

The Experience of Lower Limb Lymphedema for Women After Treatment for Gynecologic Cancer

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Purpose/Objectives: To describe women's experiences with lower limb lymphedema to inform both preventive and management clinical practices.

Design: A retrospective survey.

Setting: The gynecology/oncology unit of a tertiary referral women's hospital in Australia.

Sample: 82 women who developed lower limb lymphedema after surgical and radiation treatment for gynecologic cancers.

Methods: Structured interviews.

Main Research Variables: Psychosocial and emotional impact, physical effects, knowledge, support, treatment modalities.

Findings: Women identified changes in appearance and sensation in the legs and the triggers that both preceded and exacerbated symptoms. Women described seeking help and receiving inappropriate advice with as many as three assessments prior to referral to lymphedema specialists. Many women implemented self-management strategies. Lower limb lymphedema had an impact on appearance, mobility, finances, and self-image.

Conclusions: Increasing longevity after gynecologic oncology treatment requires all practitioners to be aware of known or potential triggers of lower limb lymphedema and the appropriate referral and management strategies available. Women at risk need to know early signs and symptoms and where to seek early care.

Implications for Nursing: The role of nursing in acute and community care of women at risk for developing lower limb lymphedema includes (a) engaging women in protecting their legs from infection or trauma pre- and postoperatively, (b) providing nursing care and education during the pre- and postoperative phases, and (c) ensuring that women being discharged are aware of early signs and symptoms of lower limb lymphedema and how to access qualified, specialized therapists so that early and effective management can be initiated.

Key Points . . .

- Development of lower limb lymphedema erodes women's sense of full recovery after treatment for gynecologic cancer.
- All healthcare practitioners require more knowledge of early warning signs and appropriate referral for care of lower limb lymphedema.
- Women at risk require predischARGE information about the possibility of developing lower limb lymphedema and where to seek early and appropriate treatment.

rich lymph fluids in the interstitial spaces of subcutaneous tissue (Logan, 1995). Lymphedema can lead to distortion of size, shape, and function of affected extremities.

No standardized guidelines are available for nursing care in the pre- and postoperative periods for women undergoing gynecologic cancer surgery involving lymph node dissection. Knowledge is needed that will inform a dynamic multidisciplinary model of continuous care for those at risk for developing lower limb lymphedema after gynecologic cancer treatment.

Researchers can only hypothesize that lymphedema in one or both legs will encroach on a woman's quality of life and well-being after an experience with a potentially fatal disease.

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Advances in surgical procedures, chemotherapy, and radiation have significantly reduced mortality from the major cancers of the female reproductive system, thus increasing longevity. Reducing sequelae that may affect quality of life is an important consideration in contemporary gynecologic cancer care. Although women may be cured from these cancers, subsequent morbidity such as lower limb lymphedema can be debilitating and require intensive, costly treatment. Few documented studies exist that focus primarily on this symptom.

Lymphedema is a chronic condition that may develop after removal of or radiotherapy to lymph nodes. Lymphedema occurs when the lymphatic system is unable to maintain tissue fluid homeostasis, resulting in accumulation of protein-

This article reports on a study of the experience of lower limb lymphedema after treatments for gynecologic cancers that was part of a larger study that also examined the incidence and prevalence of this condition (Ryan et al., in press).

Previous Research

A review of the literature revealed a paucity of information about lower limb lymphedema after gynecologic cancer treatment in contrast to upper limb lymphedema after breast cancer treatment. The management of upper limb lymphedema is not directly transferable to the management of lower limb lymphedema. The incidence and impact of lower limb lymphedema have not been studied widely. One study that observed the incidence and impact of lymphedema of all women having groin dissection for vulvar cancer during a one-year period found that 13 of 16 women were symptomatic within six weeks after surgery (Abang, de B Lopes, Regnard, & Monaghan, 1999). The researchers advocated preventive or early intervention practices for women who had lymph nodes removed during surgical treatment for vulvar cancer, but they did not suggest what practices may be effective. Another study measured the incidence of lymphedema in 54 women after treatment for cancer of the cervix (Werngren-Elgström & Lidman, 1994). Using limb volume measurements and structured interviews, the authors reported that 41% ($n = 22$) of women developed measurable lower limb lymphedema, with 22% ($n = 12$) reporting symptoms. Other available case reports each described one case of a woman with lower limb lymphedema, the management, the outcome, and the suggested best treatment models (Araujo et al., 1997; Charge, 1995; Matthiesen & Simonsen, 1990).

Measurement

Some researchers claim that the diagnosis of lymphedema is hampered by a lack of quantifiable measurement techniques (Gerber, 1998). However, women developing lower limb lymphedema commonly report perceived changes in sensation, such as a feeling of heaviness in the affected limb(s) (Abang et al., 1999; Gerber; Green, 1998; Humble, 1995; Samdani, Lachmann, & Nagler, 2001), and changes in the size of the affected limb(s) (Abang et al.).

Current practices to help minimize the incidence of upper limb lymphedema include avoiding injections and blood pressure checks in the at-risk limb (Brennan, 1992; Humble, 1995; Smith, 1998). However, the practice of avoiding injections in the legs of women who have had treatment for gynecologic cancers is not a widely documented or accepted practice.

Triggers

Some triggers thought to precipitate upper limb lymphedema have been identified and are used to educate women about how to prevent or at least minimize severity (Passik & McDonald, 1998). When lymphedema develops, stagnant fluid in the interstitial spaces can put people at increased risk for infection. Avoiding injury to the skin and keeping the skin moisturized are examples of practices that people at risk are encouraged to adopt. Good skin care is believed to minimize lower limb lymphedema (Mortimer, 2000), as is avoiding having the legs in a dependent position for long periods such as with air travel (Casley-Smith & Casley-Smith, 1996; Samdani et al., 2001).

Treatment

Current treatment for lymphedema primarily is implemented by lymphedema therapists and involves massage (lymphatic drainage), bandaging, and wearing correctly fitted compression garments (Klein, Alexander, Wright, Redmond, & LeGasse, 1988; McElrath & Runowicz, 2000; Samdani et al., 2001), with variable outcomes. None of these practices prevents lymphedema. They are aimed at reducing edema and associated discomfort.

Experience of Lymphedema

Studies focusing on the experience of having lymphedema secondary to cancer treatment have identified both physical and psychosocial concerns (Carter, 1997; Green, 1998; Velanovich & Szymanski, 1999). Carter also reported that women experienced frustration at the chronic nature of the condition and dissatisfaction with the lack of knowledge among healthcare professionals about lymphedema and management. Without more evidence, these findings imply that lower limb lymphedema would have similar effects on women after treatment for gynecologic cancer.

Purpose

The purpose of this study was to describe the experience with lower limb lymphedema of women after treatment for gynecologic cancer from a perspective that would provide guidance for nursing practice. The aim was to determine the physical and emotional impact that lower limb lymphedema has on the lives of women who had gynecologic cancer surgery in a large, urban, tertiary referral center in Australia.

Methods

A retrospective survey was conducted after ethical approval from the hospital and area health service. The study took place in a major tertiary referral women's hospital.

Sample

The names and addresses of women who had surgery for gynecologic cancer within the five-year period (May 1995–April 2000) were accessed from the gynecologic cancer database. Care and consultation took place to exclude women who were known to have died or who were terminally ill.

A total of 743 invitations to participate in a survey of lower limb swelling and stamped return envelopes were mailed to women. All women who had major surgery were included to differentiate those who had and did not have lymph node dissection. The letter of invitation consisted of a brief introduction to and rationale for the study. Each woman was asked to provide her name, type of surgery, follow-up treatment such as chemotherapy or radiotherapy, and if she had experienced any lower limb swelling after surgery. If the answer was yes, she was asked if she would consent to an interview and assessment of the affected limb(s).

Data Collection

The research team developed the invitation to participate and the interview guide. The research nurse was trained in the research protocol, which included techniques for conducting structured interviews. Women were contacted as soon as possible after consent to be interviewed was received. Appoint-

ments were made for structured interviews in their homes at their convenience. For women living long distances from the hospital, telephone interviews were booked.

Interviews took place in the homes of the women when possible. The geographic range for home interviews was about 155 miles. Interviews took place in the homes of 45 women. Telephone interviews were conducted with 35 women who lived out of traveling range. An additional two interviews took place in the hospital, where one woman was attending the outpatient clinic and another was an inpatient. Family members acted as interpreters for three women who were not fluent in English.

The interviews were tape-recorded with the permission of the women. The questions were designed to determine the emotional and physical impact that lower limb swelling had on the lives of women. The interview also sought to establish what education and information was made available to the women prior to the development of swelling and how much time and expense the women devoted to managing what became a chronic condition.

Data Analysis

Content analysis techniques were applied to the interview data. Single units of behavior within the answers to each of the questions were identified. For example, if a woman said, "The first thing I noticed was swelling and pain in my legs," this comment became two units of behavior: "The first thing I noticed was swelling in my legs" and "The first thing I noticed was pain in my legs." This process generated 1,800 units of behavior that became the data set for analysis.

Lists of units of behavior were generated for each of the questions and circulated to each member of the research team. Each member of the research team independently coded the units into categories. In the case of the earlier example, the two units of behavior eventually were categorized as "symptoms at onset." Further refinement into discrete categories was carried out until all data were included. Confirmation and consensus of the coding were carried out in team meetings, and a relationship between the categories was developed.

Findings

Sample

The final sample of women who contributed to the data collection was a cohort of 487, or 66% of those from the surveyed population. Although lower limb swelling was reported by 36% ($n = 177$) of the women, clinical diagnosis was only made in 18% ($n = 89$), all of whom had lymph nodes removed. Seven of these 89 women declined the invitation to be interviewed, leaving the sample for this analysis at 82 women who had confirmed lower limb lymphedema. These 89 women had treatment for cancer of the vulva ($n = 32$), uterus ($n = 25$), cervix ($n = 21$), ovary ($n = 10$), and vagina ($n = 1$). The interview data yielded a variety of ways in which lower limb lymphedema had affected the lives of these 82 women. These findings are presented in a sequence experienced by the women from first noticing symptoms to adapting to living with the chronic condition.

The Onset of Lower Limb Lymphedema

Symptoms: The initial changes described by 73% ($n = 60$) of the women were in appearance (85%, $n = 51$) or sensation (15%, $n = 9$). Appearance changes were swelling of part or all

of the leg, visible lumps, puffiness, and reddened areas. Sensation changes included pain, heaviness, hardness, heat, tenderness, and pins and needles.

When asked specifically about pain, 60% ($n = 49$) of the women were experiencing some degree of pain, with 27% ($n = 13$) of this cohort indicating more than one type of pain. Descriptions of pain included a feeling of heaviness and fullness (24%, $n = 12$), an ache (41%, $n = 20$), tightness (16%, $n = 8$), sharp pain (12%, $n = 6$), and throbbing sensation (6%, $n = 3$).

Triggers: Some women described several triggers that they believed had preceded the appearance or worsening of symptoms signaling lower limb lymphedema. Figure 1 identifies the types of triggers that 20% ($n = 16$) of the women believed initiated the onset of swelling. Three of the women identified more than one trigger. Incidences of trauma or infection included cellulitis, a fall, ascitic tap, sunburn, injection to affected limb, and a mosquito bite. Stasis included either being on their feet all day or long-distance traveling. Heat exposure included sitting close to a radiator, hot weather, sunburn, and being in a hot spa.

Factors that exacerbated lower limb lymphedema were identified by 59% ($n = 48$), with 33% ($n = 16$) of these women indicating more than one factor. The most common worsening of lymphedema occurred when the legs were in one position such as when traveling and especially standing (46%, $n = 22$); with temperature extremes, especially heat (29%, $n = 14$); with trauma or infection (17%, $n = 8$); and with overactivity (8%, $n = 4$).

Seeking Information and Treatment

The effort to find appropriate information and treatment was a long and convoluted one for 34% ($n = 28$) of women. They described considerable delay in finding appropriate information and treatment.

Sources of information: On noticing the onset of symptoms, 98% ($n = 80$) of the women began to seek advice from professionals. The majority of first contact was with general practitioners (54%, $n = 44$) and surgeons (22%, $n = 18$). The remaining 22% ($n = 18$) consulted various other sources such as gynecologists, nurses, and rehabilitation specialists. In the first contact with a professional about the swelling, 27% ($n = 22$) of the women were not informed about lower limb lymphedema or the specialist care available. Ultrasounds, Doppler studies, and diuretics were ordered. Verbal responses

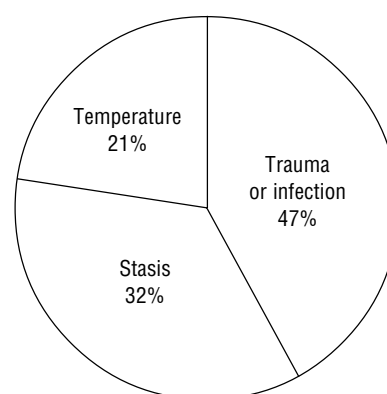


Figure 1. Categories of Reported Triggers of Lower Limb Lymphedema (N = 16)

to the swelling included, “It’s nothing,” “It’s sciatica,” “a hernia,” “part of surgery,” “You have to live with it,” and “It will clear up.” A few of the women (7%, $n = 6$) were informed about lower limb lymphedema but were not given any further advice or management techniques. At these first sources of information and assistance, 22% ($n = 18$) of the women were referred to other healthcare professionals.

Getting referral to treatment: For 83% ($n = 68$) of the women, a second or third visit was required to get a referral to a qualified lymphedema therapist. Referrals were made by surgeons (30%, $n = 25$), general practitioners (15%, $n = 12$), radiotherapists (6%, $n = 5$), physiotherapists (15%, $n = 12$), community nurses (2%, $n = 2$), gynecologists (2%, $n = 2$), medical oncologists (1%, $n = 1$), and a cancer clinic (1%, $n = 1$). Ten percent ($n = 8$) of the women found a lymphedema clinic through their own research. One woman described her experience: “My own gynecologist knew nothing about lower limb lymphedema. I am now sharing my knowledge with him.”

Timing of information: Figure 2 represents the women who reported when they were aware of the potential risk of developing lower limb lymphedema after treatment. Of the 17% ($n = 14$) of women who recalled being informed preoperatively, the information came from surgeons (64%, $n = 9$), general practitioners (21%, $n = 3$), and physiotherapists (14%, $n = 2$).

Of the 29% ($n = 24$) of women who recalled being informed postoperatively, the information came from physiotherapists (50%, $n = 12$), surgeons (42%, $n = 10$), and radiotherapists (8%, $n = 2$). Three of the women were informed by more than one source. The majority of these women were informed during the postoperative hospital stay (71%, $n = 17$), others were informed during follow-up visits, and the remainder not until after the onset of swelling (17%, $n = 4$).

Quality of information: The women who were provided with information, either in the pre- or postoperative period, described the quality of information as inadequate (38%, $n = 13$) or adequate (62%, $n = 21$). In an attempt to gain more information, 10% ($n = 8$) of the women conducted personal re-

search through library resources, newspaper articles, and the Internet. Some women (13%, $n = 11$) said they were shocked to discover lower limb lymphedema: “I had never heard of lymphedema until I had it,” “I never expected this,” and “I was very cross that I hadn’t been informed. I wish somebody had warned me about this.” Others had been told “there may be some swelling,” with estimates of “one in a million; it is very rare.” Others recalled comments that minimized lymphedema such as, “I was told to expect some swelling, but no indication was given that it could be permanent.”

Women also were shocked at the severity of lower limb lymphedema once it developed. Three of the women were familiar with lymphedema from their own previous experiences with breast cancer, and two others had learned of lymphedema from friends with breast cancer. Only one woman said she was “very informed and well prepared.” Overall, the women described their discovery of lower limb lymphedema as a shock: “It is a very much underpublicized condition that is happening to people” and “I wish I had known before. It was like a big secret, and I thought I was the only person on earth going through this.” They felt alone and somewhat betrayed.

Management Received

Complex physical therapy: Of the women who were treated by lymphedema therapists, 93% ($n = 76$) received some form of complex physical therapy (CPT). CPT includes a combination of education, skin care, lymphatic massage and exercises, routine bandaging, and compression garments, the particular combination usually depending on the severity of swelling and tolerance of treatments. The women reported variation in perceived effectiveness of the treatments from providing much relief and reducing swelling to having no effect at all (see Table 1).

Compression garments: Compression garments were the most common form of prescribed treatment. Of the 72% ($n = 55$) who had them prescribed, 20% ($n = 11$) were unable to continue wearing compression garments. They were not found to be either comfortable or attractive by 54% ($n = 30$) who said they were, however, necessary to keep the swelling controlled and reduce discomfort. Common comments were, “They are uncomfortable” and “I have never found a pair of stockings really comfortable and wish there was a more readily available range of stockings,” and that they were worn only as “a preventative measure to keep swelling down.” Women reported that they did not wear them continuously because, “They roll down and become uncomfortable” and they are “difficult to keep up,” “too difficult to get on,” and “unbearable in the summer.” Rural women believed they had little choice in stockings available to them. One woman worried that, as she got older, “How am I going to get the stockings on? It is already difficult.”

Self-management: As well as receiving treatment from professionals, 73% ($n = 60$) of the women also used self-management techniques that helped reduce swelling or provide comfort. The techniques the women used ranged from rest and elevation of the legs, gentle walking, tai chi, and line dancing. Some of the women said that they were motivated to do the time-consuming daily massage and exercise routines if they had seen pictures or encountered someone with severe lower limb lymphedema: “I saw a swollen leg, and that was good to see because I know if I don’t do the right thing, that could happen to me. It acts as a guide as I don’t want a drag leg.”

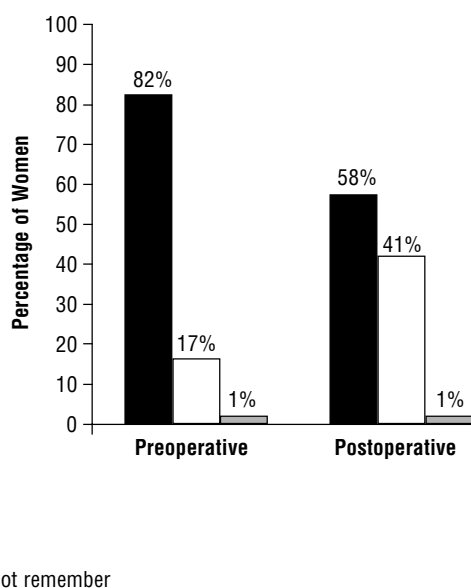


Figure 2. Percentage of Women Receiving Information Pre- or Postoperatively

Table 1. Effectiveness of Treatment Modalities

Treatment Type	% of Sample	Controlled or Reduced Swelling (%)	Minimal or No Difference (%)	Reduced Pain (%)	Unable to Tolerate (%)	No Comment (%)
Compression garments	94	41	5	15	22	17
Lymphatic massage and exercises	87	34	21	10	—	31
Bandaging	19	50	—	—	8	42
Diuretics	10	—	100	—	—	—
Care of limb instructions	5	—	—	—	—	100
Bike shorts	3	—	—	50	—	50
Anti-inflammatory drugs, analgesics	2	100	—	—	—	—
Paddling in water	2	—	100	—	—	—

Impact on Lifestyle

Financial burden: Having lower limb lymphedema created extra expenses (see Table 2). Expenses for compression garments and complex physical therapy were described as a financial burden for 27% (n = 22) of the women. Two women said the cost of compression garments was not a concern because they provided comfort and support, and two women received free treatment. Two women described being denied employment because of the visibility of their legs: “I asked for a job application at a supermarket and was told, “We can’t give you a job, look at your leg” and “Unable to find work because I cannot sit or stand for long periods.” The reduced financial resources of retirement also were a concern: “What concerns me is retirement—what is going to happen because I am still going to have lymphedema and the associated expenses.”

Changes to clothing: The women made major changes in relation to their wardrobes (see Table 3). Long pants, long skirts, or dresses were worn exclusively by 79% (n = 65) of the women to disguise the appearance of swollen legs or unflattering compression garments. They also described having to increase the size of clothes: “I only wear loose, baggy clothes to hide the swelling,” “a bigger size of pants,” and “I wear a wider shoe to fit stockings.” Swimsuits and shorts would “never be worn” by 12% (n = 10) of the women. Fashionable shoes no longer were possible for some women (9%, n = 7) because of comfort and appearance, with summer being of particular distress: “I can’t put shoes on in the heat of the summer.”

Changes to activities: A majority of the women (51%, n = 42) altered their everyday activities because of swollen legs. Table 4 shows the various ways in which the women found that lower limb lymphedema altered their activities. Some women

expressed changes in personal relationships because of restricted mobility and exercise: “I can’t walk with my husband any more. It was something we enjoyed doing together.” Several expressed the loss of interaction and intimacy with partners as a result of the appearance and restrictions from swollen legs. They also were restricted in interaction with friends because they could not participate in water aerobics or swimming: “too embarrassing,” “I can feel people looking at it,” or walking on the beach or in the bush was impossible because of heaviness and aching as well as appearance. One woman summarized her experience with lower limb lymphedema as, “My whole life seems to be turned upside down—it seems to be revolving around my legs.” Another said, “It has ruined my life, and I have to put up with it.”

Coping With Lower Limb Lymphedema

Developing lower limb lymphedema after surgery for cancer was distressing. Several perspectives existed within this sample of women, ranging from, “I would never have had [nodes] taken out if I had known—I think I would rather have taken my chances than go through this” to “At least you are alive and healthy—so you just put up with it” and “I am happy to have overcome the problem that caused it. If this is all that goes wrong, well, so be it.” A few women felt such a loss that they made comments such as, “This has been worse than the cancer, living with a swollen leg.” Others made comparisons such as, “I am pretty lucky because I have seen far worse legs than my own.” The variation in ways of living with the condition never reached acceptance but rather resignation by those who alleged, “I just cope with it. It is there, and I just try to get on and do what I have to do the best that I can” and “It has just become a routine to me, and you get on with life.”

Women reflected on learning to live with lower limb lymphedema. Protection of the leg was important. “I have a

Table 2. Lymphedema-Related Expenses

Treatment	Expense	% Reporting
Compression garments	Ranged from \$24–\$570 a pair; 1–10 pairs of garments purchased a year	60
Specialist care (massage therapist, physiotherapy, private therapy, podiatry care)	Treatment prices ranged from \$12 a visit to \$2,000 a month	28
New clothes	The purchase of new clothes including underwear and footwear	12

N = 47

Table 3. Clothing Alterations

Experience	%
Shoe alterations (e.g., increased size or broadness, difficulty putting shoes on, open shoes only, shoes for comfort over appearance, no high heels, no sling backs, adjustable elasticized shoes)	38
Increased size of garments	33
Change in type of garment worn—loose-fitting garments for comfort and appearance	27
Bike shorts worn under all clothing to prevent chafing	2

N = 82

Table 4. Alterations in Daily Activities

Experience	%
Standing or sitting for long periods	51
Unable to walk distances as long as before (many having previously enjoyed walks)	20
Retirement: change in occupation or restrictions in job opportunities related to occupations involving long periods of sitting or standing	13
Housework has had to be spaced out.	6
Shopping very difficult	4
Driving any great distance is a painful experience (especially when driving a manual automobile).	4
Unable to stand for long periods	4
Social activities limited	15
Previously played sports and social activities are unable to be participated in—tennis, gardening, croquet, swimming, and mowing a lawn.	14
Heavy objects are unable to be lifted.	1
Precautions being taken	13
Wary of participating in some activities, thinking twice before doing so	
General decreased participation in everyday activities	12
Wearing compression garments	7
Time-consuming and difficult to put on	

N = 82

Note. Some women identified more than one category.

constant fear of injury,” one said. Another who had five recent hospitalizations for cellulitis explained, “I am aware of the vulnerability of the leg and that injury can cause complications. I cannot plan on doing anything due to frequent bouts of cellulitis. I get only a couple of hours warning, then everything gets put on hold.” The women described knowing what leads to increased swelling: “If I do something around the house, I really pay for it after.” Traveling with legs down or standing for long periods also led to increased swelling. The women had to get used to the heaviness of lower limb lymphedema and its implications: “I tend to trip over a lot. I don’t realize the weight of the leg and that I haven’t lifted the leg high enough.”

Discussion

The response rate to the invitation to be interviewed was a high 92%. The women who participated were very willing to help develop more understanding of lower limb lymphedema. They revealed that developing lymphedema affected their lives in a variety of ways. Their descriptions of the challenges they encountered when lymphedema developed have considerable relevance for all those who care for women in both acute and community settings after surgery for gynecologic cancer. The path to qualified lymphedema therapists was not at all expedient or consistent for these women. They felt they encountered considerable lack of knowledge or recognition of their problems from a wide range of healthcare professionals. Appropriate information was not always received from those from whom they first sought advice. Some women were sent for Doppler scans or ultrasound or were prescribed diuretics without apparent acknowledgement of their risk for lower limb lymphedema. These findings point to a clear indication that all professionals who might be or are involved with women undergoing gynecologic cancer surgery need more knowledge about who is at risk of developing

lymphedema, how it presents, and resources for treatment. With increasing survival rates, an appropriate continuity of care model must be available.

Of note, many women reported not knowing about the possibility of lower limb lymphedema, but surgeons reported that the possibility of lymphedema was discussed in preoperative preparation. The women were unprepared when lower limb lymphedema occurred and further shocked by the “permanence” and “severity” of this outcome of their treatment for the already alarming diagnosis of cancer. Because general practitioners were the first to be consulted by 55% (n = 45) of the women, the surgical and pathology reports routinely should be copied to women’s general practitioners, with a note to alert them to the risk for lower limb lymphedema. They need to know the context for “swelling of the legs” and be able to initiate early management with lymphedema therapists.

The development of lower limb lymphedema not only altered the women’s activities but also created unexpected costs that were a financial burden. Most health insurance plans do not cover compression garments and have no or limited reimbursement for CPT. Treatment such as CPT is time-consuming and expensive. Compression garments are costly, and many women required new clothes. The fact that some women, knowing the risk of increased swelling, occasionally chose not to wear compression garments so that they could wear a nice dress “without ugly stockings being visible” indicates continued attempts to regain or have a normal body. Some women would not wear swimsuits or shorts. They preferred comfort and wore “unattractive” or “different styles” of clothes to disguise the appearance of swelling or compression garments. These findings support those of Carter (1997) and Velanovich and Szymanski (1999), whose work with women with breast cancer found that lymphedema leads to major changes in body image and self-esteem.

The individual ways in which women sought relief from symptoms are apparent in the findings. The seeking and use of self-management modalities by 73% (n = 60) of the women showed the scope and range of their desperate search for assistance in managing physical and mental distress.

Implications for Practice and Research

This study points to a clear role for nurses in the care of women undergoing surgery for cancer with resection of pelvic, abdominal, and groin lymph nodes. That role extends from the preoperative phase through community-based care.

Education of Nurses

Education of nurses about the early onset and distress resulting from lower limb lymphedema among women at risk is important. The need for women to have information is paramount. Education should begin preoperatively and occur again prior to discharge from the hospital. Information should be delivered orally and in a written format. Educating healthcare professionals, women, and their significant others is an appropriate aspect of the advanced nurse practitioner’s role. Nurses must know the signals of onset and how to help women access resources, including those available by phone and the Internet, which will be especially important for women from rural and remote areas.

Education of Women

Women facing the diagnosis of and surgery for gynecologic cancer may not take note of the possible risk for lower limb

lymphedema, even if it is described carefully. The terms “lower limb lymphedema” and “lymphedema” may not have meaning to women, particularly when they are distressed and distracted while making plans for treatment. Healthcare providers explaining the risk of lower limb lymphedema to women preoperatively may find that using language that women will understand might increase their awareness of the risk and early signs. Phrases such as “If you notice swelling in this leg or legs” or “If your leg feels heavy or aches” may help them think of lower limb lymphedema and seek advice and diagnosis at an early stage.

Preadmission clinics where nurses meet and discuss self-care with women are an important strategy in preparing women for surgery where lymphedema may be an outcome. Nurses can provide advice about how to maintain skin integrity of the legs by reviewing the women’s activities to identify those that might result in trauma or infection.

During postoperative care, nurses who are aware of at-risk women can implement strategies to protect the lower limbs. Maintaining skin integrity and avoiding the possibility of infection is important. Nurses caring for women after lymph node dissection for breast cancer do not give injections in the upper limbs, although this practice has not been tested for lower limbs. Therefore, avoiding injections in the lower limbs of such women seems reasonable. Special care can be taken during assisted mobility, and ensuring good lighting can help women avoid bumping into furniture or equipment.

Prior to discharge, nurses can be sure that at-risk women have the information they need to recognize early signs of lower limb lymphedema and where to seek early and appropriate care. When possible, this information should be provided in the presence of partners or significant others. Women need to know the possible triggers and the changes in sensation or appearance that signal a need for immediate specialized care. Referral information about lymphedema clinics and local or state lymphedema support groups is essential prior to discharge.

Nurses working in home care and community clinics also need information about women at risk for developing lymphedema, early warning signs, and the nearest lymphedema therapist. Nurse-to-nurse referrals could increase the continuity of care and support of these women and their families.

Written materials that are usable, readable, and meaningful to women are needed. The authors have developed a bookmark that contains information about triggers and needed contact numbers. Each woman in this study received a bookmark with a thank-you letter when they completed the data-collection process. The women welcomed this format. Based on their positive responses, the authors now provide bookmarks to all women who come to the unit and are at risk for developing lymphedema after treatment.

As the healthcare system tries to become effective and efficient, minimizing or treating early-onset lower limb lymphedema will have benefits to both women and the healthcare system. Lower limb lymphedema has high costs, whether borne by the women or the healthcare system. For women, the costs are more than financial and include social and mental implications.

Nurses need a combination of education and research so that they can be knowledgeable members of multidisciplinary cancer teams. This study is an example of the clinically based and clinically relevant research that nurses can perform and the understanding that can be gained. Further research is planned to test practices designed to minimize or prevent lower limb lymphedema.

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