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# Acquired Lymphedema: A Chart Review of Nine Women's Responses to Intervention

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Key Words: medical oncology • qualitative method

*The medical records of nine women who had acquired lymphedema as a sequela to a modified radical mastectomy for breast cancer were analyzed to ascertain what factors, phenomena, or experiences in their lymphedema treatment may have influenced outcomes. The women were identified as having either successful or poor outcomes. Their conservative lymphedema treatment consisted of compression pumps, compression garments, and, in some cases, manual lymph drainage.*

*The qualitative analysis of records implicated the following factors in the outcome of conservative lymphedema treatment for these women: (a) the amount of delay before starting compression treatment, (b) the size of the lymphedematous arm when treatment started, (c) the availability of social and financial supports, and (d) the presence of complicating health problems. The findings of this study cannot be generalized; however, further scientific inquiry into the phenomena that lie behind treatment outcome variations could lead to more effective treatment approaches.*

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*This article was accepted for publication July 5, 1993.*

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Occupational therapists are involved in treating people with acquired lymphedema. The focus of treatment is to reduce and control the swelling and to assist clients in adjusting to live with a chronic condition. Lymphedema is the swelling of part of the body (usually a limb) that occurs as a result of an insufficiency in the lymphatic system. It is a chronic condition that is physically and emotionally distressing because of the functional impairment, fatigue, cosmetic deformity, pain, and discomfort with which it is associated.

As mammographies become more common and precancerous tissue is more readily identified, we may see a rise in the number of women undergoing some form of mastectomy or lumpectomy and radiation. A corresponding rise in the number of women developing lymphedema could therefore be expected.

Occupational therapy treatment of acquired lymphedema at a major metropolitan hospital currently involves the use of multicell sequential or gradient sequential compression pumps, in combination with compression garments. The chronic nature of lymphedema requires the client to be treated on an outpatient basis with additional home programming of pumping and wearing pressure garments. Despite a relatively standard treatment procedure, long-term outcomes vary widely, with some people attaining almost complete resolution, whereas others see an increase in the size of the lymphedematous limb.

Excluding recurrent neoplasm, little is known about what is responsible for this disparity in outcomes. Foldi, Foldi, and Clodius (1989) suggested that the main reason for a poor or less successful outcome is failure to comply with the wearing of pressure garments. However, there are clients who do not wear garments whose limb volume is maintained at a reasonable reduction. Foldi et al. (1989) have also suggested that failure to treat the adjacent quadrant of the trunk, which they asserted will always have lymphostasis after mastectomy, will lead to less than satisfactory outcomes. Yet again, many successful outcomes occur without such intervention. Professionals in the field also implicate physical problems, such as arthritis and pain, and social circumstances as complicating factors in the outcome of lymphedema treatment, but currently they do not have empirical studies to support their intuitions.

This paper presents the findings of a qualitative research study of written records that attempted to understand the nature of the experiences of nine women who had lymphedema treatment following mastectomy. The purpose of the study was to generate hypotheses for understanding the similarities and differences that lie behind the treatment outcomes for lymphedema. From the nature of the data used, it necessarily followed that any understanding gained was from the perspective of health professionals. It is seen as a first step on the road to further research.

## Literature Review

This review of the literature comprises information on the incidence, the pathophysiology, and the treatment of lymphedema. There is a paucity of literature dealing with the experiences that contribute to and differentiate successful lymphedema treatment outcomes and poor outcomes.

### *Incidence*

Lymphedema of the upper limb most frequently occurs after axillary dissection associated with radical or modified radical mastectomy secondary to breast cancer (Axelrod & Osborne, 1989). The incidence of lymphedema ranges from 6.7% to 62.5% after a radical mastectomy (Britton & Nelson, 1962), 12.5% after a modified radical mastectomy (Axelrod & Osborne, 1989), and 4.7% after limited resection, axillary dissection, and breast radiotherapy (Axelrod & Osborne, 1989). The incidence of lymphedema increases with the inclusion of radiotherapy preoperatively or postoperatively according to some studies (Axelrod & Osborne, 1989); other studies have found no such correlation (Peznier et al., 1986).

### *Pathophysiology*

The lymphatic system assists in carrying intercellular fluid into the bloodstream, although the bulk of intercellular fluid is removed to the bloodstream via the venous system (Battezzati, 1972). The main role of the lymphatic system is to return protein molecules to the bloodstream (Foldi et al., 1989). Lymphedema occurs when the transport capacity of the lymphatic system falls below the level of the normal lymphatic protein load, creating an abnormal accumulation of protein-rich lymph in the tissue. Lymphedema is different from an overload of a normal lymphatic system, in which case there is an accumulation of low-protein tissue fluid, not lymph fluid (Battezzati, 1972; Foldi et al., 1989).

Edema that develops soon after breast cancer treatment is often mild, occurring before compensatory lymph channels or lymphovenous communication have developed (Axelrod & Osborne, 1989). It is usually resolved by the elevation of the limb, muscle pumping, and the temporary use of compression pumps or temporary pressure gradient garments. However, if the swelling persists for more than a few weeks, the lymph vessels become irreversibly distended, leading to chronic, lifelong lymphedema. Late-onset lymphedema is also invariably chronic and debilitating, frequently resulting in low-grade infection (Axelrod & Osborne, 1989).

Fatigue, functional impairment, and cosmetic deformity are associated with long-standing lymphedema (Axelrod & Osborne, 1989; Zeissler, Rose, & Nelson, 1972).

Increased tissue tension or muscle strain from supporting the weight of the limb can cause pain and discomfort, and fluid pressure impinging on the brachial plexus can lead to loss of power and sensation in the arm (Badger, 1986). Emotional distress may also be associated with the deformity, its chronicity, the loss of function, and the constant risk of infection. If left untreated, long-standing lymphedema predisposes the person to infection and the possibility of developing lymphangiosarcoma, also known as Stewart-Treves syndrome (Foldi et al., 1989; Yamazaki, Idozuki, Nemoto, & Tagawa, 1988).

### *Treatment*

Treatment of lymphedema requires the mobilization and removal of the interstitial fluid and the resorption of the stagnant proteins (Foldi et al., 1989; Janbon, Ferrandez, Vinot, & Serin, 1990; Yamazaki et al., 1988). A widely used conservative rehabilitation approach involves the use of compression pumps and compression garments (Axelrod & Osborne, 1989; Badger, 1986, 1990; De Vita, Hellman, & Rosenberg, 1989; Yamazaki et al., 1988). Manual lymph drainage is also often used in combination with compression pumps or garments (Collard, 1990; Foldi et al., 1989; Titon, Barsotti, Gaisne, & Vaillant, 1990). The aim of compression pumps and manual lymph drainage is to assist the flow of lymph by enhancing the natural pumping effect of muscle contraction. The purpose of compression garments is to compensate for the laxity of the stretched tissue that would otherwise allow rapid refilling. In general, the literature on conservative intervention discusses the principles of a particular approach or the statistical outcomes associated with that approach, but none discusses why outcomes can be so disparate over time, although this fact is acknowledged (Foldi et al., 1989; Raines, O'Donnell, Kalisher, & Darling, 1977; Yamazaki et al., 1988; Zeissler et al., 1972).

All techniques emphasize the need for attention to massage (manual or pneumatic), external compression, exercise, skin care and infection prevention, and education (Collard, 1990; Foldi et al., 1989; Yamazaki et al., 1988; Zeissler et al., 1972). According to Foldi et al. (1989), failure to follow treatment regimes (in particular, failure to comply with the use of compression garments or bandages) is the main reason for lymphedema relapse. There appear to be no studies of why people fail to comply. Studies do imply the potential of some factors to reduce the effectiveness of treatment programs, by excluding lymphedema clients who have neuritic pain, senile dementia, or other complications (Klein, Alexander, Wright, Redmond, & LeGasse, 1988; Raines et al., 1977). Diabetes, obesity, cardiac failure, idiopathic edema, and lipedema have been implicated in aggravating lymphedema (Foldi et al., 1989; Peznier et al., 1986; Treves, 1957; Yamazaki et al., 1988).

## Method

Medical records were analyzed to establish an understanding of the phenomena that lay behind the treatment outcome variations in a group of nine women who developed lymphedema after a mastectomy. Because of the broad range of phenomena covered in hospital records, they were seen as a valuable starting point for a study that had no preconceived ideas. Written documents are valid sample data that can be approached in the same way as interviews or observations (Bogdan & Bilken, 1982; Ely, 1991; Leininger, 1985; Strauss, 1987; Strauss & Corbin, 1990). In this study, the researcher was concerned with understanding the participants' lives as assessed and perceived by health professionals (Ely, 1991), thereby developing an understanding of the similarities and differences that lay behind the variation in treatment outcomes. The study was undertaken at a major metropolitan hospital specializing in cancer research where the occupational therapists run a busy outpatient clinic. More than 300 clients with lymphedema are treated each year.

Study participants were women who had developed lymphedema as a sequela to a modified radical mastectomy, and who were subsequently seen for lymphedema treatment and follow-up in the rehabilitation department. An experienced senior occupational therapist identified six women as having had successful outcomes (i.e., having maintained at least a 50% reduction in limb volume over time) and six as having had poor outcomes (i.e., having no reduction or minimal reduction). Four participants were chosen from each of these two groups for this study. Selective sampling is a method used in qualitative research, consciously undertaken to obtain the greatest opportunity for comparison and to elicit the most relevant data (Bogdan & Bilken, 1982; Strauss & Corbin, 1990). Similarly, a ninth participant was purposely chosen for inclusion because she represented an anomaly, a case that might not fit and might therefore elicit greater variation in the data (Bogdan & Bilken, 1982; Strauss & Corbin, 1990). This participant was identified by the occupational therapist as a difficult case, "a success, but she's not happy with the outcome." Each participant had undergone surgery and lymphedema treatment in the hospital where the study took place, and each had commenced treatment for lymphedema at least 1 year before this study. None of the participants had a recurrent neoplasm implicated with their lymphedema.

Each of the participants was given a pseudonym to maintain anonymity. The medical records were read in turn. A written log was kept for each participant; this log was particularly important in development of a coherent chronology because the medical records were poorly organized. Analytic memos were also written about each participant to facilitate an understanding of each participant's life as a unified whole.

From the medical records there emerged some

broad, clusters of information (e.g., family and social status, medical history, physical status, emotional and psychological status, and treatment procedures). From these, a category matrix was developed for the data analysis process; the matrix facilitated the recognition of data that repeated across the participants within a category. From this recognition, tentative themes started to coalesce. Graphs and charts were also used to illustrate information and assist in identifying themes in the data. According to Strauss and Corbin (1990), it is acceptable for data to be quantified while the data analysis remains a qualitative process.

Data, analytic categories, interpretations, and emerging themes were tested against the various sources of data within the medical records and by conferring with the two occupational therapists and the clinic physician who had worked with the participants during the previous year or years (Strauss & Corbin, 1990). Regular meetings with a research advisor were used to clarify the research process and the emerging themes (Ely, 1991). These activities address the trustworthiness of the study findings.

## Data Analysis

The order in which these preliminary themes are presented in no way reflects their importance. The first theme relates to intervention, the second to broad health issues, and the third to attitude and life-style. A brief profile of the social and medical histories of the nine women is shown in Table 1.

## Intervention

All four women with successful outcomes commenced conservative compression treatment within 2 months of the development of swelling. The women with poorer outcomes sought treatment soon after the swelling commenced, but they were treated by physicians who either adopted a wait-and-see approach or put the women on a course of antibiotics or diuretics or both (see Figure 1). In these four women, conservative compression treatment did not commence immediately.

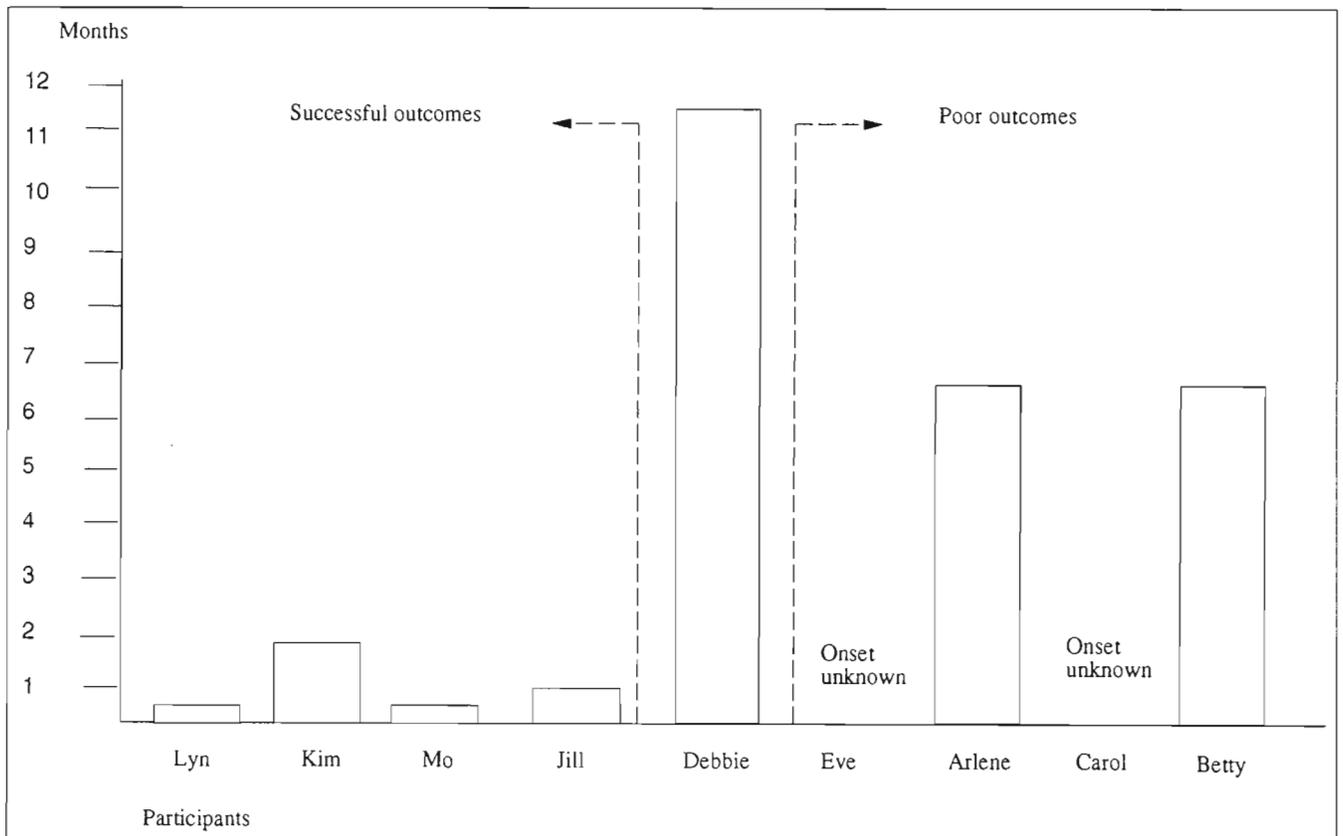
The four women with successful outcomes obtained the greatest percentage reduction in size (the main measure of success). However, these women had very little swelling to reduce, in comparison to those who had poor outcomes (see Figure 2).

For the women with successful outcomes, the circumference of the most swollen part of their arm was less than 1½ in. bigger than the same point on their unaffected arm. The women with poorer outcomes had initial circumferential differences ranging from at least 2 in. to greater than 5 in. In other words, the women with poorer outcomes had started treatment with much more lymphedema than their successful counterparts.

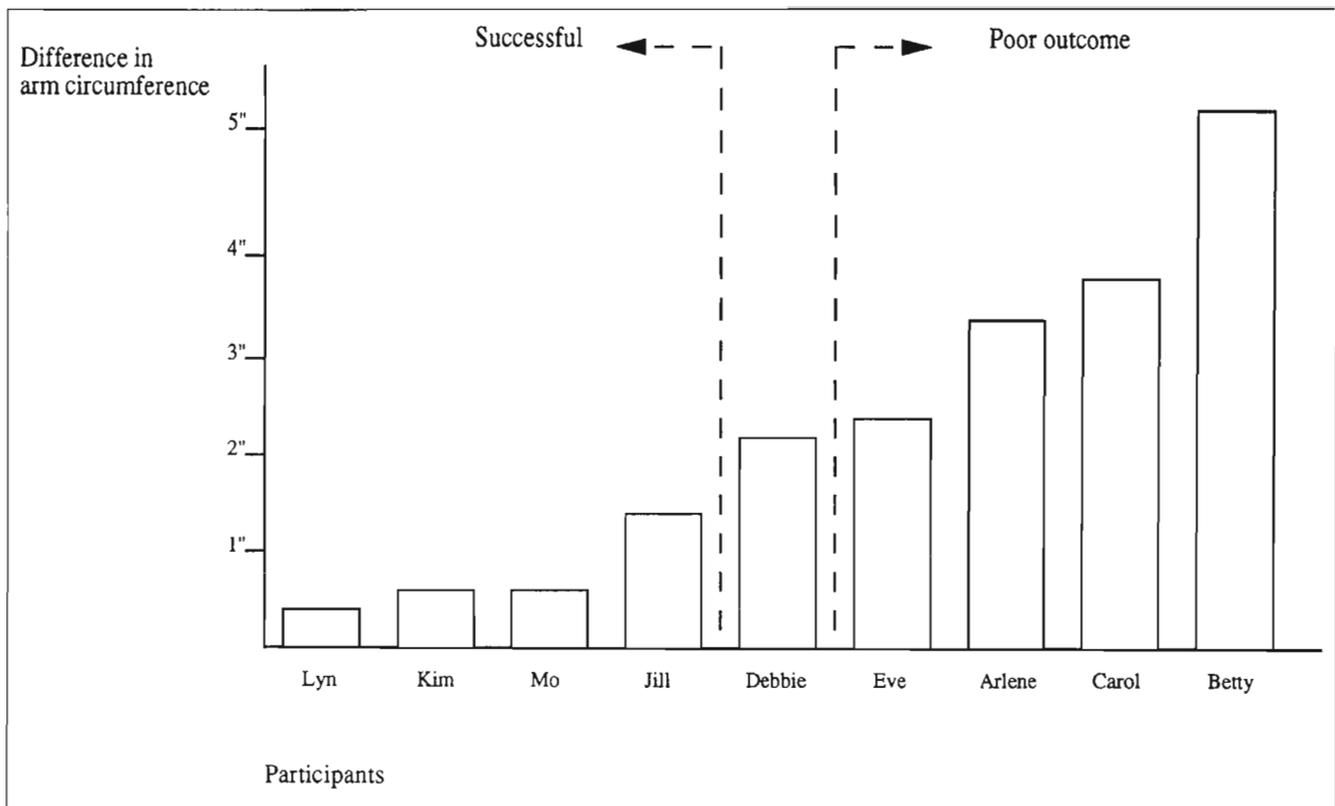
**Table 1**  
**Profile of the Study Participants**

Pseudonym	Age at Surgery (Years)	Family and Living Arrangements	Economic Situation/ Employment	Health	Long-Term Reduction of Lymphedema (%)	Interests and Activities
Arlene	47	Widowed Boarding house	On Social Security; works unofficially as a nurse's aide	Left MRM 4/84 Depression Hysterectomy	7	Watching television
Betty	59	Widowed, with 2 adult children. Lives alone.	20+ years as secretary	Right MRM 7/87	15	Playing golf and tennis, swimming
Carol	64	Lives alone	Not working — retired?	Left MRM 1982 Respiratory problems Oophorectomy Chronic lymphocytic leukemia, diagnosed 1989	0	
Eve	39	Divorced, with teenage son	Does erratic temporary work	Right MRM 11/85 Reconstruction 1987 Seronegative arthritis Depression Endometriosis	0	
Debbie	55	Married, with 2 sons	Has office job Executive husband	Left MRM 9/88	69	"Too busy for hobbies." Walking
Jill	55	Widowed, with 4 adult children (son at home)	Secretary, 10+ years as evening theater attendant	Right MRM 1985 Diabetes	79	Walking, watching sports, theater
Kim	39	Married, with teenage daughter	Vice president of financial company	Right MRM 1989	100	Exercise, active social life
Lyn	36	Single	Medical technician	Right MRM 8/89 Anxiety	83	
Mo	36	Divorced, with 1 son	Office worker	Left MRM 1986 Kesslbach Merritt Syndrome Anxiety	56	

Note. MRM = modified radical mastectomy.



**Figure 1.** Time between onset of lymphedema and start of conservative treatment.



**Figure 2.** Greatest circumferential difference between lymphedematous arm and unaffected arm at time of initial treatment.

The pathophysiology of lymphedema, as outlined in the literature review, suggests that if lymphedema were left untreated, the affected body part would continue to swell. There was no apparent connection between the outcome and the length of time between surgery and onset of lymphedema, which ranged from 2 months to 3 years for these nine women.

### Health

The treatment outcomes for lymphedema were not unaffected by the women's well-being, their treatment routine, or the lack thereof. Illness, infection, inflammation, pain, and depression may have influenced the effectiveness of treatment. Obesity may also have played a role.

*Illness, infection, and inflammation.* Illness, infection, and inflammation (and possibly the associated medication) were related to poorer treatment outcomes and, in some cases, to increased size of the lymphedematous arm. These outcomes occurred in response to both local and systemic illness.

Pumping during these episodes produced significantly less size reduction than was usually observed, suggesting that lymphedema may not be independent of local or systemic responses to the illness, infection, inflammation, or medication. The inflammatory process and lymphedema feed into each other, exacerbating both.

- Arlene obtained reductions, from pumping, of 28% to 33%, except when she had an infection of her fingernail bed, at which time she obtained reductions of 5% to 8%.
- The size of Jill's arm increased when she had a toxic response to her chemotherapy.
- On three consecutive treatments Carol recorded reductions of 20%, 6%, and 28%. The day that she recorded 6% she reported body aches and nausea.
- Eve had sero-negative arthritis and took increased doses of an oral steroid in an attempt to tolerate the pumping, but the lymphedema worsened. It is impossible to ascertain whether the medication alone or the concomitant conditions exacerbated the lymphedema.

*Pain.* Tolerance of compression garments and pumps was reduced because of the pain that was produced. This suggests that pain may be an important factor in the ability to comply with the lymphedema treatment. There is little to indicate what pain treatment was used in combination with the lymphedema treatment. Pain remained a problem for some of the women in the following ways:

- Debbie found that the pumping made the area around her elbow tender, forcing her to delay donning her compression sleeve after pumping.
- Carol had very low tolerance for the treatment. She found the pumping painful and could wear

the compression sleeves for only limited periods. She was never able to achieve an initial pump-down (a procedure done at the start of a treatment program to obtain maximum reduction; it required the client to use a compression pump continuously for 24 to 48 hr).

- Eve had multiple episodes of complications with her arthritis and had poor pain control. She had difficulty tolerating the pumping and found the material of the compression sleeves noxious.

**Depression.** The women diagnosed with depression had a diminished ability to start or maintain a treatment routine. Either they felt too overwhelmed to cope with the constant daily repetition of home treatment (Arlene stated that she could not live with having to control her lymphedema on a daily basis) or felt that the effort was pointless given the limited results it produced (Eve became so frustrated by the failure to reduce the size of her arm that she threatened to stop treatment). These experiences are obviously different from those of Mo, Kim, and Betty, who cut back on their treatment schedule because they were relatively satisfied with the results or felt that the situation was as good as it was going to get.

**Weight.** Body weight may play a role in the treatment outcomes. In terms of treatment, obesity may limit the optimum effectiveness of compression pumps and gar-

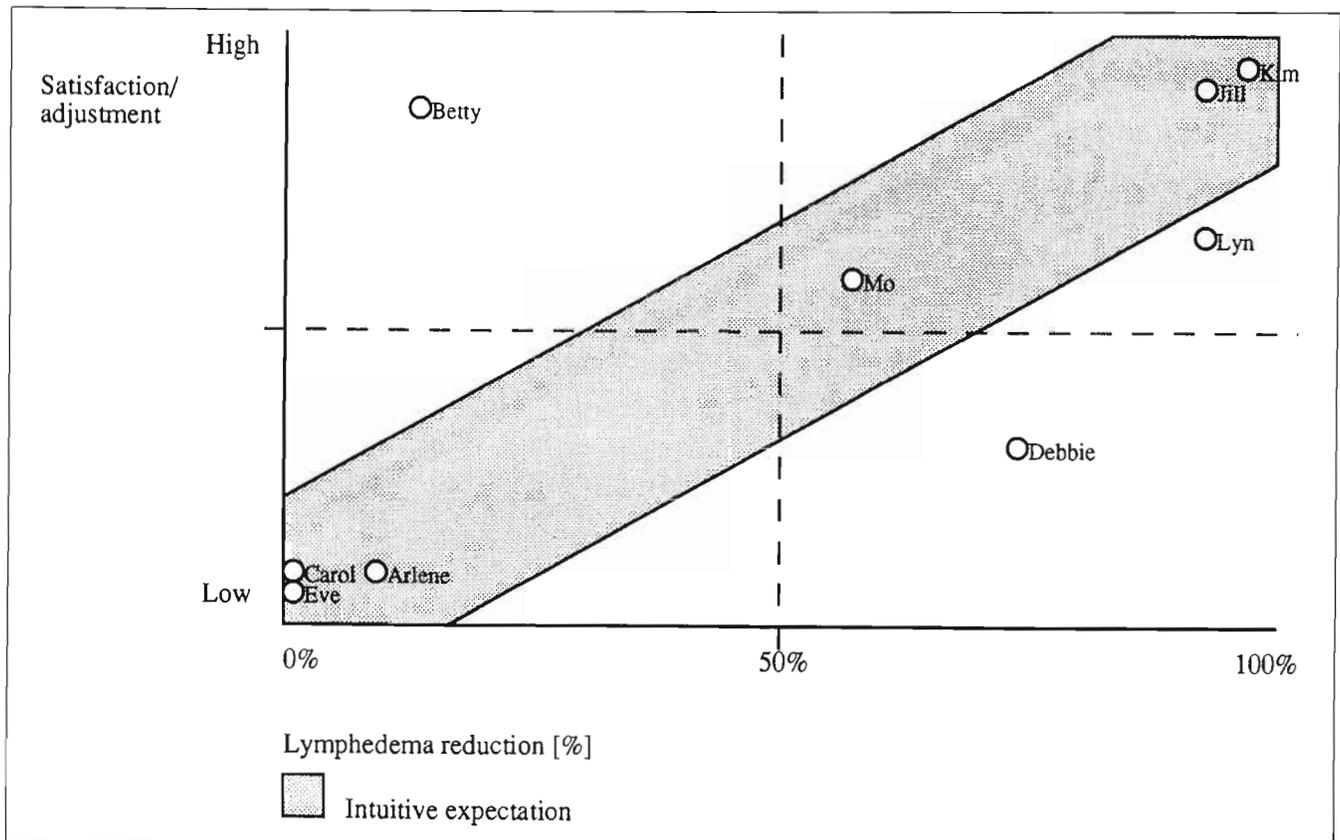
ments, given that the deep lymphatics are buffered by a greater layer of fatty tissue that would diffuse the pressure intended to reach the deep lymphatics. Also, edema invaginates itself within fatty tissue, and there is probably an increase in intracellular fluid that does not respond to compression pumping (M. Brennen, MD, personal communication, December 4, 1991). Body weight may also influence the way that outcomes are perceived by the therapists. All four women with poor outcomes were identified in the medical records as overweight, whereas three of the four women with successful outcomes weighed less than 150 lb. However, weight is not necessarily a simple issue, because factors that influence it may independently influence lymphedema.

#### Attitude and Life-Style

Satisfaction with the treatment outcome appears to be related to three issues: lymphedema reduction, location of lymphedema on the arm, and life-style.

**Lymphedema reduction.** Women's satisfaction, as interpreted from comments in the medical records, is broadly related to the overall lymphedema reduction—the greater the reduction the greater the satisfaction, the smaller the reduction the smaller the satisfaction (see Figure 3).

**Location of lymphedema.** If all of the swelling can-



**Figure 3.** Client satisfaction and adjustment to lymphedema. Intuitive expectation is the author's, on the basis of comments in the medical records.

not be reduced, then the part of the arm that remains swollen may influence how women feel about the treatment. Two anomalies existed in the category of lymphedema reduction: Betty had a small reduction but seemed quite satisfied, whereas Debbie had a greater reduction but was quite unsatisfied. Betty initially had a very large amount of swelling, with an increase of over 5 in. at her axilla in 1988. By 1990 she had obtained an overall reduction of 49%—a significant volume reduction given the initial size of the lymphedematous arm. Over the next year her arm size increased, but Betty seemed to remain relatively satisfied. But whereas the bulk of the swelling had initially been in the upper arm and axilla, the new swelling was now mainly in the lower arm. Debbie, on the other hand, had a largest point difference of a little over 2 in. and achieved an overall reduction of 69%. However, most of the reduction was in the lower part of her arm; the middle and upper part of her lymphedematous arm remained enlarged. She remains unhappy with the treatment outcome.

*Life-style.* When considering the women who appeared, from the medical records, to be the most and the least satisfied, the satisfied and unsatisfied women could be differentiated from each other by their life-style. The following were common to the three women who were interpreted as being the most satisfied:

- *Secure employment.* Kim is vice president and director of operations of a finance company; Jill has worked as a secretary at a teachers college for many years, and for the past 10 years has also worked at a theater in the evenings; Betty has worked as a secretary at a college for more than 20 years.
- *Leisure interests and activities, including some physical exercise.* Jill sees herself as active; she enjoys walking and watching sports. Betty plays golf, swims each day, and has taken up tennis. Kim describes herself as active and exercises as part of her weight loss program.
- *Established social support networks.* Kim has a supportive husband and mother and a 19-year-old daughter, and describes herself as active. Along with her work, Jill has a good relationship with her four adult children. Betty is also in an established work situation and has a very active routine outside of work.
- *Self-esteem.* Kim has a supportive husband, a prestigious job, and lost over 50 lb of excess weight. Betty has an established position at work, is physically active although overweight (indicating a degree of comfort with her body), and has friends to swim and play tennis with. Jill also has an established position at work, has a supportive family, and, although overweight, still enjoys moderate exercise.

In contrast, the following were common to the three women who were interpreted as the most dissatisfied:

- *Employment and financial difficulties.* Arlene was working unofficially as a nurse's aide. She was surviving on her husband's Social Security income. Carol does not work and is in the retirement age bracket. Eve works in temporary positions and is often without work.
- *Problems with insurance claims.* Arlene had a long and ultimately futile battle with the insurance company, trying to get disability benefits for a lymphedema pump. Both Carol and Eve have had their insurance company question the claims received.
- *Limited social supports.* Arlene came from Jamaica in 1980, her husband died recently, she does not get along with the people in her boarding house, and her brother lives far away in Florida. Carol unsuccessfully seeks support from the hospital staff members. Eve was divorced many years ago. There is no information on any family or social supports for Carol or Eve.
- *No reported interests or activities, beyond watching TV.*
- *Poor health.* Arlene has had several episodes of clinical depression. Carol has a history of respiratory problems and was diagnosed with chronic lymphocytic leukemia in 1989. Eve has sero-negative arthritis and has had several episodes of clinical depression.
- *Lymphedema decrease was slight or none.* All three women started treatment with severe lymphedema.
- *Disenchantment with the treatment program.* All had difficulty complying with the treatment program. Arlene stated that she could not live with having to control her lymphedema daily. Carol could not tolerate the treatment. She stayed away from the clinic because she did not like one of the therapists, although she realized it was a "self-defeatist" attitude, that she "should have come back sooner," and she felt "ashamed [she] had allowed [her] arm to get like this." Eve became so frustrated by the failure to reduce the size of her arm that she threatened to stop treatment.

## Implications for Occupational Therapy

The themes or findings presented here are preliminary and cannot be generalized because they relate only to the women in this study. Additional analysis of other groups of women with lymphedema secondary to mastectomy will be needed to establish the applicability of these themes to a broader population. Nonetheless, occupational therapists working with clients with lymphedema

could begin to examine within their own population the themes that have emerged from this study.

A small amount of swelling and a secure, active life-style appear to be implicated in a successful outcome for lymphedema treatment. Extensive swelling, poor health, poor coping skills, and poor support networks seem to be implicated in a poor outcome. Starting treatment while the swelling is still small depends on early intervention: obtaining quick referrals, eliminating waiting lists. All nine women in this study sought prompt attention, but not all obtained it. Therefore, improved therapist-physician liaison is needed, along with more client information and support to assist clients in pursuing early intervention.

Measuring the reduction in lymphedema may be more functionally appropriate if the location of the reduction is clearly identified rather than only the overall reduction. Reducing swelling in the upper arm seemed a satisfactory outcome for one of the women despite a poor overall reduction. Many questions can then be raised about how different pumps may affect different locations, whether different techniques (e.g., massage) work better on different parts of the arm, and whether modifying pressure garments would benefit the favored location even if it compromises the overall reduction.

Investigating and incorporating different schedules for combining treatment times, medication, and pain control methods could be an important part of ensuring treatment success for some clients. It seems that pain greatly impeded the clients' ability to adhere to a treatment schedule in this study.

Developing a support network (e.g., a group that meets regularly), particularly for those who fit a poor-outcome profile, could start to redress some potential problems by countering social isolation, providing opportunities for sharing and developing coping mechanisms, and enhancing self-esteem.

## Conclusion

At least 1 in every 20 women who receive treatment for breast cancer will develop lymphedema. This study looked at the medical records of nine women who had developed lymphedema after a modified radical mastectomy. The study found that underlying a successful outcome was early treatment intervention (ensuring only a small amount of swelling) and a secure, active life-style. A poor outcome was predicated by delayed intervention and subsequently greater swelling, poor social supports, and poor health. The location of the swelling may also influence the clients' level of satisfaction with treatment. These findings suggest that therapists should examine the difference in the size of the swelling and the amount of delay in starting treatment, and the clients' life-style and coping skills, both to identify those most at risk of a poor outcome and to develop alternative treatment strat-

egies. Further research is needed to establish the influence of these phenomena on treatment outcomes. ▲

## Acknowledgments

This study was completed as partial requirement for a Master of Arts Degree from the Department of Occupational Therapy at New York University.

I thank Jim Hinojosa, PhD, OTR, FAOTA, for his generous assistance and support during the research and the writing of this paper.

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