

Body Image and Stigma Experiences among Patients with Lower Limb Lymphedema Secondary to Genital Neoplasms, Female Surgery: A Qualitative Study

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Abstract

Objective: To explore the lived experiences of body image alterations and stigma in patients with lower limb lymphedema following surgery for gynecologic malignant tumors, aiming to provide a theoretical foundation for developing targeted psychological interventions and transitional nursing care.

Methods: Following a descriptive phenomenological approach, 14 patients were recruited via purposive sampling from the Gynecologic Oncology Center and Lymphedema Clinic of a Level-III Grade-A hospital between June 2023 and June 2024. Data from semi-structured interviews were analyzed using Colaizzi's seven-step phenomenological method. **Results:** Three primary themes were identified, supported by illustrative quotes from the participants: 1) a fragmented and dysregulated body image (encompassing perceived physical deformity, restrictive sensory heaviness, functional helplessness, and diminished femininity); 2) multidimensional internalization of stigma (including social anxiety under the public gaze, defensive concealment, self-devaluation associated with the "cancer" label, and sensitive psychological projection); and 3) alienated social and intimate relationships (characterized by sexual avoidance in partnerships, frustration and guilt regarding family roles, professional marginalization, and social self-isolation).

Conclusion: Patients suffering from lower limb lymphedema after gynecologic cancer surgery experience significant body image disturbance and profound stigma. Nursing professionals should implement early screening for psychological distress, facilitate body image reconstruction, and promote proactive coping mechanisms to enhance holistic rehabilitation and quality of life.

Keywords

Gynecologic Malignant Tumors, Lower Limb Lymphedema, Body Image, Stigma, Qualitative Research

1. Introduction

Based on the 2022 epidemiological analysis of malignant tumors in China, the incidence of cervical, endometrial, and ovarian cancers has demonstrated a steady annual increase [1]. Advances in multimodal therapies—including surgery, chemoradiotherapy, and targeted agents—have significantly extended the survival of patients with gynecologic malignancies [2], effectively transitioning cancer into a manageable chronic condition. Nevertheless, treatment-related sequelae profoundly impact long-term quality of life. Lower Limb Lymphedema (LLL) is among the most prevalent chronic complications following radical gynecologic surgery and pelvic or inguinal lymph node dissection [3]. It is characterized by an insidious onset, progressive exacerbation, and a largely irreversible nature.

Distinguished from the upper-extremity edema typically seen in breast cancer survivors, the pronounced swelling, asymmetry, and skin fibrosis (often termed “elephantiasis”) associated with LLL constitute a “visualized trauma” that severely disrupts female body image [4]. Body image encompasses an individual’s perceptions, cognitions, and affective experiences regarding their own physical self [5]. Moreover, according to Goffman’s stigma theory, such conspicuous physical abnormalities predispose patients to perceiving external stereotypes or discrimination. This results in the internalization of stigma, which frequently precipitates social withdrawal and self-isolation [6]. Current literature on cancer-related lymphedema remains heavily weighted toward breast cancer populations or focused on quantitative assessments of physical therapy outcomes and general quality of life [7] [8]. There remains a critical shortage of research exploring the profound psychological experiences specific to the gynecologic oncology population. Consequently, this study employs a qualitative methodology to investigate the lived experiences of body image alteration and stigma among LLL patients following gynecologic cancer surgery. By uncovering deep-seated psychological needs, this work seeks to provide a clinical framework for nursing professionals to develop targeted and precise psychosocial intervention strategies.

2. Participants and Methods

2.1. Participants

Participants were recruited through purposive sampling utilizing the principle of maximum variation. The study population comprised patients attending follow-up appointments at the Gynecologic Oncology Center and Lymphedema Clinic of a Level-III Grade-A hospital between June 2023 and June 2024. Inclusion criteria were as follows: 1) pathologically confirmed cervical, endometrial, or ovarian can-

cer following radical surgery and lymph node dissection; 2) a diagnosis of lower limb lymphedema (Stages I - III) based on International Society of Lymphology (ISL) standards; and 3) clear consciousness with effective verbal communication skills. The sample size was determined by thematic saturation. Ultimately, 14 patients (identified as M1 - M14) were interviewed. Participants were aged 37 - 62 years, with a lymphedema duration ranging from 6 months to 8 years. The inclusion criteria are shown in **Table 1**.

Table 1. General characteristics of participants (n = 14).

Participant ID	Age (Years)	Educational Level	Premorbid Occupation	Insurance Type	Lymphedema Stage	Duration of Lymphedema (Months)	Comorbidities
M1	46	Secondary school	Farmer	Resident BMI	Stages I	15 months	HTN
M2	51	Secondary school	Self-employed	Employee BMI	Stages II	12 months	/
M3	57	Secondary school	Self-employed	Resident BMI	Stages I	24 months	DM
M4	38	Junior college	Office staff	Employee BMI	Stages II	13 months	/
M5	38	Secondary school	Farmer	Resident BMI	Stages II	18 months	HTN
M6	49	Junior college	Self-employed	Employee BMI	Stages III	10 months	DM
M7	58	Junior college	Sales	Employee BMI	Stages II	17 months	HTN, DM
M8	50	Primary school	Farmer	Resident BMI	Stages III	9 months	/
M9	60	Primary school	Unemployed	Self-pay	Stages II	14 months	HTN
M10	52	Junior college	Office staff	Employee BMI	Stages II	10 months	DM
M11	55	Secondary school	Self-employed	Resident BMI	Stages II	9 months	DM
M12	37	Junior college	Office staff	Employee BMI	Stages I	6 months	DM
M13	39	Secondary school	Office staff	Employee BMI	Stages I	12 months	HTN
M14	62	Vocational school	Unemployed	Self-pay	Stages II	96 months	HTN, DM

Note: BMI = Basic Medical Insurance; HTN = Hypertension; DM = Diabetes Mellitus.

2.2. Methods

2.2.1. Interview Outline

Drawing upon Cash's cognitive-behavioral model of body image and Goffman's stigma theory, the interview guide was developed through a literature review and expert consultation: 1) Describe the impact of lower limb edema on your life and psychological well-being. 2) What are your thoughts or feelings when viewing or touching your swollen limb? 3) How do you perceive your legs in public or during social interactions? 4) How has this condition influenced your family dynamics and intimate relationships? 5) How do you perceive others' views of you, and what support do you require?

2.2.2. Data Collection and Analysis

Data management and initial coding were facilitated using NVivo 12 software, while the final thematic extraction and synthesis were conducted through iterative

team discussions. Semi-structured, face-to-face interviews were conducted following informed consent. All sessions were audio-recorded and supplemented with field notes. Within 24 hours, recordings were transcribed verbatim. Data were analyzed using Colaizzi's seven-step descriptive phenomenological method to extract and refine themes [9]. Specifically, this involved: 1) reading all transcripts repeatedly to achieve familiarity; 2) extracting significant statements pertaining to the LLL experience; 3) formulating meanings from these statements; 4) organizing formulated meanings into clusters of themes; 5) integrating findings into an exhaustive description; 6) distilling the exhaustive description into a fundamental structure of the experience; and 7) validating the findings by returning to the participants for confirmation (member checking).

2.2.3. Ethical Considerations

Prior to data collection, the study's purpose, procedures, and potential benefits were thoroughly explained to all participants, and written informed consent was obtained. To strictly protect participant privacy and ensure data confidentiality, all personal identifiers were removed during the transcription process. Participants were assigned anonymous codes (M1 - M14) for all subsequent data analysis and reporting. Furthermore, participants were explicitly informed of their voluntary participation and their right to withdraw from the interview at any time without any adverse impact on their ongoing clinical care.

3. Results

3.1. Theme 1: A Fragmented and Dysregulated Body Image

The limb enlargement, asymmetry, and cutaneous alterations associated with LLL caused profound visual shock and physiological discomfort, precipitating a collapse of the patients' self-identity.

3.1.1. Perceived Deformity at the Visual Level

Participants frequently employed pejorative terms such as "elephant leg", "like wood", or "weird" to describe the affected limb, reflecting a struggle to reconcile with their physical appearance.

M3: "I don't dare look down when I'm bathing. That leg is so thick and hard, and the skin is like tree bark. It doesn't feel like it belongs to me; it's just too ugly".

M8: "When I wear pants, one leg is loose and the other is bursting. Looking in the mirror, I feel like a monster".

3.1.2. Restrictive Sensory Heaviness

The physical weight of the edema was described as a constant "leaden" sensation or a "shackle", serving as a persistent reminder of their physical abnormality.

M5: "It feels like sandbags are tied to my legs. Every step requires immense effort. This heaviness makes me feel like my own body is an inescapable burden".

3.1.3. Functional Impairment and Loss of Control

Mobility restrictions resulting from limb swelling caused participants to feel a loss

of bodily autonomy, fostering a profound sense of helplessness.

M12: “I used to be a brisk walker, but now I can’t speed up even if I try. I’m even afraid the traffic light will change too fast when I’m crossing the street. This sense of powerlessness over my own body is more disheartening than the cancer diagnosis itself”.

3.1.4. Diminished Sense of Femininity

The surgical removal of reproductive organs, compounded by the presence of lower limb lymphedema, exacerbated the experience of “lost womanhood”.

M2: “Without my uterus and with a leg swollen like this, I can’t wear beautiful dresses and I don’t feel like a normal woman. I feel like I’m more than just a patient—I’m a defective, discarded product”.

3.2. Theme 2: Multidimensional Internalization of Stigma

Conspicuous physical abnormalities rendered participants hyper-sensitive during social interactions, triggering defensive and avoidant behaviors characteristic of social alienation.

3.2.1. Social Anxiety under the Public Gaze

Participants were hyper-vigilant regarding the attention of others, perceiving even neutral gazes as judgmental or repulsed.

M6: “The last time I was at the market, a child pointed at my leg and asked his mother about it. Even though she didn’t say anything, I was so embarrassed I wanted the ground to swallow me whole”.

3.2.2. Defensive Concealment Behaviors

To avoid revealing their condition, participants modified their attire as a defense mechanism to preserve their self-esteem.

M9: “Regardless of the summer heat, I only wear these dark, wide-legged pants; I never dare to wear a skirt. I have to wrap myself up completely so that no one can notice”.

3.2.3. Self-Devaluation Associated with the “Cancer”

Label Lymphedema serves as a permanent “stigma” of cancer treatment. Patients felt shame not only for their appearance but also for the underlying identity of being a “cancer patient”.

M1: “I feel inferior. It’s because of this disease that I’ve ended up like this. I feel so small, like I don’t deserve to stand among ‘normal’ people”.

3.2.4. Sensitive Psychological Projection

Participants frequently misinterpreted the benign actions of others as intentional discrimination or mockery.

M14: “When my colleagues are talking together, I’m convinced they must be whispering about my leg. Rationally, I know that might not be true, but I can’t stop myself from thinking that way”.

3.3. Theme 3: Alienated Social and Intimate Relationships

The alterations in body image and internalized stigma further impede social connectivity, precipitating relationship alienation—a phenomenon paralleling the post-operative social experiences observed in colorectal cancer survivors.

3.3.1. Sexual Avoidance in Intimate Relationships

Driven by self-loathing and a fear of spousal rejection, participants actively avoided physical intimacy.

M4: “Whenever my husband tries to give me a massage, I instinctively pull away. I can’t bear the thought of him feeling how hard and stiff the limb has become. As for our intimate life, that’s out of the question—I just don’t feel attractive anymore”.

3.3.2. Frustration and Guilt Regarding Domestic Roles

Functional limitations hindered participants’ ability to perform household chores or caregiving duties, leading to a perceived failure in family roles.

M10: “I used to manage every aspect of our household. Now, even mopping the floor is an ordeal. Seeing my husband do everything alone makes me feel like a useless burden rather than a partner”.

3.3.3. Professional Marginalization and Career Obstruction

Participants faced significant challenges in returning to work or experienced “invisible discrimination” due to their altered appearance.

M7: “I work in sales, where professional image is paramount. Since the swelling started, I’ve lost the confidence to meet clients. My company has gradually marginalized me, and the sense of professional loss is devastating”.

3.3.4. Social Self-Isolation

Participants frequently severed social ties and declined invitations to gatherings, resulting in a diminished social support system.

M11: “My close friends used to invite me for hot spring trips or traveling, but I’ve made excuses to decline every time. I don’t want them to witness my disfigurement, and I certainly don’t want to hear their hollow words of comfort”.

4. Discussion

4.1. Body Image Reconstruction as a Central Challenge in Psychological Adaptation

The findings of this study indicate that patients with LLL secondary to gynecologic cancer surgery experience significant body image disturbance, characterized by an aversion to their physical appearance and a sense of functional helplessness. This aligns with recent clinical perspectives [2], which assert that the “irreversibility” and “high visibility” of lower limb edema impose a psychological impact far exceeding that of surgical scarring, often transforming into a “visualized trauma”. Patients are forced to navigate both the existential threat of cancer and the reality

of a “dysregulated body”, echoing the findings of Wang *et al.* [10]. We recommend that healthcare providers integrate Acceptance and Commitment Therapy (ACT) to facilitate patients’ acceptance of their physical reality. By shifting the focus from “aesthetic appearance” to “functional preservation” and “reshaping health standards”, patients can undergo a psychological transition similar to that observed in colorectal cancer survivors [11], highlighting the critical role of psychological adaptation in holistic rehabilitation.

4.2. Addressing Social Avoidance Precipitated by Internalized Stigma

Stigma constitutes a formidable barrier to the reintegration of patients into social life. According to Goffman’s stigma theory, visible physical impairments lead to a “spoiled” social identity [6]. The “defensive concealment” behaviors observed in this study, such as wearing oversized clothing, corroborate the findings of Xu *et al.* [12] regarding social alienation in ostomy patients: visible physical alterations serve as primary triggers for social withdrawal. Within the Chinese sociocultural context, the concept of “face” (*mianzi*) intensifies this experience, often resulting in a fragile social support network [13]. To address this, clinical practitioners should facilitate “Lymphedema Peer Support Groups” to mitigate loneliness and provide aesthetic nursing interventions—such as the selection of cosmetically acceptable compression garments—to bolster social self-efficacy.

4.3. Repairing Intimate Relationships in the Context of Impaired Femininity

The compounded impact of gynecologic malignancy and LLL significantly undermines a patient’s sense of femininity, frequently resulting in decreased sexual quality of life and marital strain. This is consistent with de Souza *et al.* [14], who noted prevalent sexual avoidance among gynecologic cancer survivors. Furthermore, this study underscores that the spouse’s supportive attitude is a critical determinant of recovery, as noted by Liu *et al.* [15] in studies of head and neck cancer caregivers. Current nursing practices remain predominantly focused on the physiological management of edema, often neglecting psychosexual health. Consequently, clinicians should proactively assess marital intimacy during follow-up and implement dyadic coping interventions that involve the spouse, thereby fostering mutual emotional expression and acceptance.

4.4. Implementation of Multidimensional Rehabilitation Support

Parallel to the needs of colorectal cancer survivors, patients with LLL require comprehensive support spanning nutrition and physical activity. Evidence suggests that tailored exercise regimens not only alleviate edematous symptoms but also bolster bodily autonomy and a sense of mastery. As noted in the review by An *et al.* [16], exercise interventions integrated throughout the cancer survivorship continuum significantly enhance functional outcomes. Consequently, developing

personalized exercise protocols—complemented by targeted psychological counseling—represents a vital trajectory for achieving holistic biopsychosocial recovery.

5. Summary of Findings and Clinical Implications

This qualitative inquiry reveals that LLL following gynecologic oncology surgery subjects patients to a dual burden: the physiological distress of swelling and pain, and a profound collapse of body image coupled with internalized stigma. This “conspicuous” physical alteration serves as a persistent visual cue of the oncological trauma, often precipitating a maladaptive cycle of social withdrawal and isolation. Unlike standard postoperative recovery, LLL is a chronic, refractory condition with enduring psychological sequelae. Recent literature [17] substantiates that the chronic burden of lower extremity lymphedema exacerbates psychological distress, with anxiety and body dysmorphic concerns often outlasting the acute side effects of primary cancer therapy. Despite these challenges, current healthcare frameworks frequently fail to address these unmet needs. As Dessources *et al.* [2] observed, LLL in gynecologic oncology remains significantly under-recognized compared to breast cancer-related lymphedema, resulting in many patients lacking professional guidance or hesitating to seek help due to concerns about burdening their clinical team. Accordingly, future nursing interventions must transcend hospital-centric care, extending into the home and community spheres. Recent studies, such as those by Wang *et al.* [17], highlight a substantial “knowledge-to-practice” gap and significant psychological barriers during home-based self-management. It is imperative for nursing professionals to establish a multidimensional support system incorporating family-centered care, peer mentorship, and digital health interventions. In conclusion, only by embedding body image reconstruction and stigma-reduction strategies into standard clinical pathways can we empower survivors of gynecologic cancer to overcome psychological barriers, facilitating a transformative transition from merely surviving with a chronic condition to successfully reintegrating into normal life.

Conflicts of Interest

The author declares no conflicts of interest regarding the publication of this paper.

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