, was now spent on the road with her husband.

I do what I can. I don't do a lot of strenuous stuff because I get really short of breath. I do walk. Like when my husband and I are in the truck we will park at the back of the truck stop and then we will walk to the restaurant for our meals, depending on what the weather is like. If it is really hot and humid then we will park closer because that really bothers me and the cold weather as well.

Kate and Ida could not recall receiving any instructions for activity or exercise. Doris attended the cardiac education classes where exercise was discussed, however she explained she could not engage in much exercise anyway although she had not told her doctor that.

They didn't tell me I had any restrictions so I go ahead and do as much as I can. Don't get much pain except you know, when I'm down on my hands and knees doing the floor. My legs are really sore. I can only walk so far and then I kind of play out.

*Wheels: The Key to Independence:*

All of the women agreed that they needed to be able to drive or get a driver to get them from one place to another, because there was effectively no public transportation available in their communities. Transportation to appointments inside and outside of the community for follow-up or diagnostic testing, in addition to shopping was essential in

their day to day lives. Doris's sister-in law, who she referred to as her "taxi" lived nearby and Doris relied on her for all out of town, and some local appointments. The need for taxiing had increased following Doris's recent breast cancer diagnosis. Driving, or knowing someone who drove, was viewed as a necessity in rural Ontario. Some women, such as Edna claimed they had never been told they could not drive following MI, however everyone said they used good judgement in choosing how long they waited to resume driving. Four or five weeks after her MI, Fern was eager to incorporate the MI diagnosis into previous compensations she had made for her stroke, and to her fulfill her obligations to a 90 year old man who depended on her to transport him for groceries.

I would just die if I couldn't drive. Nobody told me that I couldn't drive so I drove and I have no problems whatsoever. I very rarely put the spray under my tongue. This (left) hand still shakes but it doesn't bother me. With my right hand I can do up the seat belt but if I get into a car with my left hand I can't do that but I have not trouble any other way. No, nobody has quit driving with me or anything.

The fact that others in her rural community still depended on Fern for transport reinforced her self-confidence in driving post-MI.

The world in which many of the women felt free to independently access and explore, shrank after MI and this pervaded into the longer term. Not driving meant that women had to depend on others to take them places at least for the first few weeks, or that they did not seek social contacts out of their immediate locales. For women like Laura, anxiety about driving persisted long after any driving ban was lifted and this served to reinforce her feelings of lost independence.

You can't drive for 6 weeks after a heart attack. But I don't feel comfortable

driving, like I am nervous. Since the heart attack, I don't drive long distances. It's really hard to get anywhere. You really do have to drive here but my husband usually drives. I know I hear so many times about people having a heart attack and dying on the road and it scares me and I can't get over that. I just don't feel comfortable driving. I go short distances now but that's about it.

Ida depended on her daughter exclusively for any transportation off the farm. As her mobility decreased, access to the car became a major challenge.

Well, it's hard getting out of the mobile home and down the steps, especially when it's icy. Then I have to get in the car and hope we can get out the lane. We've had to turn back a few times when the snow was too deep for my daughter's car.

### *Relationships*

It's a small community. Everybody knows everybody here. It is like a giant house. I like that – it makes me feel comfortable. But, I don't tell my fears and stuff to my neighbours. To me that is gossiping (Beth, 2002)

Relationships to health care providers, referral centers, significant others and women's communities were recurring foci in discussions with women and health care professionals over the course of the study. Women valued connections inside and outside the community. Feeling connected was a source of comfort for many, however as Beth's comment suggests, for some there was a line between feeling cared for and letting others know you may need care. Personal security in the long term, was fostered when women felt cared for and heard by their local practitioner at the time of the MI. Women associated feeling cared for as meaning they were getting the care they needed. They



depended on their practitioners to know what care they required and how to get them that care.

Women viewed their relationships with their local hospital and physicians positively. For many, these linkages were important resources over the months that followed the MI. All women viewed their local practitioners and hospitals with gratitude, and contrary to what I had anticipated at the outset of this study, no one felt they would have received better care, or that their outcome would have been different in an urban center. One nurse commented that such questioning would only make people feel insecure and because they needed to feel secure, believing in their local center was essential.

#### *Outsiders and Insiders*

Women commented on the way they believed they and their rural health professionals were viewed by those in the referral centers. There were inconsistencies in these experiences however there were situations in which the perceived lack of positive regard by referral agencies served to silence women in their communication with caregivers in the referral centers. Anna was from a community that had received a lot of negative press about a public health situation and subsequently she perceived herself to be a curiosity to some caregivers at the referral center.

Actually, when I was in London, I had people come to my door and say we want to speak with somebody from (my town). I'm serious. People really think we're different? Yeah, 2 hours away and we're a bunch of hicks.

Laura said that her husband felt he was invisible at another referral center. She also described how her rural health providers were undermined when they arrived at the

referral center. In response to her reflections about that, Laura proudly defended the doctors and nurses in her community.

Well I think people who worked in referral centers need to understand just because we live in a rural community that our nurses and the hospital staff are very qualified people, as qualified as they (in referral centers) are. You know they have taken the same schooling and they are just as adept at, you know, things that they are and that they should be respected the same. It is a small community but the medical staff that we have there is tremendous in their knowledge and the girls that work in emergency, I mean they all take their ACLS. They all have their ACLS and the pediatric one and the majority have emergency courses behind them. I have the utmost respect for them and I feel that they are knowledgeable as a city hospital. I don't think that they get the respect and the recognition that they should. If it wasn't for the staff here knowing and doing what they are trained to do a lot of these people (the patients) wouldn't even get to Hamilton.

Dr. Green viewed relationships between rural health care providers and tertiary care centers as one based on power – and it was centralized in urban settings.

If care was centralized in a region, the further on the periphery you were, the less likely they (tertiary centers) are going to listen to you. If we were regionalized, we would be out of the catchment area that we have developed links with. We are at the far fringe. We would lose the flexibility to bargain for access. People who live near tertiary centers arrive at the ER door and they are in the system. If you're at the periphery there's no room. When you're out far enough they can put

you off- that's the reality. The tertiary centers decide what they'll do based on their resources and rural people are at the receiving end.

Some women talked about using relationships they had in their communities to access care or information after their MI. Anna perceived her connections within her community helped her access information after her MI. She viewed herself as privileged in knowing the resources that existed.

I used my connections. Now, I am not saying that the others (who have had MI's) don't use their connections. I just don't think a lot of people realize what's out there for them.

Hanna had similar perceptions about the power of "who you know." She believed that family connections she had in the medical community helped her access a rehabilitation group in a nearby city that other women in her area would not have knowledge about.

The invitation or referral to attend cardiac education classes or rehabilitation was dependent on connections women had to health care professionals and friends. For women to be invited to an outpatient cardiac education class, someone within the local institution had to make the referral. The way in which this occurred varied with the institution. For one of the four hospitals, there were women interviewed who said they had no idea about the classes. One nurse commented that she believed some women "fell through the cracks" and for some reason, they did not get called to attend the classes. Kate and Ida had no knowledge of such outpatient opportunities. Other women chose not to attend because of commitments at home, feelings of self-sufficiency or physical access challenges.

Nurses who were the patient educators at the rural hospitals were held in high regard by the six women who had attended the classes. These women perceived the patient educators as their advocates, relied on the information nurses gave them, and appreciated the facilitated access to dietitians, physiotherapists and pharmacists in their communities. The access to these services increased women's feelings of security in their post-MI lives.

Women who used the outpatient education services espoused feeling "lucky" to have such services available. Luck however implies chance, and the inconsistencies in what was available for post-MI women, or what they perceived to be available may reflect that luck or chance was essential for rural women to access care and information after the MI. Laura's experience with trying to resolve mental health needs related to her post-MI life meant that she did not have luck in finding a solution that was within the realm of available resources.

Being close to their homes and being cared for by people who knew them or their families and/or their communities was reassuring for women and it was where they wanted to be when their lives were in danger. There was a feeling of confidence that if more care was needed, the rural professionals would ensure that this happened. Two women returned home from trips so they could go to their rural hospitals when they were experiencing their MI's. Jean opted for returning home and bypassed the many available urban alternatives when she became ill prior to her 2 day journey home from Tennessee. Being known by her caregivers as an individual who was part of the community increased Beth's comfort level in accessing care in the months after her MI.

Over here it's so different. Your doctor knows you and remembers you, remembers what you had. You go to the doctor in the city – he takes your number on a piece of paper basically. I felt the same way as I did in Kitchener (with a former family doctor) when I go to London, it's very cold. Like the doctor says can I ask you a few questions and they check your blood pressure and your heart and you just go like that. I understand they are busy and they have a job to do and they don't have much time as a small community doctor. There is people from all over that go to London. Here it is just the people from around here and they get to know you and know your family and know that you have children and they know...it's different.

Like all of the other women interviewed, Beth felt she could see her rural physician or access emergency care in her local hospital whenever she needed it. Physical proximity to care in potential emergency situations was not a dominant worry for most women. All had worked out the way in which they could access emergency care. Kate was confident that a new provincial hotline for medical advice would help her when or if she required care. She had used the hotline effectively in the middle of the night at the time of her MI.

Women who had connections to neighbours and friends within their rural communities prior to their MI, benefitted from these connections post-MI. This was true for newcomers and those who were “old-timers” in their current rural communities. Friends and families were important in driving women to appointments, for child care and day to day housekeeping. Edna who had moved to a village from her farm following the death of her husband, had established caring connections as a newcomer in the community.

I am different. I have a lot of friends and I belong to a good church and that, support is unbelievable. They prayed for me until I came back to church and you know when I came back to church, three weeks later, after the heart attack, on the Tuesday I had a heart attack, in a week the second Saturday I was already invited by Harry's for supper. They came, they picked me up, took me back. I had so, many good friends. Bev came six weeks to clean my house!

Kate relied heavily on her daughter after her MI.

She is so good to me. She or my son calls or drops by every day. They pick me up to take me shopping, shovel my driveway – keep an eye on me. But there's not much to do in this town- they moved the bingo hall out of town and now I can't get to it without somebody having to come get me.

Two of the women had established positive relationships with home care workers who provided support that enabled them to stay in their own homes in spite of decreased activity levels following MI. Fern appreciated the help she got from community care agencies and friends.

I have some good friends here and there are some a bit on the nosey side. For the most part, everybody is very nice and they are right there to help you out- people that you wouldn't expect come. I also have a girl that comes from home care- she is a good worker. She comes in and takes right over, does the wash , does everything I tell her too.

Ida had no connections except for her daughter and her family. The connections both Ida and her daughter formed with the community care agency were viewed by them as instrumental in allowing Ida to safely stay in her home.

We got the Lifeline put into the mobile home here. If I need help, I just push the button. I have ever had to use it but the thought of it being there is good.

Ida's daughter went on to say that

Living here, I cannot see how we could do without that Lifeline. It allows her to get help when and if she needs it. It really is my lifeline too.

For most women there was a paradox in wanting help and having social contact and in keeping people at a distance that respected their need for privacy. Beth appreciated her community but would not use her social connections for seeking support related to her post-MI anxieties.

It's a small community. Everybody knows everybody here. It is like a giant house. I like that – it makes me feel comfortable. But, I don't tell my fears and stuff to my neighbours. To me that is gossiping. I stay as far away from that as I can. I don't want to know your business. You go and tell something to a neighbour and they go another and tell another. Like I said my sister (in New Brunswick) is my friend and my confidante or George. That's the only two people I can really trust. If I have a problem, I can just go over to my doctor's or the nurses at the hospital. No appointment.

For women who did not have community connections prior to their MI, new connections to anyone except for their health providers were unlikely to be initiated after the MI. Whether women were regarded as newcomers to a rural area or not, did not seem to influence their access to medical care, but there were indications that newcomers who did not establish social networks in their communities felt more alone than those with social connections after the MI.

Three women who were relatively new to their communities did not have community connections pre-MI and because their cardiac status limited their activity, they did not have the energy to establish social contacts post-MI. These women verbalized a need feel connected to women like themselves who had sustained MI. They were frustrated in their quests to make those connections.

Gerry relied heavily on her family for support. As a newcomer to the area she did not experience a warm country welcome from her community when she returned home. Over the course of interviews Gerry continued to try to understand her situation, on one hand appreciating what she had, on the other reconciling that her post-MI experience did not fit with portrayals of a woman after MI that she had seen on television.

I think, because I am out here...I am not that far from town... but on the same hand the people, they are not like me... like I never... like when I read the book a woman wrote about her heart attack (that she had seen on the talk show “Oprah”) she said her whole family was there, sisters, brothers, whoever, their whole life was on hold for a year, doing for her. I didn’t come home and things were done and I didn’t come and my fridge was full of food and my freezer full. I didn’t have anybody. My friend cleaned my house for a year. I am isolated in a way. Really if it wasn’t for (my husband) and my kids than I would definitely be alone and then I would feel isolated.

Gerry challenged the idea that rural people united together in adversity as this had not been her experience.

My neighbours have probably been here thirty years now, and the people over there, nine and they didn’t even know each other. I wouldn’t know her if I saw



her. He comes over her to hunt once in a while and we say no and away he goes home again and that's it. Sometimes you think, okay is it because none of us... are we just too private? That's why we moved out here in the first place. Other neighbours lost their daughter a couple of years ago after I had the heart attack. There is no communication between us. You can sense they don't want to and I am thinking is that the way it is everywhere? Especially if it is women who are sick. If they are sick it's (the poor communication) even more so.

Gerry had pondered ways in which she could establish some connection with other women.

Other women I have met who have had a heart attack are mostly back up and running and functioning. I think I needed somebody in my position...The emotional aspect (of a heart attack) is not over 6 months after like they say...It's taken me 4 years to get to this point...You know I've often wondered about going and renting that Masonic Lodge in town and see if there are others out there that might want to get together and talk...you know have a person like you (interviewer) kind of lead it. I don't know – maybe no one would come.

During the course of this study, Gerry was asked to be the “representative survivor” to speak prior to the inaugural mother-daughter walk for the Heart and Stroke Foundation in a nearby community. She was excited by what she saw as an opportunity to connect with women like herself and put great energy into developing a short speech that would give hope to other women facing heart disease. However the goal of the walk was to fundraise, not network, and Gerry came away disappointed after she met no other post-women who had a MI.

I would have thought there would have been a chance to talk to others, to hear what they had experienced. Maybe those women (who have had MI) don't go out on these walks.

The search for connections with others was something Hanna hoped could help sort out her feelings. She felt that her family obligations had only increased since her MI's. Her comments reflected the burden that family connections had become for her as her health deteriorated.

It's almost a turn around I guess since I had these heart attacks. As I said, the family doesn't understand. I would love to know what other heart people feel, whether they feel the same way. I feel like I am here alone.

To manage her feelings of despair, Hanna had tried unsuccessfully to make contact with a priest she had met some time ago. Although she wanted some emotional support, she was hesitant to get into any group situations that could offer that where her vulnerability would be visible.

I shy away from it because I feel I have not got control of my emotions or of myself. I am just not comfortable doing that.

It was difficult for all of the women interviewed to think about not being in control of their emotions, to be comfortable in reflecting about the forces influencing their experiences, choices and challenges post-MI. To offset this discomfort, women had become expert in the art of reassurance, recalling the positive experiences with people and institutions associated with their MI's and frequently recounted with gratitude the caring and expertise in their rural communities.

*Stitching the Patchwork: Making Sense of the Themes*

The patchwork quilt metaphor that evolved to illustrate the issues and lives of the women who volunteered to tell their stories, reflects unpredictability and haphazardness that characterizes the post-MI trajectory of rural women. Reticence, resourcefulness, referral games and relationships were the narrative themes around which I came to view the scattered and solitary patches that represented the lives of post-MI rural women. The faces, voices and circumstances of the twelve rural women who volunteered to be part of this study continued to resonate in my head as I wrote and reflected, ever cognizant of my commitment to let their voices be heard. I envisioned them each as a complex “patch” in a patchwork quilt. The quilt landscape was scattered with the stories of women’s lives, solitary patches of various patterned hues that represented the uniqueness of their stories. They were connected one to the other and the central narrative themes by complicated networks of barely visible threads. The threads blended into the fabric and required the naïve observer to actively search for connections. There were vital fibers that appeared invisible. There were breaks in the threads, where connections were broken or non-existent.

In the following chapter I will discuss the dynamics that have helped perpetuate the current situation in which women are grateful, accepting and without a voice in changing the future for themselves and other rural women who sustain MI. It is hoped that exploration of the thematic patchwork will enlighten our understandings of the influence of rurality on women’s lives and that concepts may have relevance in promoting the health of all rural people.

## CHAPTER 6

### *Reflective Analysis*

#### *Summative Discussion, Limitations and Implications*

##### *Reflective Summary and Discussion*

Study findings have been described in the preceding chapter according to the four emergent narrative themes, Reticence, Referral Games, Resourcefulness and Relationships, and there is need to critically reflect on these findings in relation to previous understandings and future directions. In this chapter I will examine the relationship of rurality and narrative themes to current knowledge and the ways in which themes are products of socially embedded assumptions and structures that marginalize and constrain. I also will reflect on the nature of rurality arising from this study and its relevance to exploring women's post-MI lives. I will conclude with a discussion of study limitations and implications of study findings for nursing practice, research and policy development.

The focus of previous post-MI research has been on treatment, interventions, recovery processes and experiences, however examination of the influence of social structures on those aspects has been limited. In keeping with Thomas's (1993) instruction, the critical ethnographic approach taken to explore how rurality influenced the lives of women post-MI was intended to identify and expose forces shaping their life experiences, choices and challenges and ultimately offer the possibility of emancipation from current perspectives related to their post-MI lives. The compelling stories shared by the twelve post-MI women also raised questions about the utility of rurality as a concept in exploring illness experiences.

Rural women have generated little interest for specific inclusion in post-MI research and seldom have their issues been specifically identified in research findings. It is arguably unlikely, though not impossible, that the women who participated in this study would have been included in populations in traditional research programmes. The distance that women lived from tertiary centers with research initiatives, the fact that all but one was cared for in a rural hospital during the acute MI phase, that only two had (aborted) opportunities to be in full cardiac rehabilitation and that women agreed to participate in this research if it meant they could stay in their home communities, indicates their inclusion in traditional urban-centric cardiac research was improbable.

*Rurality as an Assumed Reality*

The rural lens through which women's post-MI experiences were viewed was intended to penetrate beyond the description of events and identify the forces giving rise to women's perceptions and experiences. Rurality, as viewed through the eyes of the participants was most easily articulated when they viewed their experience in comparison to their understandings about urban people and life, or when a specific characteristic previously attributed to rurality (such as access to resources), was probed. For the women participants, rurality was the "taken-for-granted (reality of their) everyday world" (Becker, 1996, p. 61) and as such, it was challenging for them to specifically identify and explicate its components and its influence on their lives. This may illustrate what Thomas (1993) referred to as 'ideological domestication', in which the influences of the social ideologies that shape everyday existence go unrecognized (p.8-9). Lincoln's (1993) guidance for researchers to allow participants the time to identify and articulate their words and stories was relevant for me as I encouraged women to search for, and to

consider the dynamics of “rural.” The women offered their time and energy with some uncertainty, finding it unusual that someone was interested in their story, and somewhat curious their rural roots were critical to inclusion in the study. For all women interviewed, linkages between their post-MI experience and their rural lives had not been considered previously and to varying degrees, the interviews became a conscientization process (Freire, 1970). Lather (1991) coined the term “catalytic validity” to describe the impact of critical research in assisting the study population to understand themselves, their situations and to take action to change it. Although the study process offered women the opportunity to find their voices, raise their questions, dare to consider alternatives to their experience, some women had difficulty finding the words to articulate their thoughts. For some, this reflected a lack of previous opportunities to focus on themselves and their reflections were accompanied by tears followed by surprise about the presence and strength of their emotion.

As I came to know the stories of these women I was struck by the uniqueness of their narratives, the commonalities imposed by the MI diagnosis, and yet for some time, disquiet prevailed about the influence of rurality on their collective experience. As I began to comprehend the dynamics of the post-MI experience for rural women, I came to more fully appreciate the multiple and elusive dimensions of rurality. Viewed through the rural lens, women’s post-MI lives took the form of a patchwork. The metaphor of a patchwork quilt illustrates the influence of rurality on the post-MI lives of the rural women. The human dimensions of the patchwork are embedded in the women’s patches (stories) and there were indications that at multiple levels, issues, like invisible threads holding the quilt squares together, were silently absorbed, rationalized, denied or

accepted by rural people as inevitable and often acceptable consequences of rural existence. These issues will be more fully explored according to thematic headings.

To greater and lesser degrees, all of the women viewed their lives as a “half-full cup” and considered themselves fortunate to live in their rural communities, believing their rurality was a more positive than negative influence. When they allowed themselves to consider alternatives, viewing their rural life from a deficit position, most were quick to remind themselves they were lucky to have survived the MI(s), to have caring and competent health care professionals in their communities, and to have been able to eventually access any tertiary care for which they were referred. This feeling of “being lucky” gave rise to hesitancy to critically reflect on their experiences.

#### *Rurality Fostered Reticence*

Reticence, a narrative theme rising from this study, has not been previously identified as a specific component relating to rurality. Reticence may relate to the “stoicism and independence” recommended by Humphreys (1998, p.214) as qualitative attributes to be included in rurality measurement but they have yet to be clearly established as rural traits.

Hesitancy to focus on themselves, to question or complain and women’s desire to resume their lives as quickly and quietly as possible, have contributed to silencing and decreasing the visibility of post-MI rural women as a unique group within cardiac care and rural communities. Rural society has been viewed as largely traditional in its expectations of women and their nurturing role (Bushy, 1990). Laura saw rural women as the ones who “do everything’ and there were many examples in the interviews of women who felt they were letting others down when they could not fulfill previous roles

in their lives. The hiding of emotional needs was also evident and when they recognized they had them, women had no expectation that anyone but themselves would meet those needs. Women's inclination to focus on the "other" instead of self has been described by Hawthorne (1993) and it has been suggested women in general, who are recovering from a cardiac event such as MI, focus on others when they sense families are unable to deal with their emotional pain (Arthur, Wright & Smith, 2001).

All women in the study commented about their need to protect their family's emotional state, not wanting them to worry, and they did this by being optimistic about their own condition, often pretending they were doing well. This is in keeping with other research which identified the fulfillment of traditional, domestic role expectations (Boogaard, 1984; Johnson & Morse, 1990; MacKenzie, 1993), minimization of their needs and the continued nurturing and protection of others (Benson et al., 1997; Lisk & Grau, 1999; Sutherland & Jensen, 2000) were priorities for post-MI women drawn from urban populations and/or women from populations that did not identify place of residence. Whether differences exist in the degree to which rural and urban women experience these behaviours could not be discerned from this study although many of the rural women perceived themselves as different from urban women in terms of the demands of their roles, or the contexts in which their roles were carried out.

Some rural women received messages from their physicians, nurses and families that reinforced their facades and negated their views of self. When the health care professionals were cued about her level of emotional distress, Laura's experience reflected there was effectively no professional mental health support available short of antidepressant medication. The lack of mental health services in rural communities has



been previously recognized (Health Canada, 1996), however the failure to urgently meet Laura's needs related to depression offers reinforcement for her and others to "keep up appearances," look after themselves and place no expectations on the health system.

Drawing on his experience with MI, Frank (2002) identified the cost of keeping up appearances for ill people and the rewards others try to bestow on them for maintaining the façade. This raises questions as to whether "keeping up appearances" is different for men and women and whether urban - rural differences exist in this regard.

In this study, women's reticence was manifested in a hesitancy to interfere with the doctor's consultation agenda and to raise issues that were important to them as individuals. Gerry spoke of "not wanting to put them on the spot" to answer her questions, Anna "didn't want to hold them up" and Edna was concerned about the amount of money she may cost the system when she considered making requests of her physicians. In effect, women were inclined to protect the health care system, possibly at the expense of their own health, and feel guilty when they were the recipients of what they had been told were scarce resources. This served to reinforce feelings they were lucky and privileged to receive care and extinguished the likelihood they would speak out against the system they viewed had saved them. The attribution of these findings to entirely rural influences is questionable however, as minimization of their needs and experiences have been documented in other samples of post-MI women (Boogaard, 1984; Fleury, Kimbrell & Kruszewski, 1995; Lisk & Grau, 1999). Rural communities have been regarded as bastions of "traditional" androcentric society in which women have little formal authority and have not been encouraged to voice their concerns (Bushy, 1993; Health Canada, 1996; Teather, 1998). It may be that such influences are not

isolated to rural communities and that the socialization of women to focus on others at the expense of themselves, is a cross-cultural phenomenon.

The solitary nature of their lives as MI survivors was evident in women's stories and the forces acting to suppress the formation of a collective voice were multiple. Women were very uncomfortable focussing on themselves and many were intimidated by the medical system outside of their communities, as opposed to the security they felt with their local health care providers. Reticence may be attributable to a feeling of intimidation and/or a lack of sophistication women felt as rural people, when they perceived power differentials while they received care in unfamiliar places or by unfamiliar health care professionals. Once women were in the tertiary centers, they sometimes felt small and insignificant, "country hicks" as Anna described. Several stated they were aware how busy these "big" doctors were and they did not want to be seen as taking up more time than they thought they were entitled.

As a group, rural women have lacked visibility in post-MI research although, even in their local communities, there were indications post-MI women saw themselves and were seen by others as a rare breed. Some of the women interviewed knew of no other woman who had a MI and the perception that few women have MI's was echoed in interviews with nurses who were very supportive of the study, in communities in which participants lived. Conversely, MI was viewed by women as a major problem for men. Many women minimized their MI experience saying that they thought men "had a harder time" after MI. Women viewed themselves as stronger than men, more able to seek help from the physician. Anna said "If a rural man says he needs help, he must really have a problem. They are very tough." Women's minimization of their own needs through

positioning their experience into “man’s life cycle” was reported two decades ago by Gilligan (1982, p.17) and fits with tendencies noted in rural societies to regard a woman’s identity in relation to someone else, (such as wife or mother) and which negatively impacts on self-image and health-seeking behaviours (Bushy, 1990). The degree to which rurality influences women’s adoption of such behaviours cannot be ascertained from this study. However, with rural women viewing their MI experience in this way, it is arguably unlikely they will be motivated to question current practices, advocate for themselves or initiate system change, and thus the status quo can be maintained.

#### *Rurality Necessitated Referral Games*

As I drove north from my home along the stretches of county and township roads to interview women and attend groups, the distance between the tertiary urban cardiac centers and the rural settings in which women’s lives were lived out was tangible. Women’s stories reflected that the distance was more than physical. The referral system was the sanctioned mechanism rural physicians used to help rural women access specialty cardiac care and although referral mechanisms are used by urban and suburban physicians, from the perspective of health care practitioners and women interviewed, there was a distinctly rural flavour to their version of the referral game.

Women and their families viewed the tactics sometimes employed to strategically position women for necessary care in urban centers as advocacy for which they were very grateful. Women viewed rural physicians as having no choice in accepting the imposed referral game rules, saw no alternative for them, and physicians viewed it as a flawed but workable system. This perspective may well serve to maintain the status quo.

Competition for access to specialized knowledge and technology and for an actual “bed”,

intimidated women and their reliance on their physician strategists to help them access these services served to reinforce their passivity and low self-confidence to question the process. The power wielded by the referral centers in accepting or denying patient access to their services lead to patients feeling “lucky” to get in, thus establishing a sense of privilege that served to silence complaints.

In examining why it is that the referral game continues to be played in its current form, it is of interest that the health care professionals working in rural areas are products of similar tertiary urban institutional structures to which they now refer. This has afforded them insider knowledge of the referral system, associated power sources, and power plays. Moving to a rural community has placed them on the outside, where they find themselves knocking on the door to be let in, attempting to access marginalized resources. In reviewing issues affecting public involvement in health care, Starzomski (2002) identified that “communication, collaboration, and effective decision-making among health care providers are fraught with concerns about asymmetrical relationships, “turf wars,” who has power in the system (and) vertical versus shared decision-making models” (p.77) and other interpersonal and institutional constraints. Thus the perception that referral games are a strictly rural phenomenon is not supported, but it may be that rural people have more or different issues with referral than those whose point of entry to health care is in an urban setting.

In this study, rural physicians learned to “work the system” for their patients and like the women, viewed this advocacy in a positive light and subsequently were not inclined to want to change the game rules. Should the referral game change? What difference would it make to women’s post-MI lives? Is there value in altering the status

quo? Is it possible for rural women and their practitioners to be marginalized from resources but not oppressed, to be equal players in the referral game? Hall (1999) pointed out that “being marginalized without being oppressed is from a critical theory view, a time-limited lack of awareness of one’s oppression and exclusion” (p.90). It could be argued that when, having taken on characteristics of the oppressor, rural practitioners and rural patients play the system, even in the best immediate interests of the patient, they perpetuate the paternalistic and oppressive cycle (Freire, 1970; Kendall, 1992) established by dominant urban systems.

### *The Keeping of Secrets*

In the post-hospital phase following MI, rurality limited the women’s choices about and access to cardiac rehabilitation. Full cardiac rehabilitation with an exercise component was not available within the communities where these twelve women lived and where they accessed rural health care. Gerry and Hanna did briefly attend cardiac rehabilitation at some distance outside their communities; nine of the twelve women did not know about such programmes or did not recognize there were appreciable differences between local programmes and those with a full exercise rehabilitation component operating in urban centers. Full cardiac rehabilitation was not a choice offered to the majority of rural women yet accumulated evidence indicates that rehabilitation with a structured exercise component has benefits including decreased mortality for patients with coronary disease (Jolliffe, Rees, Thompson, Oldridge & Ebrahim, 2003).

Nurses identified they “just felt too badly” for patients, knowing that there was no cardiac rehabilitation and specifically exercise programming available in the rural areas. Subsequently, many patients were generally not told about it; what was the point of

knowing about it, if it was not available? For the physicians, nurses and patients who knew about the existence of services elsewhere, there was acceptance and resignation that rural areas couldn't have everything, including exercise rehabilitation. Health professional's silence was intended to protect women from feeling under serviced, disadvantaged and frustrated.

Two concerns arise from this situation; namely a lack of availability of the resource and secondly, a well-intentioned paternalism that leaves women without the information on which they can make a decision in their own best interests. For the practitioners involved, the failure to address the benefits of full cardiac rehabilitation could be rationalized. Why should the benefit of exercise cardiac rehabilitation be shared when the resource is relatively unavailable? How does the right for the patient to make informed decisions balance with emancipatory principles and practice, and the possibility of inflicting harm through emotional angst if the patient chooses rehabilitation but cannot access it? From a critical theory viewpoint, keeping the benefits and principles of exercise rehabilitation a corporate secret, helps to secure power in the urban decision-making centers and continue the allocation of resources primarily to those in privileged communities.

Low referral rates to cardiac rehabilitation and poor attendance when rehabilitation was available, have been reported for women (Daly et al.,2002) and for rural women and men (King et al.,2001). Given cardiac rehabilitation has not been widely embraced by women when it was available, the establishment of cardiac rehabilitation for rural women is arguably a questionable endeavour. Yet what is troubling about the lack of choice in attending such a programme, is the urban-centric

bias in resource allocation and that without information about the structure and benefits of cardiac rehabilitation, rural people are further marginalized and sheltered from the opportunity to advocate for change.

*Rurality Engendered Resourcefulness*

Consistent with Humphrey's (1998) call to attend to qualitative indicators in defining rurality, women in this study described their efforts to be resourceful and self-sufficient in meeting their health needs. In this study women assumed a pragmatic approach to resolving the access issues, waiting as necessary, and when they could, finding ways to meet their own needs rather than depending on "the system." Women in this study did not identify distance to their local hospital or physician for emergency or follow-up care as problematic as has been the case for other rural people (Weinert & Boik, 1995; Schreffler, 1996; Johnson et al. 1998; Humphreys, 1998; Kralj, 2000). Distance to resources was viewed as an unchangeable reality of rural life and was consistent with findings by Pierce (2001) who reported that well rural women viewed distance and other access issues as challenges to be met and creatively solved by them, rather than problems obstructing their care and to be solved by others. Women's stories about challenges in accessing specialists, diagnostic testing and referral centers, and concerns about the impact of weather on access to health care, were in keeping with factors and challenges previously advocated as rurality indicators (Health Canada, 1996; Leduc, 1997; Humphreys, 1998; Kralj, 2000).

Confronted with these realities and marginalized from some resources important in post-MI care, rural women in this study were left to make themselves fit with the dominant paradigm, or fend for themselves. The conformity to traditional expectations

about women's roles and tendency to minimize individual needs lead women to find ways to use their resourcefulness to manage post-MI challenges, often depending on themselves. These findings support other literature that identified women's employment of self-reliance and resourcefulness in managing their post-MI recovery (Fleury et al., 1995; Tobin, 1996; Helpard & Meagher-Stewart, 1998; Jackson et al., 2000; Sutherland & Jensen, 2000) and are consistent with tendencies noted for rural women to rely on themselves instead of seeking help (Bushy, 1993; Viens, 1997). Rural women's descriptions of their post-MI lives was aligned with the "struggle to regain control" identified by Johnson & Morse (1990) for women and men enrolled in a rehabilitation programme. In the context of rural life, women had fewer and possibly different resources from which to choose to negotiate their recovery. For instance, no public transportation existed to facilitate access and most rural women were not referred to, did not know about, or could not access full cardiac rehabilitation programmes that were available for women in the majority of research populations. Mental health care was not available for the one rural woman who was referred specifically for depression. Alternatively, rural women's great confidence in their rural practitioners and institutions was a support that is not readily apparent in the cardiac literature.

As the interviews progressed, it became clear that most women had very limited knowledge about activity and few parameters around which they based their judgement about activity. At some personal risk, women designed their own programmes that included the purchase and use of exercise equipment. Use of home exercise equipment has been cited as contributing to decreased participation by urban women in cardiac rehabilitation (Halm et al., 1999). Hidden in their basements, alone on country roads or



on the sidewalks of small towns, women set out to “get exercise,” guided by the idea that any activity was good for them, determined to try to help themselves. For most women, their self-imposed exercise regimen was a solitary activity, unmonitored, and out of the view of others. Most women recalled they listened to advice and instructions, and “tried to do what they were told” or “could manage.” Empirical evidence supports that individuals who require cardiac rehabilitation should be risk-stratified to determine the need for exercise supervision and monitoring prior to the establishment of institutional or home-based exercise programmes (Canadian Association of Cardiac Rehabilitation, 1999). The lack of personnel to develop, implement and monitor structured exercise programmes with therapeutic goals was generally not perceived negatively by women, particularly when they felt able to engage in activity or exercise at home on their own. For many women, feelings of security were not based on sound knowledge of cardiac rehabilitative concepts, but instead arose from feelings of increased energy and/or “getting back to normal,” likely attributable to increased self-efficacy. Self-efficacy is increased with repeated successful performance of a task (Bandura, 1977) although task completion does not necessarily equate with a medically safe behaviour. Although health care professionals encouraged resourcefulness in the promotion of activity, women’s assumption of self-care behaviours when information, human or physical resources were lacking, may have served to place system needs over their own, limiting their wellness potential.

The self-care experiences women described can be examined within the context of what Northrup (2002) identified as the myth of self-care, in which the assumption of self-care as an empowering behaviour “has the capacity to contain and dissipate

widespread feelings of powerlessness and victimization while acting as a mechanism of social control aimed at preserving social order” (p.131). When women “make the best of it” and use their resourcefulness to achieve illusory outcomes, it is fathomable that the promotion of self-rehabilitation arises not from a moral-educational imperative, but from systemic insufficiency to meet women’s post-MI needs. Masked as emancipatory action, the promotion of self-care places the burden of responsibility on women to recover in the long term, and allows the system to maintain its focus on saving others from the acute threats of MI. The tendency for women to view heart disease as an acute problem has been previously noted ( Lisk & Grau, 1999). While the focus on acute care cannot be viewed simply as a rural or female cardiac phenomenon, in this study acute post-MI care was perceived by rural women and health care providers as a priority to be pursued with a fervour that long term cardiac rehabilitation was not.

If, knowledge is emancipatory as the epistemological tenets of critical theory suggest, it is questionable if women who are not informed about possibilities and/or alternatives can realistically perceive their situations in the relation to cardiac recovery and engage in the necessary self-care behaviours to maximize wellness. Women in this study demonstrated resourcefulness in managing their post-MI lives and generally viewed this coping as a positive process and outcome following MI. An alternative and provocative view of coping put forward by Brown and Kulig (1996/97) proposes a relationship between coping, ideologies and social structures that challenges the positive interpretation of rural women’s resourcefulness in coping with their recovery.

Coping is what people do in the absence of choice (Gerrard, 1990), and people

who cope are less resilient and more controllable. Conversely, people or communities, which activate their choices, would tend to be more healthy and more resilient. In our contemporary society there are many structures and norms that encourage people to be “copers” or “survivors” rather than “choosers” or “agents.” But for individuals to be healthy they need to move from becoming survivors to being agents (p.41).

There are unsettling questions that challenge practitioners to consider the rewards for them when women are coping, feel grateful and lucky to be alive. How would the gratitude women felt be affected by the move from survivor to agent? Would women feel grateful if they knew the possible consequences of their limited choices? Are they likely to ask for more and place demands on an already strained system? How is the current system perpetuated when women are resourceful? From a critical perspective, healthcare professionals are challenged to reflect about whether their perceptions women are coping in the aftermath of MI has fostered complacency in advocating for system change.

#### *Rurality Affected Relationships*

Study findings did not support that differences in relationships existed between women who were lifetime community residents (insiders) and those who were newcomers to a community (outsiders) as has been noted to occur in other rural female populations (Porter, 1998; Pierce, 2001). It may be that the changing face of rural society, the increasingly mobile nature of the rural communities and telecommunication linkages have lessened the impact of the insider/outsider phenomenon particularly in southwestern Ontario.

Women's tendencies to keep their worries about their MI and its effects to themselves and not seek the support of neighbours and friends, were consistent with reports of other rural Canadian women who preferred to keep concerns private (Health Canada, 1996; Viens, 1997; Zupko and Shearer, 2001). The valuing of, and pride in, rural health care practitioners and hospitals was a strong thread in the women's narratives and is a positive theme that has not been apparent in reviewed rural or cardiac literature. This finding challenges deficit views of rural, in which descriptors of rurality tend to include problems or challenges. Women participants viewed their relationships with rural nurses and physicians as a great resource and strength in their recovery. In contrast to the lack of positive regard that women from an urban research setting perceived in their interactions their physicians (Benson et al., 1997), rural women in this study felt cared about and advocated for, by their rural physicians. Threats to the existence of rural hospitals and an inadequate supply of rural physicians are therefore of concern when they are viewed as a mainstay of women's sense of security in their post-MI lives.

#### *Implications for Nursing Practice*

Some of the nurses who worked with the post-MI rural women had previously advocated for women when they imitated outpatient coronary education programmes. While these programmes were aimed at providing information to help patients consider and adopt healthy behaviours, there is need for nurses to move beyond helping women to fit into a system that has marginalized them and to help them become active participants in advocating for their own needs. Traditional post-coronary patient education programmes have focussed on helping patients fit their experience into the dominant medical system. Moccia (1988) contended that when nurses engage in acts that

help people accept the limitations of that system, they became participants in their patients' oppression. Kendall (1992) maintained that nurses must eschew their roles as oppressors by adopting emancipatory actions instead of encouraging the internalization of the dominant paradigm and promoting "inequality by focusing on adaptation and coping" (p.12). Thus, post-MI education must include educating women about the choices they should have versus the choices they do have as rural dwellers. Groups such as women living with breast cancer, the HIV/AIDS community and the physically disabled have successfully utilized critical dialogic emancipatory processes to shift the balance of power between stakeholder groups. Nurses can play a role in the emancipation of post-MI rural women by engaging them in critical dialogue about what is currently known to best guide and support post-MI recovery. There are inherent risks in this as nurses must also be prepared to take leadership in creating and supporting avenues to request and access services.

The potential exists for rural nurses to develop further confidence in their ability and expertise to bring about change and opportunity for rural cardiac patients. In addressing the challenges faced in rural practice, MacLeod (1999) advocated that "a crucial ingredient in the sustaining of innovation is the presence of a strong clinical leader" (p.175). The initiative shown in rural communities by nurses who implemented cardiac education classes could be celebrated and expanded utilizing other capacity building strategies. Clinical fellowship opportunities offered by the Registered Nurses Association of Ontario (RNAO) offer nurses paid time in which a nurse with specialty preparation mentors them. A rural nurse who accepted this opportunity could link with a Clinical Nurse Specialist (CNS) in Cardiovascular Care and return home to the rural area

to provide leadership for other health care professionals in developing in-hospital and community post-MI protocols and rehabilitation that include a mental health component. A potential benefit to this is the possibility for increasing awareness about rural contexts in nurse mentors and other cardiac team members whose practice is centered in tertiary environments. The CNS could provide leadership, consultation and advocacy in the review and coordination of rural cardiac initiatives, and in the development of patient-centered communication paths between referral and rural institutions. Liaising with mental health professionals and taking leadership in establishing mental health resources that are accessible in the rural community for women post-MI would increase the resource base for rural women and their practitioners. Establishing clear, patient and family centered protocols and policies about the transport of patients when they are referred, establishing paths for information sharing between referral and rural providers for follow-up and monitoring when women return home from referral centers and forging linkages with cardiac rehabilitation initiatives underway within the province are ways in which women's needs can begin to be addressed.

The development of professional rural nurse networks that identify, promote and support best practices in relation to post-MI care could act to empower nurses and lessen their reticence in questioning the current system and foster leadership in changing it. Rural nurses could be supported to create a rural health interest group as a sub-group of a provincial nursing professional organization or join national rural nursing organizations. This would increase the visibility of rural issues and take advantage of organizational supports and political liaisons. Subsequently, opportunities could be created to provide

rural nurses an audience in the provincial health forum in which rural issues could be raised.

### *Implications for Research*

The development of research initiatives that intentionally include rural women and rural contexts is necessary for developing an evidence base on which decisions for rural care and policy are based. Subsequently the reporting of research results from rural populations and contexts must be strategic so that decision-makers and policy-makers consider the rural implications of health decisions.

Given that rurality remains an elusive concept, studies that compare the experiences of rural and urban women and men may better extract the influences of rurality and help to explicate the nature of rurality, than studies focused exclusively on rural population.

Shifting the power of research embedded in traditional research programmes to a model in which rural women and health providers collaborate in research efforts that are relevant to their life context, is an avenue that holds promise for the future. Vanderplaat (2002) challenges that “traditional approaches (to knowledge generation) have always relied on the “expert” to identify problems experienced by a population and to recommend the most feasible solutions” (p89). Participatory Action Research (PAR) is a methodology based on emancipatory principles that could be used so the development of initiatives to meet the rural needs would be grounded in the voices of rural people. Questioning the assumptions on which past research and practice has been based may contribute to the development of rural solutions for rural challenges. For instance, given that cardiac rehabilitation programmes have been poorly attended by rural (and urban)

women, the PAR approach could be used to identify, develop and implement programme alternatives that would fit the context of rural women's lives and maximize therapeutic outcomes. The ways in which women demonstrated resourcefulness in their own post-MI lives is instructive in considering ways to meet post-MI needs within the rural context.

There were many indications that issues related to the experience of rural men and children existed and that there may be some overlap in their focus. For instance, there are many instances in rural communities when people of all ages and stages of the lifespan require referral to tertiary urban institutions. Studies that focussed on referral processes and experiences of rural patients, families and practitioners could have relevant and broad applications for those dealing with various medical problems.

The psychological and emotional needs reflected in the stories of rural women were an indication that studies related to mental health could be of benefit to women and health care providers. Probing the underlying forces contributing to mental health issues and challenges for rural women recovering from MI and living with the effects of chronic illness could provide direction in helping communities generate relevant interventions and supports.

#### *Implications for Policy*

Policy decisions about rural health care are driven by the adopted definition of "rural." There is need to examine and question if the current definitions that are used to filter funding requests and resource allocation serve the contextual health needs of rural women. The uniqueness of rural communities may be lost in the political positioning of a region as "rural" and result in further marginalization and establish a hierarchy of rural



communities that does not serve the health needs of its citizens. Policies that are centered on community needs and contexts instead of imposed definitions of rurality may better serve the health needs of rural women. Policy based on research that reflects what rural women and rural people view as “rural” may be different from rural definitions created by experts attempting to quantify characteristics.

Given this research did not provide strong evidence that rurality was the key to understanding the challenges, choices and experiences of rural women post-MI, caution must be exercised in advocating policy change based on these results. However, from the critical perspective, rural health policy must be informed by knowledge generated by those in the margins, in other words the rural women, and it could be argued, their rural health care advocates (Vanderplaat, 2002). There is some concern among rural practitioners that policies focussed on changing the “accepted” current hierarchical models that drive decision-making about referral mechanisms, resource allocation and programme implementation could alter the referral game in such a way as to destroy current “working” patchwork mechanisms and possibly render the rural practitioner impotent in the bartering for service.

If the rural lens is to facilitate the inclusion of rural women in Canadian health policy and system change, there is need to question the mechanism by which women living in rural communities after MI are to be heard. If, as Douglas (1999) advocates, health policy adheres to a consultative “bottom-up” approach, rural women, both patient and practitioner, would be engaged in policy discussions that focussed on protecting the resources rural women valued in their post-MI lives, specifically their rural practitioners and institutions. Health policy and cardiac care delivery models based on the principles

of primary health care and that place rural women's needs and contexts at the center, could shift power to rural communities and foster the development of community post-MI initiatives that are inclusive of expert "insider" and "outsider" knowledge and which could increase the predictability of the rural post-MI patchwork.

#### *Limitations*

This study reflects the experiences of twelve women who had survived MI and lived in a rural area of southwestern Ontario. Although the women who participated in this study were a diverse group, they were volunteers and they may not be representative of rural women who are post-MI. The fact that women in this study also represented a small geographic rural area and that the area was located in "resource rich" southwestern Ontario could limit the applicability of findings to other rural settings. Issues may be different for rural post-MI women who live in areas more distant from urban centers, in depressed economic conditions and/or who are part of unique cultural groups such as the old order Mennonite community that has a presence in rural Ontario.

The fact that no consensus exists about the definition of rural or rurality, it is possible that my rural lens has failed to capture the true nature of rurality in the lives of the women. It is possible that the findings reflect other issues, such as socioeconomic indicators that exist in other environments. Including socioeconomic indicators in designing and interpreting the data could alter and enhance the findings and interpretations.

The study intentionally focussed on rural women, excluded men. There were indications however, that rural men also experienced challenges to post-MI recovery and their inclusion may have resulted in additional and different results. Additionally, it may

be that urban women experience similar issues post-MI and that the effect of rurality has been overstated. It may be there are urban communities which lack the resources of tertiary centers and that similar issues exist to those identified for the rural population.

This study was driven by the assumption rurality, related hidden influences and power imbalances, influenced the lives of rural women who survived MI. The strength of the association between rurality and the four narrative themes generated in the study could not be concluded. It is possible and probable that rurality alone does not explain the themes. The extent to which the themes were related to gender and/or cardiac care issues in addition to their relationship to rurality, further challenges the attribution of findings to strictly rural influences. The themes may also be of relevance to women and men in urban settings and if this is the case, it may be the issues are more related to certain components embedded in a definition of rurality, than they are to rurality as a gestalt. For instance, whenever access to resources is an issue in any population, it is possible that the narrative themes arising from this study, could be relevant. It is also possible that a different study approach, such as PAR, may have resulted in different participants, questions and outcomes.

Although I made intentional, systematic and concerted attempts to understand, apply and reflect on the critical approach taken, I was not prepared for the ethical angst that occurred during some interviews. My therapeutic versus critical response to some women's distress may have resulted in a failure to fully probe underlying issues that could have subsequently influenced my interpretation and findings.

*Epilogue*

My privileged position as researcher, as the instrument for investigation, meant that women's voices were filtered through my interpretive screen and that it was my interpretation of their stories that became the "privileged" version. My intention in this research was to provide a mechanism by which the voice of rural post-MI women could be heard. The fact that similarities were found between their experiences and findings from urban women does not detract from their narratives, nor does it render useless, the quest to include rural women in research. It is of importance that previous understandings can be seen to have relevance for rural women.

Following the conclusion of this study, findings and the rural context within which study participants experienced cardiac care, were reviewed with a Nurse Practitioner who has been hired by a tertiary center to develop a cardiac surgery programme that will service urban and rural areas. As a result of discussions following that review, interest was expressed in collaborating to develop initiatives that would be responsive to and inclusive of, rural women's cardiac needs.

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Appendix A  
Letter of Introduction to Gatekeepers and Informants

R.R. 2  
Ariss, ON  
N0B 1B0

Date: \_\_\_\_\_

Dear \_\_\_\_\_:

I am a doctoral candidate in the Ph.D. programme in Clinical Health Sciences (Nursing) at McMaster University. In my roles as a nurse, nurse educator and graduate nursing student, I have become interested in the health care of people who live in rural communities. Specifically, I am conducting a study to understand the lives of rural women after their heart attack and how living in a rural community influences the choices, challenges and experiences they have. It is hoped that this research will contribute to the limited knowledge base about the health of rural women and may expose issues for rural people in general. It is my intent to make the stories of rural women visible and that the study results will inform professional practice, health policy and health services.

Currently, I am recruiting women to participate in the research process. I am contacting you in the hopes that you might know a rural woman who has survived a heart attack and that you would share this invitation with her. Participants will be required to agree to an interview with me at their convenience. The study has received ethical approval through McMaster University.

**If you know a woman who has had a heart attack and lives in a rural area, please consider passing this information and contact number to her. I have enclosed some cards containing contact information for you to distribute if you choose. If you have questions about the study, please feel free to contact me. I have also included a flyer about the project that you may wish to display in your office.**

Sincerely,

Appendix B

**ARE YOU A WOMAN LIVING  
IN A RURAL COMMUNITY  
WHO HAS HAD A  
HEART ATTACK?**

**I invite you to share that experience with me as part of a research study to help understand the world of rural women after heart attack. For more information about this, please contact me.**

**Patricia Caldwell R.N. M.Sc.**



## Appendix C

### Consent to Participate in Research

STUDY: Lives of Rural Women After Myocardial Infarction: A Critical Ethnography

#### **BACKGROUND:**

As part of her PhD programme at McMaster University, Patricia Caldwell, is conducting a research study about women who have had heart attacks and live in rural communities. The research is under the direction of her supervisor, Dr. Elizabeth Rideout from the School of Nursing at McMaster University in Hamilton Ontario.

#### **PURPOSE OF THE STUDY:**

There is very little known about the lives of women who have had a heart attack and return home to live in rural areas. In order that health care and health policy meets the needs of rural women who have had heart attacks, it is important that we understand the choices, challenges and experiences they face. This study is intended to hear women's stories about how rural living affects their lives after heart attack.

#### **PROCEDURES:**

If I choose to participate in this study I agree to the following:

- 1) One or more interviews with the researcher at a mutually agreed upon date, place and time. The interview(s) will last for approximately one hour each and can be terminated by me at any point. Questions will be asked that relate to my perceptions about rural life, my heart attack and my experience living in a rural community since my heart attack. (For instance, how was my heart attack diagnosed, what choices, decisions and experiences did I have in hospital and upon return home? How did my life change after my heart attack?)
- 2) The interviews will be taped using a tape recorder and transcribed into written format at a later date. All contact information about me and tape and transcripts will be kept secure at all times. A pseudonym will be assigned in the transcripts so that my name or the names of others will not appear. Names of places appearing in the interview will also be changed to maintain anonymity. I will be given a verbal or written summary of the interview(s) as I choose, to check for accuracy. Any request to withhold or destroy information will be honoured by the researcher.
- 3) At any time during the research process, I am free to request information or clarification or decline to answer any question. I understand that I may withdraw from the study at any time and that this decision will be respected. If I choose to withdraw, I can do so verbally or in writing to the researcher at the number or address listed.
- 4) When the study is completed, the study will be available for me to read, or if I choose, a verbal or written summary will be made available to me by the researcher.
- 5) At the completion of the study all tapes will be destroyed.

**RISKS AND BENEFITS:**

This study does not require me to do any physical activity. If physical discomfort occurs at any time during the interview process, the interview will be stopped at my request. It is possible that discussion of my heart attack and the effect it has had on my life may cause me to experience emotions or thoughts that might be uncomfortable. If I do not feel well enough to participate in the interview or to continue in the study, I am free to withdraw at any time.

I understand that there is no financial remuneration for my participation. I understand that the interview process might cause me to ask questions about my situation. It is also possible, that through discussion with the researcher, I may discover new or alternative ways of seeing choices and challenges that I face. In addition, I may see or generate new opportunities for women like me, who live in rural areas and have a heart attack. This may contribute to care given in the future by health care professionals and to the development of policies about rural health care.

**CONCERNS AND QUESTIONS:**

This research has been reviewed and received ethical approval through the McMaster Research Ethics Board (MREB). If I have questions about the research I can call the researcher, Pat Caldwell at any time at 519-846-9759 or in writing at R.R.2 Ariss, On., NOB 1B0. If questions or concerns about my participation arise during this project that cannot be answered to my satisfaction by the researcher, I am free to contact the MREB at

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**CONSENT:**

I have read and understand the contents of this letter. I agree to participate in this study and know that I am free to withdraw at any time with no reprisal. I have been given a copy of this agreement.

**PARTICIPANT NAME (print)** \_\_\_\_\_

**SIGNATURE:** \_\_\_\_\_

**DATE:** \_\_\_\_\_

**PRINCIPAL INVESTIGATOR : Patricia Caldwell**

**SIGNATURE:** \_\_\_\_\_

**DATE:** \_\_\_\_\_

Appendix D

Participant Information Sheet

STUDY TITLE: Lives of Rural Women After Myocardial Infarction: A Critical Ethnography

Principal Investigator: Patricia Caldwell R.N., M.Sc.  
McMaster University

As part of my doctoral programme at McMaster University, I am conducting a study to hear about the lives of women who live in rural Ontario and who have had a heart attack (myocardial infarction) in the past year.

Much of what we currently know about heart attack comes from research on men and on people who are cared for in large cities after their heart attack. Although it is accepted that city and rural life are different, there is very little known about how those differences might affect life after a heart attack.

If health care professionals (including nurses and doctors) are to meet the needs of women who live in rural areas, it is important that we hear and understand your experiences, challenges and choices after heart attack.

As a participant in this study you will meet with the principal investigator on one or more occasions at your convenience, and talk about what life has been like since the heart attack, the choices and challenges you faced and the choices you made. While there is no financial compensation for participating, you might find that in sharing your story, you could find new and positive ways of viewing your abilities and options.

You may choose to withdraw from the study at any time. Results will be shared with you and your contribution to the research will be anonymous.

Thanks for your interest in this study.

Appendix E  
Interview Guide

The following interview questions will serve as a guide in the interview process. Primary questions and secondary probes are outlined for each of the themes. Further questions will be generated based on individual participant responses.

Demographic Information

Age, Time post-MI, Marital status, Number and ages of children, Other health problems, education, Employment status, Place of residence.

History of Heart Attack and In-Hospital Experience

**Describe the experience of having the heart attack, how the diagnosis was made and the experience that unfolded.**

Where did women receive care and what choices or decisions were made related to that?

What formal and informal services, structures and social supports were available? Were there supports and services that were not available or that they wished they had?

Life as a Rural Woman

**How would women describe their lives (in the country, in a small town, on a farm) before heart attack and how has that changed since then.**

How, if at all, do women see themselves in comparison to women who live in urban areas?

What do women perceive as to how being from a rural community has affected choices, experiences and care since the heart attack?

How do women perceive their experience with heart attack to be similar or different from that of rural men?

What are women's perceptions as to why any differences exist?

Life after MI

**What were womens' expectations and the expectations of others after returning home?**

How were they prepared for return home?

What lifestyle changes were women advised to make and how did they go about that?

What people, supports and services were available to make these changes?