

LYMPHOEDEMA AND SEXUAL RELATIONSHIPS IN MID/LATER LIFE

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Abstract

Background: Women with breast cancer-related lymphoedema (LE) can experience physical, psychological, and sexual problems as a result of both physical limitations and appearance associated with this condition. **Aims:** This study investigated the effect on quality of life of the sexual relationships with intimate partners for women with LE. **Methods:** Participants were 11 women with LE. Qualitative in-depth interviews were used to elicit participants' descriptions of quality of life with breast cancer-related LE, and in what ways breast cancer-related LE has impacted on their sexual relationships. A cooperative, inductive approach to data analysis was used. **Results:** These findings show that breast cancer-related LE has an important and often negative influence on women's experiences of sexuality and intimacy and demonstrates how sexuality includes multiple domains of influence, including feelings about self as well as relationships. **Conclusions:** Family life educators and healthcare professionals should use these findings to assist women with breast cancer-related LE in their intimate relationships following diagnosis. **Declaration of interest:** None.

Key words

Lymphoedema
Sexuality
Ageing
Qualitative
Breast cancer

Breast cancer-related lymphoedema (hereafter LE) may result from successful cancer treatments that have eliminated cancer but leave an estimated 20% of survivors with physical, emotional and social effects that can diminish quality of life (Clark, et al, 2005). Women who live with LE are unique, as they have coped successfully with the physical and emotional distress of cancer (Passik and McDonald, 1998) only to be met

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with this often disabling complication of their cancer treatment (Radina and Armer, 2001). Changes in physical appearance and limitations created by LE can affect physical and psychological health, as well as social and sexual relationships (Casley-Smith, 1992; Tobin et al, 1993; Passik et al, 1995; Passik and McDonald, 1998; Petrek et al,

Breast cancer-related LE is a unique condition that is at the intersection of sexuality and self-image.

2000; Thomas-MacLean et al, 2005). In addition, those coping with this chronic, sometimes disabling condition are subject to frustrating physical limitations (e.g. being unable to lift heavy objects; having to reduce activities that require repetitive motions with the arm; having to keep the arm elevated; needing to protect oneself from sunburn, insect bites, injections, or cuts that may lead to cellulitis) (Radina and Armer, 2001; Ridner, 2002). At the same time, these women must also engage in time-

consuming self-care in order to reduce and control the swelling associated with LE (e.g. manual lymph draining, wrapping, wearing a compression sleeve). Many women are encouraged by their therapists to also wear night garments that resemble arm-length oven mitts, in order to maintain consistent compression (Lasinski, 1999). These are not only hot to wear at night, but also take up additional room in the bed, certainly an issue when the bed is shared with someone else.

Radina and Armer (2001; 2004), in their studies of how women with LE describe coping with this chronic condition in the context of their families, identified the need for further investigation of changes in relationships with family members (e.g. spouses/partners, children, grandchildren) that occur due to functional limitations and social stigma created by LE. This paper builds on Radina and Armer's (2001; 2004) work and reports on qualitative data from an exploratory study that investigated the following aspects of life with LE:

▶ Perceived changes in lifestyle

- ▶ Perceptions of functional and psychological independence
- ▶ Relationships with others
- ▶ Personal coping.

The purpose of the data analysis reported here was to explore the ways LE may have an impact on intimate relationships, with a specific focus on the influence of LE on the sexual relationships women have with their intimate partners. We chose to examine the specific concept of sexuality among this population for several reasons. Initial interviews with early participants suggested anecdotally that sexuality was indeed an issue for these women (i.e. many women brought up sexuality as a concern, despite not being asked in the initial interview guide); the study of sexuality in women in mid and later life is lacking in general; and LE is a unique condition that is at the intersection of sexuality and self-image (i.e. the association of LE with breast cancer combined with potentially long-lasting changes in a woman's physical appearance that may influence her self-perception and her perception by intimate partners) among women in mid and later life.

Sexuality

Sexuality can be examined as an interaction of biological, psychological, and social domains of life (Lindau et al, 2003; National Institute on Aging, 2005). How individuals feel about themselves as sexual beings is impacted by a combination of all three of these areas of influence. Individuals experience both normal biological changes as they age, as well as the biological impact of illness and disease, which have been found to have an impact on how they feel as sexual beings, their desire for sexual activity, and how their bodies physically respond to sexual stimulation (Kralik et al, 2001).

Social factors that impact sexuality involve such things as an available partner, the nature of the relationship with that partner, and cultural messages regarding sex. Societal messages leave the impression that older adults are asexual and that sex is the purview of the young. Psychological factors that

impact on sexuality can include our past sexual histories, as well as how individuals react to biological changes. How individuals respond to ageist societal messages about their aging bodies and sex, and how they feel about themselves and their bodies also has an influence on experiences of sexuality (Koch et al, 2005).

Age, health and sexual activity

Although historically, aging was viewed as having a negative impact on sexuality (Kennedy et al, 1997; Kellet, 2000), there has been a shift towards a lifespan

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approach to this topic focusing on people's need for intimacy and many people's desire for sex throughout life (Crose et al, 1997; Gibson, 1993). In a recent study of middle-aged and older adults in the United States, Lindau et al (2007) found that many of their 3,005 study participants, aged 57–85 years, were still sexually active: 73% of respondents were aged 57–64; 53% were 65–74; and 26% were 75–85. In addition to demonstrating that sexual activity occurs throughout adulthood, their findings demonstrated that the likelihood of being sexually active declines with age. With age, the factor most significantly associated with sexual activity was health. Those who reported being in good health were also more likely to report being sexually active.

Body image and sexuality

An important contributor to one's attitudes about sex and feelings about sexuality, which touches on all three domains mentioned earlier, is body image. The connection between women's body image and sexuality has been reported in numerous studies (Wiederman and Hurst, 1997; Koch

et al, 2005). Women's subjective views of their attractiveness have been shown to be positively related to their cognitive views of their own sexuality, or sexual self-schema (Wiederman and Hurst, 1997).

Some normal physical changes can be expected with aging. How women feel about these changes and the degree to which they internalise negative societal messages about these changes can have an impact on sexuality. The Midlife Women's Health Survey explored attitudes about women's aging bodies and sexuality with 307 women aged 39–56 (M=50) (Koch et al, 2005). A majority of the women (51.5%) felt less attractive than they did ten years ago. Fifty-seven percent of the participants reported desiring sex less in the past ten years, and 57.7% reported having sex less often. The more a woman felt less attractive at her current age than in the past, the more likely she was to report less sexual desire and activity over the previous decade. However, regardless of these declines in sexual behaviour, 72% of the women in this study who had partners reported being both physically and emotionally satisfied in their current sexual relationship. These findings support a connection between women's body image and feelings of sexuality and demonstrate the distinct difference between behaviour and satisfaction with one's sexual relationship.

Breast cancer and sexuality

As women with breast cancer-related LE have already faced breast cancer, these two issues are intertwined. Although it may not be possible to completely distinguish between body image issues, feelings of sexuality, and the impact on sexual relationships brought about by breast cancer and those resulting from LE, it is useful to take the existing literature on breast cancer and sexuality and build on it, as additional research adds to the discussion of the impact of LE on sexual relationships.

Many articles have explored the impact of breast cancer on sexuality and sexual relationships (e.g.

Henson, 2002). Some of the topics of investigation include the impact of breast cancer and its treatment on hormones and sexual functioning (Henson, 2002), attitudes of a romantic partner (Henson, 2002), the impact of fatigue brought about by treatment on sexual relationships (Henson, 2002), and how an altered body image resulting from (breast) cancer can impact one's sexuality and sexual relationships (Price, 1992; Gould et al, 2006). Also of importance is research into the lack of information on how the impact of breast cancer and treatment on sexuality provided to breast cancer survivors and their partners can negatively impact their sexual relationships (Henson, 2002; Gould et al, 2006).

LE, breast cancer, body image, aging and sexuality

As previously mentioned, LE can impact one's quality of life. With LE, women may experience changes in their appearance as well as pain and physical limitations due to swelling (Passik and McDonald, 1998). As sexuality is connected to a woman's feelings about herself and her body, not only the experience of breast cancer, but also the development of LE can have a serious impact on her views of herself as sexual and her willingness to be physical with a partner. As Passik and McDonald (1998) pointed out, having survived breast cancer to now have to contend with post breast cancer LE can be seen 'as a secondary blow to their physical and emotional well-being', including their intimate relationships with others.

There are numerous studies that explore the connection of sexual satisfaction, self or body image, and physical disability (Taleporos et al, 2002; Galvin, 2005; Kedde and van Berlo, 2006). As LE is a condition that has both disfiguring and debilitating effects, literature on disability and sexuality is relevant to this discussion. What Galvin (2005) called the 'disabled identity' has been shown to be affected by appearance, sexuality, and the negative attitudes of others. Galvin studied narratives of disabled people with a diverse range of disability and

impairment. Shame and fear of rejection were related to reactions from others for those whose impairment was evident or visible. Feelings of loss of attractiveness, negative reactions of others, and internalised societal messages about the asexuality of disabled people contributed to feelings of loss of sexuality in many of the narratives (Galvin, 2005). Although not a disability, because of the disfiguring and disabling aspects of the condition of LE, the disabled identity, which is impacted by an internalisation of how others view this condition, can negatively impact on sexuality and one's desire to be sexual with others.

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Given the intersection of the biological changes with aging, psychological and social factors, combined with potential changes brought about by having experienced breast cancer and now the changes in appearance and physical functioning as a result of LE, it stands to reason that there may be an impact on these women's experiences of their own sexuality, as well as their sexual relationships with significant others.

Present study

The current research explored the connections of breast cancer-related LE with feelings about self, health and relationships. The present study is a subset of a larger qualitative study that looked at the effects of LE on various areas of quality of life among women diagnosed with this chronic condition. The focus of this paper is the analyses of responses to semi-structured interview questions regarding issues of sexuality and sexual relationships with intimate partners. Questions that guided

this study were:

- ▶ How does LE impact sexuality and intimate relationships?
- ▶ How would diagnosed women describe how it has impacted their relationship with their partner/spouse?

Methods

Participant recruitment and rationale

Convenience sampling was used to recruit participants who had been diagnosed and treated for LE resulting from breast cancer treatment. Several venues were used to recruit these participants, including: breast cancer and LE support and advocacy groups; internet discussion board postings; articles and recruitment notices in newsletters circulated to breast cancer survivors; and referrals from participants who had taken part in this study. Hospital or clinic settings were not used as recruitment sites because this study sought to access potential participants who may or may not be currently receiving treatment. The four avenues for recruitment described above were viewed as providing the widest range of access to potential participants.

Being a convenience sample aimed at recruiting as many participants as possible, there were limited additional inclusion criteria for participants. All participants needed to have been diagnosed with and treated for breast cancer. At the same time, all participants needed to have been diagnosed with LE that had developed either concurrently with, or following treatment for breast cancer. As women in mid or later life are more likely to be diagnosed with breast cancer (American Cancer Society, 2007a), the authors anticipated that most participants would be at least in mid-life (i.e. having launched adult children, roughly 50 years old). Thus, no specific criteria for age of participants were specified for this study. No other limitations (e.g. cancer stage, type of treatment for either breast cancer or LE) were made for inclusion of participants. The above procedures reflect participant recruitment for the larger study of which the data presented here are a sub-set.

Participants

A total of 11 women participated in this study. All participants were Caucasian and ranged in age from 51–78 years ($M=60.6$ years). Nine participants were married, one was divorced, and one was single/never married. Participants were well educated, with an average of 16.7 years of formal education (range=14–20 years). All the participants had adult children who no longer lived at home. On average, participants were 4.9 years past their breast cancer diagnosis (range=2–17 years) and 3.6 years past their diagnosis of LE (range=0.75–13 years).

Procedures

The data for this paper were generated from a larger qualitative study that investigated the experiences of functionally autonomous women with breast cancer-related LE and paid specific attention to off-time transitions from familial caregivers to care recipients (e.g. Radina, accepted for publication). Human subjects' approval for this larger study was obtained from two mid-western higher education institutions where the first author was employed and where data were collected over a four-year period. The results presented here focus specifically on changes in sexuality and sexual relationships with intimate partners among women with breast cancer-related LE.

Data collection

Data collection involved the use of a semi-structured interview guide. For these analyses we specifically focused on those questions that addressed participants' perceptions of how LE had impacted their sexuality, their partner/spouse, their relationship with their partner/spouse, and their sexual relationship with their partner or spouse. Questions about sexuality and sexual relationships were asked of all of the women, even those not currently in a sexual relationship. Partly this is because sexuality and feeling sexual are not wholly dependent on the existence of a partner, and also because some women had had sexual relationships since their LE diagnosis, but were not having one at the current

time. Examples of interview questions aimed at obtaining this data included: 'How has LE impacted your sexual relationship with your partner/spouse?', 'What would your partner/spouse have to say about how LE has impacted your sexual relationship?', and, 'Has this impacted how you think about yourself as a sexual being?'

All participants, regardless of current intimate relationship status, were offered the opportunity to respond to questions regarding their sexual relationships. Often, but not always, those without a current partner chose to decline responding to this set of questions. The data reported is from those participants who chose to respond to this set of questions. These experiences were collected in the form of one-time, face-to-face or telephone interviews that were audio recorded. These were conducted by the first author and graduate and undergraduate research assistants who were being trained in interviewing techniques and procedures for administering the interview protocol for the larger study. Interviews typically lasted between 30 and 60 minutes, and all were transcribed verbatim by graduate and undergraduate research assistants. In total, data collection took place over a two-year period.

Data analysis

Data were analysed using a cooperative, inductive approach that began with the first and second authors individually reading through the entire data sub-set and making note of recurrent ideas expressed by multiple participants (Hill et al, 1997; Patton, 2002) with specific focus on the influence LE has had on sexual relationships. This use of consensual qualitative research (CQR) enhanced the dependability of the data analyses in that it employs the use of triangulation — the use of multiple perspectives in data analysis to provide a more complete understanding of the phenomenon under study (Daly, 2007; Hill et al, 1997). Consistent with Hill et al's (1997) description of CQR, the first and second authors met following their individual read-through of the data

sub-set so that they could present their thoughts about recurrent ideas to each other. Through these presentations and subsequent discussions, consensus was reached on predominant themes. Once these themes were identified, each of the two authors returned to the data sub-set to clarify sub-themes by identifying evidence (i.e. specific quotes) from within the data sub-set.

Data quality

Several steps were taken both prior to and during data collection and analysis to ensure the trustworthiness, rigour, and quality of the data and its analysis. The authors acknowledge, as is consistent with qualitative research philosophy, that no research is entirely objective (Morrow, 2005). The credibility of these data and findings was enhanced due to the research team's ability to establish rapport with participants that was based on the first author's extensive experience with breast cancer-related LE patients and work with local breast cancer communities. Some of the participants for this study were recruited from venues where the first author volunteered and worked with breast cancer and LE support and advocacy groups. Potential participants contacted the first author about the study. At this time, the author began the process of establishing rapport with the participants. The participants then extended the regard afforded to the author from these activities to student research assistants. In addition, the findings for this study were reviewed by a qualitative health researcher who was not involved in the study to provide feedback and verify the findings.

Transferability (i.e. generalisability) was established using detailed descriptions in the presentation of these findings. This includes the clear and detailed description of the research team, data collection, analysis processes, and participants. Readers are therefore permitted to judge if and how findings transfer or are generalisable to other populations, contexts, or situations (Gasson, 2004). Care has been taken in the presentation of the findings to avoid implications that they are

generalisable to populations, contexts, or situations beyond those similar to what was directly studied here (Morrow, 2005).

Dependability (i.e. reliability) was achieved in two ways. First, data analysis was conducted by a multi-level (i.e. faculty and graduate students) and multidisciplinary research team (i.e. family services/studies, gerontology, and communication). Following their independent reading of the entire data set, the first and second authors discussed areas of agreement and disagreement regarding themes and sub-themes and how to resolve any conflicts that arose. The result was clarification of themes and sub-themes that the first and second authors elucidated by returning to the dataset to find examples of the themes and sub-themes. Second, dependability of these data and findings were established by continuing to collect data from participants until, through the first author's concurrent examination of the data, it was determined that data saturation was reached (Morrow, 2005). That is, the author periodically examined the transcripts of completed interviews with special attention to interview consistency across research assistants and degree of redundancy by participants in response to interview questions. When the author determined that few new data (i.e. new ideas, variability in responses) were being generated by the interview guide, data collection was stopped.

Results

Data analysis resulted in the identification of two predominate themes for participants:

- ▶▶ Not feeling sexy anymore
- ▶▶ Changes in intimate relationships.

Not feeling sexy anymore

The first theme, not feeling sexy anymore, related to the specific influence LE seemed to have on these participants' sense of themselves as sexual beings. While this theme appears to be largely a reflection of participants' self-perception, it is important to recall that one's perception of body image and thus, physical attractiveness, can

have an impact on sexual relationships (Galvin, 2005). Four participants expressed that they no longer felt sexy. The remaining seven participants did not offer this self-perception in response to questions asked during the interview. Participants were not directly asked if they felt sexy or not. Because data collection involved open-ended questions in a semi-structured interview guide, participants were free to respond in various ways to interview questions. It was not until data analysis took place that the researchers were aware of the salient role that 'not feeling sexy' plays for these women. Based on the emphasis placed on this self-perception and the evidence provided in the literature regarding self-perception and sexuality (Taleporos et al, 2002; Galvin, 2005; Kedde and van Berlo, 2006), this pattern of responses among participants appeared important enough to constitute a theme within the results.

Participants' self-perceptions of lacking the feeling of being sexy stemmed from being self-conscious of their bodies, feeling embarrassed about having to accommodate their swollen limb during sex, not perceiving themselves as being attractive or desirable to a partner as a result of the LE, and feeling insecure about their future as a cancer survivor. The reality of having LE negatively impacts one's perception of being sexual and a desirable partner, as Carol (all names given are pseudonyms to ensure confidentiality) (56, married, 7.5 years since breast cancer diagnosis, 7 years since onset of LE) explained:

... when you have lymphoedema you don't feel attractive. If you look at yourself in the mirror, you're not attractive by any ordinary standards that are routine. When you don't feel good about yourself, you're less likely to be [sexually] responsive.

Sharon (51, divorced, two years since breast cancer diagnosis, two years since onset of LE) even described how the effects of the surgery and her condition had made her not desire being sexual anymore and, more

specifically, the idea of being naked with someone because she felt so unattractive and undesirable now:

I'm not as interested in even doing anything sexually because it's just... I feel even more unattractive. Of course, part of that's the cancer too. The lumpectomy and the scarring and... it's kind of the lymphoedema and the cancer. It just doesn't really make you wanna get naked with people. [laughs] Part of that's the feeling that you feel just so undesirable.

Sharon's response draws attention to the intertwined nature of breast cancer and LE for several of these participants. Radina and Armer (2004) have noted that breast cancer-related LE is a constant reminder of the individual's breast cancer experience. Thus, it is not surprising that some women may have difficulty in identifying which condition they should attribute changes in their self-perceptions.

Nancy (56, married, 2.3 years since diagnosis of breast cancer; nine months since onset of LE) expressed how the garment she wore for her arm, although she could still engage in sex while wearing it, was a deterrent to the spontaneity of being sexual with her spouse and feeling attractive:

Well, I can say one thing, is that, wearing this thing, I mean it looks like a barbecue mitt you know. It goes all the way from the end of my fingers all the way up to my shoulder. It looks kind of like that Michelin tyre guy, you know. So, it's like I have to wear that at night and so it's kind of, there is a certain spontaneity of things, I mean I can have sex with this on, but you know I would have to say that it is probably minimal really.

This demonstrated that feeling sexy is not only an individual feeling, but also the result of the reactions of others, Nancy went on to mention the response of her partner as influential.

Interviewer: *What would your partner or spouse have to say*

about lymphoedema and how it has impacted your sexual relationship?

Nancy: *Probably the same thing, you know, that having this big mitt on my arm is kind of a drag.*

Nancy's statements are significant in that, unlike some of the other women, her husband also sees the compression garment as not very sexy.

Sharon, who is divorced and without a full-time partner, does not want to establish a new intimate relationship not only because of the way she perceives her appearance, but also because of concerns about her future as a cancer survivor (i.e. long-term survival):

I've not really pursued [on-line dating] because I feel undesirable. I feel like, 'what can I offer somebody?' I mean I always felt like that with my weight, but now you add on top of that that I've got an arm that messes up all the time and a breast that's really, really ugly and... I just don't feel... I'm afraid, I feel so lonely and... that's one thing that going through the whole cancer experience has made me realise that life is so precious. And I don't want to be alone. But I feel because of the cancer I'm gonna be alone.

Changes in intimate relationships

The second theme, changes in intimate relationships, involved participants describing the presence and absence of changes in both sexual and emotional aspects of their intimate relationships with their partners as a result of LE and/or breast cancer. This theme was included to allow for a broad interpretation of what participants considered important to their intimate relationships with their partners.

Four participants reported no changes of any kind in their sexual relationships. Three participants reported no changes but qualified their statements by explaining that the reason they did not experience changes was because they: did not

currently have a partner ($n=1$); or did not feel that having an active sex life with a partner was as important as it was when they were younger ($n=1$); and/or they had already made adjustments sexually as a result of natural physical aging ($n=1$). The remaining four participants described specific changes in their sexual relationships with their partners that they attributed to breast cancer survivorship, specifically LE. These changes included: reduced sex drive (a side-effect of taking tamoxifen); concerns about sexual performance (being impeded in foreplay by LE); and changes in their relationship with their partners, who were generally more supportive following the onset of LE.

In regards to a diminished sex drive, Sharon responded:

It's just, I don't really wanna [have sex], and, of course, between that and the tamoxifen, I have like zero sex drive so... [laughs].

Susan (57, married, seven years since breast cancer diagnosis, 2.5 years since onset of LE) also said:

I would say the changes would have occurred, more because of the hormonal changes with the breast cancer. And we were adjusting to that.

As well as a reduced sex drive, participants also expressed concerns about their sexual performance/sexual satisfaction. Linda (61, married, 4.8 years since breast cancer diagnosis, 3.6 years since onset of lymphoedema) explained how LE had influenced her sexual performance with her husband:

It [the lymphoedema] has made a difference in the amount of foreplay and the type of foreplay that we do. Because I don't have, shall we just say, as much arm strength or grip as I used to [laughing]. So that's where it's, that's where it's affected us. It hasn't affected us as far as um, like, I dunno, overall satisfaction or, whatever, but, you know, it has had an effect.

In spite of some of the negative effects, participants did share that since being diagnosed with breast cancer-related LE, they had become more aware of the support that they were receiving from their partner. Judith (58, married, two years since breast cancer diagnosis, 1.75 years since onset of LE) said:

He laughs at me when I put on my sleeves at night. It's like an upper garment, it's like a big one too, and I put my arm in it and then I put my compression sleeve over that. And I don't know how many times as I'm pulling on my compression sleeve in bed. My hand will slip off and I'll hit myself in the face. And he gets a real kick out of that... The routine I go through for care for lymphoedema is just my... just my way of life and I have not made an issue out of it. And, so he doesn't think anything of it. It's a non-issue with him. He has been very supportive throughout this whole thing. He is an impeccable man. He knows my frustration with clothing. 'You're beautiful. You know'. I go, 'You know you always say that, and you eat all my burnt food,' and you know [laugh]. Things haven't changed in that regard. So, he's a great guy.

Discussion

Breast cancer-related LE affects 20% of women who undergo treatment for breast cancer that involves damaging the lymph nodes under the arm (Clark et al, 2005). It has been well documented that physical and psychological health can be impacted by changes in physical appearance and limitations created by LE (Petrek et al, 2000; Radina and Armer, 2001; Radina and Armer, 2004; Thomas-MacLean et al, 2005). The present study has extended Radina and Armer's (2001; 2004) work in that it has explored the influence of LE on women's sexual relationships with their intimate partners.

Some of the participants reported no longer feeling sexy. As found in other research (Wiederman and Hurst, 1997; Koch et al, 2005), the negative ways that these women felt about

their bodies diminished their desire to engage in sex with a partner. The disfiguring aspects of LE made them feel unattractive and self-conscious about their bodies in the same way that altered body image, brought about by breast cancer, has been shown to do in previous studies (Gould et al, 2006). There was also a feeling that a current or future partner might not find them sexy because of the LE and/or because of the compression garments. Such feelings support research that found that others' opinions of one's attractiveness impacts how one feels about oneself (Henson, 2002; Galvin, 2005). The notion that a partner would not see her as sexy, even if it was not explicitly stated by the partner, impacted some of the women's attitudes about their own sexuality and desire to engage in sex.

For three women, LE did not have a negative impact on their sexual relationships. For the two women who were in relationships, they felt that they had already adapted their sexual relationships as they aged. Changes in the nature of sexual relationships among mid and later life partners has been well-documented (Hinchliff and Gott, 2004). These participants considered changes in their relationships to be a natural result of aging, not the result of LE.

For the four participants who had experienced changes in their relationships in connection with LE, breast cancer was also eluded to as a contributing factor. As previously mentioned, breast cancer and LE are linked. In future studies, the authors want to try and tease apart more of these complex issues. The specific aspects of breast cancer mentioned here were the medications and hormonal changes that impacted their sex drive (Henson, 2002).

For these participants, LE was related to self-perception in terms of not feeling sexy to themselves or their partners. This, together with the actual physical limitations can explain the LE-related changes in sexual relationships that these participants experienced.

This study demonstrated how sexuality includes multiple domains of influence, including feelings about self as well as relationships. These women had experienced physical changes brought about by LE that, in turn, had an impact on their feelings of attractiveness, body image, desirability, sexuality and intimate relationships. In accordance with a lifespan view of sexuality, the authors want to acknowledge intimate relationships as being important in people's lives as they age, and to address factors such as chronic illness, which tend to increase with age, that can inhibit the expression of sexual desire. This research has shown how the impact of breast cancer-related LE on sexuality needs to be recognised by those working with women who are adjusting to life with LE. Established research on the effects of LE on quality of life should be expanded to include areas of sexual intimacy. The authors hope that these findings will be used by family life educators and healthcare professionals to assist women with breast cancer-related LE in their intimate relationships following diagnosis of this chronic illness.

Limitations and directions for future research

This study is not without limitations. First, the small sample size, while appropriate for qualitative and exploratory studies such as this, does limit the generalisability of the results. The small sample size was largely due to the actual number of participants who volunteered prior to reaching conceptual saturation with the data that were collected. As said, the data analysis presented here was part of a larger study that explored participants' lives following the development of lymphoedema. Future research should address issues of sexuality and sexual relationships with a larger number of women with breast cancer-related LE. Second, this study focused on sexual relationships from the point of view of female members of the intimate couple. In future, how both heterosexual and homosexual intimate partners of women with breast cancer-related LE cope with and adjust to their partners' limitations should be explored. Third,

the present study focused only on the experiences of women. It is important to note that, in rare cases (one-tenth of 1% of all men) men also develop breast cancer and therefore are at risk for developing breast cancer-related LE (American Cancer Society, 2007b). Despite the small proportion of the population that this does affect, a study of how men cope with breast cancer-related LE would provide greater insight into how sexuality and sexual relationships may be impacted by LE. Although the literature demonstrates that breast cancer itself can have an impact on sexual relationships, it is difficult to tease apart how sexuality and sexual relationships are influenced by breast cancer and/or by LE. Based on our initial exploratory study, the authors would like to further investigate these complicated issues. Finally, the participants in this study were in mid and later life with a mean age of 60.6 years. Given that 50% of women who develop breast cancer are under the age of 61, future research should consider the experiences of younger women who experience breast cancer-related LE (American Cancer Society, 2007a). JL

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Key points

- ▶ Participants mentioned being self-conscious of their bodies, feeling embarrassed about having to accommodate their swollen limb during sex, not perceiving themselves as being attractive or desirable to a partner as a result of the lymphoedema, and feeling insecure about their future as a cancer survivor.
- ▶ Participants described changes in their sexual relationships that they attributed to breast cancer survivorship, specifically lymphoedema: reduced sex drive; concerns about sexual performance; and finding their partners to be more supportive following the onset of lymphoedema than they had expected.

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