

Living with lymphedema: A qualitative study of women's perspectives on prevention and management following breast cancer-related treatment

by M. Victoria Greenslade and Colleen J. House

Abstract

A phenomenological research method was used to investigate the experience of lymphedema in 13 women following breast cancer-related treatment. The women, ranging in age from 45 to 82, living on the east coast of Canada, had lymphedema of the upper extremity for at least one year, and had no evidence of active cancer disease. Semi-structured interviews were used to examine the physical and psychosocial suffering that women with lymphedema experienced. The lack of appropriate pre-intervention education and post-intervention support by health care professionals as well as the lack of effective protocols to prevent lymphedema combined to intensify the suffering.

Data analysis incorporated van Manen's (1990) six research activities which give human science its vigor. These non-sequential steps assisted in identifying five major themes: 1) Constancy; 2) Yearning for Normalcy; 3) Continually Searching; 4) Emotional Impact; and 5) Abandonment. The prevailing thread or essence salient to all five themes in this study is denoted as Existential Aloneness as each participant expressed a sense of isolation, of being on their own, of being set adrift to discover what they could about lymphedema, in the best way that they could. Nursing implications and recommendations for change are highlighted.

Breast cancer is the most frequently diagnosed cancer in Canadian women (Canadian Cancer Society, 2004). Although incidence rates have stabilized since 1993 and death rates have declined steadily since 1990 (Canadian Cancer Society, 2002), statistics indicated there would still be an estimated 21,200 women diagnosed with breast cancer in 2004 and 5,200 women would die as a result (Canadian

Cancer Society, 2004). Trends suggest that women are more likely to be diagnosed with breast cancer at a younger age and at an earlier stage of the disease (Chirikos, Russell-Jacobs, & Jacobsen, 2002). It is anticipated that technological advancement in the detection and treatment of breast cancer will continue to manifest a declining mortality rate (Chu et al., 1996). As a result, more women are living as breast cancer survivors and having to deal with the after-effects of treatment (Chirikos et al., 2002; Wingo, Ries, Rosenberg, Miller, & Edwards, 1998). Although there is insufficient evidence to demonstrate that women with breast cancer have greater long-term functional impairment than women without breast cancer, it is known that interventions of surgery, radiation therapy, and adjuvant chemotherapy reduce physical and emotional capacities of women with breast cancer (Burstein & Winer, 2000; Chirikos et al., 2002; Ganz, Rowland, Meyerowitz, & Desmond, 1998; Polinsky, 1994; Wyatt & Friedman, 1998). One condition attributable to breast cancer treatment is the widely recognized but poorly understood and most problematic complication of lymphedema.

Background Information

Lymphedema is the accumulation of lymphatic fluid in the tissues as a result of damage to or removal of lymphatic vessels and/or nodes. The accumulation of fluid creates excessive swelling and pressure in the affected extremity and if left untreated, can become disfiguring and sometimes painful and disabling (National Cancer Institute, 1999). This abnormal collection of protein-rich fluid in the interstitial spaces precipitates the development of cellulitis and fibrosis of the surrounding tissue (Brennan, 1992; Humble, 1995; Pappas & O'Donnell, 1992; Wilson & Bilodeau, 1989).

The incidence of women affected with lymphedema of the arm following breast cancer treatment is difficult to determine. Harris, Hugi, Olivotto, and Levine (2001) cite inconsistent definitions and lack of a standard lymphedema classification system result in a varied incidence rate of six percent to 70%. The risk of lymphedema increases with irradiation of the axilla (Harris et al., 2001) and is influenced by the extent of axillary dissection, increasing age, and obesity (Box, Reul-Hirche, Bullock-Saxton, & Furnival, 2002; Erikson, Pearson, Ganz, Adams, & Kahn, 2001; Harris et al., 2001). Approximately one-third of women having axillary lymph node dissection will experience some degree of lymphedema post treatment (Radina & Armer, 2001).

Despite improved radiation therapy and decreased use of radical mastectomy as the surgical standard, continued high incidence of breast cancer and increased breast cancer survival rates cause concern for both breast cancer survivors and health care

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professionals (Hull, 2000). Paskett and Stark (2000) found that 48% of breast cancer survivors with lymphedema reported that lymphedema impaired their routine daily activities. Woods, Tobin, and Mortimer (1995) found that women with lymphedema experienced more psychosocial maladjustment and psychological morbidity associated with breast cancer and related lymphedema than did the women who did not develop lymphedema after breast cancer treatment.

Studies have shown that lymphedema is associated with a self-reported decreased quality of life in women diagnosed with breast cancer (Beaulac, Lindsay, McNair, Scott, LaMorte, & Kavanah, 2002; Coster, Poole, & Fallowfield, 2001). Hare (2000) reported "that breast cancer-related lymphedema has a huge impact on patients' lives" (p. 39). The salient issue influencing the impact of lymphedema on individuals' lives is whether they received information about lymphedema. Research has shown that many women with lymphedema do not know or understand the risk of lymphedema development, what causes it to develop, or how to treat it when it develops (Bosompra, Ashikaga, O'Brien, Nelson, Skelly, & Beatty, 2002; Coward, 1999; Radina, Armer, 2001; Radina & Armer, Culbertson, & Dusold, 2004; Thiadens, Armer, & Porock, 2002). Woods et al., (1995) had reported similar findings a decade earlier.

Lymphedema contributes to physical and psychosocial challenges encountered by women in their daily activities, yet the literature indicates inconsistencies in lymphedema care by health care professionals. Further research is necessary to gain a greater understanding of the lived experience of lymphedema. Examining the amount of pre-intervention education and post-intervention support by health care professionals as well as the types of lymphedema protocols used to prevent and manage the condition may assist health care professionals to help individuals achieve a better quality of life.

Purpose of the Study

This study used a hermeneutic phenomenological approach to explore the experience of lymphedema in women in order to discover an understanding of the meaning of those experiences for women with breast cancer-related lymphedema. Exploring the many ways that these women experience and understand their world will hopefully contribute to an increase in reflective practice among health care practitioners and produce recommendations for lymphedema prevention and management practices that positively impact the adjustment of living with lymphedema and improve quality of life.

This paper presents the findings and recommendations for change.

Methodology

Design

A purposive sample of 13 women was recruited from the east coast of Canada through newspaper, television, and radio advertisements. The women ranged in age from 45 to 82 years, with an average age

of 63. Three participants had spent their adulthood working within their homes. Of the 10 who had worked outside the home, seven had worked within the health care system in professional or semi-professional capacities. None of the women was receiving chemotherapy or radiation at the time of the study; however, some participants were on long-term use of the drug Tamoxifen. Tamoxifen is an anti-estrogen therapeutic agent that inhibits the growth of breast cancer cells.

Lymphedema ranged from mild to severe (Figure 1) and time of onset was described as immediate post-operatively to as late as 25 years after surgery. More than 50% of the participants developed lymphedema within the first year following surgery.

Data Collection

Ethical approval was granted from a Human Investigation Committee. Criteria for inclusion in the study were: a) upper extremity lymphedema following breast cancer-related treatment; b) presence of lymphedema for at least one year; c) resident of a particular geographic area; and d) no current evidence of active cancer disease or cancer recurrence. Interested potential participants contacted the principal investigator through an advertised telephone number. The geographic area was determined as a result of the researchers' financial restrictions. If the women met the criteria for inclusion, they were accepted as participants in the study and a time was established for an interview. Those who did not have upper extremity lymphedema for at least one year, had active cancer disease or recurrence, or who resided outside the set geographic area were excluded from participating.

Once consent was obtained, data were collected through audio taped, semi-structured interviews. The principal investigator conducted vis-à-vis interviews at a time and location convenient for the participants (e.g. their homes) and interviews ranged from 60 to 90 minutes. Guiding questions such as, "Describe what it is like to live with lymphedema" and "Tell me a story of how having lymphedema has impacted your daily activities" were designed to stimulate discussion. Other questions helped to elicit the type and amount of preparation these women received from health care providers for the prevention and management of lymphedema. It was also important to ascertain the support these women received from the health care system to deal with the lymphedema; the changes and adjustments they had to make to adapt to their condition; and the physical and psychosocial impact that lymphedema had on them. Demographic data, such as age, occupation, and time of lymphedema onset, were also collected. Follow-up contact with the participants was made to verify interpretation of findings and obtain further explanations when required.

Analysis

Data were transcribed verbatim. Using van Manen's (1990) process, thematic analysis began with the first interview soon after the collection of data. Each interview was reflected upon following its conclusion and subsequent interviews were enriched by the

Figure 1.



Mild Lymphedema



Severe Lymphedema



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learning gained from preceding ones. Both investigators listened to the audiotapes and read the transcripts several times both independently and then together. Through several readings of the transcriptions, the researchers identified and decided upon which words to focus on in the text. Only after repeated reading of the transcripts and listening to the tapes did essential words and phrases emerge. Using van Manen's (1990) selective reading approach, words and phrases were highlighted to illuminate the true meaning of the lived experience.

Reflection was very important to the analysis process to ensure that trustworthy descriptions of the women's experiences emerged. Reflection aims to bring out the inner meaning of the women's experiences and begins with recognizing one's initial suppositions and assumptions. As researchers, it was important to recognize our own health professional status and to ensure the presence of a prior belief did not impede or influence the findings. Much care was taken to "bracket" our pre-existing beliefs and frequent investigator checks were completed.

The Qualis Research computer program Ethnograph v.5 was employed to assist with thematic organization of data. Further analysis ensured systematic organization of themes.

Findings

The findings produced five major themes: 1) Constancy; 2) Yearning for Normalcy; 3) Searching; 4) Emotional Impact; and 5) Abandonment. Prevalent throughout all the themes was the essence of Existential Aloneness.

Theme One: Constancy

Participants describe their experiences with lymphedema as a complication that impacts just about everything they do in their daily activities. They describe it as a nuisance that never goes away.

Like you go to a conference in a hotel. The chairs are beastly uncomfortable, but you sit sideways and put your arm up on the back, or if there's a chair next to you, put your arm on that. Go to church, you put your arm along the pew. I mean... you wonder if the people behind you think that it's a bit strange when you put your arm around your husband in the middle of a church service. You know, there're all sorts of small things. (5)

The majority of participants experience some form of discomfort in the affected limb either with pain, feelings of fullness or pressure, or tingling and numbness. They describe the continuous need to compensate for the discomfort, protect the arm, or accommodate it in some form or other.

I find holding my arm up for any length of time, I get pain under my arm. Well, I love knitting and crotchetting and I find if I knit for half an hour now, that's as long as I can... It's changed my life completely. (11)

Participants report that the constant coping with the lymphatic limb is frustrating, tiring, and annoying.

You know, there are so many changes that a person has to adjust to because... it is a very frustrating thing and probably a very depressing situation for people... You've got to be really, really positive to try and feel good with your lymphedema and even then, it's really frustrating at times. (3)

Theme Two: Yearning for Normalcy

Inter-related to the theme of constancy is theme two: Yearning for Normalcy. Participants wish to once again be normal - to not have to buy specially sized clothes to accommodate the affected limb; to not have to constantly wear long sleeves to cover the limb; and to not have people question why one arm was bigger than the other.

I want to be normal; to be able to do normal things; and not have to say, Oh I've got to do this or else pay the consequences if I don't. (1)

Participants discuss how "sausage fingers" or the wearing of a compression sleeve automatically identifies them as being different. This "difference" seems to give others licence to inquire about their condition.

Even in the summer I have to wear something with long sleeves. I hate to go swimming. It hurts, you know, because you hate for people to be looking at you and wondering what's wrong or feeling sorry for you. It hurts emotionally; and even the kids say "What happened to your arm" and then you have to explain it to them and so it does hurt, yes, no question about it. (13)

Theme Three: Searching

While inter-related to themes one and two, theme three speaks more directly to the participants' experiences with the local health care system. Identified as searching, participants are concerned with the inconsistencies in the information available to manage lymphedema. It speaks to when health information becomes no information. Participants discuss the minimal amount of information they received as well as the credibility of the information available to help them manage their lymphedema.

The other challenge I think is to convince yourself about the things that you read because you can read conflicting information... (for instance, don't exercise the arm that is involved; other places, people are doing Dragon Boat races and a lot of exercise)... So the challenge is, what do you read, what information do you absorb, and what is it that you personally are going to do. And I think...for people who have lymphedema, it's hard to know what to do because the information is so conflicting. (8)

Many participants feel that they are on their own trying to find information. Participants state that what little information they have about lymphedema, they discovered on their own - either by searching the internet, by self-discovery through trial and error, or by incidental discovery through social networking. They find "threads of something" but not enough information for the threads to form into anything meaningful.

You're sort of on your own, not knowing. You know what your problem is but you don't know what you're looking for and you don't know where to go to try to get something that's going to help you through, so you try different things. (3)

Theme Four: Emotional Impact

Closely related to searching is the fourth theme described as Emotional Impact. Participants discuss myriad emotions about having lymphedema: anger, fear, self-blame, and frustration. Some participants feel sad, hopeless, and resigned that they have developed lymphedema and feel that they have little choice but to cope with it.

One participant discussed the amount of attention paid to the temporary condition of hair loss during chemotherapy while no attention was given to the prevention of the chronic, permanent complication of lymphedema.

I got more information and more of a heads up on my hair falling out than I did on this. Now I know that's very devastating when your hair falls out and all that, but I mean that's temporary. That's not permanent, right. A lot of people, you know, grow back even nicer hair; but there was a lot more information handed out, and people came and talked to me about that, than there was about my arm, which is permanent and affects your life permanently and is a lot more painful and hurtful in a lot of ways, you know, so... but there was nobody ever that... [talked about lymphedema]. (12)

The “failure” of the health care system to help them is devastating. They resign themselves that there is little else they can do except hope that their stories will be heard and that, in some way, will help others. One participant when asked how the health care system prepared her to meet the challenges of lymphedema responded sharply,

It didn't. It didn't give you any preparation whatsoever. And to my knowledge, no one informed me that... whether this was usual, unusual, if it was particular to me or if others experienced it... (10)

Some participants blame themselves for the development of their lymphedema. They berate themselves for overworking their arm, or doing some activity they should not have been doing.

In the beginning I was told to do my exercises; but there, I thought this was supposed to be for the muscles because they had removed – I don't know 16 or 18 lymph nodes and I kept doing my exercises at home – maybe, not as I should have. Maybe that's what caused it; maybe it was my own fault because I didn't do the exercises. Like I don't blame anybody really and maybe I'm to blame myself. I should have been more... I don't know what I could have done... (9)

Theme Five: Abandonment

The final theme of Abandonment is expressed by most participants. Most participants express some form of anger at their situation, others at what they perceive as apathy of the health care system in dealing with their lymphedema questions. Numerous descriptions of anger are evident in the data.

Nobody talked about it; and when I brought it up in the oncology clinic, they all nodded and changed the subject... I was given the impression that since it was non-life threatening, since I had cancer and had to have surgery/radiation, I should be grateful and not

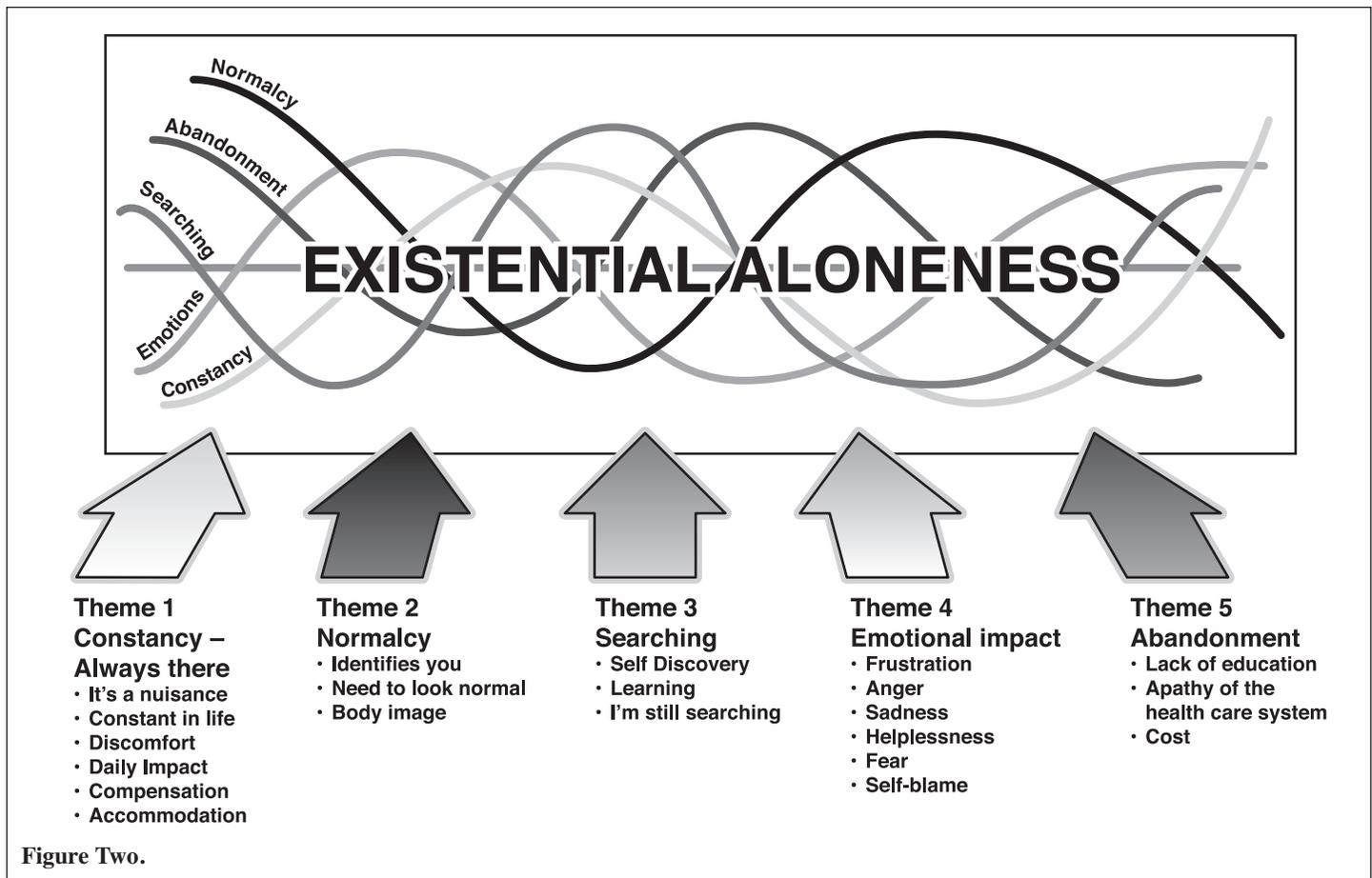
complain about lymphedema... I was so angry and I no longer go to the cancer clinic... my most pressing problem, the thing that changed my life the most was lymphedema and they always give me the impression that I should be grateful that's all I had... Why was I complaining about something that made no difference but... it made a big difference to me. (8)

The lack of education on lymphedema prevention and maintenance, the encountered apathy in the health care system, and the high, often uninsured costs of compression sleeves, compression pumps, and complex decongestive massage therapy all contribute to participants' feeling that they are dismissed and abandoned by the health care system. They feel that the health care system was neither fair nor just in the treatment of their condition. They feel that the health care system has not only “failed” them but that it has also “abandoned” them.

Why should I have to go and pay for my own treatment when other things are all taken care of, and that's not being mean or stingy or anything; but this is a common condition that I have which is an extension of the cancer, and if somebody else had a condition that was a part of another major condition, it would all be taken in as one thing and treated that way, but it's like this didn't happen. This is your problem. You go look after it. And, like I said, all the problems: money, emotional, physical, everything – you know, I feel that there should be something to help. (12)

Essence: Existential Aloneness

The prevailing thread or essence salient to all five themes in this study is denoted as Existential Aloneness (See Figure 2). Van Manen (1990) describes essential themes as knots in the webs of our experience, around which certain experiences are spun. Existential Aloneness became evident as such a knot. Each participant



expresses a sense of isolation, of being on their own, of being set adrift to discover what they could about lymphedema in the best way they could.

Figure 2 schematically portrays the weaving of the five major themes identified as they relate to the prevailing thread of existential aloneness.

Participants feel abandoned by a health care system that in many ways created their situation and now they are on their own to cope and deal with the consequences. Throughout the interviews, participants describe their sense of isolation in just about everything they do. They describe that aloneness as it persists throughout everything they do, everywhere they go, and with whom they interact. They cover up the arm, make allowances for it, hide it from view, compensate for its size and shape and limitations. They feel that lymphedema identifies them as “different”. It is something that other people don’t understand, want to be around, or essentially care about. It isolates them, makes them different, and emotionally disturbs them. They yearn to be “normal” once again.

When participants try to search for answers or means of managing the lymphedema they don’t know where to turn for help. Participants who know how to search the professional literature encounter the challenge of having to decipher mounds of conflicting information. Participants who turn to health care professionals for help are met with the same inconsistencies. There is a lack of treatment protocols or inconsistency of protocols between health care professionals.

The isolation or aloneness is compounded by feelings of abandonment from an apathetic health care system. Participants feel they are no longer a priority within the health care system. The system, which has cared for them so well when they were initially diagnosed with breast cancer, has now abandoned them to cope with this constant, disturbing complication of treatment.

Discussion

This paper describes the experiences of thirteen women who are living with lymphedema following breast cancer treatment. The findings offer insight into the participants’ long and arduous struggle with lymphedema and the health care system. This study provides undeniable evidence that health care practices related to lymphedema resulting from breast cancer treatment are not sufficiently meeting the physical and psychological needs of all clients. Participants who developed lymphedema following breast cancer treatment did not receive adequate education about the risk of lymphedema development or about the care required for an edematous limb. They were challenged with searching for means of treating their condition and they left isolated in their search. They encountered little help from their health care professionals and when they did receive information, it was of a conflicting nature. They felt they were set adrift to discover what they could, in the best way that they could.

Living with lymphedema produced a continuous day-to-day struggle. Decisions about what to wear became a daily challenge. Participants described buying clothes to fit the “big” arm and wearing long-sleeved blouses and dresses to hide the “unsightly, swollen” limb. They avoided wearing rings, bracelets, and watches because they were either restrictive or drew attention to the swollen wrists and fingers. These findings are similar to those noted by Carter (1997) and Paskett and Stark (2000) who reported that lymphedema affected social relationships, undermining body image and self-esteem.

Participants indicated that the constant pain, discomfort, and limb heaviness produced an enveloping shadow over their daily lives as the need to function at jobs, and care for their homes and families often created an overwhelming sense of frustration, hopelessness, sadness, and anger. Similar physical complications interfering with everyday functioning have been previously reported by other women with lymphedema (Brennan, DePompolo & Garden, 1996; Paskett & Stark, 2000; Woods, Tobin, & Mortimer, 1995).

Many participants avoided wearing compression garments when out in public and hid the arm behind their back in their desire to look normal. They were very much aware of their body image and sometimes avoided situations that would draw attention to the arm. Self-descriptive phrases included “I just want to be normal again,” “It’s like you’re disfigured,” “It’s like you’re not human.” The resultant disfigurement was often associated with emotional pain and decreased self-esteem and resulted in feelings of aloneness and isolation. Participants stated, “You just know that people are looking at you and wondering,” and “It hurts emotionally...No question about it.” These findings are consistent with Backett’s (1992) reports that lymphedema could result in negative feelings in body image and self-perception. Goffman (1990) found that chronic conditions might result in profound emotional and social anxiety. Carter (1997) also reported that women with lymphedema struggled with social and relationship anxieties, and concerns regarding body image.

Participants’ continual searching for answers about lymphedema was an important finding of this study. Of particular concern was that more than 50% of the participants interviewed for this study were health care professionals. Despite their intimate knowledge of the health care system and their ability to search professional literature, these participants reported that conflicting information and uncertainty of what would be the best method of treatment caused them much frustration. They felt alone in their search, abandoned by the health care professionals who were supposed to help them, and they became angry with a health care system that was apathetic to their situation.

Searching by participants also included chatting with others with lymphedema, searching the Internet and seeking advice from friends and family. Independent and haphazard searching resulted in participants exploring and trying any treatment that offered some degree of hope for improvement. Options ranged from manual lymph drainage, pneumatic compression pumps, drinking concentrated carrot juice, and considerations of amputation. Woods (1993) reported that 90% of patients with breast cancer-related lymphedema did not receive information in relation to their risk of developing lymphedema. Similarly, Paskett and Stark (2000) found that more education and counseling are needed for breast cancer patients who are at risk for developing lymphedema. Finding out and receiving information about lymphedema was the most important issue for the 20 participants studied by Hare (2000).

The emotional impact of living with lymphedema was found to be quite consuming. The array of emotions expressed by participants attests to the energy expended. Constant coping with and compensating for the edematous arm was both frustrating and fatiguing. Sadness, anxiety, self-blame, hopelessness, and resignation were common emotional themes mostly related to impaired physical function, altered body image, and self-esteem issues. “Silent” emotional suffering was how Hare (2000) described similar participants’ experiences.

Participants were especially sensitive to comments about lymphedema made by health care professionals and the type and amount of support received from these professionals had a profound effect on participants. When the majority of participants in this study received unsatisfactory responses of dismissal from the health care system, they endeavored to search as many avenues as possible to obtain answers. This continual probing for information led to emotions of abandonment, loss, sadness, frustration, and anger. Participants described their anger at a health care system that they felt had abandoned them. They then felt distressed for having those emotions which was, in itself, emotionally draining. This combination of emotions has been found in previous studies (Carter, 1997; Velanovich & Szymanski, 1999). Participants felt a conflicting sense of discontentment and gratitude towards a health care system that had saved their lives yet had released them to cope on their own without education and support. Participants complained of receiving

insufficient or conflicting information about lymphedema and about the general insensitivity of their physicians. The women asked for answers, received conflicting information, and generally found themselves alone. Some participants were told to wear a compression sleeve, others were told to use a pump, and others were told, "There is nothing that can be done. Once you have it, you have it." Participants' actual phrases such as "should be happy to be alive," "there is nothing that can be done, just learn to live with it", and "lymphedema is a chronic problem" were uncannily consistent with those of Carter's findings. Hare's (2000) study reported that participants did not receive enough information from healthcare professionals at the time of diagnosis and experienced an overwhelming sense of loss and often suffered in silence. According to Barush (1997), older women sometimes cope by "counting blessings." The words of this study's oldest participant, "I'm lucky" and "There's lots of people a lot worse off than I am" and "it's a sin for me to complain if I haven't got to complain", are similar to those of Barush's (1997) participants.

Another aspect of abandonment described by some participants was the lack of financial support available to cover the costs of treatment strategies. High-pressure garments such as compression sleeves were expensive to buy and a number of participants did not have insurance. Those with insurance policies stated that there was insufficient coverage for sleeve replacement costs. Participants stated that the need for frequent cleaning causes compression sleeves to lose elasticity and require regular replacement. A number of participants found the cost of compression pumps and massage therapy prohibitive.

The predominant theme throughout this study is the participants' sense of being set adrift to live and cope with lymphedema on their own. Most participants lacked knowledge about the complications of breast cancer treatment, in particular lymphedema. Paskett and Stark (2000) reported 77.5% of the 40 women studied were not informed prior to treatment about the possibility of developing lymphedema. Participants were dissatisfied with the lack of attention received from physicians, the inadequate lymphedema prevention education received, and the lack of and inconsistent treatment guidelines for lymphedema care. Comments revealed that although grateful to be alive, these women faced a new battle for which they were not prepared, one that was not life threatening yet one that would greatly affect their daily existence. They felt supported by the health care system in their fight with breast cancer but then felt abandoned, uncertain, and frustrated in their war on lymphedema. The need to receive more education and support with lymphedema prevention and management predominated every interview. Previous literature has identified a need for health information and education from physicians and other health care providers to assist women to cope with cancer-related chronic conditions (Carter, 1997; Coward, 1999; Fitch, Deane, & Howell, 2003; Hare, 2000; Hull, 2000; Humble, 1995; Paskett & Stark, 2000; Passik & McDonald, 1998).

In summary, the sense of isolation and aloneness defining the concept of existential aloneness was the prevailing essence throughout the participants' experiences. Various treatments were sought by the participants in this study and undertaken to help assuage the irritating and frustrating symptoms of lymphedema and to improve quality of life. Some treatments resulted in temporary relief whereas others increased participants' level of dissatisfaction. Participants consistently expressed reactions such as constant discomfort and frustration; the overwhelming sense of loss and abandonment permeated the interviews.

Implications

Health care providers need to become more cognizant of the impact that the development of lymphedema has on the quality of life of breast cancer survivors. Finding out and receiving information about lymphedema was the most important issue for the participants

of this study; followed closely by feelings of abandonment from an apathetic health care system. The perception of an apathetic response by health care providers suggests that psychosocial issues will continue to be a problem for women at risk for, or having developed lymphedema. Health care providers need to be cognizant of the content (both verbal and non-verbal) of messages sent to patients who are seeking assistance in dealing with this chronic, poorly understood, frustrating condition.

There is a continued need to implement lymphedema education sessions to key personnel regarding the aftercare of women at risk for lymphedema development. Consistent information about and psychosocial support for this chronic condition were the quintessential needs identified by participants in this study. The chronicity associated with lymphedema and the resultant negative impact on quality of life implores the need for lymphedema prevention and management protocol development. Health care professionals must develop consistent guidelines and education practices that are implemented in every breast cancer treatment situation. Clients must be involved early in prevention strategies and they must receive consistent guidelines from all health care professionals involved. Doing so should help alleviate the sense of isolation expressed by the participants in this study.

The majority of participants indicated that they felt more comfortable seeking advice from nursing personnel as they felt nurses had more time to discuss problems and concerns with them. Nurses, the professional group most often responsible for pre- and post-operative teaching, need to be diligent in their teaching to ensure that women are taught how to assess for lymphedema development and implement prevention strategies. Particular emphasis needs to be placed on the rationale for doing post-operative arm and chest exercises as many women tend to stop the exercises after muscle stiffness is no longer an issue and muscle movement is back to "normal".

Recommendations

Consistent interdisciplinary practice guidelines for the prevention, monitoring, and maintenance of breast cancer-related lymphedema should be developed and implemented across all sectors of health care.

Continuing education sessions on lymphedema care should be implemented for key interdisciplinary personnel across all health care sectors.

A resource person such as Breast Health Nurse or a Provincial Breast Cancer Nurse Specialist should be established to provide a regular consultation for women undergoing breast cancer surgery.

Further Research

Further research is required to determine the most appropriate amount of information to provide to breast cancer patients about lymphedema risk prior to and post-breast cancer surgery and the most appropriate timing for lymphedema education delivery. Research is also indicated to assess the impact of long-term follow-up of breast cancer patients on prevention and management of lymphedema.

It is worth noting that an interprofessional ad hoc committee to develop and implement practice guidelines has been established in the region where data collection took place. The committee members represent three sectors of health care, the acute care, cancer care, and community care. This committee is also investigating the development of continuing education courses on lymphedema prevention and management for health care providers. ♣

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References

- Backett, K. (1992). Taboos and excesses: Lay health moralities in middle class families. *Sociology of Health and Illness*, **14**(2), 225-273.
- Barush, A.S. (1997). Self concepts of low-income older women: Not old and poor, but fortunate and blessed. *International Journal of Ageing and Human Development*, **44**(4), 269-282.
- Beaulac, S.M., McNair, L.A., Scott, T.E., LaMorte, W.W., & Kavanah, M.T. (2002). Lymphedema and quality of life in survivors of early-stage breast cancer. *Archives of Surgery*, **137**(11), 1253-1257.
- Bosompra, K., Ashikaga, T., O'Brien, P.J., Nelson, L., Skelly, J., & Beatty, D.J. (2002). Knowledge about preventing and managing lymphedema: A survey of recently diagnosed and treated breast cancer patients. *Patient Education and Counseling*, **47**, 155-163.
- Box, R.C., Reul-Hirche, H.M., Bullock-Saxton, J.E., & Furnival, C.M. (2002). Physiotherapy after breast cancer surgery: Results of a randomized controlled study to minimize lymphedema. *Breast Cancer Research and Treatment*, **75**, 51-64.
- Brennan, M.J. (1992). Lymphedema following the surgical treatment of breast cancer: A review of pathophysiology and treatment. *Journal of Pain and Symptom Management*, **7**, 110-116.
- Brennan, M.J., DePompolo, R.W., & Garden, F.H. (1996). Focused review: Postmastectomy lymphedema. *Archives of Physical Medicine and Rehabilitation*, **77**, S-74-S-80.
- Burstein, H.J., & Winer, E.P. (2000). Primary care for survivors of breast cancer. *New England Journal of Medicine*, **343**(15), 1086-1094.
- Canadian Cancer Society (2002). *Canadian Cancer Statistics 2002*. Retrieved March 4, 2004 from http://www.cancer.ca/ccs/internet/mediareleaselist/0,3172_15232_355999_langId-en.html
- Canadian Cancer Society (2004). *Canadian Cancer Statistics 2004*. Retrieved July 23, 2004 from http://www.cancer.ca/ccs/internet/standard/0,3182,3172_14435langId-en,00.html
- Carter, B.J. (1997). Women's experiences with lymphedema. *Oncology Nursing Forum*, **24**(5), 875-882.
- Chirikos, T.N., Russell-Jacobs, A., & Jacobsen, P.B. (2002). Functional impairment and the economic consequences of female breast cancer. *Women & Health* **36**(1), 1-20.
- Chu, K.C., Tarone, R.E., Kessler, L.G., Ries, L.A., Hankey, B.F., Miller, B.A., & Edwards, B.K. (1996). Recent trends in U.S. breast cancer incidence, survival, and mortality rates. *Journal of National Cancer Institute* **88**(21), 1571-9.
- Coster, S., Poole, K., & Fallowfield, L.J. (2001). The validation of a quality of life scale to assess the impact of arm morbidity in breast cancer patients post-operatively. *Breast Cancer Research and Treatment*, **68**, 273-282.
- Coward, D.D. (1999). Lymphedema prevention and management knowledge in women treated for breast cancer. *Oncology Nursing Forum*, **26**(6), 1047-1053.
- Erikson, V.S., Pearson, M.L., Ganz, P.A., Adams, J., & Kahn, K. (2001). Arm edema in breast cancer patients. *Journal of the National Cancer Institute*, **93**(2), 96-111.
- Fitch, M.I., Deane, K., & Howell, D. (2003). Living with ovarian cancer: Women's perspectives on treatment and treatment decision-making. *Canadian Oncology Nursing Forum* **13**(1), 8-13.
- Ganz, P.A., Rowland, J.H., Meyerowitz, B.E., Desmond, K.A. (1998). Impact of different adjuvant therapy strategies on quality of life in breast cancer survivors. *Recent Results Cancer Research*, **152**, 396-411.
- Goffman, E. (1990). *Stigma: Notes on the Management of spoiled identity*. Harmondsworth, Penguin.
- Hare, M. (2000). The lived experience of breast cancer-related lymphoedema. *Nursing Standard*, **15**(7), 35-39.
- Harris, S.R., Hugi, M.R., Olivotto, I.A., & Levine, M. (2001). Clinical practice guidelines for the care and treatment of breast cancer: 11. Lymphedema. *Canadian Medical Association Journal*, **164**(2), 191-199.
- Hull, M.M. (2000). Lymphedema in women treated for breast cancer. *Seminars in Oncology Nursing*, **16**(3), 226-237.
- Humble, C.A. (1995). Lymphedema: Incidence, pathophysiology, management, and nursing care. *Oncology Nursing Forum*, **22**(10), 1503-1509.
- National Cancer Institute. (1999). *Lymphedema*. <http://www.cancer.gov/cancertopics/pdq/supportivecare/pain/patient>
- Pappas, C.J., & O'Donnell, T.F. (1992). Long term results of compression treatment for lymphedema. *Journal of Vascular Surgery*, **16**, 555-564.
- Paskett, E.D., & Stark, N. (2000). Lymphedema: Knowledge, treatment, and impact among breast cancer survivors. *The Breast Journal*, **6**(6), 373-378.
- Passik, S.D., & McDonald, M.V. (1998). Psychosocial aspects of upper extremity lymphedema in women treated for breast carcinoma. *Cancer* **83**(12): 2817-2820.
- Polinsky, M.L. (1994). Functional status of long-term breast cancer survivors: Demonstrating chronicity. *Health and Social Work*, **19**(3), 165-169.
- Radina, M.E., & Armer, J.M. (2001). Post-breast cancer lymphedema and the family: A qualitative investigation of families coping with chronic illness. *Journal of Family Nursing*, **7**(3), 281-299.
- Radina, M.E., Armer, J.M., Culbertson, S.D., & Dusold, J.M. (2004). Post-breast cancer lymphedema: Understanding women's knowledge of their condition. *Oncology Nursing Forum*, **31**(1), 97-104.
- Thiadens, S.R.J., Armer, J.M., & Porock, D. (2002). NLN preliminary statistical analysis of survey data on lymphedema. *National Lymphedema Network*, **14**(1), 5-6, 8.
- van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany: State University of New York Press.
- Velanovich, V., & Szymanski, W. (1999). Quality of life of breast cancer patients with lymphedema. *The American Journal of Surgery*, **177**(3), 184-188.
- Wilson, C., & Bilodeau, M.L. (1989). Current management for the patient with lymphedema. *Journal of Cardiovascular Nursing*, **4**, 79-88.
- Wingo, P.A., Ries, L.A.G., Rosenberg, H.M., Miller, D.S., & Edwards, B.K. (1998). Cancer incidence and mortality, 1973 - 1995. *Cancer* **82**(6), 1197-1207.
- Woods, M. (1993). Patient's perceptions of breast cancer-related lymphoedema. *European Journal of Cancer Care*, **2**, 125-128.
- Woods, M., Tobin, M., & Mortimer, P. (1995). The psychosocial morbidity of breast cancer patients with lymphoedema. *Cancer Nursing* **18**(6), 467-471.
- Wyatt, G.K., & Friedman, L.L. (1998). Physical and psychosocial outcomes of midlife and older women following surgery and adjuvant therapy for breast cancer. *Oncology Nursing Forum*, **25**(4), 761-768.