Comparing issues faced by younger and older women with breast cancer

By S. Cameron and M.E. Horsburgh

Abstract

The purpose of this qualitative study was to explore issues identified by women with breast cancer to determine if the experiences of women over 60 years of age differed from younger women. Twenty women were interviewed and asked about their experiences with diagnosis and treatment; issues and concerns which presented special challenges for them; whether they were experiencing other health problems in addition to their cancer, as well as who, and what, they found most helpful to them during the experience. Some of the issues specific to older women included: greater hesitation in seeking initial treatment; their strong desires to maintain their independence; and a greater number of health problems being experienced. Findings are relevant to nurses working with seniors diagnosed with breast cancer.

Background

It is projected that the Canadian senior population will increase in size from the current rate of 12% of the population to 25% by 2031. Cancer rates are highest in our older population, consequently, it is projected that we will experience a growing population of patients with cancer (Canadian Cancer Statistics, 1993 & 1996). Breast cancer is a significant problem in older women and, because of aging trends, it will become an increasing problem (Silliman, Balducci, Goodwin,

Holmes & Leventhal, 1993).

Greenfield, Blanco, Elashoff & Ganz (1991), in a chart review study of treatment in breast cancer patients (n=374), found that choice of cancer treatment related to chronological age rather than physiological condition. They concluded that age bias may result in a less favourable prognosis for senior women than could be achieved using currently recommended cancer therapy regimens. Furthermore, because of variations in breast cancer treatment among these women, and the lack of information regarding relationships between breast cancer treatment and health outcomes in women 75 years of age and older, it has been difficult for health care providers to determine which treatment protocols may best meet the needs of these women. Cancer registry records for a cohort of 2,252 women over age 66, diagnosed with non-metastatic invasive breast cancer, revealed that age-related treatment patterns were not a by-product of increased comorbidity in older women (Newschaffer, C.J., Penberthy, L., Desch, C.E., Retchin, S.M., Whittemore, M., 1996). They concluded that other factors were affecting treatment preferences of patients and clinicians.

In addition to the physical issues of cancer care, psychosocial needs of patients with cancer are often complex and difficult to resolve. In a study conducted at the Ontario Cancer Institute/Princess Margaret Hospital, Toronto, Bunston and Mings (1995) reported that the most frequently-cited needs in a group of men and women with different cancers included fears of recurrence, the unknown, treatment efficacy and death. Additionally, health-related quality of life is considered to be as important to older women as the risk of recurrence or death from breast cancer. Given factors such as these, Silliman et al. (1993) suggest that it is imperative that older patients be involved in decision-making regarding their treatment.

Literature specific to senior women with breast cancer is limited, particularly in Canada. Findings from research conducted raise a number of issues related to this population. Specifically, they include issues related to diagnosis, treatment, decision-making, as well as the personal concerns of senior women with breast cancer. (Silliman et

ABRÉGÉ

COMPARAISON DES ENJEUX DEVANT LESQUELS SE TROUVENT LES JEUNES FEMMES ET LES FEMMES ÂGÉES AYANT UN CANCER DU SEIN

Cette étude qualitative avait pour but d'explorer les enjeux identifiés par les femmes atteintes de cancer du sein afin de déterminer si le vécu de la maladie chez les femmes de plus de soixante ans différait de celui de leurs cadettes. On a interviewé vingt femmes à propos de leur expérience relative au diagnostic, au traitement, aux préoccupations et aux enjeux qui ont représenté des défis pour elles; on voulait également savoir si elles avaient des problèmes de santé autres que ceux liés au cancer et qui ou quoi les avait le plus aidées au niveau de leur vécu du cancer. Les aînées ont souligné, entre autres, les questions suivantes: une plus grande hésitation à faire les démarches menant au traitement initial, leur vif désir de conserver leur autonomie et la présence d'un plus grand nombre de problèmes de santé. Les résultats seront d'une grande utilité pour les infirmières oeuvrant auprès d'ainées diagnostiquées d'un cancer du sein.

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al., 1993; Balducci, Schapira, Cox, Greenberg & Lyman, 1991; Bilodeau & Degner, 1996).

The purpose of this qualitative study was to explore the issues identified by women with breast cancer to determine if there were differences in the experiences of women over 60 years of age and women less than 60 years.

Method

Procedures

Women were recruited from a radiation oncology department in a regional cancer centre. In order to learn if there were differences in the needs of women in two age categories, women less than 60 years as well as over 60 years of age were interviewed. The sample included women who (a) had been recently diagnosed, (b) were currently in treatment, (c) had experienced recurrence, (d) as well as others who were attending for routine follow-up. Women were approached by staff and provided with a letter of introduction to the study. Participation was voluntary and women signed a consent form if they were willing to have a personal interview. Women were assured that their participation, or non-participation, would in no way affect their cancer care.

Initially, senior women were less willing to participate than women under 60 years of age. The investigators modified the recruitment procedures. One of the researchers participated in recruitment of seniors and they stopped requiring signing of forms at the time of first contact, merely asked women to consider the study, provided them with an information letter, and asked permission to follow up by phone. This recruitment strategy resulted in 98% participation from those approached. In total, 20 women were interviewed, 16 in their own homes and two at the cancer clinic. One interview was conducted by telephone and one was held in the office of one of the interviewers. The women selected the place of interview. Interviews were conducted by the two researchers.

Subjects

Ten women aged 59 years or less and 10 women over age 60 years at time of first diagnosis were included in the sample. Three women had been diagnosed in the previous six months, 12 women had been diagnosed in the period between seven months and five years previously, and five women had been diagnosed between six and 14 years previously. Table One includes age ranges of women at the time of diagnosis. Table Two shows treatment received by younger and older women.

Questionnaire

A questionnaire was developed with open-ended questions to elicit information about:

- (a) experiences with diagnosis and treatment of cancer;
- (b) issues and concerns that presented special challenges for the women;
- (c) concurrent health problems in addition to their cancer;

Table One: Age at time of diagnosis	
Age	n
30-39	1
40-49	5
50-59	4
60-69	5
70-79	4
80+	1

Table Two: Treatment regimens	
30-59	3 mastectomy 6 surgery and radiation 1 surgery, chemotherapy and radiation
60-80+	2 mastectomy 8 surgery and radiation

(d) what and who was most/least helpful to these women (family, friends, health care providers).

The two researchers conducted the interviews, and permission was requested to tape the interviews; all but one client agreed to taping.

Data analysis

Interviews were transcribed verbatim and analyzed by the research assistant under the supervision of the first author. Data analysis started with the first transcribed interview. The data were coded using "open coding" and "latent content analysis". Parts of text that appeared to convey an intact message/meaning were highlighted and sorted; furthermore, messages/meanings were interpreted within the context of the individual participant's entire interview (Morse & Field, 1995). As the data continued to be coded and compared, codes were grouped into categories and clustered through "axial coding". Axial coding is a set of procedures that reveal relationships among categories, context and consequences (Strauss & Corbin, 1990). To achieve consistency of coding, testing was done by the first author to ensure intra-rater reliability (that the data were coded by the research assistant in a consistent manner over time). The "Ethnograph" computer program was used to help manage the data.

Similarities and differences between women under 60 years of age and women over 60 years of age were examined and issues specific to the senior women with breast cancer were identified. These latter factors/concerns provided insights into what additional nursing assessment information should routinely be collected from women over 60 years of age in order to facilitate planning and implementation of appropriate nursing care.

Limitations

The convenience sample used in this study limits generalizability of findings. However, the interviews did allow the investigators to identify similarities and differences between the two groups of women. The investigation was retrospective and included women who had been recently diagnosed as well as women who had first experienced cancer on average three to five years previously. All women appeared to recollect clearly events which occurred at the time of diagnosis, as well as their treatment experiences, and how they perceived their lives had been affected. However, future prospective studies on a larger population of older women could provide further insights into their issues and concerns when confronted by breast cancer, and during their various stages of treatment.

Results

Issues related to diagnosis

The responses of women to finding "lumps" appeared to vary with age. One older woman (77 years) had not been having regular mammograms and it was only when her daughter encouraged her to go for a pap test that her physician suggested a mammogram should also be done. She had noticed "little clusters" in her breast, like "little peas... I could feel them... I thought oh... well... I was really not concerned... it never dawned on me... it happens to other people." This approach to discovering something unusual was quite different from women less than 60 years of age who usually sought medical advice after finding a lump of any kind. For example, one younger patient acted immediately on finding something suspicious: "I knew right away when I found it in the shower and went to see the doctor the next day... that's how fast it all happened. It sent shivers up my spine and I thought something's not right here... it was a big shock."

A number of women of varying ages reported different "sensations" in their breasts which prompted

them to seek medical attention. One younger woman who was having regular mammograms described "an awful funny feeling" in her breast. "It wasn't sore, it wasn't aching... maybe a little bit tender... but not sore to touch... it just felt different." She felt uneasy about this sensation and when she followed up on it was then diagnosed with breast cancer. One senior woman who had been having mammograms sporadically recalled "several sharp pains" in her breast but ignored them. As she described it: "then something just clicked... I thought to myself... go... it only takes a few minutes" and subsequently her breast cancer was diagnosed.

The women identified three ways in which their breast cancer was diagnosed: by regular mammogram, finding lumps themselves or by unusual sensations in their breast. As stated, women over 60 years were more likely to "put off" checking out unusual findings or sensations compared to younger women.

Discovering they had breast cancer was obviously an issue experienced by all women. Many women in both age groups found their lumps by accident and were not performing breast self-examination regularly. "I have to say I have never been good at breast self-exam... it made me squeamish and I'm not a squeamish person... but for me to do a breast self-exam on myself for some reason or another just scared me... I wouldn't know if I'd done it properly or if I was doing it right." This younger woman felt that a health professional would be a more effective examiner.

Although women over 60 years of age often did find lumps in their breasts, they were not regularly doing self-examination, or having mammograms. Only four of the 10 seniors we interviewed were having regular mammograms. Statistics Canada's Winter 1997 Health Report documented that less than 18% of women over 70 years of age have had a mammogram. McCool (1994) in a review of barriers to screening found decreased screening in advanced age, even though older women's mortality from breast cancer is higher. The need for health promotion activities targeted towards encouraging older women to have regular mammograms and regularly examine their breasts are further supported by our findings.

Treatment issues

Patients described a wide range of reactions to surgical procedures. "I didn't like to look at myself for a long time... I can live with it now but I'm still not happy when I put on my bra every day... but once I get a bra and clothes on... it's gone." One woman was extremely upset at the possibility of having her nipple removed: "it's taking away my womanhood". She recalled this fear vividly. Age did not seem to be a significant factor in body image. Some women preferred to have the whole breast removed "to get rid of everything" while others felt any surgery had a profound effect on their body image and much preferred the option of resection with radiation treatment.

Most women did not report significant issues related to surgical procedures. However, women who had mastectomies "hated" the drainage equipment. Many women the researchers talked to had undergone radiation treatments. For most, this did not present any special problems and many women took responsibility for travelling to appointments independently even when this involved walking and busing. All were aware that transportation could be provided to them. However, most seemed to prefer maintaining their independence when possible. Skin soreness, bathing restrictions, especially in hot summer months, and tiredness later during treatments were all described by women more as irritants than significant problems.

One younger woman explained that her "breasts felt engorged after treatment" and wished someone had told her that this was normal. She added: "maybe they did [tell me]... in that situation you don't really hear what they are saying." This theme "not hearing" was supported by other women who, particularly in the early stages of

diagnosis and treatment, were often overwhelmed by the whole experience. These findings suggest that health care providers should continually assess the knowledge of women and repeat information as often as necessary. Opportunities should also be afforded to women to ask additional questions, especially in the early weeks/months of treatment.

There did not appear to be differences between younger and older women regarding cancer treatment issues and both groups described their experiences in a similar manner. Virtually all women found the emotional trauma of their cancer diagnosis a greater burden than the physical aspects of the disease.

Issues and concerns

Fears and anxieties

There is little doubt that a diagnosis of cancer, regardless of prognosis, evokes great fear and anxiety in women of all ages. Women expressed feelings of shock and fear. As one described the experience: "it makes you look at your own mortality."

"Worrying and wondering if it's somewhere else in my body" was a theme expressed by many women. Fear of recurrence appears to remain with the women even after considerable time had passed. They often recounted stories of long-term survivors and were always heartened by success stories they had heard. However, many knew other people who had experienced recurrence and this was a continuing concern. Women would frequently talk of others they saw at the clinic; they were encouraged when they saw "survivors" and very concerned when they saw others who were obviously very sick. While waiting for treatment in a room full of patients and relatives, one woman felt: "I didn't want to be with those people. I just wanted to be somewhere with people like me, or by myself even."

Fear of chemotherapy was a significant issue for most women; many "worried for weeks" if they would need chemotherapy. Some had cared for relatives receiving chemotherapy and this seemed to increase their fears... "they were so sick". "I hate going to the cancer clinic because of the smell of the place... it makes me think of chemo, makes my stomach go... I pray to God I never have to go through it again." Not surprisingly, it was evident that older women had had more experiences knowing or caring for friends and/or relatives with cancer.

Sharing information

How to share information about their cancer was an issue for most women. Reactions of women differed widely among those who "kept the information to themselves", those who shared information with family, and those who shared it with all of the significant people in their lives. Women who lived alone and were independent and accustomed to relying on their own resources were much more likely NOT to share information, or share it with just a few close friends. These women were also more likely, but not always, older. One woman in particular chose not to discuss her illness with anyone: "to me... the cancer bit was a dirty word." She assumed people would conclude: "oh, so you've got cancer, so you're going to die."

Some older women told no-one in the early weeks (or months) following diagnosis. Some of these women had siblings they did not want to concern, or sons and daughters who were living some distance away. One woman whose daughter lived in the west did not tell her initially. When she did, her daughter wanted to come and visit, but she said: "no need to come... but it would have been good to see her". Older women particularly valued their independence and did not want to be a burden to others.

Independence

This became a recurring theme with women of all ages, but it presented special issues for senior women. Even when offered transportation to the clinic, many of these older women drove

themselves for daily radiation or went on the bus. This independence persisted despite increasing fatigue as treatments progressed. One particularly poignant story was shared by an older woman who drove herself daily through a very hot July and August, even though feeling quite exhausted. She had blood pressure problems, but had no energy to go to her regular doctor to get it checked and she didn't mention it to clinic physicians. Within 10 days of completing radiation she had a stroke which left her with a significant degree of paralysis. Now she wishes she had taken time to have her "other health problems" monitored as well, but she felt her energies had been focused on getting to her treatment appointments and she had not attended to other health issues. Early in our conversation, this woman reported her cancer as being her only significant health problem. However, as we chatted, some of her health history unfolded and she revealed multiple surgeries (including two hip replacements) which, in a short conversation, she would never have revealed. It was clear that she was not the kind of person to "dwell" on her past difficulties and it was very unfortunate that she had not been more open about additional symptoms experienced during her radiation therapy.

Additional health problems

During the interviews, the researchers asked women to discuss any other health problems they experienced in addition to their cancer. Common ailments included thyroid conditions, endometriosis, hypertension, stroke, arthritis, fibromyalgia, cholecystitis, asthma and gastric ulcer. One senior had recovered from a brain aneurysm in 1987. Hip replacement and hysterectomy for both benign and malignant tumours were also reported. One elderly woman reported "depression" which occurred unexpectedly after treatment. She stated: "That's not usually my nature to be like that."

Many of the older women experienced a multiplicity of health problems in addition to their breast cancer. Information regarding these additional concerns was not conveyed readily; women often shared this information late in the interview and in response to direct questioning. These findings suggest that it is essential to allow elderly women sufficient time for health interviews and specific questions regarding co-morbid conditions/injuries should be asked.

Reason/cause

It seemed difficult for most women not to ask: "Why me?" and "What did I do to cause my illness?" Regrets were expressed by some women about having taken estrogen and progesterone supplements after a hysterectomy because "they were what could have caused it." Estrogen replacement therapy to prevent heart attacks and osteoporosis was a prevalent concern. "Estrogen probably predisposes women to things like breast cancer... if you don't know your family history... it's hard to make a decision" (even though some women felt their physicians strongly advised them to take estrogen).

With a history of excellent health and optimal lifestyle, one woman was "amazed" that she developed cancer. It did not "seem logical to her". In an attempt to determine what contributed to their cancer risk, the women tended to question heredity factors, early menses, pollution, chemicals in food, age of child-bearing, birth control, smoking, alcohol and coffee consumption.

One woman had, years before diagnosis, "hit" her breast on a car door mirror "exactly where the cancer later occurred". She continued to wonder whether that trauma played a role in developing cancer. Another woman was convinced her untreated mastitis after childbirth and/or radioactive iodine given for a thyroid condition at age of 45 contributed to her illness.

Understandably, many women voiced their anger with their diagnosis of breast cancer, because they "tried to take care of themselves", there was no cancer in the family, or they had regular

mammograms. "Women should not assume it can't happen to them... it's very possible and no one knows why." "You constantly try to figure out why... you can't help but do that." No differences between age groups were found on these issues, many women expressed concerns about causation.

Daughters

Invariably, mothers who had experienced breast cancer expressed concern about their daughters and their chances of developing the illness. One daughter, in fact, was planning to be one of the first candidates to undergo genetic testing for the breast cancer gene since she was considered a prime candidate due to her strong family history of breast cancer. Worried mothers were especially concerned that their daughters receive early and regular diagnostic testing to detect breast cancer at its most treatable stage. This led to confusion since some doctors advised that the appropriate age for mammography to commence was in their 30s with annual testing to follow, while other physicians were hesitant to order mammograms "on someone that young".

In general, women found information on breast cancer confusing and consequently frustrating. Many were aware of differences in U.S. and Canadian recommendations regarding the timing of mammograms. They expressed difficulty dealing with the different opinions and wanted definitive answers to their questions. One woman stated: "Woman's Weekly said a mammogram can find a lump that is seven years old... but wait a second... if a mammogram finds something seven years old... then what happened to all those mammograms I was having?"

All women, regardless of the age of their daughters, reported "preaching" to their daughters to go for regular check-ups. "Don't do what I did," cautioned one mother who had delayed mammography. Generally, women felt their daughters tended to take their potential risk of developing breast cancer seriously.

Helpful

Family and friends

In identifying who and what was most helpful during their experience with breast cancer, the women identified several themes. Family, friends (especially those who had themselves experienced cancer) and co-workers all played an important role in supporting and encouraging their loved one. It was clear, however, that some family members and friends were more comfortable than others in this capacity and at times women felt the need to "protect" family members from their worries and concerns. When individual women perceived that they had strong support, they often decided not to use community groups and services. It was apparent that as much as the bond of support groups and relaxation therapy sessions were invaluable for some women, they were "not for everyone". In retrospect, there were women who regretted their decision not to share their feelings with a group or individual. "If I had someone to go to meetings with, I would go". "I think that would really have helped. To sit down with other women who had it, talk it all out..." A period of adjustment and acceptance often had to occur before a woman made the choice to "open up" to another person. In the group of women interviewed, only one woman in the over-60 age group had used a support group for emotional support. This is an important issue to consider when planning supports for older women, who may be more accepting of individual rather than group support.

Spouses were most often described as optimistic and supportive; however, several wives worried about their husbands' ability to really cope with their illness. One husband did not want his wife to discuss her illness with others, to which she replied: "I want to talk about it. I feel better when I talk about it. There is nothing to hide."

Health services

Women interviewed were extremely supportive of the kind of care

they had received from physicians, nurses, therapists and volunteers at the cancer centre. They were appreciative of the time taken to listen to their questions and concerns; as one woman stated: "You feel like you're being treated like a human being". Some women, however, did find it difficult to attend a "cancer" centre and their anxiety and fear did not necessarily diminish with time. Women of all ages expressed similar feelings about the services.

An abiding faith and spiritual awareness gave some women strength and courage to deal with their challenges. One woman "decided to put it in the hands of the Lord". Retaining a positive attitude through exercise programs, volunteer work and their children's activities also helped women to feel needed and appreciated. Radiance therapy was for one woman "the best thing in the world", just as therapeutic touch, imagery and music helped others to relax and meditate. Most of the women we spoke with reported "cancer has given lots of new friends, lots of support, lots of inspiration". "It's a learning experience." It appeared that most women had come to terms with their cancer and had adjusted to living with a potentially life-threatening illness.

Similarities and differences in women's experiences

While the investigators found commonalities among the experiences of the women interviewed in this study, this research suggests that older women with breast cancer do perceive some aspects of their experiences with cancer diagnosis, treatment and care differently than younger women.

Specifically, the findings suggest that how nurses approach older women may be extremely important. First, many seniors are less likely to ask questions and involve themselves in the decision-making process about their treatment and care. Several senior women followed "what the doctor" said, and many seemed surprised by the interview question which focused on how they made decisions regarding their treatment. "That was what they said... I never questioned that... he never even gave me that choice..." "he more or less decided for me... which... was fine... if I had been faced with that... that would have been even a bigger thing... I just went along." "Not too many choices - it's good that you like a doctor and... just, just go on with it." This presented a sharp contrast to the questioning of physicians by younger women and clearly illustrated differences between generations. Younger women were more likely to want to discuss options for treatment and appeared more interested in participating in decisions about their health. These findings support the work of Bilodeau & Degner (1996) and Beisecker (1988) who also found that older women were more likely to assume a passive role in treatment decision-making and leave decision-making authority to the physician.

The researchers found it important to spend extra time with older patients as they often got "off topic" and didn't freely elaborate on relevant accompanying health problems without focused prompting. Taking time is important at initial assessment visits, and at follow-up appointments, as seniors are most likely to experience changes in their health and capabilities as well as personal supports. As with younger women, seniors did express satisfaction with time given to them to explain treatments and provide open and honest answers to their questions. However, "forgetfulness" was an issue for senior women and many appreciated having a friend or relative with them who could also "hear" the information provided. One woman stated: "they suggest that the whole family comes in... and I had my neighbour with me because I wanted another woman there because sometimes when our mind is overwhelmed, we can't remember everything... and men don't remember everything either when they're upset like that."

It behooves all who have contact with women diagnosed with breast cancer to remember the significant trauma this disease may

cause. Nurses must constantly endeavour to listen to the women's feelings and stories if they are to provide care to meet their issues and concerns.

Directions for clinical practice

In conclusion, it is apparent that the growing Canadian population of senior women with breast cancer does warrant special consideration. Nurses have an opportunity to play an important role with this population. This may include focusing on areas of special need such as accompanying health problems, medications being used, as well as women's personal living arrangements. Support needs for self-care as well as the social supports available to seniors are particularly important areas of focus as many older women were living alone and valued their independence highly. How seniors are approached is also important to ensure that caregivers take time to ensure their issues and concerns are "heard" and that the care being planned considers their specific needs and desires.

Nurses can also play an important role in the teaching of breast self-examination as supported by Clarke and Sandler (1989). Health promotion strategies targeted to senior women are also needed to encourage them to be alert to the benefits of self-examination, mammography and early diagnosis. As our Canadian population of older women continues to increase in size, it is imperative that health care focus on health education programs to reduce both mortality and morbidity from breast cancer.

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