Living With Breast Cancer–Related Lymphedema: A Synthesis of Qualitative Research

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Purpose/Objectives: To describe the experience of female patients living with breast cancer–related lymphedema (BCRL) to gain a comprehensive understanding of this experience. The review is designed as a qualitative meta-synthesis.

Data Sources: Electronic searches were conducted in MEDLINE®, CINAHL®, EMBASE, PsycINFO, and Social Sciences Citation Index. Articles were included where researchers used qualitative research methods and when a comprehensive description of methods and the study's findings were provided.

Data Synthesis: From 2,185 references, 13 articles were included. A total of 94 author and participant aggregations were extracted, qualitatively assessed, and assigned to one of 14 categories. Four themes relating to the experience of living with BCRL were identified: experience of everyday life, energy sapping, personal empowerment, and contribution of others.

Conclusions: Requirements of living with BCRL may only be influenced to a limited extent by the women themselves. They struggle with their situation, appearance, and the concomitant uncertainties. They feel strengthened where they succeed in developing a helpful view of their situation and where support structures are available to them.

Implications for Nursing: Professionals can employ this meta-synthesis by contextualizing it as part of a process of critical reflection on their own endeavors to meet the requirements of women living with BCRL.

Key Words: systematic review; lymphedema; breast cancer; quality of life; nursing research; qualitative

ONF, 41(4), E220–E237. doi: 10.1188/14.ONF.E220-E237

Lymphedema of the arm is one of the most common symptoms following breast cancer treatment (Pinto & de Azambuja, 2011), affecting every area of women's lives. Lymphedema is mainly caused by procedures such as axillary lymph node dissection or axillary radiation (Shah & Vicini, 2011), which are associated with an accumulation of high-protein lymph fluid in body tissue that leads to swelling, chronic skin alterations, fibrosis, and functional impairment in the arm or upper body.

The incidence of breast cancer–related lymphedema (BCRL) varies depending on the kind of treatment received. The risk is estimated at around 2% when lumpectomy has been carried out in isolation and increases to as much as 65% when more extensive surgical techniques or radiation therapy are required (Shah & Vicini, 2011). The routine use of sentinel lymph node biopsy and modified treatment options has reduced the occurrence of BCRL (Morrell et al., 2005), but for the women concerned, it still means a considerable loss of quality of life (Pusic et al., 2013).

Women with breast cancer are at risk of developing lymphedema for the rest of their lives, and a distinct possibility remains that it may occur beyond the first year of treatment (Armer & Stewart, 2010), a time when the woman will have overcome an exhausting period of her life and, if no symptoms of cancer are apparent, may view life more optimistically. Specific research findings reveal many problems associated with BCRL, including pain, depression, and anxiety (McWayne & Heiney, 2005; Ridner, Bonner, Deng, & Sinclair, 2012). In comparison to who did not go on to develop lymphedema, women who did so experienced a much poorer quality of life (Ridner, 2005). Although a systematic search in relevant databases (e.g., the Joanna Briggs Institute, MEDLINE®, CINAHL®) included reviews focusing on the health-related outcomes of women with breast cancer, no systematic review of qualitative research exploring the particular experience of living with lymphedema after breast cancer treatment was found. Bringing together these perceptions of the women's experience, by adhering to the nature of the qualitative approach, could benefit healthcare practitioners by offering a greater understanding of the phenomena and its complexities.

Therefore, the aim of this synthesis is to gain comprehensive insight into the experience of living with BCRL by aggregating the findings of available qualitative research in this field. In line with a pragmatic meta-aggregative approach (Hannes & Lockwood, 2011; Joanna Briggs Institute, 2011), the authors provide a set of practical implications derived from the participants' combined statements (i.e., "based on the voices of the relevant stakeholders" [Hannes & Lockwood, 2011, p. 1633]), with the aim of assisting healthcare practitioners in their work.

Methods

Synthesis Methodology

The review was designed as a qualitative meta-synthesis based on the guidelines of the Joanna Briggs Institute (2011). Numerous qualitative studies have been conducted that explore the experience of survivors living with lymphedema following breast cancer treatment. To gain a deeper understanding of the knowledge acquired from accumulative research into BCRL described and interpreted in these studies, the authors have opted for meta-synthesis as the most appropriate format in which to elucidate various points of view and insights. The synthesis of qualitative studies is much debated and includes a number of approaches, but with little general agreement on the various aspects of technique (Downe, 2008; Walsh & Downe, 2005).

The current study approaches meta-aggregation in a structured manner in that it systematically identifies and assimilates all relevant qualitative research exploring the topic. This approach of enquiry is suitable for combining the results of qualitative studies conducted according to different designs (i.e., grounded theory, phenomenology, or ethnography). In contrast to other methods of qualitative evidence synthesis, the meta-aggregation approach focuses on integration rather than interpretation (Joanna Briggs Institute, 2011). A particular characteristic of meta-aggregation is that it seeks to provide practical implications of the synthesized findings (Hannes & Pearson, 2012; Joanna Briggs Institute, 2011).

Literature Search and Selection

Studies were included if researchers applied qualitative research methods with the specific aim of describing the experience of living with BCRL. This includes all studies published in journals, books, or as thesis publications within the naturalistic paradigm, such as phenomenologic or grounded theory studies; or gathering data using particular methodologies, such as from focus groups or interviews. Integrating subthemes like coping strategies or stressors could influence an understanding of the findings. However, because the authors concentrated on statements rather than the findings' frequency of occurrence, the decision also was made to include articles addressing specific subthemes.

Interpretations in the original research (e.g., metaphors, categories) had to be supported through participants being quoted verbatim. In addition, the study methods had to be adequately reported. The authors also restricted publication language to English or German and only considered publications with accessible abstracts.

The period of publication was from 1992–2012 to take into account the increasing awareness of BCRL in clinical practice guidelines (Harris, Hugi, Olivotto, & Levine, 2001; Seifart et al., 2007) and the change in circumstances which the authors theorize could have led to significant changes in living with BCRL in the past 20 years.

Data sources and search strategy: To identify qualitative studies examining patient-reported data, "subject-specific search strategies" have proven more sensitive in retrieving relevant studies than qualitative methodology search strategies (Gorecki, Brown, Briggs, & Nixon, 2010). A sensitive subject-specific search strategy was then developed that combined Medical Subject Heading (MeSH) terms for the condition (i.e., swelling or lymphedema) and terms that refer to patients' experiences (i.e., well-being). Each search strategy was tailored to the preconditional

Table 1. MEDLINE® (PubMed) Search Strategy

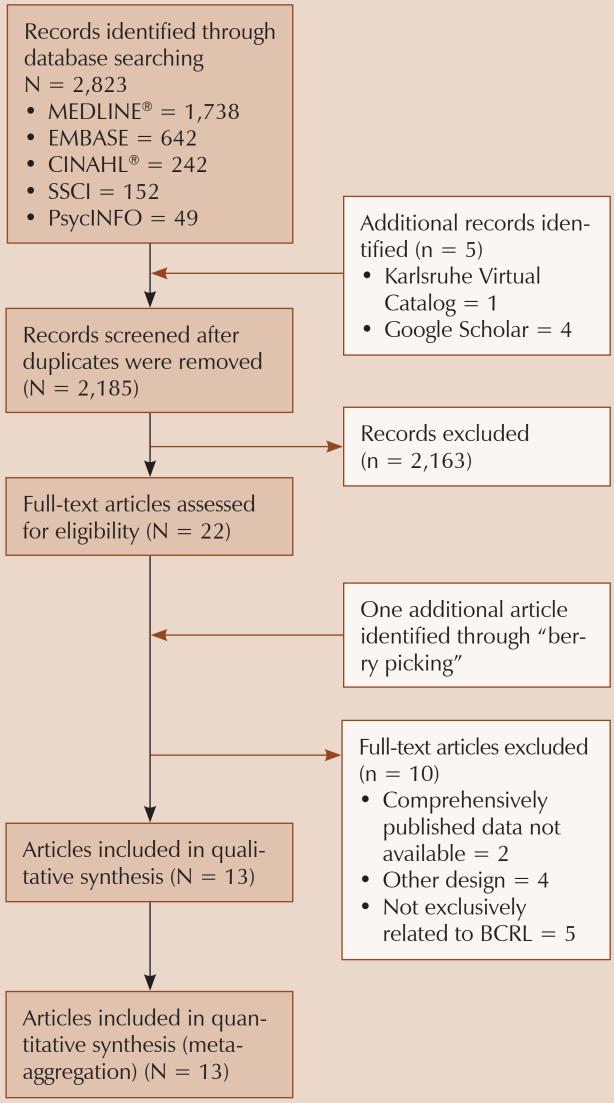
Step	Term or Strategy
1.	Lymphedema
2.	Lymphoedema
3.	Elephantiasis
4.	“Lymphedema” [MeSH]
5.	1 OR 2 OR 3 OR 4
6.	“Quality of life“
7.	“quality of life“ [MeSH]
8.	“Health-related quality of life”
9.	“HRQL“
10.	“HRQOL“
11.	“patient satisfaction“ [MeSH]
12.	“patient satisfaction“
13.	“experience“
14.	“experience*“
15.	“well-being“
16.	“Body Image“ [MeSH]
17.	“Body Image“
18.	“Body-Image“
19.	Psychology [subheading]
20.	psychology
21.	“Self efficacy“
22.	“Self Efficacy” [MeSH]
23.	“Stress, Psychological” [MeSH]
24.	“Stress, Psychological”
25.	6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24
26.	5 AND 25
27.	5 AND 25 filters: Abstract available, Publication date from 1992/01/01 to 2012/07/12, English, German

MeSH—Medical Subject Heading

search terms of the specific databases. Full details of the search strategy for MEDLINE (PubMed), including term-specific hits, are presented in Table 1.

Based on these systematically preplanned search strategies, searches of the following databases were carried out in July 2012 with the aim of locating qualitative research examining patients' experiences of lymphedema: MEDLINE (PubMed), CINAHL (EBSCO), EMBASE (Ovid), PsycINFO (Ovid), and Social Sciences Citation Index (SSCI) (Web of Knowledge).

To identify further qualitative research in German, insufficiently indexed in journal databases, the authors used the meta-search interfaces of the Karlsruhe Virtual Catalog and Google Scholar using simple broad German search terms such as lymphedema and quality of life. In addition, hand searches were carried out in the German-language academic journals *Vasomed*, *Lymphologie in Forschung und Praxis*, and *Physioscience*. Reference lists identified in all relevant articles were scanned for additional material. All articles identified through hand searching, meta-search interfaces, or reference lists were retrieved from July to August 2012.



BCRL—breast cancer–related lymphedema; SSCI—Social Sciences Citation Index

Figure 1. Flowchart of Article Selection Process

Study screening methods and study selection: The total number of records retrieved from databases was 2,823. The search in Google Scholar resulted in four results, and one article was identified via the Karlsruhe Virtual Catalog meta-search interface. The hand search provided no relevant results. Figure 1 provides a flowchart of the article selection process. All articles, as well as the findings from the literature, including thesis publications and hand searches, were downloaded in EndNote X5 bibliographic management software for further assessment and processing. After removing duplicates, 2,185 references remained.

The abstracts were screened independently by two reviewers, applying the predefined inclusion criteria. In cases of disagreement, a third researcher was consulted. If eligibility for the purposes of this review could not be based solely on the abstract, then the full text was screened. If there was any indication of possible publication (i.e., Congress abstracts), attempts were made to contact the relevant authors.

Twenty-two full-text articles were included for additional analysis. Ten of these articles were excluded because they were not congruent with the review objectives: six were excluded because of issues of design or nonavailability of published data, and another four were excluded because they didn't exclusively relate to BCRL. One article (Wanchai, Stewart, & Armer, 2011) had a slightly different focus by comparing the experiences of affected women living in different ethnic groups. Because research has not been restricted to one ethnic group, the authors included the study but focused on living with lymphedema as a general category. By scanning reference lists and footnotes, one additional article was included (Fu, 2008), resulting in 13 articles.

Appraisal Process

A total of 13 articles were eligible for the review. A debate occurred in the area of qualitative synthesis concerning the application of quality criteria (Downe, 2008). In addition, the exclusion of studies on the basis of inadequate methodologic description is a matter of some controversy (Sandelowski & Barroso, 2003). Because critical appraisal tools have not been found to be superior to expert opinion (Dixon-Woods et al., 2007), the authors could not rely on a generally accepted scientific approach and, therefore, decided not to exclude studies *a priori*. Instead, the researchers decided on a more general quality assessment, one which considered whether the original authors described conducting their studies with sufficient scientific rigor for the current authors to be able to rely on the data presented.

Based on existing criteria for appraising and reporting qualitative research (Joanna Briggs Institute, 2011; Russell, Gregory, Ploeg, DiCenso, & Guyatt, 2005; Tong, Sainsbury, & Craig, 2007), the authors developed a critical appraisal tool that enabled them to assess each particular study within the following domains: purpose or research questions, description of study sample (selection of participants, reasons for study sample selection), descriptive clarity of data collection (methods used, procedural rigor), and description of data analysis. These tables enabled the authors to assess the study results in context and the approach of the authors. A scoring or weighting system was not applied. The appraisal of the studies was conducted by one reviewer, reassessed by a second reviewer, and, where necessary, adjusted by both. None of the articles were excluded. Table 2 provides a summary of the 13 articles included, giving information on study characteristics and methods.

Data Extraction

According to the Joanna Briggs Institute (2011), findings are defined as, "Conclusions reached and reported by the author of the paper, often in the form of themes, categories, or metaphors" (p. 40). The findings are generally supported by the quotes of participants (Hannes & Pearson, 2012). They were based on origin and level of interpretation and sorted as authors' conclusions into themes or categories, authors' interpretative or descriptive comments, and quotes of participants.

The authors identified a total of 94 findings and categorized them by using the Joanna Briggs Institute Qualitative Appraisal and Review Instrument (JBI-QARI) degrees of credibility scale (Joanna Briggs Institute, 2011). The creation of categories was derived from identical categorizations in the original articles from studies included in the review where consensus was reached between two independent reviewers. An overview of all the findings, including their level of

Knowledge Translation

This systematic review summarizes the experience of women with breast cancer–related lymphedema (BCRL) described in qualitative research articles.

Four themes women with BCRL experience were identified: experience of everyday life, energy sapping, personal empowerment, and contribution of others.

The findings from this synthesis can be employed by healthcare professionals to critically reflect on their work and adapt treatment standards and nursing plans to the individual needs of the affected women.

Table 2. Summary of Included Articles

Study	Country	Design	N	Methods
Carter, 1997	USA	Phenomenologic	10	Two semistructured in-depth interviews per person
Fu, 2005	USA	Phenomenologic	12	Three semistructured in-depth interviews per person
Fu, 2008	USA	Phenomenologic	22	Three semistructured in-depth interviews per person
Fu, 2010	USA	Phenomenologic	34	Three semistructured in-depth interviews per person
Fu & Rosedale, 2009	USA	Phenomenologic	34	Three semistructured in-depth interviews per person
Greenslade & House, 2006	Canada	Phenomenologic	3	One semistructured interview per person
Hare, 2000	UK	Grounded theory	20	Four focus groups with five participants
Heppner et al., 2009	USA	Consensual qualitative research method	10	One semistructured in-depth interview per person
Johansson et al., 2003	Sweden	Phenomenologic	12	One semistructured interview per person
Ridner et al., 2012	USA	Expressive writing	39	Narrative writing (20 minutes)
Thomas-MacLean et al., 2005	Canada	Qualitative research; not further reported	22	15 interviews using a guide with four major themes
Wanchai et al., 2011	USA and South Africa	Ethnographic	29	One semistructured in-depth interview per person
Whyte, 2010	USA	Phenomenologic	10	One semistructured interview per person

credibility, according to JBI-QARI degrees, is presented in Table 3. However, because the comprehensiveness of study results was a prerequisite for inclusion, only one finding was appraised as credible and no findings were appraised as unsupported.

Categorizing and Synthesis of Findings

Microsoft Visio® software was used to group and connect all findings extracted from the authors' results based on their similarities. The authors used different grouping approaches (e.g., context, theme, temporal connection). As a basic principle, the authors followed the most effective inductive approach available, trying to avoid all predefined categories associated with theories of chronic conditions. The authors discussed all the possible connections and retraced them by comparing them with the original interpretations of researchers and participants until a consensus of opinion was reached on suitable categories well-grounded in the original data.

Similar to Hannes and Pearson (2012), the authors of the current article decided to use more complex sentences to support the short titles of categories so as to avoid too much generalization, which could lead to misinterpretation of the findings because of insufficient information on the context. By constantly reflecting on overall meanings, connections, and dependencies, the authors combined the categories of synthesized findings statements, reflecting across-the-board findings related to different aspects of living with BCRL. At each stage of the process, the authors returned to the original literature and compared their understanding and interpretation of data, resulting in establishing overarching categories and synthesis with the original study context and study results.

Table 3. Summary of Findings

Study	Findings	Designation of Findings
Carter, 1997	3 (1–3)	1. Abandonment by medicine 2. Concealing the imperfect image 3. Living the interrupted life
Fu, 2005	4 (4–7)	4. Keeping in mind the consequences 5. Preventing lymphedema from getting worse 6. Getting ready to live with lymphedema 7. Integrating the care of lymphedema into daily life
Fu, 2008	3 (8–10)	8. Having a visible sign: Disability versus a need for help a. Having a visible sign: Disability b. Having a visible sign: Need for help 9. Having physical limitations: Being handicapped versus the inconvenience 10. Worrying constantly versus feeling fortunate a. Worrying constantly b. Feeling fortunate
Fu & Rosedale, 2009	4 (11–14)	11. Living with perpetual discomfort 12. Confronting the unexpected 13. Losing the prelymphedema being 14. Feeling handicapped
Fu, 2010	3 (15–17)	15. Reluctantly shifting responsibilities to others 16. Constantly needing others for physical labors 17. Unwillingly projecting emotional burdens to others
Greenslade & House, 2006	5 (18–22)	18. Constancy 19. Yearning for normalcy 20. Searching 21. Emotional impact 22. Abandonment
Hare, 2000	3 (23–25)	23. Finding information 24. Suffering silently 25. Counting blessings
Heppner et al., 2009	16 (26–41)	26. Negative emotional and cognitive reactions 27. Attractiveness and sexual issues 28. Negative social support 29. Lack of adequate health insurance coverage 30. Stress and anxiety in partners and/or children 31. Actively sought information or treatment options 32. Learned physical strategies to manage lymphedema symptoms 33. Accepted the limitations associated with lymphedema symptoms 34. Focused on the positive aspects of life 35. Used spiritual/religious methods 36. Openly talking and educating about lymphedema 37. Impact of their racial and socioeconomic backgrounds on coping 38. Opportunity to nurture others 39. Reliable alliance of others besides partners 40. Concern and support from healthcare providers 41. Spiritual support from others

(Continued on the next page)

[a] Credible finding: Relates to findings that are plausible in light of the data and theoretical framework.

Note. All other findings were assessed with the Joanna Briggs Institute Qualitative Appraisal and Review Instrument and labeled as unequivocal. This means that they relate to evidence beyond a reasonable doubt, which may include findings that are a matter of fact, directly reported/observed, and not open to challenge.

Results

The experience of the women was ascertained in semistructured interviews (Carter, 1997; Fu, 2005, 2008, 2010; Fu & Rosedale, 2009; Greenslade & House, 2006; Heppner et al., 2009; Johansson et

Table 3. Summary of Findings *(Continued)*

Study	Findings	Designation of Findings
Johansson et al., 2003	3 (42–44)	42. Reaction from others 43. Chronic disease 44. Coping a. Problem-focused coping b. Emotion-focused coping
Ridner et al., 2012	14 (45–58)	45: Lack of support from healthcare providers 46: Disease management failure 47: Lack of financial support from the healthcare system 48: Lack of sensitivity from friends and family 49: Body image disturbance 50: Loss of control over time 51: Loss of function 52: Permanent uncertainty 53: Adverse effects on relationships 54: Impact on psychological well-being 55: Frustrated aspirations for normalcy 56: Damaging attempts to regain a sense of normalcy 57: Psychosocial support 58: Spiritual resources
Thomas-MacLean et al., 2005	4 (59–62)	59: Lack of information 60: Triggers and symptoms 61: Access to treatment 62: Effect on daily life
Wanchai et al., 2011	9 (63–71)	63: Difficulties with daily activities 64: Unmet lymphedema preparation 65: Facing public curiosity 66: Time-consuming wrapping 67: Trouble with fitted clothes 68: Reminder of breast cancer 69: Using compression garments 70: Performing physical activities 71: Using faith
Whyte, 2010	20 (72–91)	72: It never bothered me, but having to ask for help 73: It never bothered me, but hope it doesn't get worse 74: It never bothered me, but unsympathetic employers 75: It never bothered me, but restrictions 76: It never bothered me, but never going away 77: Unwanted baggage: Only when I wear it 78: Unwanted baggage: A visual bother 79: Unwanted baggage: It's my arm 80: Unwanted baggage: It costs money 81: Who knew? I had no clue 82: Who knew? Does anyone know? 83: Who knew? Curiosity 84: Self-preservation: I can do this 85: Self-preservation: Do what the doctor tells me 86: Self-preservation: Moving on 87: Self-preservation: What's best for me 88: Self-preservation: Not putting health at risk 89: Hopeful determination: Proud survivor 90: Hopeful determination: Previous experience[a] 91: Hopeful determination: Encompassing support

[a] Credible finding: Relates to findings that are plausible in light of the data and theoretical framework.

Note. All other findings were assessed with the Joanna Briggs Institute Qualitative Appraisal and Review Instrument and labeled as unequivocal. This means that they relate to evidence beyond a reasonable doubt, which may include findings that are a matter of fact, directly reported/observed, and not open to challenge.

al., 2003; Thomas-MacLean, Miedema, & Tatemichi, 2005; Wanchai et al., 2011; Whyte, 2010), expressive writing style (Ridner et al., 2012), or focus group discussion (Hare, 2000). One research group provided information of a research project spanning six years, which is presented in several articles focusing on different subthemes of living with lymphedema (Fu, 2005, 2008, 2010; Fu & Rosedale, 2009). It, therefore, is possible that these different subthemes were quoted, at least to some extent, from the same participants.

The women had to have completed surgical treatment for breast cancer at least three months to one year in advance and to have shown no apparent evidence of active breast cancer disease (e.g., metastases). Most of the studies were conducted in English-speaking countries and one in Sweden. No article was found in the German language or originating from Germany. The studies mostly used a phenomenologic approach. Based on the aforementioned quality assessment, both reviewers agreed that all studies were comprehensively reported. Although all studies explored the lives of women living with lymphedema, three had slightly different foci: understanding the effects of lymphedema and developing coping strategies, identifying similarities and differences in the healthcare systems of two countries (South Africa and the United States), and survivors' experience of work.

The authors identified 94 findings in the included studies and aggregated them into 14 categories that reflected similar meanings and dimensions of the experience of BCRL. Finally, four syntheses were developed from the categories.

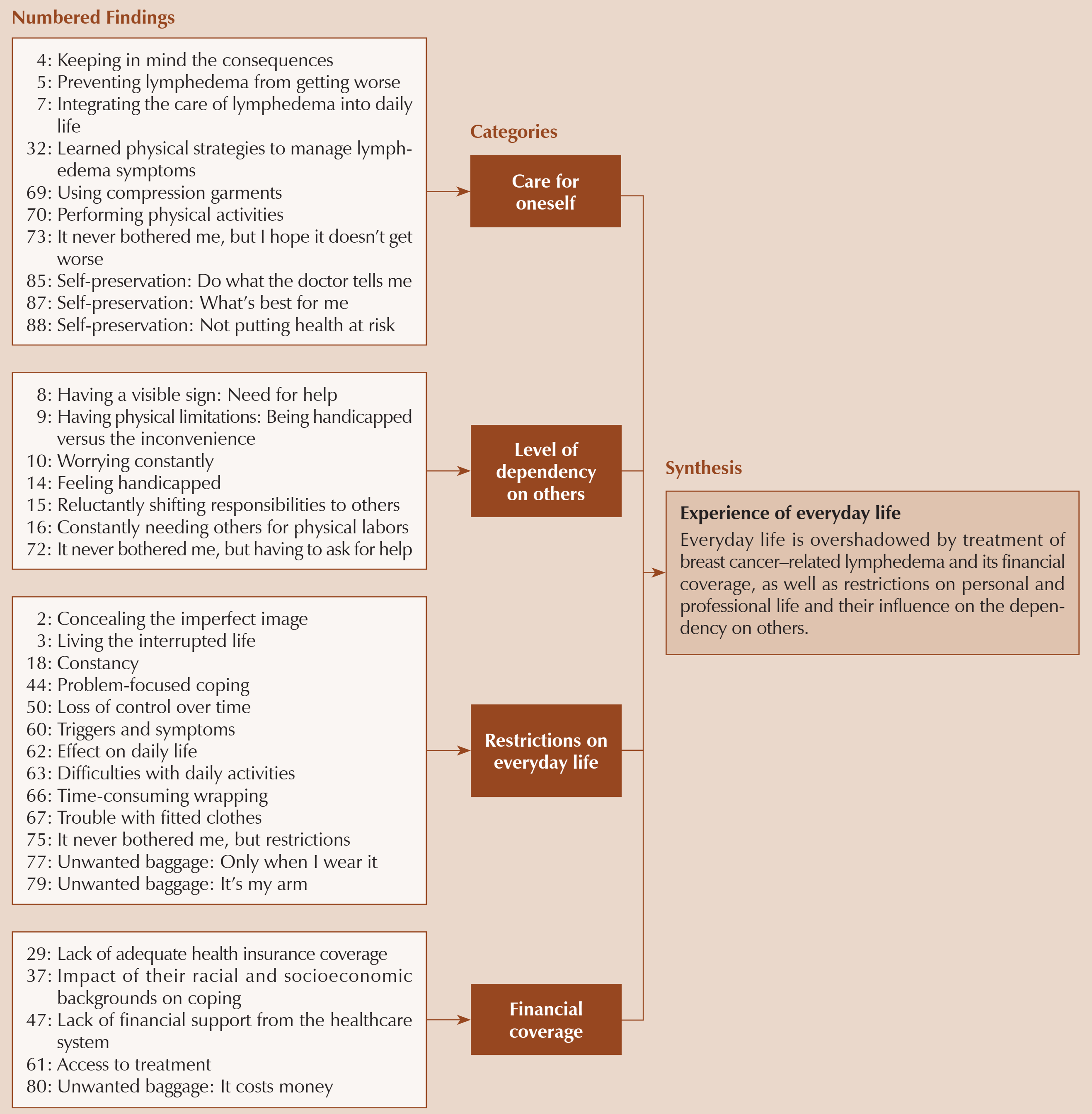
Synthesis 1: Experience of Everyday Life

The women's everyday life is overshadowed by the demands of treatment for BCRL and its financial impact, as well as restrictions in their personal and professional life and their influence on the level of dependency on others. This synthesis is based on 35 findings grouped into four categories (see Figure 2 and Appendix A).

Care for oneself: The women take care of themselves in the hope of preventing the progress of lymphedema. The use of a compression garment, physical exercise, lymph drainage, skin protection, and the permanent monitoring of the affected arm are predominant needs in preventing the aggravation of lymphedema and its adverse effects on the daily routine.

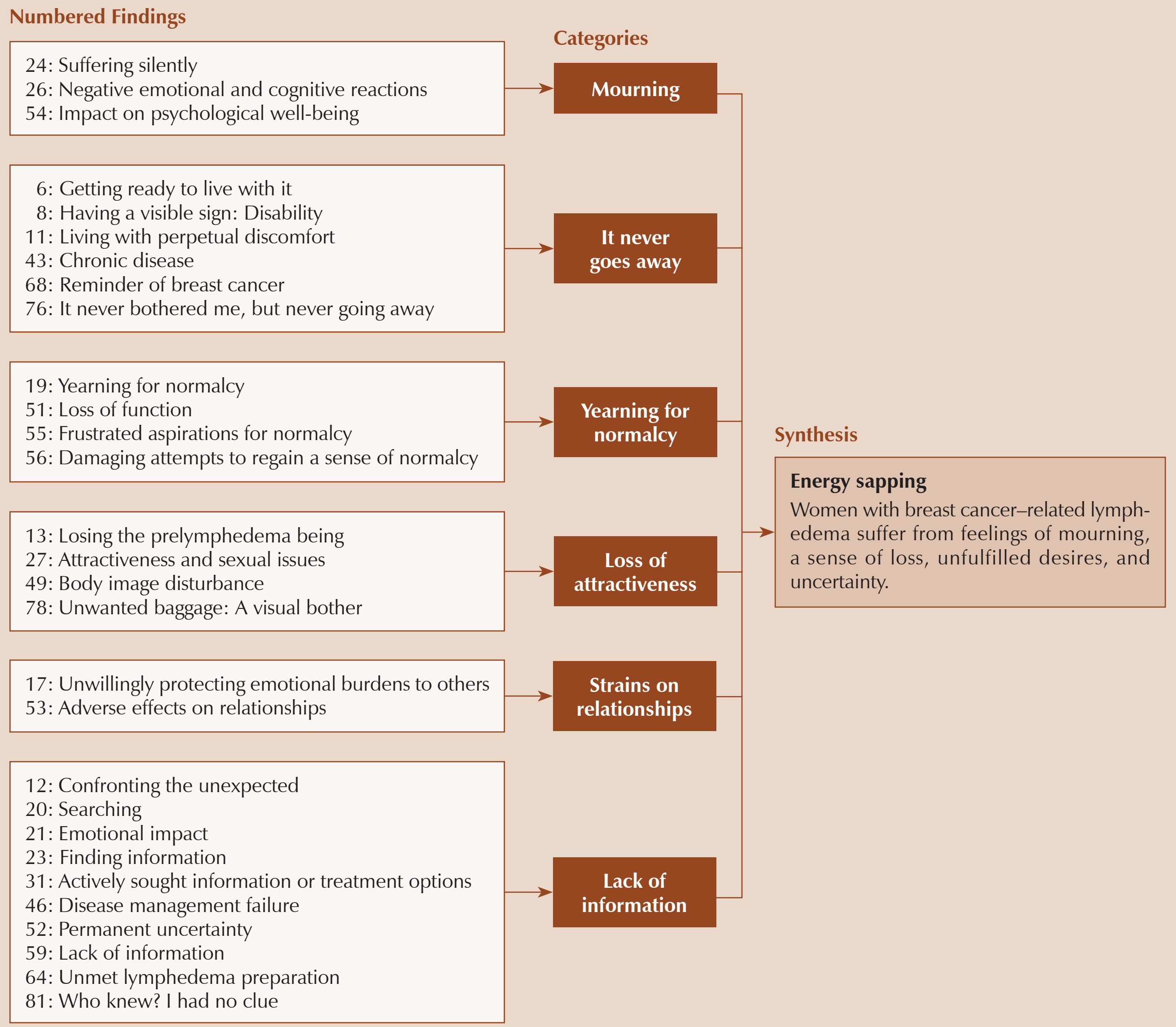
Level of dependency on others: The awareness of being handicapped and dependent on others is directly related to the degree of intensity to which the affected arm is used (i.e., heavy lifting needs the support of others).

Restrictions on everyday life: The women experience restrictions and the negative impacts of BCRL on their daily lives and activities. Simple, everyday routines become a challenge; finding well-fitting clothes becomes particularly difficult. Circumstances the women are unaccustomed to, such as attending meetings or traveling, need to be prearranged. Precious time is lost to time-consuming treatment.



Note. The numbers correspond with findings per article as listed in Table 3. Associated original quotations are listed in Appendix A.

Figure 2. Breast Cancer–Related Lyphedema: Experience of Everyday Life



Note. The numbers correspond with findings per article as listed in Table 3. Associated original quotations are listed in Appendix B.

Figure 3. Breast Cancer–Related Lymphedema: Energy Sapping

Financial coverage: The costs of medical care for those suffering from lymphedema are a permanent financial burden and the ability to bear it depends on the cover provided for lymphedema-related health expenditure.

Synthesis 2: Energy Sapping

Women with BCRL suffer from feelings of mourning, a sense of loss, unfulfilled desires, and uncertainty. This is supported by 29 findings grouped into six categories (see Figure 3 and Appendix B).

Mourning: The first awareness of having lymphedema is associated with overwhelming feelings of sadness, anger, and frustration—feelings similar to that of mourning.

It never goes away: Women realize that lymphedema is a difficult reality, something they will have to deal with for the rest of their lives as a constant reminder of breast cancer.

Yearning for normalcy: The women yearn for their former way of life and to feel normal, but they are permanently confronted with the consequences associated with the affected arm.

Loss of attractiveness: The women describe their altered body shape with powerful language, using words like ugly, horrible, swollen, or damaged; they are aware of a loss of attractiveness which can impact on the quality of their sex lives, as well as their self-image.

Strains on relationships: The women are concerned about the negative effect on relationships that could be caused by lymphedema. This includes a sense of guilt, the feeling of alienation from friends and relatives, or close relationships being stretched to the limits.

Lack of information: Initial symptoms of lymphedema could be misinterpreted and lead to uncertainty as to the cause of swelling. The women consider information from healthcare providers to be conflicting, ill-timed, and insufficient.

Synthesis 3: Personal Empowerment

Personal empowerment depends on the women's capacity to adapt their values and view of life to the situation in which they find themselves, as well as the availability of support and the women's acceptance of it. This synthesis is supported by 17 findings grouped into two categories (see Figure 4 and Appendix C).

Helpful view of life: It helps women to cope if they manage to change their values and view of life. These changes range from the enforced acceptance of lymphedema to the attitude of the proud, self-confident survivor.

Psychosocial and spiritual support: Women benefit if they are able to share fears and worries with others (i.e., if they can accept psychosocial or spiritual support).

Synthesis 4: Contribution of Others

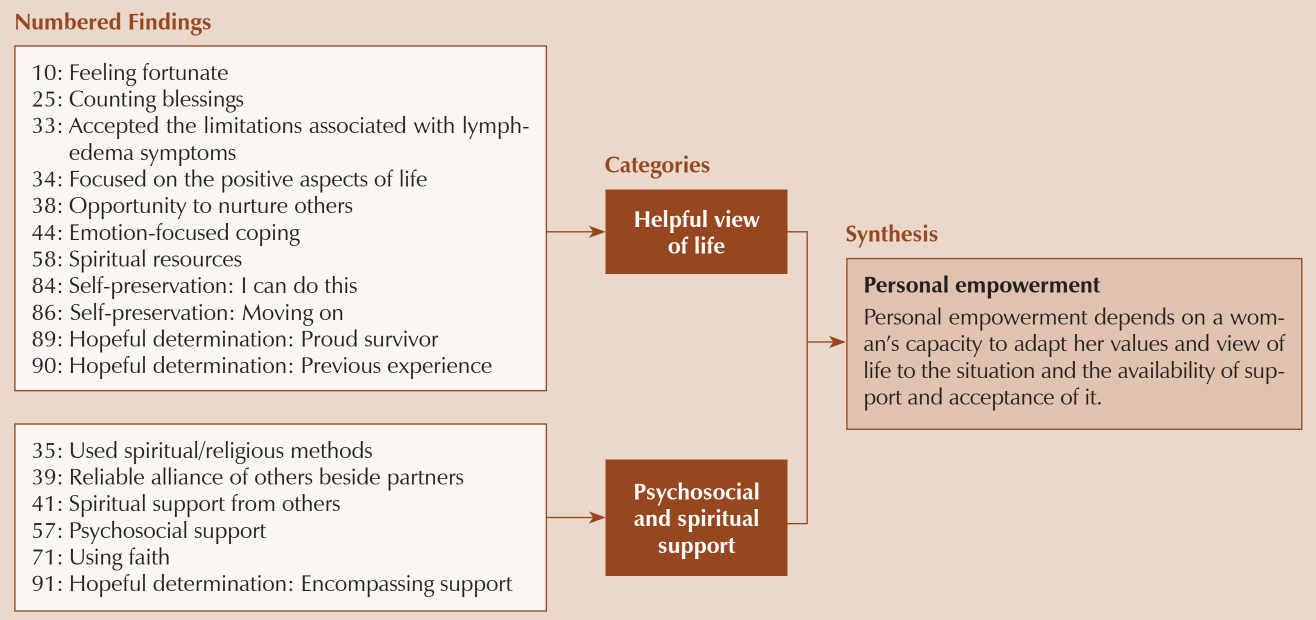
The contribution of the women's immediate circle and healthcare providers depends on the degree of empathy and knowledge. This synthesis is based on 13 findings grouped into two categories (see Figure 5 and Appendix D).

Healthcare providers' performance: Among healthcare practitioners, lymphedema is considered less dramatic than breast cancer. Where medical professionals trivialize the impact of lymphedema, the women feel abandoned and misunderstood. However, if the condition is taken seriously and treated as a profound problem for the women, they perceive themselves as supported and well cared for. This indicates that they associate being cared for with well-being and its trivialization with abandonment.

How the woman's immediate circle contributes: Those in the women's immediate circle often are uninformed, feel helpless, and are unable to cope with the situation. This leads to misinterpretation, and the aforementioned trivialization of the women's condition, as well as a morbid curiosity and a lack of understanding. If friends, relatives, and close associates were better informed, the women's needs for support and empathy would be better met.

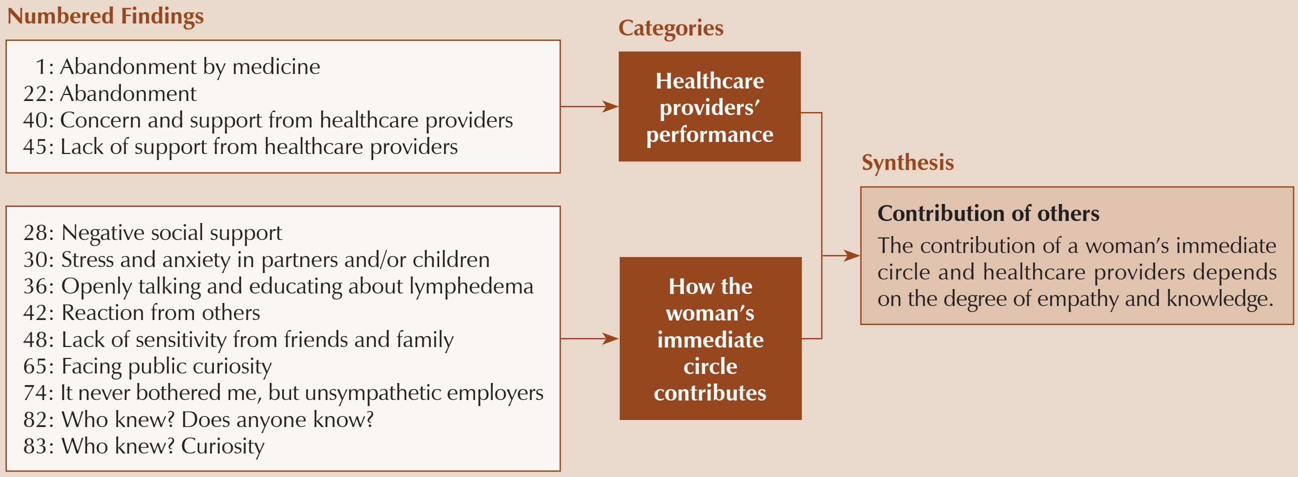
Discussion

By summarizing and synthesizing the findings of the articles included, it is apparent that lymphedema affects women across the broad spectrum of their lives. However, the restrictions on, as well as the needs and requirements of living with BCRL, may only be influenced to a limited extent by the women themselves. This also applies to the level of dependency experienced. The overall outcome of the synthesized studies reveals that women with BCRL struggle with their situation, appearance, restrictions, and the concomitant uncertainties that sap the sufferer's energy and impact on relationships, self-confidence, and self-efficacy. On the other hand, they feel strengthened where they succeed in developing a helpful view of their situation, and where social or psychosocial



Note. The numbers correspond with findings per article as listed in Table 3. Associated original quotations are listed in Appendix C.

Figure 4. Breast Cancer–Related Lymphedema: Personal Empowerment



Note. The numbers correspond with findings per article as listed in Table 3. Associated original quotations are listed in Appendix D.

Figure 5. Breast Cancer–Related Lymphedema: Contribution of Others

support structures are available to them. Finally, the contribution of others plays a role in the experience of living with BCRL.

A lack of information within the women's immediate circle could lead to misunderstandings and misinterpretations, negatively influencing the women's sense of well-being. Others, particularly healthcare providers, can support the women by taking their concerns seriously rather than by trivializing them. Regrettably, their mindfulness of the patient's need for support when being treated for breast cancer does not extend to the sufferers of BCRL.

The approach taken in the authors' research was to collect all published articles on the topic and to summarize and synthesize the findings presented by numerous women living in a variety of circumstances. The authors also tried to retain an inductive way of connecting findings by trying to avoid interfering with common theories of living with chronic conditions. It also was imperative that the view of the problem did not impede the veracity of the method.

Even considering all these precautions, the danger of generalization in these review findings must be kept in mind. This literature review reflects living with BCRL in various ways. However, each woman affected should be viewed and respected as a unique individual, but with varying circumstances and experiences. This review also mainly consists of study findings from English-speaking countries, which have to be considered by assigning the synthesis and implications to other contextual circumstances. Ultimately, it contains only data preselected by the original researchers following their study goals and perceptions (e.g., when choosing quotes from the affected women and grouping them) or by interpreting the study findings.

Considering all the limitations of synthesizing qualitative data, the approach provides a comprehensive insight into the restrictions and various needs of caring for, supporting, and protecting the affected arm in the course of daily life.

Implications for Nursing

This review revealed some factors influencing well-being and self-efficacy of women with BCRL. The results suggest implications on healthcare practice. Healthcare professionals are requested to critically reflect on their work and adapt treatment standards to the individual needs of women with BCRL. The results should be considered for implementation in nursing care plans before lymphedema has developed. In any case, women need to develop strategies to cope with the cause and the swelling itself at the time symptoms first occur. Nurses must be aware that the risk of lymphedema may not be a woman's first concern during breast cancer treatment. It might be possible that women neglect the risk of BCRL. Therefore, patient information and follow-up care should indispensably focus on this topic, emphasizing coping strategies on how to live with BCRL. Engaging significant others in information delivery may ease the burden related to BCRL. BCRL must not be underestimated by nurses because it has a major impact on affected women, particularly at its first occurrence. Nurses should offer information on psychosocial support and contact to self-help groups. These efforts should be supported by policymakers and health insurers (e.g., by adapting workplaces and/or financial support of treatment costs). Eventually, use of compression garments should be encouraged, which does not only support functional abilities but also improves personal appearance.

Conclusion

Insight into women's various needs and restrictions can be used in interventions to support social participating, coping, and functional abilities. Research projects should focus on aspects of everyday experiences of women with BCRL, and researchers should develop evidence-based interventions to improve quality of life, social participation, and functioning.

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Appendix A. Synthesis 1: Experience of Everyday Life

Finding	Quotation
Care for Oneself	
4. Keeping in mind the consequences	"I have to take care of my arm because I am afraid that my arm will get bigger and bigger and out of control. My worst fear is that it's going to get huge to the point that I cannot use it" (Fu, 2005, p. 450).
5. Preventing lymphedema from getting worse	"I put sun lotion on my arm. I wash my arm frequently and I keep my arm pretty clean. Mainly, I just try to protect my arm from getting injured. So, it won't get worse" (Fu, 2005, p. 451).
7. Integrating the care of lymphedema into daily life	"In the morning, I take off my ReidSleeve® [a heavy compression sleeve for nighttime] and put on my other older Elvarex® sleeve [a light compression sleeve for daytime]. I drink my coffee. Then, I dress myself and go for my 30-minute walk. When I come back home, I have my shower and do my arm exercise. After that, I put on my newer Elvarex sleeve. I wear the newer sleeve all day until I get ready for bed. At bedtime, I take off my sleeve and put on my ReidSleeve and sleep in that ReidSleeve. Then I repeat the process seven days a week without a break, especially when I am traveling or during my vacation" (Fu, 2005, p. 454).
32. Learned physical strategies to manage lymphedema symptoms	"I think you need to do all the activities … massage … exercises, and wear the sleeve … if you slack off, it makes it worse" (Heppner et al., 2009, p. 332).
69. Using compression garments	"I use the Legacy garment. It's very helpful. I sleep in a Legacy garment and use the sleeve during the day. The Legacy reduces the fluid and the sleeve maintains that" (Wanchai et al., 2011, p. 120).
70. Performing physical activities	"I do exercise my arm. I recently have been taught to do some lymph drainage myself" (Wanchai et al., 2011, p. 121).
73. It never bothered me, but hope it doesn't get worse	"It's always there in the back of my mind because I don't want to get to the point where I could never use my arm. Consciously, I'm thinking, don't mess up, don't make it [lymphedema] worse than it is" (Whyte, 2010, p. 140).
85. Self-preservation: Do what the doctor tells me	"I'm just a big believer, if a doctor suggests something, I'm going to do it" (Whyte, 2010, p. 159).
87. Self-preservation: What's best for me	"My sleeve is something I have to wear. I have to watch me and do what's best for me" (Whyte, 2010, pp. 159–160).
88. Self-preservation: Not putting health at risk	"I know what to do if I see it getting worse. I will contact the specialists and have it [her arm] looked at" (Whyte, 2010, p. 161).
Restrictions on Everyday Life	
2. Concealing the imperfect image	"It bothers me a great deal. I just bought a jacket, and I had to buy it two sizes too big because you need comfort with a jacket. I can't buy anything with a lining because it's too warm. Even in winter, it's just too warm. I can't handle it. Then I have to take everything up. This one, I had to take the shoulders up, and this arm is kind of tight. And it just doesn't look normal. It looks like there is something wrong with me, which there is. I just wish [the lymphedema] would go away" (Carter, 1997, p. 879).
3. Living the interrupted life	"I think [my husband] feels sad that we have to endure any more. . . . [The lymphedema] is a financial burden and a physical burden. I even have a hard time going for a walk because as soon as I'm swinging my arm, it swells up and is uncomfortable. So we tend to not even go for a walk. It's like always something. And it's very discouraging when you are ready to move on but the body is not ready to move on with you" (Carter, 1997, p. 879).
18. Constancy	"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 is 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 are all sorts of small things" (Greenslade & House, 2006, p. 167).
44. Problem-focused coping	"I have a house all by myself. There I have been given some thought to having help. I realize that I can't do anything and everything there. I limit myself and do the gardening. It has become sort of automatic that I work a couple of hours and then go in and shower and get dressed and that feels all right. Yes, I do think ahead a little nowadays" (Johansson et al., 2003, p. 39).

(Continued on the next page)

Appendix A. Synthesis 1: Experience of Everyday Life *(Continued)*

Finding	Quotation
Restrictions on Everyday Life *(Continued)*	
50. Loss of control over time	"So much of my time and my husband's is now taken up by appointments, exercise, bandaging, and washing bandages. It's time I can't get back, and time is so very precious once you've been through cancer" (Ridner et al., 2012, p. 22).
60. Triggers and symptoms	"The doors were all frozen in the car . . . and I climbed in the backseat and got one door open, but the other door was frozen shut and I pounded it with my arm . . . it hurt at the time and it was shortly after that, I noticed the swelling" (Thomas-MacLean et al., 2005, p. 251).
62. Effect on daily life	"I can't really make a bed, like to throw the sheet or the blanket, I have to get my husband to help me. . . . I can't vacuum. . . . I just do the lighter things around the house; my husband does the other things. . . . I can't hold any sort of weight. . . . I don't know what would be the limit of pounds that I could take but I would say 10. I don't carry the groceries, if I do, I'll carry the bread, the light things. I don't grocery shop. It's hard to reach sometimes, and although I do the exercises, I just find it hard to extend my arm" (Thomas-MacLean et al., 2005, p. 252).
63. Difficulties with daily activities	"There are a lot of things I used to do that I cannot do anymore like volleyball or basketball. I cannot pick up my kids. I can't carry in the groceries, or if no help, it takes me many trips to get the job done. I cannot do simple things like opening a jar. I can't do it. I don't bake any more because I cannot stand and stir things. It's hard on me trying to do the simple household chores" (Wanchai et al., 2011, p. 119).
66. Time-consuming wrapping	"With the wraps, everything takes you twice as long. Getting dressed, I used to get up and be out of here in 10 minutes. You got to be kidding. To be up and out of here in 35 minutes now because it take you 20 minutes to put on your wraps. It takes you 45 minutes to roll" (Wanchai et al., 2011, p. 120).
67. Trouble with fitted clothes	"Your clothes don't fit. You have to buy jackets 2–3 sizes larger because the arm is so swollen" (Wanchai et al., 2011, p. 120).
75. It never bothered me, but restrictions	"When you have kids, you don't have the option of not lifting" (Whyte, 2010, p. 143). "It's especially hard doing housework. My husband helped at first, but he is busy too" (Whyte, 2010, p. 143).
77. Unwanted baggage: Only when I wear it	"I try to do things with it [sleeve] but it's hard to exercise and do house cleaning with it on. It gets in my way. It hurts, rubs, and is so tight. And I hate it in the summertime. I can actually do more without it" (Whyte, 2010, p. 147).
79. Unwanted baggage: It's my arm	"Something as simple as drying your hair became a challenge. Trying to keep my arm up as well as holding the hair dryer now has to be done in steps which take longer . . . and I can't reach back as far as I used to . . . things that you took for granted you now have to think about" (Whyte, 2010, p.151).
The Level of Dependency on Others	
8. Having a visible sign: Need for help	"When my coworkers saw my hand swell up, they tried to help me with the vertex machine. But, when Mr. XX [my supervisor] saw them help me, he was very upset. He pointed to my swollen hand and said, 'You'd better apply for disability since you can't do the job so that I can hire someone to do the job'" (Fu, 2008, p. 23).
9. Having physical limitations being handicapped versus the inconvenience	"I am handicapped by lymphedema. I cannot lift my patients just using my right [nonaffected] arm. I have to ask people to help me to lift patients. Often, people are busy with their own work and I have to wait. It can be very depressing for women like me in the working field" (Fu, 2008, p. 23). "Nothing has really changed for my job with lymphedema because I have a very sedentary job. I sit and look through the microscope. Even when I had my arm wrapped under lymphedema treatment, I could still do my job because all I had to do was to look through the microscope and I could use my other hand to move the slides" (Fu, 2008, p. 24).
10. Worrying constantly	"I am afraid that some day my boss will just let me go home when she sees my arm is getting bigger and bigger" (Fu, 2008, p. 24).
14. Feeling handicapped	"I am handicapped by lymphedema. I used to be a very independent person. With lymphedema, I cannot lift just using my right [nonaffected] arm . . . I have to ask people for help. Very often, people are very busy with their own work and I have to wait. It is really depressing to rely on others, especially for women like me in the working field" (Fu & Rosedale, 2009, p. 856).

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Appendix A. Synthesis 1: Experience of Everyday Life *(Continued)*

Finding	Quotation
The Level of Dependency on Others *(Continued)*	
15. Reluctantly shifting responsibilities to others	"Being independent to take care of my garden. . . . Reluctantly, I have to shift some of the responsibilities to my husband, such as shoveling the garden, planting flowers, and watering plants. He is very supportive, but he is not a gardening person, I feel that I've given him unwanted burdens" (Fu, 2010, p. 11).
16. Constantly needing others for physical labor	"My boss was upset when my friends try to help me to carry a heavy food tray. He yelled and shouted at me . . . I am scared that I will lose my job at any time" (Fu, 2010, p. 11).
72. It never bothered me, but having to ask for help	"They [her physician] sent me [for treatment] a lot sooner than I went . . . I have to do the wraps every six months now . . . I can't do it by myself. I've got to ask for help and that makes me mad because I'm not used to asking for help. I'm very independent and that's changed . . . but I have to stick with it 'cause if l don't it hurts" (Whyte, 2010, p. 139).
Financial Coverage	
29. Lack of adequate health insurance coverage	"If I had known my insurance had a limit, I might not have done anything and waited to get treated when it really got worse" (Heppner et al., 2009, p. 331).
37. Impact of their racial and socioeconomic backgrounds on coping	"I think in our culture, in general, it [being Caucasian] affects everything. It doesn't give us total access to things, but it does give us access to things other people may not have. . . . That's just a reality. . . . There's a lot of racism still in this old rural state. So yes, I think definitely the fact that I have access to things, like good health insurance you know, have good jobs, definitely makes it easier for me to cope with this" (Heppner et al., 2009, p. 332).
47. Lack of financial support from the healthcare system	"Whenever I had to have a sleeve and a custom-made glove, my insurance wouldn't pay. . . . I had a feeling of being abandoned and shoved aside" (Ridner et al., 2012, p. 22).
61. Access to treatment	"We have a private health plan, and it won't cover my sleeve. It will cover my prosthesis, but I've called and they just won't cover my sleeve. I said I had a prescription, I have to get measured, I have a prescription but that didn't matter" (Thomas-MacLean et al., 2005, p. 252).
80. Unwanted baggage: It costs money	"My insurance paid for it [sleeve] but not the treatment visits" (Whyte, 2010, p. 151).

Appendix B. Synthesis 2: Energy Sapping

Finding	Quotation
Mourning	
24. Suffering silently	"A great sadness swept over me, as if I was in mourning. I just felt so sad about my arm" (Hare, 2000, p. 37).
26. Negative emotional and cognitive reactions	"I felt angry, I felt discouraged that this is something that can never go away. It's like you are stuck with it forever. And it can get worse if you don't know or follow certain precautions. . . . So, I was very discouraged, very dismayed" (Heppner et al., 2009, p. 331).
54. Impact on psychological well-being	"How have I felt about the lymphedema diagnosis? Frustrated, angry, sad, and perplexed" (Ridner et al., 2012, p. 23).
It Never Goes Away	
6. Getting ready to live with lymphedema	"Lymphedema is something that you have to deal with every day. It's something you have to deal with physically and you have to deal with mentally. You know, lymphedema will never go away. You have lymphedema for the rest of your life. I think, when you realize that you have to deal with lymphedema for the rest of your life, you know that you have to change your life both from a physical and emotional standpoint" (Fu, 2005, p. 452).
8. Having a visible sign: Disability	"Lymphedema is so physical that everybody can see it. It's a reminder every minute of the day that I have lymphedema" (Fu, 2008, p. 22).
11. Living with perpetual discomfort	"With breast cancer, you go in for your treatment, once cancer is under control you are kind of done with it [breast cancer]. With lymphedema, you will never be done with it because you are having this big arm, pain, burning, heaviness, and soreness every day. It's something that you have to live with for the rest of your life" (Fu & Rosedale, 2009, p. 853).
43. Chronic disease	"I had so many problems then [after surgery] so it [discovery of lymphedema] was nothing special. But, later, it became a problem. I wasn't prepared for having it for the rest of my life. I thought it would pass. I didn't realize that I might have to wear the sleeve for the rest of my life" (Johansson et al., 2003, p. 39).
68. Reminder of breast cancer	"It's a constant effect. It will be with me the rest of my life. I guess it is always present. It's always something that I have to cope with" (Wanchai et al., 2011, p. 120).
76. It never bothered me, but never going away	"There are some days that are easier. It's never going to go away, but if you do these things [restrictions], it'll sure make it a whole lot easier. You'd like to be able to put it [cancer and lymphedema] behind you, but it just doesn't happen" (Whyte, 2010, pp. 144–145).
Yearning for Normalcy	
19. Yearning for normalcy	"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 have to pay the consequences if I don't" (Greenslade & House, 2006, p. 167).
51. Loss of function	"He [doctor] says not to lift over five pounds, no vacuuming, no repetitive motions; otherwise, baby it. I do not like the idea of having to always be aware of what I might be doing to my arm. I want to do things normally" (Ridner et al., 2012, p. 23).
55. Frustrated aspirations for normalcy	"I don't want to be easily identified as being sick. I am not sick! I am a survivor, I can make a full recovery. I don't want people to look at me funny, I don't want people to pity me. I just want to look and feel normal again" (Ridner et al., 2012, p. 23).
56. Damaging attempts to regain a sense of normalcy	"I don't like having lymphedema, but I don't take care of myself like I should. I don't wear my glove and sleeve daily. I don't wrap like I should, and I don't sleep in my JoViPak®" (Ridner et al., 2012, p. 24).
Loss of Attractiveness	
13. Losing prelymphedema being	"It's kind of hard to be sexy. I have to dress with this big, ugly sleeve" (p. 855). "I am so different now because lymphedema is so physical and everybody can see. It's a reminder every minute of the day that I have lymphedema" (Fu & Rosedale, 2009, p. 855).
27. Attractiveness and sexual issues	"It's definitely a hindrance, especially when yours had the wrapping . . . forget it. It [sex] was just out the window, I found another bed completely" (Heppner et al., 2009, p. 331).
49. Body image disturbance	"I don't feel ugly, just not beautiful. I feel scarred, lopsided, and swollen. I don't like to use the word *damaged*, but that's what comes to mind" (Ridner et al., 2012, p. 22).

(Continued on the next page)

Appendix B. Synthesis 2: Energy Sapping *(Continued)*

Finding	Quotation
Loss of Attractiveness *(Continued)*	
78. Unwanted baggage: A visual bother	"I would look in the mirror and say, 'Well I guess I'm not wearing that shirt today.' . . . Clothes that looked okay now look awful you know . . . where it fits on one side it looks horrible on the other. . . . Yeah, I think that's [visual aspect] what bothers me the most" (Whyte, 2010, pp. 148–149).
Strains on Relationships	
17. Unwillingly projecting emotional burdens to others	"In a way, I give my responsibility to them regardless, whether they like it or not. For me, they have to receive my burden. Sometimes, if they did not wrap my arm well, I get frustrated and distressed. Unwillingly, I project my frustration to them. So, I also give them emotional burdens" (Fu, 2010, p. 12).
53. Adverse effects on relationships	"I feel guilty about being the one who causes all of the worry, extra work, exhaustion, and boredom" (p. 23). "I cannot lift my nieces and nephews or tote them around like I used to. I can't hold them in my arms, and it makes me feel as though I can't be close to them" (Ridner et al., 2012, p. 23).
Lack of Information	
12. Confronting the unexpected	"I was not told about lymphedema before and I was not told about lymphedema after cancer treatment. When I started having swelling, I had no idea what it was because I never even heard about the word lymphedema" (Fu & Rosedale, 2009, p. 854).
20. Searching	"The other challenge I think is to convince yourself about the things that you read because you can read conflicting information . . . (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" (Greenslade & House, 2006, p. 167).
21. Emotional impact	"In the beginning I was told to do my exercises; but there, I thought it 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" (Greenslade & House, 2006, p. 168).
23. Finding information	"I wish I'd been told about the possibility of developing lymphedema and then I'd have been prepared for this terrible shock" (Hare, 2000, p. 37).
31. Actively sought information or treatment options	"Once I found out that [lymphedema] was probably what I had, I started educating myself [immediately] . . . and learning what to do and not to do to make it worse. And I also started treatment for it in the form of manual lymph drainage massage" (Heppner et al., 2009, p. 331).
46. Disease management failure	"I have gotten different answers from different people regarding activity with the affected arm. My general surgeon says to treat it completely normal, lift whatever I want, do whatever I want, and so on. The lymphedema therapist, of course, says otherwise" (Ridner et al., 2012, p. 22).
52. Permanent uncertainty	"Will I be able to do the things I've always done?" (Ridner et al., 2012, p. 23).
59. Lack of information	"She didn't even talk to me about it when I had my surgery . . . even my surgeon, or the oncology department [staff] that you go to once a year, they did not mention it. Really, nobody ever mentioned it to me, ever" (Thomas-MacLean et al., 2005, p. 251).
64. Unmet lymphedema preparation	"I'm so sorry because no one told me about that, not even the doctor. He didn't tell me that I must expect this and that and that, you know. I didn't know I was just only worried [about] what is going on now. I was all right but why this arm is swelling now?" (Wanchai et al., 2011, p. 119).
81. Who knew? I had no clue	"He [the surgeon] said there could be some swelling. But I didn't realize how much lymph nodes could be affected and how it went through your body . . . and I basically didn't have a clue. You know I'm thinking at that point just get the cancer out and do what it takes to get the cancer out" (Whyte, 2010, p. 154).

Appendix C. Synthesis 3: Personal Empowerment

Finding	Quotation
Helpful View of Life	
10. Feeling fortunate	"I am just grateful that I am alive and have lymphedema" (Fu, 2008, p. 24).
25. Counting blessings	"Lucky to be alive" (Hare, 2000, p. 38).
33. Accepted the limitations associated with lymphedema symptoms	"You just have to deal with it. You can get mad. You can get angry. You can pout. . . . But get over it because you are gonna have to still deal with it" (Heppner et al., 2009, p. 332).
34. Focused on the positive aspects of life	"It [lymphedema] isn't minor, but the gratitude is that I have learned so much about my body. Because out of negative experiences can come positive, and I suppose that's one of the ways I cope. I try to look for what positive can come from this. And if you can see positives, you can cope a little better. It doesn't become so dramatic" (Heppner et al., 2009, p. 332).
38. Opportunity to nurture others	"It's [lymphedema] a good conversation piece in the hospital for people I'm visiting" (Heppner et al., 2009, p. 333).
44. Emotion-focused coping	"I have changed my values. I don't care about things like that [the arm's appearance] today. The main thing is that I am healthy. So, that doesn't matter" (Johansson et al., 2003, p. 39).
58. Spiritual resources	"I am living with this condition every day but not as an invalid but as a survivor. God spared my life, and lymphedema was part of the package. That's okay when you consider the alternative" (Ridner et al., 2012, p. 24).
84. Self-preservation: I can do this	"I can accomplish a lot of things because of my strength" (Whyte, 2010, p. 159).
86. Self-preservation: Moving on	"I accept what it is, make the best of it, and move on" (Whyte, 2010, p. 159).
89. Hopeful determination: Proud survivor	"I am proud I beat cancer. I am a survivor" (Whyte, 2010, p. 163).
90. Hopeful determination: Previous experience	"Things like cancer and lymphedema are out with my control. But I knew what to expect, at least with the cancer" (Whyte, 2010, p. 164).
Psychosocial and Spiritual Support	
35. Used spiritual/religious methods	"Have you ever felt like you've had a weight on your shoulders that you just couldn't get to go away? Or a weight on your chest or your heart? And then it's suddenly lessened or even gone? That's how it feels like. . . . You feel calmer. . . . I just ask Him [God] to help me cope, not take it away. Just to help me deal with it. Be able to do the things I need to do to deal with it. . . . I know that God just chose to answer my prayers in His good time. That's how I feel and now I ask more on behalf of other people and for me to cope, not to change things" (Heppner et al., 2009, p. 332).
39. Reliable alliance of others besides partners	"The daughter of one of my closest woman friends, I guess, she won't let me go. She concentrates on me all the time, trying to rebuild my health [laughed]. Almost every day I hear from her. She must spend a lot of money buying stamps and get-well cards. It is nice to be remembered by people and to know they care" (Heppner et al., 2009, p. 333).
41. Spiritual support from others	"My boss asked me if I wanted him to put me on his prayer list at church. And I said 'yes.' And a couple of days later, I could tell. I could feel the difference . . . and it helped me cope" (Heppner et al., 2009, p. 333).
57. Psychosocial support	"I have wonderful friends and family. They take me as I am and are very concerned about what I call my leftovers from cancer. I don't think I could ask for better people in my life" (Ridner et al., 2012, p. 24).
71. Using faith	"I just said, 'Please, Lord, help me.' And, instantly, my panic attack disappeared and a feeling of peace enveloped me which lasted me through the biopsy, through the cancer, and right now even into the lymphedema. I've had this fantastic sense of peace" (Wanchai et al., 2011, p. 121).
91. Hopeful determination: Encompassing support	"I surrounded myself with family and friends and church too" (Whyte, 2010, p. 166). "If your husband and family is supportive, it makes all the difference" (Whyte, 2010, p. 166).

Appendix D. Synthesis 4: Contribution of Others

Finding	Quotation
Healthcare Providers' Performance	
1. Abandonment by medicine	"As far as the medical profession is concerned, I would like to see [the physicians] more aware, more concerned about the lymphedema. [A lot of] people that I have come in contact with . . . just shrug it off and say 'It's there, there is nothing that can be done, just live with it'" (Carter, 1997, p. 878).
22. Abandonment	"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" (Greenslade & House, 2006, p. 168).
40. Concern and support from healthcare providers	"My oncologist has been wonderful. He put me in touch with [hospital name] where the woman has been specially trained to do the massage" (Heppner et al., 2009, p. 333).
45. Lack of support from healthcare providers	"I wish that doctors would be more sensitive toward the matter [lymphedema] and act like they care instead of acting like women should just be glad to be alive" (Ridner et al., 2012, p. 21).
How the Woman's Immediate Circle Contributes	
28. Negative social support	"I really don't need their pity, it's not something they have to say 'poor me' about. That I don't appreciate. I prefer that they just say, 'Well, what's that? What's going on?' And let me explain to them and move on" (Heppner et al., 2009, p. 331).
30. Stress and anxiety in partners and/or children	"Is mom going to survive?" (Heppner et al., 2009, p. 331).
36. Openly talking and educating about lymphedema	"I told them from the beginning what I had and to the best of my knowledge what was going to happen, where I was going to be, what I might be like, look like, and I wouldn't be as active. . . . I think that helps to make the adults . . . more comfortable too because you are not trying to keep something quiet from the children . . . and don't worry about keeping any secrets, letting anything spill" (Heppner et al., 2009, p. 332).
42. Reaction from others	"It helps, it's good, but it is difficult to wear. And then you notice that people are looking at you all the time" (Johansson et al., 2003, p. 37)
48. Lack of sensitivity from friends and family	"My son and parents don't see the big deal and think I'm being weird for letting this bother me. . . . They all say, 'Well, at least the cancer isn't back'" (Ridner et al., 2012, p. 22).
65. Facing public curiosity	"Well, people look at you like you are an idiot. Someone told me to try the sling, you know. People keep asking me, 'May I help you?' because I have my arm in the air" (Wanchai et al., 2011, p. 120).
74. It never bothered me, but unsympathetic employers	"It doesn't really matter what your problems are if you work for a selfish boss" (Whyte, 2010, p. 141). "For the workplace, there needs to be an understanding about what this [lymphedema] is" (Whyte, 2010, p. 141).
82. Who knew? Does anyone know?	"People aren't very educated in that area [lymphedema]. I think there's a lot of people who don't understand lymphedema" (Whyte, 2010, p. 154). "There needs to be more information out there about lymphedema" (Whyte, 2010, p. 155).
83. Who knew? Curiosity	"The main time they ask is when I am wrapped. . . . I think a lot of people think it's for burns, but I just tell them I had surgery on my arm" (Whyte, 2010, p. 156).