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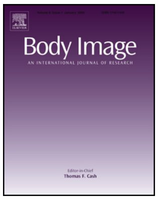

“You’re naked, you’re vulnerable”: Sexual well-being and body image of women with lower limb lymphedema

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ABSTRACT

Lower-limb lymphedema is an incurable illness manifesting as visible swelling enlarging the leg(s) and/or feet, buttocks, and genitals. This study used semi-structured interviews and thematic analysis to explore sexual well-being among women with primary (congenital) lymphedema ($n = 11$) or secondary lymphedema associated with gynecological cancer ($n = 8$). Five themes (subthemes) summarized women’s responses, with Attractiveness and Confidence (Publicly Unattractive, Privately Unconfident, Lymphedema or Aging?) describing women’s central concern. These body image-related concerns accounted for sexual well-being in association with Partner Support (Availability of Support, Languages of Support, Fears About Support) and the degree of Functional Interruptions (Lymphedema in Context, Enduring Impacts, Overcoming Interruptions). Successful Lymphedema Coping (Control, Acceptance) and self-perceived ability to fulfill a valued Sexual Role also affected sexual well-being. Few differences between women with primary versus secondary lymphedema were evident. Lymphedema clinicians should screen for sexual concerns and have referral options available.

Introduction

Lower-limb lymphedema is a chronic, progressive, and incurable condition occurring when lymphatic fluid accumulates in one or both legs, feet, buttocks, and/or the genital area (Ridner, 2013). This accumulation can cause visible alteration to body shape and movement, raising concerns about body image (Barlow, Hacker, Hussain, & Parmenter, 2014; Lloyd, Briggs, Kane, Jeyarajah, & Shepherd, 2014; Ryan, Stainton, Slaytor, et al., 2003), in addition to functional and medical issues (Fu et al., 2013). Lymphedema can be primary (congenital), but in developed nations it is often associated with lymph node surgery or radiotherapy due to cancer treatment (Ridner, 2013). It is estimated that lymphedema affects 20% (Cormier et al., 2010) of the 1.2+ million women in first world countries diagnosed with gynecological cancer in the last 5 years (including uterine, ovarian, cervical, and vulvar cancers; Ferlay et al., 2013). In addition, an unknown number of people have primary lymphedema. However, despite the prevalent psychosocial morbidity associated with lymphedema, little is known about the impact of lower-limb lymphedema on sexuality and sexual well-being.

Links between body image and sexuality have been empirically confirmed and systematically reviewed (Woertman & van den Brink, 2012). However, conceptual problems justify a fresh, exploratory approach for lower-limb lymphedema. Much body image research has equated sexual well-being with adequate sexual *function*, that is, desire, physical arousal, orgasm, freedom from pain, and sexual satisfaction. Evidence suggests that healthy women with negative body image experience lower desire, difficulty with orgasm, and lower sexual satisfaction (Woertman & van den Brink, 2012). However, after reviewing sexual well-being in women with breast and gynecological cancer (many of whom have lymphedema), researchers have argued that function is only part of sexual well-being, which also involves interrelated psychological, relational, and social factors (Gilbert, Ussher, & Perz, 2010b, 2011). Indeed, the World Health Organization (WHO, 1975, 2006) defines “sexuality” as a central aspect of human life including biological sex, gender roles, eroticism, pleasure, intimacy, and reproduction; experienced and expressed in thoughts, desires, beliefs, fantasies, attitudes, values, behaviors, roles, and relationships; and influenced by interacting biological, psychological, social, and cultural

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factors (WHO, 2006). Thus, it is critical to frame body image *itself* as being an aspect of sexual well-being, and link it to functional *and* mental-emotional *and* social-relational facets of sexuality (Abbott-Anderson & Kwekkeboom, 2012; Cleary, Burton, & Hegarty, 2014; Gilbert et al., 2010b, 2011).

Some studies of body image in medically well women have implications for women with lymphedema. For instance, negative body image (trait and state) is associated with negative sexual self-esteem for undergraduates (La Rocque & Cioe, 2011; Weaver & Byers, 2006), independently of attractiveness (Wiederman & Hurst, 1998). Similar associations are evident for genital appearance dissatisfaction specifically (Schick, Calabrese, Rima, & Zucker, 2010), which is relevant to women with genital lymphedema. Negative body image is associated with cognitive representations of the sexual self (self-schemas) as being less open to sexual experiences (Donaghue, 2009). Extrapolating from these data, women with lower-limb lymphedema may be at risk for negative sexual self-esteem and self-schemas. Yet such generalization is problematic: past research has focused on young women, and it is unknown whether the same associations apply amongst the women in middle age and older at risk for secondary lymphedema. Furthermore, the role of body image in relational factors relevant to sexuality is unknown (Wiederman, 2012). The present study aimed to extend knowledge about the role of body image within a WHO-informed framework for sexual well-being.

No research has specifically examined the sexual impact of lower-limb lymphedema. However, some evidence is available from studies of sexuality in women after gynecological cancer which incorporated women with lymphedema. The results are qualified as appropriate, as gynecological cancer itself is associated with extensive disruption to functional, emotional-mental, and social-relational sexual well-being (for systematic reviews see Abbott-Anderson & Kwekkeboom, 2012; Cleary & Hegarty, 2011; Gamel, Hengeveld, & Davis, 2000; Gilbert et al., 2011). A survey of women ($N = 616$) with endometrial (59%), cervical (23%), or other gynecological cancers (18%) found no association between lymphedema and sexual dissatisfaction (Dunberger et al., 2013). However, better long-term sexual outcomes tend to be observed in cervical, compared to endometrial or vulvar cancers (Gamel et al., 2000), which were combined in the analysis. Another study avoided this possible confound by analyzing a homogeneous sample of women with vulvar cancer ($N = 60$) whose groin lymph nodes were dissected (Farrell, Gebski, & Hacker, 2014). Those diagnosed with lymphedema rated their sex life 37 points lower on average, 95% CI [8,65] (scale from −100 to 100), than women without lymphedema. Therefore, there is evidence that lymphedema is negatively associated with physical-functional sexual outcomes, at least for women treated for vulvar cancer.

Emotional-mental and social-relational concerns are also reported by women with lower limb lymphedema, who attribute negative body image to lymphedema up to 18 years after uterine, ovarian, cervical, and vulvar cancer diagnoses (Barlow et al., 2014; Lloyd et al., 2014; Ryan, Stainton, Slaytor, et al., 2003). Many changed their clothing style over time to conceal lymphedema (Barlow et al., 2014; Ryan, Stainton, Slaytor, et al., 2003). Furthermore, some women attributed lost sexual intimacy to the visual appearance of lymphedema (Ryan, Stainton, Jaconelli, et al., 2003). Therefore, lymphedema may have substantial implications for emotional-mental and social-relational domains. However, this evidence base is limited in that only one study has focused specifically on sexual concerns (Barlow et al., 2014), and that only five participants were diagnosed with lower-limb lymphedema. Moreover, no publications have addressed sexual concerns in women with primary lymphedema.

This study aimed to qualitatively understand the sexual concerns of women with lower limb lymphedema, both primary and secondary to gynecological cancer. We framed data collection using the WHO definitions of sexuality, covering the physical-functional, emotional-mental (including body image), and social-relational effects of lymphedema.

Method

Participants and Procedure

Between August 2013 and February 2015, 22 women with lower-limb lymphedema ($n = 12$ primary, $n = 10$ secondary to gynecological cancer) responded to a survey and consent form offered by their lymphedema clinician in consultations or by mail. We chose to limit our sample to women, given that lymphedema prevalence in men is low (0.47/1000) compared to women (2.15/1000; Moffatt et al., 2003), and our lack of clinical access to men raised recruitment concerns.

Women reported age, marital and menopausal status, lymphedema history (diagnosis date, location), cancer history (diagnosis date, surgery, date finished chemotherapy/radiotherapy, type/duration hormone therapy), and lymphedema treatment. Recruitment occurred at a lymphedema rehabilitation unit in a private hospital, a lymphedema surgical clinic, an occupational therapy lymphedema practice, and a physiotherapy clinic. All were diagnosed using International Society of Lymphology (ISL, 2013) guidelines by a health professional and: (1) had persistent swelling, or needed active treatment to control swelling (e.g., compression garment); (2) were at least 12 months post radiation therapy and chemotherapy (if applicable); and (3) aged 18 years or older. One woman declined to be interviewed and two further women left the study before the interview because their cancer recurred. All participants were native English speakers.

Participants chose between phone ($n = 18$) or face-to-face interviews at the university ($n = 1$) conducted by three female interviewers trained by the research team: (a) a provisional psychologist in her 40s doing a Masters of Clinical Psychology, with a year of lymphedema research assistant experience; (b) a 40-year-old research officer with a Masters of Public Health and experience conducting telephone and face-to-face health surveys; and (c) a 47-year-old Ph.D. candidate with 2 years' experience doing qualitative study into bereavement. Progress was monitored by a 52-year-old female academic with 15 years' experience in qualitative, cross-sectional, and longitudinal lymphedema research. Interviews averaged 32 min (range: 20–66) and were audio-recorded and transcribed verbatim for analysis.

The analyzed sample consisted of 19 women, 11 diagnosed with primary lymphedema and eight with secondary, cancer-related lymphedema. Demographic and medical features of interviewed women are summarized in Table 1. Participants' mean age was 56 years (range: 32–75) and 14/19 were in long-standing marriages (mean length 28 years, range: 8–51). Women with secondary lymphedema had fewer years since their lymphedema diagnosis (mean = 8, range: 0–18) than those with primary lymphedema (mean = 16, range: <1–42). Women with secondary lymphedema all had radical hysterectomies entailing removal of their ovaries, so were post-menopausal by definition. Of women with primary lymphedema, 7/11 were post-menopausal. A separate report details a qualitative analysis of 19 women with breast cancer-related upper-limb lymphedema recruited concurrently (Winch et al., 2015). In total, lymphedema clinicians distributed invitations to 117 women with primary, breast- or gynecological cancer related-lymphedema (35% response rate). The institutional Human Research Ethics Committee approved the research. No incentive was offered to participate.