ABSTRACT

Purpose: To identify experiences and needs of women with coronary artery disease.

Methods: Qualitative research utilizing focus groups and grounded theory. Women were recruited from the University of Ottawa Heart Institute Alumni, a group of former Heart Institute patients, and from the Heart Institute cardiac rehabilitation program.

Findings: All women had difficulties recognizing their symptoms as heart disease and 35% reported they were initially misdiagnosed. In the post-diagnosis period, the experiences of older and younger women differed. For women over 60, maintaining their functional capacity, memory problems and a focus on resiliency were the main issues. For women under 60, emotionally focussed concerns were predominant. Both groups had to contend with over-protective family members.

Conclusions: These findings could contribute to the development of more effective public education campaigns. They also highlight the need for programs and research in the area of women's heart health and rehabilitation that address emotional aspects of the illness.

ABRÉGÉ

Objectif : Recenser l'expérience et les besoins des femmes souffrant de coronaropathie.

Méthodes : Recherche qualitative faisant appel à des groupes types et à la théorie empirique. Les femmes ont été recrutées parmi les anciennes patientes de l'Institut de cardiologie de l'université d'Ottawa et parmi les participantes au programme de réadaptation cardiaque de l'Institut de cardiologie.

Résultats : Toutes les femmes ont eu des difficultés à associer leurs symptômes avec une maladie du coeur; et 35 % ont indiqué qu'au départ, elles n'avaient pas reçu le bon diagnostic. Après le diagnostic, les femmes âgées n'ont pas ressenti les mêmes effets que les plus jeunes. Les femmes de 60 ans et plus qui sont restées actives se sont principalement plaintes de problèmes de mémoire et d'une préoccupation relativement à la récupération alors que les moins de 60 ans ont surtout signalé des préoccupations d'ordre émotionnel. Les deux groupes ont eu à faire face à des membres de la famille qui voulaient trop les protéger.

Conclusions : Ces conclusions permettront de mettre sur pied des campagnes d'éducation plus efficaces. Elles soulignent également la nécessité de lancer des programmes et des recherches dans le domaine de la santé et de la réadaptation cardiaque qui tiennent compte des aspects émotifs de la maladie chez les femmes.

The Experiences of Women With Heart Disease: What Are Their Needs?

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Only recently has it been appreciated that the number one cause of death in women is heart disease.¹ This fact is spurring health care professionals to take a whole new look at research and health care delivery in the area of heart disease, as the focus in the past has been almost entirely on men.

It has become clear that there are important gender differences in the diagnosis, treatment and outcomes of heart disease. Women delay seeking treatment for their symptoms of coronary artery disease longer than men.² Diagnosis of a myocardial infarction is more difficult in women than men as they are more likely to present without chest pain,³ have less pronounced cardiac enzyme increases and have lowered electrocardiogram sensitivity and specificity rates.⁴ Women tend to be older than men, and have more concurrent medical conditions when coronary artery disease is first diagnosed.⁵ This may explain, in part, why women are less likely than men to be referred for coronary angiography, angioplasty and coronary artery bypass surgery⁶ and when they do undergo these procedures, have a poorer outcome.⁷ Women are less likely than men to be referred to cardiac rehabilitation⁸ and when they are referred, are less likely to complete the program.⁹

What is less well-known is how women experience their heart disease. This is useful to know as it can reveal women's satis-

faction with the health care they have received and identify needs that have arisen for them as a result of their heart disease. Qualitative research is particularly well-suited to address this type of research question as it helps to identify attitudes, beliefs and experiences.¹⁰ Some qualitative research has already been done in this area. Dempsey et al.¹¹ for example, did in-depth interviews with women in the coronary care unit to better understand why women delay seeking care when they begin to have cardiac symptoms. They found women rarely attributed their symptoms initially to heart disease, they had concerns about not wanting to bother family members, or not being able to keep commitments to others, and they tended to resort to self-care strategies first. Fleury et al.¹² conducted a content analysis of a support group for women recovering from an acute cardiac event. She identified how women's struggle with the uncertainty engendered by their heart disease became an incentive for creating new and positive health patterns. Unfortunately, the study did not examine the effectiveness of the support group itself, or women's satisfaction with it.

We conducted two focus groups of women with coronary artery disease. The objectives of this study were to identify some of the common experiences and needs of women with coronary artery disease and to identify the program implications of these findings.

METHODS

This study took place at the University of Ottawa Heart Institute, a tertiary care centre offering comprehensive services for the prevention, treatment and rehabilitation of heart disease; over 1,000 coronary

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TABLE I
Experiences of Older and Younger Women with Heart Disease and Health Care Implications

Experiences	60 and Over	Under 60	Implications
Pre-diagnosis	Non-recognition of cardiac symptoms	Non-recognition of cardiac symptoms	1. More public information campaigns 2. Continuing education for health care professionals
In-hospital	Surprise and confusion	Surprise and confusion	1. In-hospital peer support program
	Informally spoke with other women who had heart disease	Wanted to speak with other women who had heart disease	2. More research on women with heart disease
Recovery period	Focus on problem-solving	Focus on anger	1. Ongoing support group for women with heart disease 2. Family support (or education) programs 3. More flexible Homecare programs
	Concern with instrumental activities of daily living	Memory and sleep difficulties	
	Memory and sleep difficulties	Overprotective family	
	Overprotective family	Work problems	

artery bypass grafts (CABG), for example, are performed each year.

Two focus groups of 8-10 women were organized; one for those 60 and older, and the other for those under 60. The rationale for the age distinction was that it seemed the issues for women in these age groups would be different. Women 60 and over were more likely to have co-morbidity, husbands who were retired and adult children. Women under 60 were more likely to be working,¹³ have working husbands and might still have children living at home. The focus group for the older women was organized during the day; for the younger group, in the evening.

Sampling

All women with coronary artery disease (angina, post-MI or revascularization procedure) known to the Heart Institute and who were within two years of their most recent cardiac event, were eligible to join the study. Other inclusion criteria were competency in English, ability to arrange transportation to and from the Institute, and an ability and willingness to give free and informed consent to participate in the study.

Both women who had, and had not, undergone cardiac rehabilitation were invited to join the study. A list of women who had undergone cardiac rehabilitation was obtained and in order to get a broad cross-section of views, a semi-random sample of every second to third person on the list was telephoned and invited to join the study. Women from the Ottawa-Carleton

region who had not undergone cardiac rehabilitation were identified from a list of Heart Institute "alumni" (previous patients) and they were also telephoned and invited. In both cases, the invitations ceased after 10 women were found for each focus group.

Information collection

A conceptual framework was determined beforehand that identified areas to cover in the focus groups. This included the identification of experiences, feelings and needs of women with heart disease post-diagnosis, in hospital, on the waiting list for bypass surgery (if applicable) and post-discharge. This conceptual framework was used to generate questions to guide the focus group. Women's suggestions regarding program implications from any of these areas were also noted.

One author (JM) led the focus groups. An overview of the project was given and written consent was obtained from each participant. Each participant introduced herself on a first-name basis and confidentiality of the proceedings of the group was agreed upon. The topics were covered in an open-ended manner. The only direction that was given was to keep the discussion focussed on the women's experiences, feelings and needs regarding their heart disease as well as any program implications. One author (PO) took notes during the focus groups and another (PH) observed. Direct quotes and verbatim comments were recorded for both groups.

Analysis

Grounded theory was the basis for analysis. This involves the development of a theoretical model based on a comparative analysis of a social situation (like a focus group).¹⁴ To do this, topics of discussion from the groups were noted in each cell of the conceptual framework and any other area discussed was also noted. A content analysis was then conducted whereby the findings were analyzed in an inductive, iterative and interactive manner.¹⁴ Specifically themes were identified and dependability was ensured by checking each theme for redundancy in the notes of the focus groups.¹⁵ The credibility (or internal validity) of the data was established by concordance in category development and looking for exceptions in the focus group transcriptions.¹⁵ The findings were then verified by random checks with some of the participants. The conceptual framework was the basis for the format of Table I. The analysis filled in the cells of the Table.

The project received Research Ethics Board approval.

FINDINGS

Sixty and over

To form the group of older women, 30 telephone calls were made; 22 people were contacted, 11 agreed to participate and 8 actually did so. Reasons given for non-participation included "not well enough", "not a convenient time" and "not comfortable in groups."

TABLE II
Characteristics of Older and Younger Women with
Heart Disease Participating in the Focus Groups

Characteristic	60 and Over 68-80	Under 60 38-59
Age (range)	68-80	38-59
Angina	2 (25%)	4 (88.8%)
Myocardial Infarction	2 (25%)	4 (88.8%)
Bypass Surgery	4 (50%)	1 (11.1%)

The women ranged in age from 68 to 80. They were all white and middle class, and all lived independently in the Ottawa area. Most were married, one had a dependent husband (with Parkinson's disease), two were widowed. Most had concurrent medical conditions, such as arthritis and hypertension. Most of the women had had recent cardiac events (Table II), and half of them had undergone bypass surgery in the previous year. Three of the women were in the rehabilitation program, one was just about to begin and four had not participated in cardiac rehabilitation.

Pre-Diagnosis

In response to the question "What has your experience with heart disease been like?", most women initially emphasized the difficulty they had had in recognizing their symptoms as heart disease. One woman said: "I didn't recognize the symptoms; I expected the pain to be in my heart, not my jaws." They also noted that physicians had difficulty recognizing their heart disease as well: "I was treated for an ulcer for 7 weeks, then admitted to hospital and had emergency [bypass] surgery." They felt there was a need for more education about the signs and symptoms of heart disease in women. They expressed concern about how this problem with symptom recognition would affect younger women.

Diagnosis/In Hospital

At diagnosis almost all women recounted feelings of surprise, confusion and concern. "I was surprised I had heart disease; I'd done everything right, followed my husband's diet..." They were surprised to find that so many women were affected by heart disease. They recounted how the education classes in hospital helped to address their feelings of confusion and how they enjoyed speaking with the other women at the classes. Overall they focussed

more on the difficulty they had in getting the diagnosis than on their hospital experience.

Those who were put on the waiting list for surgery found this an extremely difficult time. "I felt my life was on hold." "I didn't go to Florida, stopped gardening, was afraid of making things worse." "I can't make any plans."

Recovery Period

In the post-event recovery period following hospitalization, many older women experienced memory problems. "I can't remember names; the names of streets and of places." A number of women also experienced changes in their sleep patterns: "I now wake up 4-5 times a night," and changes in their energy level which affected their ability to do things: "I feel I will never be the same. I used to have a lot of energy. Now I can't race around like I used to." One woman had increased energy following her bypass surgery, but acknowledged that she still needed help for some things she had previously managed on her own.

The older women seemed to focus on resiliency as they emphasized how important it had been to get back to their previous level of functioning. "...getting my kitchen floor washed was a major accomplishment." "You need to get up and at it." "I go to the shopping mall every day; I walk there; it is what helped me most." "I do things for others, I knit for the Red Cross." They discussed their concern about being able to continue living at home and their difficulties in getting the home care services they wanted; at least one woman said she did not want anyone to help her with a bath, but because of this she was not eligible for the homemaking help she felt she needed.

Three of the women discussed problems they had had with their family. "They have a fear of losing you and so [they] put limits

on you." One woman thought her family had been hiding something from her about her condition because they were so protective of her. She said: "Family puts doubt in your mind."

Overall, although the women over the age of 60 reported problems in the areas of diagnosis, initial acceptance of having heart disease, instrumental activities of daily living, memory and sleep; they focussed on getting back to their previous level of functioning (resiliency) and presented themselves as coping quite well. (See Table I)

Under 60

From the "Alumni" list, we were unable to recruit any women under the age of 60 who were not in the rehabilitation program; thus all the women in this group were undergoing cardiac rehabilitation. One woman who had expressed an interest in developing more services for women with heart disease was invited and the rest were chosen by identifying every second or third person from the list of current rehabilitation patients. All 11 women invited from this group were interested but 2 were unable to participate due to previous commitments.

The nine women who participated ranged in age from 38 to 59 (Table II) with a mean age of 49 years. All were white and middle class. Seven of the women were married and living with their partners, while two were divorced. Two had children at home (ages 7 to 17) and two had young adults in the home. At least one woman also had responsibility for aging parents. All of them worked outside the home; some part-time. Almost half the women had been diagnosed with angina, four had had a myocardial infarction and only one had undergone bypass surgery.

Pre-Diagnosis

We began the session by stating: "We want to learn from you what your experience with heart disease has been like from the time of diagnosis up until now – what it's been like for you as women with heart disease. Let us know how it has affected you and how you think we could be more helpful." These women echoed the older group in first discussing their pre-diagnosis experience. They described a lack of

knowledge about the symptoms of heart disease as well as the perception that physicians were also often not aware of the signs and symptoms of heart disease in women. One woman said: "My doctor told me women don't get heart attacks." Five of the nine identified that they had been struggling with feelings of depression for up to one year prior to being diagnosed with heart disease. One woman said: "The doctor wanted me to go on antidepressants; I said no....but I should have."

Diagnosis/In Hospital

In hospital, the younger women echoed the same feelings of surprise and confusion as the older women. They identified that they wanted to speak with other women who had the same problem. "When people have a breast removed ...in cancer treatment, don't they have other patients or people who have had the same procedure done visit them and see if they need to talk? Why couldn't we as women who have had heart attacksvisit other women in the hospital.... They could see you do survive it."

Recovery Period

In the recovery period, the women expressed a variety of concerns; primary among these were emotional issues. "My problems are more psychological than physical," said one. "I was at the hospital ten times between September and January due to fear," said another. Yet another woman said: "I just find a lot of anger, frustration. I'm finding it very difficult to cope." Many expressed anger about their heart disease and the experiences of misdiagnosis. "There is a lot of anger involved with what's gone on, frustration and denial." Many of the women struggled with return-to-work issues. "My boss is really annoyed that I can't go back to work... he won't let me work part-time." They described how since they looked "okay", many co-workers could not understand why they could not work at the same capacity as previously. Some had needed to go on disability insurance and recounted how they felt guilty about this. One woman said: "I was made to feel I was milking the system."

The younger women recounted the same tendency for family members to become

overprotective as the older women did. "When I had my heart attack, I was lucky if my husband even let me drink my tea by myself." There were many murmurs of agreement with this statement. Those who had younger children had additional concerns. "My 7 year old son stuck really close to me, he didn't want to go to school," and another noted: "Children expect everything from you."

Memory loss and sleep changes were mentioned by this group, but not as frequently as by the group of older women. Two women reported a relationship between their angina, energy level and menstrual cycle: "Angina comes on one week pre-period." The women expressed a concern about the lack of research done on women with heart disease.

All but one woman in this group identified the desire to speak with other women on an ongoing basis about coping with heart disease: "...just being with other women who are in the same boat is so important." They suggested that a support group be established to fulfill this need: "I would like to see a support group for women between the ages of 40 to 60 meeting once a week or every second week."

In summary the women under 60 identified some of the same concerns as the older women; for example, non-recognition of cardiac symptoms, surprise and confusion about the diagnosis, and memory and sleep difficulties. They also had concerns about their children as well as issues related to return to work. Unlike the older women, however, many of them presented as having difficulty in coping and tended to be focussed on anger.

DISCUSSION

Despite public education campaigns,¹⁶ all the women in our focus groups had difficulty identifying their symptoms as cardiac and some recounted how physicians had difficulty arriving at the correct diagnosis as well. This finding was particularly striking in that our initial conceptual framework did not include a "pre-diagnosis" category, yet both groups found this important to discuss. This is similar to the findings of Dempsey et al.¹¹ who examined the psychosocial processes by which

women make the decision to seek care for symptoms of acute myocardial infarction (AMI). They reported that women were influenced to disregard the significance of symptoms by their belief that AMI symptoms involved crushing chest pain or loss of consciousness, the tendency to attribute symptoms to a non-cardiac cause, and their view of AMI as being primarily a disease of men; two women also reported being misdiagnosed by physicians prior to their MI. This suggests there is an ongoing need for continuing medical education in this area.

Women in both groups had to contend with overprotective family members. This underlines the important role of family in adjustment to illness.¹⁷ It also highlights the need for rehabilitation programs and primary physicians to provide education, support and counselling services to the couple or family, not just the patient.

While there were some similarities between the two groups in terms of their pre-diagnosis experiences, difficulties with memory and sleep, and the tendency of families to be over-protective, there were also some important differences. For the older women, some of whom had coped with other health problems, their heart disease was something else to "deal with" and the focus was on resiliency. For the younger women, their heart disease was a serious disruption and the focus was on anger. Many of the younger women felt they were depressed prior to the cardiac diagnosis and so were perhaps more vulnerable than those in the over 60 group who did not mention this. The younger women used emotion-focussed coping strategies; they tended to spend a lot of time expressing their emotions and seeking support. The older women used problem-focussed coping strategies; they tended to focus on ways of solving the problems they faced as a result of their heart disease, such as going to the shopping centre to walk daily, and trying to focus on living one day at a time.

All women discussed how helpful it was to speak with other women with heart disease. This is similar to LaCharity's¹⁸ findings and suggests that the need for social support is an important aspect of women's cardiac care needs. Older women seemed

to need this support primarily when in hospital and most of these women were able to get it informally. The younger women identified this need both in hospital and in the recovery period and thought that a more formal program for this would be helpful. This is especially striking given the fact that all of these women were participating in the Cardiac Rehabilitation program at the time and thus had access to the support of the health care staff as well as informal support from other participants. It appears that support groups for women should be offered as an integral part of cardiac rehabilitation. This finding echoes Moore's¹⁹ findings that women who had recently participated in a CR program reported that they wanted more opportunities to talk with individuals who were experiencing similar health problems; they suggested that group therapy sessions be offered. Not only were education and peer support programs identified as needs in the care of women with heart disease, but research was identified as a need as well. Although estrogen is well known to have a cardioprotective effect in general, women noted that very little is known on how the hormonal cycle may affect the course of heart disease.

There are some important limitations to our study. All the women who participated were white and middle class, which limits the generalizability of these findings. There may well have been a self-selection bias, especially in the older age group, as those who were not doing as well may have declined participation in the study. As a

whole, the older women showed excellent coping skills and appeared to have a more problem-solving approach to dealing with their heart disease than the younger women. This may reflect more of a "best case scenario" than an important difference between the two age groups. It may also have been influenced by the fact that 50% of the women in the older age group had had bypass surgery as compared to 11% of the younger women; perhaps the older women felt they had received a more definitive treatment and were more confident about the future as a result. The differences between the age groups is an area that requires further research.

These focus groups represent an exploratory study that deserves substantiation by conducting in-depth interviews or a large survey. These findings offer some insights into the experiences of women with heart disease and point to the ongoing need for public and professional education, social support programs for women with heart disease and their families, and further research into the unique aspects of women's experiences of heart disease.

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