

Women and Heart Disease: The Treatment May End But the Suffering Continues

**Heather M. Arthur, Donna M. Wright,
and Kelly M. Smith**

Bien que le principal problème de santé qui touche les femmes soit les maladies du cœur, la majorité des patients inscrits dans les programmes de réadaptation cardiologique axés sur la prévention secondaire sont des hommes. Les recherches indiquent que les programmes de réadaptation classiques ne satisfont pas les besoins des femmes convalescentes suite à un accident cardiaque. Chez celles-ci, le besoin le plus fondamental sur le plan de la réadaptation pourrait être le besoin de soutien, en particulier celui de femmes ayant vécu une expérience semblable; ce besoin peut en outre persister au-delà de la période de récupération à l'hôpital. Le projet avait pour but de concevoir et de mettre en œuvre, en milieu communautaire, un groupe de soutien à l'intention des femmes atteintes de maladie du cœur, qui serait axé sur la communication et fondé sur une approche psychopédagogique. On a choisi la recherche-action comme méthodologie. On a organisé deux groupes de femmes ($n = 16$), qui se sont réunis une fois par mois pendant une période de cinq mois. Les rencontres étaient animées par une infirmière clinicienne et une infirmière chercheuse. On a demandé aux participantes de tenir un journal intime entre les réunions. Les données de recherche comprenaient des bandes vidéo et des transcriptions des rencontres, des observations sur le terrain, les journaux tenus par les participantes et une évaluation finale. Une première analyse indique que les participantes ont apprécié l'expérience sous trois angles : les rencontres les ont aidé à analyser leurs émotions, à se sentir soutenues par l'entourage et à faire face à leur problème de santé. Une analyse itérative a mis en lumière un méta-paradigme compatible avec le concept de la souffrance. Dans l'ensemble, le bienfait que semblent procurer les groupes de soutien de ce type réside dans la reconnaissance et le partage de l'expérience de la souffrance, un aspect qui n'est pas toujours présent dans les autres sphères de la vie des femmes atteintes de maladie du cœur.

Though heart disease is the number one health problem among women, men continue to represent the majority of those in cardiac rehabilitation for secondary prevention. Research has shown that conventional rehabilitation programs do not meet the needs of women recovering from cardiac events. Women's primary rehabilitative need may be support, particularly from women with similar experiences. Furthermore, the need for

Heather M. Arthur, RN, PhD, is Career Scientist and Associate Professor, School of Nursing, Faculty of Health Sciences, McMaster University, Hamilton, Ontario, Canada. Donna M. Wright, BHScN, is Regional Cardiac Care Coordinator, Cardiac Care Network of Ontario, Hamilton Health Sciences-General Site. Kelly M. Smith, MSc, is Research Associate, CADENCE Research Group, Hamilton Health Sciences-General Site.

support in living with heart disease may persist beyond the in-hospital phase of recovery. The purpose of this study was to develop and implement a community-based communication and psycho-educational support group for women with heart disease. Participatory action research was the methodology selected. Two groups of women ($n = 16$) met monthly for 5 months to develop the program. Sessions were facilitated jointly by a nurse clinician and a nurse-researcher. Between sessions, participants kept diaries of their experiences. Data consisted of videotapes and transcriptions of the sessions, field notes, and the women's diaries and final evaluation. Initial analysis revealed that the value of the group for the women was threefold: it helped them to cope with their emotional reactions, offered social support, and helped them to manage their health problem. Iterative analysis unveiled a meta-paradigm consistent with the concept of suffering. The apparent overall benefit of a community-based psycho-educational support group for women with heart disease is acknowledgement and sharing of suffering, something that cannot readily occur in women's other life arenas.

Background

Contrary to the conventional belief that heart disease is a serious health concern primarily for middle-aged men, coronary heart disease (CHD) is the leading cause of death for women in Canada, accounting for 41% of all female deaths annually (Heart and Stroke Foundation of Canada, 1995), and carries a worse prognosis for women than for men (Mielahn, Becker, & Carrao, 1995; Wenger, Speroff, & Packard, 1993). Until recently, heart disease research focused on men. Emerging evidence suggests that heart disease has serious physical, psychological, and social ramifications for women and that these ramifications are different from those for men. Upon examining gender-sensitive issues, some investigators have found that women's quality of life is significantly lower than men's after a cardiac event and that women report more psychosomatic symptoms and sleep disturbances (Brezinka & Kittel, 1995; Hamilton & Siedman, 1993).

With respect to rehabilitation in heart disease, there is little evidence beyond women's below-average enrolment in rehabilitation programs and above-average dropout rates (O'Callaghan et al., 1984; Thomas et al., 1996). Conventional rehabilitation goals do not often reflect goals for the female heart patient, and rehabilitation environments tend to be unappealing and inaccessible to women (Moore & Kramer, 1996). Recent work by Benson, Arthur, and Rideout (1997) and by Thomas et al. suggests that women's primary rehabilitative need may be that of support, particularly from women with the same experience. Researchers have cited social support as an important factor in recovery from CHD, for both women and men, with respect to survival and morbidity (Williams et al., 1992). In a 9-year follow-up of the Alameda County Study, Wingard and Cohn (1987) found that women

who lacked social support had a higher risk of fatal CHD after adjustment for other coronary risk factors. Powell, Shaker, and Jones (1993) found that divorced women were most at risk of dying following a myocardial infarction (MI).

A limitation of much of the available research is that women have not been asked about the nature of their experiences. The instrumental work of Boogard (1984) and of Johnson and Morse (1990) illuminates the uniqueness of women's experience with cardiac illness. For example, women's recovery and rehabilitation seem to be heavily influenced by what Hawthorne (1993) calls an "otherness" orientation, referring to the tendency of women (whether healthy or ill) to put the needs of others before their own. In general, findings indicate that women tend to resume household activities immediately upon discharge from hospital and do not perceive these activities to be work or harmful to their health. As well, women report difficulty accepting help from others and are inclined to experience guilt when family members help with household tasks (Benson et al., 1997; Johnson & Morse; Lisk & Grau, 1999). Finally, women are more likely to make lifestyle changes independently, taking care not to disturb the family routine. The findings of Benson et al. and of Lisk and Grau corroborate earlier findings related to women's rehabilitation issues, which suggests that little progress has been made in the past 10 years with respect to helping women to live with heart disease after the acute, in-hospital phase.

At present, there are no known community-based programs for women living with heart disease in the province of Ontario, Canada. Therefore, the focus of this study was issues related to community-based assistance for women with heart disease, as an adjunct to existing institution-based cardiac rehabilitation services. Two key areas were targeted: psychosocial factors associated with women living with heart disease; and women's special needs with respect to community-based, long-term recovery and rehabilitation. A potentially useful model of rehabilitation for women would include psycho-educational support groups; provision of such groups in the community would enhance women's accessibility to the resources required for living with heart disease beyond the acute phase.

Purpose and Sample

The purpose of the study was to develop and implement a community-based communication and psycho-educational support group for women living with heart disease.

Twenty was determined to be the ideal number of participants, based on two factors: previous experience with the number of women required for data saturation (Benson et al., 1997), and the 1-year term stipulated by the funding agency.

Women were eligible to participate if they met the following criteria: had experienced MI, coronary artery bypass graft surgery (CABGS), or percutaneous transluminal coronary angioplasty (PTCA) within the previous 6 months or angina during the previous year; had made a commitment to participate in the group process; reported no physical or mental health disabilities that would preclude participation; were able to speak, read, and understand English; and provided written informed consent. The criterion of within 6 months post-MI or -CABGS was based on evidence suggesting that the first 6 months is a period of transition and adaptation, after which time a patient's needs change (MacKenzie, 1993; Young & Kahana, 1993), and also on the likelihood that the need for community-based support is at its peak in the first weeks and months after such an event, and thus a prototype for assisting women to resume their lives would be most useful during this period.

Prior to commencement of the study, the research protocol underwent ethics review by the joint hospital-university Research Ethics Board and was approved.

Method

Participatory action research was selected as the most appropriate design for this study. This method involves the systematic collection and analysis of information to be used in developing a plan of action. Smits (1997) describes action research as "the process of attending to experience, open(ing) up possibilities for conducting practice more thoughtfully" (p. 291).

With this design, community representatives from the target group are key players. Participants not only share their subjective views on the specific issues being examined but actually generate those issues. Further, they contribute to the decision process surrounding interpretation and utilization of the data. In this study, the participants co-designed the program that they thought would be of most benefit to other women living with heart disease, through a process of discussion, deliberation, and evaluation.

Potential participants were identified daily from hospital admission lists of patients who had experienced MI, CABGS, PTCA, or angina.

These women were approached by a research assistant, either in hospital (the Hamilton Health Sciences hospital) or within 6 weeks of discharge. They were provided a detailed description of the study as well as an opportunity to pose questions. The women who agreed to participate provided written informed consent.

As the women consented to take part, they were given the names of other women enrolled in the study and were asked to phone and introduce themselves, as a means of developing a communications network outside of the planned group sessions. Once 10 women had agreed to participate, the first group session was convened. After an additional 10 women had agreed, the second group session was convened. The groups met in a church, the selection of which was based on maximum accessibility from the participants' homes; the meeting location was carefully chosen based on literature suggesting that access issues account for a significant proportion of women's non-participation in rehabilitation programs after a cardiac event (Moore & Kramer, 1996).

The two groups met monthly in 2-hour sessions for 5 months to develop the program. The sessions were facilitated jointly by a nurse clinician with expertise in cardiac disease and women's issues (DMW) and a nurse-researcher with expertise in group process and women and heart disease (HMA). A research assistant (KMS) videotaped the group sessions and made field notes during all meetings.

At the first session, issues related to group process and confidentiality were discussed. The research goals were presented for discussion and the objectives of each participant elicited. The purpose of the telephone network was described. The participants were reminded that the telephone network was a suggestion only and that their evaluation of its usefulness was critical. Each woman was given a diary, pen, and folder. She was asked to write in the diary after or between sessions, describing her experiences living with heart disease both within and outside of the group. The diary had both a therapeutic and an evaluative purpose. The women were constantly reminded of the participatory nature of their role in developing the program. Comments such as "please tell us what women with heart disease need from a group like this" or "tell us what we should consider in planning a group for women with heart disease" were repeated frequently throughout the five sessions.

During the first session, the women spent a significant amount of time getting to know each other and describing their particular cardiac event. They were then encouraged to identify any issues they felt

needed to be addressed in subsequent sessions. Consensus was used to choose the focus for session two. This process of consensus-driven issue identification continued throughout the course of the five monthly meetings.

Between sessions, the two primary investigators (DMW and HMA) independently reviewed and analyzed transcripts of the videotapes and the videotapes themselves, then discussed their interpretations and reached consensus on the main themes. A typewritten summary of their interpretations was distributed at the next session. The first part of sessions two through five was dedicated to a review of the summary, thus providing the women an opportunity to accept, reject, or refine the investigators' interpretations; they made corrections as necessary, but these were minor and infrequent, with no substantive changes around the main themes. Utilization of the telephone network and the diaries was also discussed at the start of each session. The final session was dedicated to overall evaluation.

Analysis

The two primary investigators reviewed the videotape and transcript of each session independently and made interpretive notes. Statement-by-statement analysis was used to find exemplars of thick descriptions in the women's accounts of living with heart disease. Based on these exemplars, the researchers attempted to interpret the observed and described experiences as well as the meanings they conveyed. A combination of analytical approaches was used (Streubert & Rinaldi Carpenter, 1995). The constant comparison method was selected for the simple processing of data. According to Jenks (1995), when used in naturalistic inquiry, constant comparison is performed not to generate theory but to develop formulations applicable only to the study being conducted. The second method of analysis used, reflexive critique, is particularly suited to action research in that it includes analysis of the written and spoken language of both participants and researchers. Reflexivity in the context of participatory action research refers to the "belief that the language individuals use to describe an experience reflects the experience being described and also all other experiences in the individual's life" (Jenks, p. 258). The text was not semantically coded or themed, based on the assumption that understandings may deserve recognition or exploration even if they occur in a single instance (Gadamer, 1960/1989). Prior to making their interpretations known to the participants, the investigators agreed that their emerging understandings were substantiated by the data. Typewritten summaries

were distributed to the participants as described in the preceding section. Primary categories were generated from the text, first within each session and finally across all sessions and groups.

Results

A total of 43 women were approached over a 3-month period and 20 consented to participate. Two groups of 10 women each were formed. One person dropped out of group 1 and three dropped out of group 2. Reasons for dropping out were: health concerns and family constraints ($n = 1$), moving in with daughter/situation changed ($n = 1$), no longer physically mobile ($n = 1$), and complications due to recurrent angina and congestive heart failure ($n = 1$).

Ultimately, group 1 comprised nine women: three had undergone CABGS and five PTCA, one had angina; group 2 comprised seven women: three had undergone CABGS and two PTCA, two had had MI.

The 16 participants ranged in age from 46 to 76 years ($mean = 59.4$ years); 11 were married, four were widowed, and one was separated from her husband. Eight of the women were retired from work outside the home, two were working full-time, five were on sick leave from their jobs, and one was a career homemaker.

Interestingly, though the two groups met separately and had no contact with each other, the topics they chose for the group sessions were essentially identical. The first issue that both groups identified and wanted to focus on was the stress of living with heart disease and associated family pressures, in particular the need to find a way of coping with emotional reactions as opposed to the logistics of everyday living. The second issue that emerged from both groups was the need for support and information related to heart disease, medical management, and communicating with physicians. Although the women selected these specific topics for discussion, the overriding theme identified in the data was that their expression of suffering was facilitated by both the relationships among the women and the relationship between the women and the nurse-facilitators.

Care as Recognition of Suffering

Arthur Frank (1991) describes suffering primarily in terms of loss and isolation. From the physical losses that accompany illness to the emotional isolation that results from the illness, suffering the pain of loss and isolation is an integral part of any disease process.

The participants said they felt alone, vulnerable, and confused. They revealed that they suppressed their feelings and emotions both within the family and with friends. One woman stated that the group was "one way of expressing your feelings where your family may not understand. I feel that these group meetings give you better insight on life with heart disease and how to cope with it." Another said, "It's important to talk to people who share your problem. Family and friends seem to want to protect you."

Some women described the recovery period as "terrible," "you are fighting your battle alone," and termed the isolation as "destructive." Frank (1991) describes this suffering in the following way: "The loss that accompanies illness begins in the body then moves out until it adversely affects the relationships connecting that body with others" (p. 36).

The participants expressed the need to talk about their feelings and share their experiences. It helped to relieve anxiety and to bring suppressed emotion to the surface, and it provided insight into lives that had been changed by heart disease:

Talking helps with stress. It's much easier to talk about our problems with those who have similar problems. I thought support groups showed weakness. I now believe it's a place to find strength.

It was nice to have a place to go to share common feelings — somewhere that just dealt with issues common to women. I felt close to the women even though we only met once a month. I felt like I belonged. I also felt genuine concern from people who were really strangers when this all began.

Although I thought I had handled this event well, I discovered through the group that I had suppressed my emotions. After my first group meeting I noticed, with each meeting, more and more emotions coming to the fore and a need to talk about it.

It is Frank's (1991) view that losses must be mourned, and mourned in an appropriate environment. For women, the home and family environment may not be the ideal setting to gain the support required to mourn losses.

Frank (1991) also describes the emotional work of "keeping up appearances." The ill are not praised for expressing their fear or grief. At home they must appear to be engaged in the normal family routine. For women, this may mean focusing on the needs of other family members. In order to maintain family function and prevent further losses to self, they may need to resume the "otherness" orientation of their role in the family post-event.

"Keeping up appearances" seemed to be a part of the women's relationship with their physician as well. They reported being given almost no opportunity to express their suffering to their physician, generally being encouraged to "put the heart problem behind you and move on." Because of discussions with their physician, the women interpreted heart attacks, CABGS, and angioplasties as static events — "blips" in one's life path or brief interruptions in normal functioning. If, as suggested by Frank (1991), losses must be mourned, women appear to have few opportunities to openly and comfortably mourn their experiences with heart disease.

The participants told us that family members were less likely than their support-group peers to understand their expressed feelings. They sensed that family and friends were inclined more to protect than to acknowledge and share feelings. They told us that they would be reluctant to share not only their fears and their feelings, but also the thoughts written in their journals, on the assumption that family and friends would not want to know of their pain. Frank (1991) suggests that there is a deliberate weighing of the need for support against the potential for receiving it: before taking any action, persons who are suffering make the most conservative estimate of the support they are likely to get; thus in everyday life there may be many consciously chosen missed opportunities for revealing suffering and receiving support.

The participants indicated that they understood the feelings expressed by other members of the group and felt both supported and supportive. One woman stated, "I heard other ladies' problems and felt great concern. This caring sends a message that they are being heard and understood." Another said, "I have felt the support of other women. You can make a comment and not be criticized." In this caring environment, group members felt heard, understood, supported, and strengthened. Frank's (1991) contention that human suffering becomes bearable when it is shared was substantiated by the findings of this study.

The role of the expert facilitators appeared to be an essential element in the promotion of caring and revelation of suffering. Though the researchers had envisioned each group becoming self-sustaining, the participants said they could not foresee a time when it would function without the facilitators. Apparently the facilitators were not only a resource for information about heart disease, but also a comforting and understanding presence concerning women's issues.

Tapp (2000) explains that although health professionals have knowledge, information, and ideas to impart, at times it may be best to resist the expectation that we propose solutions or interventions and, instead, invite patients to reflect upon their own explanations, possibilities, and preferences with respect to decisions about their lives. "The nurse can choose to offer advice, but can do so in a manner that might enable the recipient to choose whether they want to accept the advice" (Tapp, p. 86). In the present study, the facilitators communicated their ease with and acceptance of the women's overt demonstrations of suffering, without rushing them forward to an adaptation stage. As Tapp suggests, we explicitly acknowledged that we did not have their particular firsthand experience of illness and suffering, and that their choices were legitimate and worthy of our respect. Thus, although the women may have identified problems in their relationships (e.g., marital strain) or difficulty in making lifestyle changes (e.g., with diet and exercise), ultimately it was accepted that they had to decide for themselves the best way to proceed. This relational stance, we think, was critical to the reported benefits of the support groups.

Finally, the participants had mixed feelings about the telephone network. Though they appreciated the concept, they found it difficult to use in practice. They described impediments to calling other women such as a reluctance "to interfere with people's personal lives" and "not knowing when it would be a good time for others." They also described the act of phoning another woman as "selfish" and "needy." These descriptions reinforce Frank's theories about "keeping up appearances" and weighing the need for support against the potential for receiving it.

Limitations

As noted, 43 women were approached and 20 agreed to participate. It is possible that those who chose not to participate did not require this type of group support and that the needs of some women living with heart disease are adequately met by standard programs.

In addition, the findings of participatory action research are not generalizable beyond the study situation. The main result of action research is the production of practical knowledge, which can be used to improve a system or change a pattern of practice in a given situation.

Summary

The participants in this study identified a current deficit in both institutional and community-based health care (including care provided by

family physicians), in terms of dealing with women's issues around living with heart disease. They also indicated that their recovery needs might be better addressed in a setting that emphasizes information-seeking, sharing, and mutual support. Though they demonstrated strong support for typical institution-based cardiac rehabilitation programs that focus on exercise and education related to CHD risk factors, the women expressed a belief that such programs do not meet the emotional and coping needs of women with heart disease over the long term. Cardiac rehabilitation programs are typically 4 to 6 months in duration. This study found that women living with heart disease may have issues that take longer than 6 months to resolve. While all but one of the participants had their cardiac events in the previous 6 months, they were still attempting to cope with the sequelae well beyond 6 months, given that from the time of consent to the time of completion of research an additional 6 months had passed. As well, the issues for these female participants were different from those reported in the literature for men. This in itself is not a new finding. However, the "otherness" orientation (Hawthorne, 1993) that has been described as responsible for the uniqueness of women's recovery may in fact be related to women's inability to deal openly with their suffering within the family.

An ongoing community-based support group for women with heart disease, in which understanding these issues is part of the experience of all members, may enhance coping due to the sense of caring that results from shared suffering.

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Authors' Note

Correspondence may be directed to: Dr. Heather Arthur, Faculty of Health Sciences, School of Nursing, McMaster University, 1200 Main Street West, HSC-2J29, Hamilton ON L8N 3Z5 Canada. Telephone: 905-525-9140, ext. 22404. Fax: 905-570-0667.