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## La vie des femmes rurales après un infarctus du myocarde

## Patricia Caldwell, Heather M. Arthur et Elizabeth Rideout

Cette étude examine les influences de la ruralité sur la vie des femmes qui ont subi un infarctus du myocarde (IM). Utilisant une approche ethnographique critique, les chercheuses ont analysé des entrevues en profondeur réalisées auprès de 12 femmes vivant dans le Sud-Ouest de l'Ontario, au Canada. Ces entrevues visaient à identifier les liens entre l'expérience de ces femmes et les forces sociales, politiques et culturelles associées à la ruralité. L'analyse des données a révélé quatre thèmes : la *réticence*, caractérisée par une tendance à minimiser l'inquiétude et à accepter la vie après un IM; le *jeu d'aiguillage vers d'autres services*, ou les défis associés à l'identification des soins tertiaires; l'*esprit d'initiative* relativement à la gestion de leur propre convalescence; et les *relations*, dans le cadre desquelles les professionnels et les établissements de santé ruraux prennent une grande valeur. Les résultats offrent de l'information pertinente pour les infirmières œuvrant en milieux ruraux et urbains, et au chevet de femmes survivantes d'un IM, tout en jetant une base pour l'élaboration et le maintien de soins post-IM culturellement appropriés.

Mots clés : rural, infarctus du myocarde, femmes

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# Lives of Rural Women After Myocardial Infarction

## Patricia Caldwell, Heather M. Arthur, and Elizabeth Rideout

This study examines the influences of rurality on the lives of women postmyocardial infarction (MI). Using a critical ethnographic approach, the researchers analyze in-depth interviews with 12 women from southwestern Ontario, Canada, for the ways in which their experiences were related to social, political, and cultural forces associated with rurality. Data analysis revealed 4 themes: *reticence*, characterized by a tendency to minimize worry and accept one's life post-MI; *referral games*, or the challenges associated with accessing tertiary care; *resourcefulness* in managing one's recovery; and *relationships*, with rural health professionals and institutions being highly valued. The findings have relevance for nurses in both rural and urban settings who care for women post-MI and form a basis for supporting and building culturally specific post-MI care.

Keywords: rural, myocardial infarction, women, critical ethnography

#### Background

Ischemic heart disease (IHD) is the leading cause of death among Canadian women (Heart and Stroke Foundation of Canada, 1999). Although the numbers of women who experience myocardial infarction (MI) have been on the increase, mortality rates are decreasing (Heart and Stroke Foundation of Canada). These trends have been attributed to, respectively, an increased number of aging women in the population and advances in treatment (Chan & Young, 1999). Should these trends continue as expected, more women will return home to their rural and urban communities to recover after MI.

Knowledge about rural cardiac issues is sparse at best, although recent Canadian data identify the existence of rural-urban differences (Naylor & Slaughter, 1999). Specifically, rural women have been found to have higher age- and gender-specific hospitalization rates for MI than urban women (Chan & Young, 1999). In the Ontario Health Survey, rural women were more likely than urban women to self-report three or more cardiac risk factors (Shin, Jaglal, Slaughter, & Iron, 1999). Evidence suggesting that rural women are at risk for cardiac events continues to mount, yet rural women lack visibility in cardiac-related research.

#### **Rural Culture**

Health research has tended to draw research problems and populations from urban environments, leaving questions about the relevance of the findings for those who live in rural communities. The diversity among rural women precludes generalizations about their lives, yet the commonalities arising from their geographic context arguably distinguish them as a cultural group. According to Van Maanen and Barley (as quoted in Thomas, 1993, p. 12), "culture can be understood as a set of solutions devised by a group of people to meet specific problems posed by situations they face in common." For rural women, these commonalities include threats to the rural way of life, fragmentation of traditional social structures, and dominance of centralized urban systems (Troughton, 1999). The challenge of defining a general rural culture (Ramp, 1999) is further complicated by a lack of consensus on the definition of rural. In this study we use the Organization for Economic Cooperation and Development (OECD) definition, according to which a rural community has a population density of fewer than 150 people per square kilometre (Canadian Rural Information Service, 2002).

With respect to health care, indicators that have been proposed to quantify and capture the essence of rurality include the existence and proximity of a local hospital; proximity of a referral center; access to a family doctor, specialists, diagnostic services, and ambulance services; weather conditions (Kralj, 2000); perception of distances; and willingness to seek care (Porter, 1998). However, despite these efforts to define rurality, a rural person is more than the sum of proposed rural indicators.

#### Literature Review

There is a worldwide tendency to view heart disease as a predominantly male problem. This distorted image is reinforced by the number of studies with all-male populations and the number of studies in which the small numbers of female participants preclude the drawing of firm conclusions about women in general (Beery, 1995). Most cardiac study populations have been recruited from urban centres, and some studies have included only those women who reside within city limits. Similarly, many studies of women's recovery from MI have drawn their samples from those who have accessed resources such as cardiac rehabilitation programs or support groups located in cities, thereby failing to identify issues in the lives of women who lack access to such resources.

A number of issues have been reported in qualitative studies with urban women post-MI. These include early return to domestic tasks and nurturing roles (Boogaard, 1984; Johnson & Morse, 1990; MacKenzie, 1993), stress related to resumption of traditional roles (Helpard & Meagher-Stewart, 1998; Lisk & Grau, 1999), and reluctance to ask for or accept help upon returning home (Benson, Arthur, & Rideout, 1997). In some cases urban women have initiated and developed their own support networks (Helpard & Meagher-Stewart; Jackson et al., 2000) while attending to the well-being of others (Sutherland & Jensen, 2000).

With regard to the experience of rural women, Tobin (1996) reports that women living within a 60-mile radius of a tertiary centre in Newfoundland, Canada, took charge of their own recovery, with little reliance on health professionals, and did not consistently adopt recommended post-MI lifestyle changes. It can be speculated that these findings are related to rurality. No studies were found that specifically focused on rural women's recovery from MI.

#### **Research Questions**

Rural women have been marginalized in studies of post-MI life, and the role played by rurality in shaping women's recovery from MI remains unexplored. The primary question guiding this study was: *How does rurality influence the lives of women after MI*? Secondary questions were: *What does their rural existence mean for women? What recovery and life choices do women have after MI*? What choices do women make after MI, and what do they view as influencing those choices? What formal and informal structures influence women's lives, and in what ways?

#### Methods

The approach chosen for the study was critical ethnography. This approach was chosen so that the researchers could move beyond rural women's descriptions of post-MI events and invite reflection on the influences that gave rise to their collective experiences in order to generate possibilities for change (Thomas, 1993).

Ethical approval was received from the Research Ethics Board of the associated university. Study questions were derived from rurality indicators relating to actual and perceived access, environmental factors, and health-seeking behaviour. The women were viewed as expert "knowers"; hence their perceptions about the physical environment, social norms and relationships, community structures, supports, and practices were probed.

The study was based on a convenience sample drawn from communities in rural southwestern Ontario, Canada. Key informants and gatekeepers were given a letter outlining the research and a poster providing contact information. Recruitment was carried out through word of mouth and distribution of the poster by nurses involved in cardiac teaching programs, rural physicians, and a rural hospital. Potential participants contacted the researchers via a toll-free phone line or gave permission to a key informant for the researchers to contact them.

The primary data-collection technique was in-depth semi-structured interviewing. Of the 12 participants, 11 were interviewed two or three times, each providing up to 4 hours of data. One woman died prior to follow-up; however, her interview was reviewed with her daughter, who had been present during the interview. At the request of the participants, all but one of the interviews took place in their homes. The interviews were audiotaped and transcribed verbatim and then re-read while tapes were being played to ensure that all written words and phrases accurately represented the dialogue (Easton, McComish, & Greenberg, 2000). Detailed fieldnotes were made immediately following the interviews. Sandelowski's (1993) guidance on member checking was adhered to so that any revised comments during the second or third interview became new data to be analyzed. After 12 women were interviewed and no new themes were being identified, recruitment was suspended.

Additional fieldwork approaches included the following: accompanying a participant and her family on a fundraising walk, attending nursedirected post-MI educational sessions at two rural outpatient sites, interviewing rural staff-nurse patient educators caring for post-MI rural women, and holding discussions with two rural physicians. The researchers also reviewed rural newspapers, post-MI educational literature, a letter from a participant, a reflective book written by a rural woman post-MI, and e-mails from rural women with cardiac histories. These additional data sources proved valuable in question formulation and triangulation of data sources (Patton, 1999).

During the interviews the women were initially asked to describe their experiences during and following the heart attack. Questions were formulated to explore links between previously identified rurality concepts and the narratives. Sample questions included: Tell me about the distances you had to travel to get to care following your heart attack. What was that like for you? How do you think that living here affects the care and choices you had/decisions you made after your heart attack? How do you think your experiences might be the same or different from a woman living in the city? Constant attention was paid to the occurrence of "cultural rhetoric" (Thomas, 1993, p. 40), whereby superficial descriptions are offered or data seem contradictory. In such cases, the questions were reformulated and additional data sources employed to examine the issue. For instance, when referral became a repetitive focus, referral processes were investigated during a group patient-education session, interviews with physicians, and follow-up interviews with participants.

## Participants

Women who met the following criteria were eligible to participate in the study: diagnosed with MI, living in a rural community as defined by the OECD, living in southwestern Ontario, able to speak English, and available for one-on-one audiotaped interview(s). All participants were initially cared for in one of four rural hospitals in the study region. At the time of the first interview, six women were in their first year post-MI, four were in their second year, one was 4 years post-MI, and one had been diagnosed recently but the exact time of MI could not be established. The participants ranged in age from 43 to 80 years. Of the five women under 60 years of age, two were on disability pension because of cardiac damage, one had returned to homemaking, and two had returned to work outside the home. Seven women were married or in commonlaw relationships and five were widows. One woman had a university education, five had a high-school education, and six had not completed high school.

## Analysis

Manual line-by-line analysis and coding of the transcribed interviews were conducted and data from other sources were reviewed. Data analysis was guided by a return to the research questions (Becker, 1996; Miles & Huberman, 1994) and by maintaining a critical stance (Thomas, 1993). Initial coding consisted of identifying data chunks from each narrative and additional data sources that related to the pre-identifed rurality concepts. Secondary coding was guided by the critical approach outlined by Thomas: data chunks were scrutinized to determine whether and how the women were influenced or affected by the beliefs, social structures, and/or processes they identified, thus perpetuating the status quo. A list of codes was kept in order to track data. A search for cross-interview, cross-data linkages and negative cases was undertaken to identify narrative themes. As part of an audit trail, continuous self-reflection about the researchers' influence on data and analysis decisions was recorded in a journal, fieldnotes, and memos (Miles & Huberman).

#### Findings

The researchers identified four themes describing the influence of rurality on the choices and challenges that shaped the lives of the 12 post-MI women. These were *reticence*, *referral games*, *resourcefulness*, and *relationships*.

#### Reticence

The women accepted post-MI events and circumstances with few questions. This may have worked to their disadvantage in terms of accessing resources that could have affected their recovery. They were hesitant about being the focus of attention, asking questions, requesting help, and raising issues; they considered themselves fortunate to have survived and to have access to what they viewed as life-saving treatment. Uncomfortable focusing on themselves, the women placed the spotlight on others. They did not expect their lives to be different post-MI:

I think rural women are uncomfortable asking for help, because...rural women are women who are very strong and able to stand on their own... They tend to do everything, and I think after they've had a heart attack...it really affects them... We are supposed to hold everything together. I think they feel inadequate after a heart attack. I know I felt inadequate...for a long time.

A feeling that the context of their lives was not understood in urban treatment centres contributed to a silencing of their voice. One woman who had driven to a rehabilitation facility on the advice of a friend explained why she decided to reject rehabilitative care:

The doctor was saying it's better to exercise, drop everything else, exercise, exercise, exercise, but what this woman [in the class] was 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 to say to our families, "You know what you are all making for your supper for the next month? I am going to do nothing but jog, jog, walk, walk." It didn't take much for me not to go back.

For all participants, living in a rural community meant one had to accept the fact that some services would not be available nearby, and the women and their families were not keen to challenge that reality:

Patients and their families know there are waiting lists and 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 do what they are asked and don't complain.

## **Referral Games**

At some point in their post-MI care, all participants were referred to a service outside their local community. One woman used the phrase "referral game," implying that there were rules, players, and the possibility of winning or losing with regard to accessing a particular service. For the most part, the women were silent players in the referral game. They waited in the local hospital while their physician negotiated their referral to a tertiary centre. They viewed their rural physician as having no choice but to play the referral game, and expressed the belief that the physician viewed this system as flawed but functional. The perception that referral would be more successful if the patient remained in hospital was conveyed by the daughter of the elderly participant who had died:

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." You can get things done if you stay in hospital.

The women were commonly transported to and from the referral centre by family members. They were unclear about how decisions were made regarding the mode of transport to referral appointments. Since many referred services were as far as a  $2\frac{1}{2}$ -hour drive from their homes, the participants found travel to be stressful, especially in the face of poor weather and their fear of another cardiac event. One woman had driven 2 hours for angioplasty, only to discover that

It was a big screw-up. They were supposed to send an ambulance to transfer me there because I had a heart attack but the local hospital said, "No, just get someone to drive you there." So my husband took the day off work and drove me. Then, when I got there, those people jumped all over my hospital because they said I should have been in an ambulance.

Some women were confused as to how the flow of information and follow-up needs were managed between their rural and urban physicians. Some of the variation in practices could be attributed to different practitioners and referral sites, but the process was not transparent and was not always understood by the women or their families.

The participants did not always feel they were being treated respectfully by health-care providers at the referral sites. One woman sensed that she, her husband, and her rural health-care providers were judged negatively at a referral site, which left the couple feeling alone, alienated, and frightened:

They just felt we were country bumpkins. Even my husband...got treated that way. Even 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 she is one of the most knowledgeable nurses you can get.

## Resourcefulness

There were many examples of women turning to themselves as resources to fill gaps created from living in a rural place. They tended to "make do" with what they had and take initiative to problem-solve when faced with challenges. While reticence was manifested in hesitancy to ask, resourcefulness was the option when women were uncertain about what to do, whom to ask, and what to ask for. Some women viewed self-sufficiency as their civic responsibility, both because this would help control healthcare costs and because they did not believe that others could or should meet their needs. Consequently, several women would not ask healthcare professionals for advice they thought could be easily obtained from knowledgeable friends or from television:

I was always taught, from little on, [to] 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 the absence of structured and individualized post-MI exercise programs, the women found their own ways to meet what they deemed to be their exercise needs, including buying and using a home treadmill. Those who had been advised to increase their physical activity found it difficult to incorporate exercise routines into their lives. They approached exercise tentatively and experimented with increasing their activity with minimal or no guidance. For many, walking in rural areas presented logistical challenges in terms of terrain and social support. They feared that if they experienced difficulty or an emergency while walking, they would be unable to get help.

## Relationships

The women valued their relationships with their families, rural health professionals, and institutions. However the value women placed on these relationships also served to limit the demands women would make on them. For many, these linkages were important resources over the months that followed the MI. None felt they would have received better care or would have had a different outcome had they lived in an urban area. On the contrary, they found it reassuring to be close to home and cared for by people who knew them, their families, and/or their communities; this was where they wanted to be when they perceived their lives were in danger.

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... 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...it's different.

Confident that if more care was needed the rural professionals would provide it, the women seldom made requests or complained about their lives. All of the women felt they could see their rural physician or access emergency care in the local hospital whenever necessary. In this sense rurality was viewed as a positive force.

Women who had friends and were connected with neighbours in their rural community pre-MI benefited from these connections post-MI. This was true for both newcomers and those who had lived all or most of their lives in the same location. Three women who were relatively new to their communities did not have local connections pre-MI, and because their cardiac status limited their activity they were unable to establish social contacts post-MI. Like most of the other participants, the newcomers expressed a desire to form long-term relationships with women in similar situations, but did not envision how this could happen in their communities.

#### Discussion

While limited access to specialists, diagnostic services, and referral services, due partly to poor weather conditions, is consistent with proposed rurality indicators (Humphreys, 1998; Kralj, 2000; Leduc, 1997) and rural challenges (Health Canada, 1996), its qualitative impact on women's post-MI lives has not been previously documented. In contrast to the results of other studies (Humphreys; Johnson, Weinert, & Richardson, 1998; Kralj; Schreffler, 1996; Weinert & Boik, 1995), the participants in this study did not identify physical distance from their local hospital or physician as problematic in terms of emergency or follow-up care; consistent with the findings reported by Pierce (2001), they viewed distance as an unalterable fact of rural life.

In the post-hospital phase, rurality limited the participants' referral to, awareness of, and access to full cardiac rehabilitation. Low referral rates to and participation in cardiac rehabilitation have been reported for rural women and men (King, Humen, Smith, Phan, & Teo, 2001), yet accumulated evidence supports structured exercise rehabilitation (Jolliffe, Rees, Thompson, Oldridge, & Ebrahim, 2003). Therefore, rural women appear to be at a disadvantage compared to their urban counterparts, in spite of their resourcefulness. Women's self-reliance and resourcefulness in managing their post-MI recovery has been noted previously (Fleury, Kimbrell, & Kruszewski, 1995; Helpard & Meagher-Stewart, 1998; Jackson et al., 2000; Sutherland & Jensen, 2000; Tobin, 1996) and are consistent with rural women's particular tendency towards self-reliance (Bushy, 1993; Viens, 1997). Although self-care is frequently advocated by health professionals, its promotion in rural settings, where services are scarce, may serve to limit wellness potential and ease the demand for rehabilitation services, thus protecting an under-resourced system and leaving the status quo unchallenged, with rural women the grateful

recipients of services from a centralized but patchwork health system.

The participants' resumption of their traditional nurturing and domestic roles is consistent with the findings of previous studies (Benson et al., 1997; MacKenzie, 1993; Sutherland & Jensen, 2000). However, it was fuelled by a sense of being fortunate to have survived MI, to have access to rural health care, and to have access to any form of tertiary care. This gratitude served to create a culture of reticence, with the women choosing not to challenge a system they viewed as having saved their lives and not to place increased demands on that system. This reticence is consistent with the reported tendency of rural women to keep their worries to themselves (Health Canada, 1996;Viens, 1997) and may be a feature of traditional androcentric rural cultures that leave women with little formal authority or voice (Bushy, 1993; Health Canada). Inherent in such behaviour is an inability to recognize or articulate issues that impact on one's recovery, or to envision alternatives, and thus the danger that the women will leave it to others to set the terms for their recovery.

To varying degrees, the interviews became a process of "conscientization" (Freire, 1970), as the women began to examine their relationships and their options and to ask questions about their recovery, the availability of resources, and the needs of women like themselves. All of the women viewed their participation in the study as a means of effecting change. For this process to continue, rural women must be informed of the evidence on which best practices are founded. This knowledge would promote their self-advocacy and, from the bottom up, support their valued rural health institutions in developing more equitable and transparent post-MI processes and supports. Rural issues will not be considered within provincial health systems, which are subject to the competing interests of urban populations and lobby groups, unless policy-makers and professional leaders include rural women in the creation, evaluation, and reshaping of policies and practices relating to post-MI care.

The promotion of rural nursing practice, and specifically clinical leadership in rural nursing (MacLeod, 1999), can serve to educate players in the health system in culturally sensitive cardiac care. Possible avenues for clinical leaders to consider when addressing women's post-MI needs include collaborative efforts to establish patient- and family-centred protocols and policies regarding transportation to referral sites, informationsharing paths between rural health-care providers and referral sources, monitoring of women once they return home to their communities, and links with cardiac rehabilitation programs. The development of professional networks of rural nurses for the identification, promotion, and support of best practices for post-MI care could help nurses advocate for change and increase the visibility of MI as an issue among rural women. Research to develop cardiac rehabilitation specifically for the rural context and research focused on tailoring the referral process to the needs of rural women and their families would further support cardiac care in rural communities.

## Limitations

Given the diversity of rural regions and the adoption of the OECD definition of rural, the extent to which the present findings can be generalized to other rural women is unknown. This study drew from a diverse sample of rural women. There are indications that rural men also experience challenges to recovery from MI, and their inclusion in future studies may help to increase our knowledge about rural cardiac care. Because rurality remains an elusive concept, it is also possible that the present findings are a function of gender versus rurality, or some combination of the two factors. Clarity with regard to gender and rurality influences may be enhanced if future studies were to compare the experiences, challenges, and choices of rural and urban women and men following MI.

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