

Feminist Understandings of Embodiment and Disability: A "Material-Discursive" Approach to Breast Cancer Related Lymphedema

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Abstract

Breast cancer related lymphedema (BCRL) is a disability related to breast cancer treatment which may significantly affect women's everyday lives. We used a "material discursive" lens to analyze women's accounts of BCRL. Themes which emerged are: 1) moving beyond breast loss; 2) implications of disability; and 3) beyond limitations.

Résumé

Le lymphoedème relié au cancer du sein (LRCS) est une invalidité reliée au traitement du cancer qui peut affecter de manière significative la vie quotidienne des femmes. Nous nous sommes servis d'une lentille de "matériel discursif" pour analyser les comptes-rendus des femmes sur le LRCS. Les thèmes qui en sont découlés sont: 1) aller au delà de la perte; 2) les répercussions de l'invalidité; et 3) au -delà des limites.

Introduction

Recently, embodiment and disability have emerged as areas of inquiry in feminist research. However, feminist understandings of what it means to be embodied or disabled have not been extensively incorporated into health research. This is problematic in breast cancer research wherein publications tend to reflect positivist paradigms, despite the fact that treatment can have long-term effects on women's lives. This suggests that feminist understandings of embodiment and disability can enhance existing research. In this article, we are applying a "material-discursive" lens to examine the social and material experiences of women who have undergone breast cancer treatment and have developed the chronic condition of breast cancer-related lymphedema (BCRL). A "material-discursive" lens allows us to understand a woman's experiences as "rooted in, and arising from, a reality that includes how she lives, where she lives and the kind of body she lives in" (Miedema, Stoppard & Anderson 2000,18).

Materiality refers to physical elements of experience (for example, pain) and more concretely manifested aspects of existence (for example, income). Although materiality may be implicated in discursive practices, we take the position that materialist aspects of culture deserve separate consideration, while the discursive lens encompasses an understanding of socio-cultural constructions, or ideology (for example, gender stereotyping). Our use of a material-discursive

approach reflects our background both as sociologists who are concerned with how reality is socially constructed, and as feminists who are concerned with the material expression and experiences of inequality and the physicality of bodies. We draw upon theoretical foundations established in socialist feminist approaches, and employ an interpretive approach to demonstrate how feminist approaches to embodiment and disability can be used to understand the lived experiences of women suffering from chronic BCRL.

We begin with an introduction to the clinical aspects of BCRL. Our focus is upon the chronic manifestation of this condition, rather than temporary experiences. Next, we present the theoretical foundations of our research, as rooted in feminist understandings of embodiment. Third, we discuss our findings, concluding with some suggestions for the application of our research beyond this particular context.

Clinical Background

BCRL is one of the most distressing and incurable long term health problems faced by breast cancer survivors, which may occur years after completion of treatment (Harris, Hugi, Olivotto and Levine 2001). BCRL defines an accumulation of fluid in the arm or trunk, involving an impaired lymphatic system that results from lymph node dissection, radiation or advanced cancer (Petrek, Pressman and Smith 2000). BCRL often results in symptoms of pain and swelling, thereby contributing to disability (Harris, Hugi, Olivotto and Levine 2001; Marcks 1997).

Approximately 21,100 Canadian women will be newly diagnosed with breast cancer in 2004. Given that survival rates have increased, it seems likely that there will be an increase in women who may suffer from BCRL. Incidence rates range from 6-70%, but diagnostic criteria are varied, as are recommended treatments (Brennan, DePompolo and Garden 1996; Brorson 2000; Harris, Hugi, Olivotto and Levine 2001; Marcks 1997).

While less invasive surgical procedures may reduce the incidence of BCRL, research in this area is ongoing and subject to debate (Golshan, Martin and Dowlatshahi 2003; Rietman et al. 2003). Prevalence rates of 15% to 30% are considered reasonable estimates (Stanton et al. 2001).

The treatment of BCRL is also controversial and various options have been proposed, including manual lymph drainage and compression garments (Brennan and Miller 1998; Brorson 2000; Chau and Harris 2002; Harris, Hugi, Olivotto and Levine 2001). Most common is physical decongestive therapy, under the supervision of a physiotherapist. A few studies have advocated dragon boat racing (Courneya, Blanchard and Laing 2001; Harris and Niesen-Vertommen 2000). While dragon boating may be empowering, the authors of these studies also conclude that further research in this area is needed, due to small samples. Currently, chronic BCRL can only be managed and cannot be cured. Since BCRL may be disabling, feminist perspectives of embodiment may be helpful in understanding women's experiences.

Theoretical Orientations

Feminist theory has emphasized the social conditions of women's lives, while embodiment has received less attention. For example, few feminist researchers have addressed how a woman with a physical disability experiences her day-to-day social life in a society that adheres to a rigid cultural standard of what is normal.

Embodiment has been conceptualized as an aspect of being - the body is not simply an object (O'Loughlin 1998, 289). Feminists and other interpretive scholars have suggested that we do not simply have bodies, but we are our bodies (Barral 1969,171; Butler 1988, 521; O'Loughlin 1998, 290). Embodiment may be thought of as the dialectical intersection of various dimensions of experience, such as one's physical being

and the "sociological body" (Barral 1969, 175; Merleau-Ponty 1974). It is important to also recognize that "People construct and use their bodies, though they do not use them in conditions of their own choosing" (Frank 1991b, 47).

Phenomenological orientations to body resonate with some feminist conceptualizations of the body and its intersection with culture and have been discussed in greater detail elsewhere (Grosz 1994; Munhall 1994; Shildrick 1997; Young 1992). Feminists originally addressed the body in terms of medicalization (Boston Women's Health Collective 1984, original publication 1969; Ehrenreich and English 1978). More recently, feminists have expanded such critiques of the dominance of patriarchal expertise (Miller and Findlay 1994; Riessman 1998; Smith 1987). Despite such research, Moira Gatens has suggested that further work is needed to convey the connections between female embodiment and the body politic (1996, 49; Wakewich 2000).

Despite disparate domains of interest, what appears to be shared by feminists is a concern with women's experiences, the social constraints that influence such experiences and a desire for social justice (Olesen 1998, 300). Arguably then, "feminist thinkers have raised the most radical issues about cultural attitudes to the body" (Wendell 1989, 105). Thus, "[i]n establishing the self/body/politics/violence nexus, feminism has set an agenda for the sociology of the body" (Frank in Faith 1994, 39).

With regard to illness, Margrit Shildrick writes that the devaluation of the female body and subjectivity is congruent with the devaluation of those who are ill (1997, 168). Feminist scholars have shown that those who are ill are "carriers of life's negatives" and such bodies are "private, generally hidden, and often neglected" (Barnard 1990, 544; Wendell 1989, 111). Wendell writes: "Most of us will live part of our lives with bodies that hurt, that deprive us of activities we once took for granted. We need an understanding of

disability that does not support a paradigm of humanity as young and healthy" (1989, 108). She argues that understanding both "the nature of embodiment and the experience of oppression" are essential to constructing knowledge about disability (1989, 105). Rosemarie Garland-Thomson states that "[w]e need to study disability in a feminist context to direct our highly honed critical skills toward...unmasking and reimagining disability, not only for people with disabilities, but for everyone" in order to gain a better understanding of what it means to be human (2002, 4). Yet Beth A. Ferri and Noel Gregg (1998) argue that the voices of women with disabilities are not being heard.

We recognize the complex interplay between ideology, discourse, technology and embodiment, using a material-discursive lens to further knowledge of what it means to experience disability via BCRL. Our work is congruent with that of scholars who argue that there exists a "dialectic of embodiment" which is reflected in both discursive practices and material aspects of embodiment (Gadow 1989, 12). This position departs from post-modernism, which might state that "the very notion of the biological body is itself a fiction" (Bordo 1993, 288).

Methods

The study was approved by a hospital research ethics committee. Only women who were nineteen years of age or older, had completed active breast cancer treatment, were able to provide informed consent, resided in the province of New Brunswick, and had BCRL were eligible to participate.

Drawing upon our previous experiences with interviewing women with breast cancer (Thomas-MacLean 2000 & 2004a), we facilitated a focus group discussion with seven women with BCRL. Women were invited to participate with the help of support groups who distributed letters of introduction at their meetings. Using the focus group transcript, we devised a

semi-structured interview guide and subsequently interviewed fifteen women with BCRL. Again, we received assistance from support groups, and we also used newspaper articles and advertisements, along with a "snowball" recruiting technique - women who knew of potential participants were asked to distribute letters of invitation.

Interview questions covered the following areas: personal information and history of breast cancer and BCRL; access to treatment; information received about BCRL; its impact on daily life; and support. All interviews were completed by the first author of this paper and concluded with an open-ended question that asked participants to share any additional information about BCRL that they felt had not been covered by our guide.

Interview participants ranged in age from thirty nine to seventy years. The women came from rural (47%) and urban (53%) areas. All fifteen women indicated that they received lymph node removal and nine reported that they were also treated with radiation. The shortest time between the interview and breast cancer diagnosis was eighteen months and the longest time was twenty years. Of the fifteen women, nine had received treatment for BCRL.

Each interview was tape-recorded and transcribed verbatim. These transcripts were then analyzed collaboratively. Both authors read all of the transcripts. We highlighted major themes and also made notes directly on the transcripts. Meanings of themes were formulated and we discussed them extensively. Transcripts were then coded with the assistance of a software program (NVivo), using these themes. This fine level of coding resulted in more than 100 themes which were then examined comparatively. These comparisons generated larger thematic clusters, three of which are presented herein.

As we "[heed] the call of reflexivity in research practice" (Sinding and Aronson 2003, 96), we

recognize that there are socially preferred narratives (Thomas-MacLean 2004b) which may have influenced what participants shared with us. However, we were struck by the mixture of both vulnerability and accommodation (Sinding and Aronson 2003). This article represents our attempt to show how women create "liveable stories - stories about loss that can be 'lived with'" (Sinding and Aronson, 2003, 115), illustrating the tension between ability and disability.

Our analysis was validated through a presentation to a breast cancer support group which included study participants, along with other women who had BCRL. Members of the group indicated that our findings resonated with their experiences. Likewise, a presentation at a lymphedema conference that included breast cancer survivors also received positive feedback. Each of the participants received a report of this study, with an invitation to comment on the study. None of the participants indicated that our findings were problematic.

Key Themes

Three broad themes illustrate how BCRL affects many aspects of participants' lives and how cultural standards shape these women's altered body image. The first theme demonstrates the need to capture a wide range of embodiment experiences after treatment. The second theme shows that while it is important to recognize the particularity of each participant's experiences (that is, the first theme), it is also imperative to understand the social context of BCRL and the implications of disability for women. Paradoxically, the third thematic category exists as a contrast to the first two, thereby illustrating the complexity of understanding BCRL as disabling. Participants stated that they were not limited by BCRL, illustrating that understanding disability is a complex undertaking. Participants suggest that traditionally feminine activities and work are not always experienced as sites of

oppression (Miedema 1999). Rather, these women demonstrate that they value "women's work" through their experiences of limitations in these areas, suggesting that they have indeed felt a tension between ability and disability via BCRL.

Appearance and Sensation

Feminist researchers have suggested that emphases on breast loss in prior studies have replicated existing gender-based power imbalances via a focus upon appearance rather than feeling (Kasper 1994; Langellier and Sullivan 1998; Musick 1997). Young (1992) asks what a feminist understanding, based on sensation, might entail. Our participants suggest that this is an important area of inquiry. For them, sensation figures prominently in everyday experiences of disability and BCRL.

One participant searched for words to describe the sensations she associated with BCRL: How can I explain how it [her arm] feels? It feels like it has gone to sleep somehow [pauses], sort of numb, and like it's asleep, and it's more uncomfortable and the feeling goes from the top of my fingers, up to the elbow here (T1). Another participant said: The pain goes around my shoulder, across here and right down to my arm, and it feels like it's burning or something. It's very tender to touch (T15). A third participant described the sensations associated with BCRL: The pain is right inside this arm, and when I clench my fist, there's pressure (T9). Other participants used words such as cramping, tightness, aching, heaviness and tingling. While sensation was a significant aspect of BCRL experiences, participants also shared information related to the appearance of their arms/hands.

Several participants reported that they did not wear short sleeved shirts after experiencing BCRL symptoms or wearing compression garments. Their accounts show that appearance is an area of concern for breast cancer survivors, but that prior emphases on

the appearance of the chest may have thwarted exploration of other changes to appearance that result from breast cancer. Participants reported that they could, if they wished, hide the fact that they had a mastectomy, but that the symptoms of BCRL were much more difficult to disguise.

When asked if she felt comfortable wearing short sleeves, one woman responded: I didn't for a long time and I still don't (T8). Another participant also responded negatively (T15), while a third woman said that wearing short sleeves meant she would get more questions (T5). A fourth participant described her feelings more elaborately: I figure people are looking at me, saying "Oh, look at her. She's got one arm that's so big and one arm that's so small." I wear short sleeves, but I'm thinking people do stare at people when they've got something wrong with them (T1). Thus, participants showed that they felt that BCRL made them different from others and some participants took measures, such as avoiding short sleeved clothing, in order to minimize the impact of BCRL upon their daily lives. The impact of BCRL was not limited to an altered appearance, but also involved a variety of sensations, including pain. These sensations contributed to experiences of disability.

Implications of Disability

BCRL was most often described in a manner conducive with a disability in relation to participants' experiences of limitations as they were connected to work - both paid and unpaid labour - and the pursuit of leisure activities.

Work:

BCRL severely limited participants' abilities to work. One participant described limitations to housework: If I happen to bring in any heavy bags, it will cramp my fingers...I find the cramping is the most difficult thing that happens with me (T1). Another woman concurred:

I don't carry the groceries...If I do help, I'll carry the bread, the light things. I don't grocery shop. It's hard to reach things sometimes. I do the exercises, but I just find it hard to extend my arm (T8). This same participant said that she relied on her husband to do the laundry, as the lifting associated with this task was unmanageable. A third participant described her limitations as follows: One day, I was ripping up an old sheet...It was repetitive and my arm was tired, but I rested it, and it seemed to be fine. And then, two days later, with the Christmas cooking, I think it was just too much for the system. I had aggravated it (T13).

This woman also had to modify her paid work as a nurse because many tasks became too difficult, and even pulling the privacy curtain around a patient's bed was challenging.

Interestingly, anticipation of BCRL symptoms also constrained women's activities, as one participant showed: I had to be careful shovelling snow and doing things like that, because I knew my arm would swell quite a bit more, so I had to be conscious of that (T5).

BCRL symptoms, whether experienced or anticipated, led to many constraints in the work that participants were able to perform.

Leisure

Many participants reported that they had been very active in the pursuit of sports and physical activity prior to experiencing BCRL. One woman said: I find you're restricted in what you want to do, especially in exercising and walking. When I walk, I like to walk really briskly and swing my arms, but I can't with this one [affected arm]. I have to tuck it in a pocket (T2). When asked if she had given up any activities as a result of BCRL, one participant responded:

I don't cross country ski anymore, I don't go on my bike very much [pauses]...I don't do anything that's really like concentrates on my

arms. I don't even dance as much as I used to and it's probably not totally from lymphedema either but it's just that you get moving around and you don't realize what you're moving and all of a sudden you get achy and you have to sit down. You're limited, at least I feel I am...I don't do as much physically as I used to (T10).

Other participants said that BCRL made it difficult to pursue hobbies they had previously enjoyed: Well, getting close to Christmas, I started knitting again and the pain got worse (T12). Another woman said: I used to knit a lot...And, I used to quilt some, but I don't now, and I find even if I put a thimble on my finger and leave it on for a while, then my finger starts to swell (T15). Taken together, the participants' descriptions of their limited ability to pursue physical and leisurely activities illustrate some of the constraints, or disabling aspects of BCRL.

Beyond Limitations

While most participants' descriptions of BCRL showed that the condition carried constraints for their lives, some of the participants indicated that they did not find BCRL limitations to be severely intrusive. For instance, one participant described severe cramping associated with BCRL and carrying heavy objects, but she also said:

I don't let anything stop me...I never give up. I just keep going and I try to do the things I do every day...I just keep going...I don't let it bother me. I try to go about my daily routine and stuff...It sort of bothered me at first, but I just took it in mind that it was something that I was going to have to get used to and it's just as well to start getting used to it now than it is later (T1).

A second participant said: I've had a lot of support from family and friends and tried to adopt a positive attitude and lifestyle (T7). Another participant echoed the statements of the first: I keep on going...If the pain got severe enough, you know I would [stop activities]. But, I usually keep on going (T12). While most participants spoke of the constraints of BCRL, a few indicated that they just keep going. This suggests that feminist understandings of disability must incorporate recognition of the tension between constraints and perseverance.

Discussion

A material-discursive lens permits exploration of a chronic condition such as BCRL, illustrating some of the intersections of social and physical aspects of embodiment. Adrienne Asch and Michelle Fine argue that people who have had cancer may be impaired socially as a result of changes to their appearance, thus providing a foundation for understanding what it means to be embodied within a particular social context. Asch and Fine, like many other scholars, conceptualize disability as a socially constructed phenomenon (1988). However, our research shows that experiences of disability are also rooted in the material (physical) nature of changes to the body, although the body is subject to discursive construction and regulation. Material aspects of experience are connected to a larger social context in which disability is socially constructed within an ableist culture.

We interpret participants' accounts to be illustrative of what Wendell terms the "rejected body" and the "negative body" (1996, 85). She uses these terms "to refer to those aspects of bodily life...that are feared, ignored, despised, and/or rejected in a society and its culture" (1996, 85). Given participants' concerns about the reactions of others to their altered appearances, experiences of BCRL may be interpreted as a form of disability, in keeping with Wendell's

assertions, although it is not necessarily recognized as such in the medical community, or by the women themselves.

Discursively, participants' avoidance of wearing short sleeves may be read (Miller 2000) as indicative of participants' awareness of their own embodiment. That is, participants' physical experiences of altered appearances may reflect awareness that the appearance of disability may be constitutive of the "negative body" as perceived by others. Disability is then experienced both physically or materially (via an altered appearance, or a swollen arm), but it is also discursively indicative of social values, thereby providing illustration of the complexity of embodiment.

Like Wendell, S. Kay Toombs has written extensively about disability. Toombs states that experiencing the onset of a disabling condition such as BCRL means that women can no longer "engage in the world in habitual ways" (1992, 62). Consideration of the disruption of everyday life is an important aspect of understanding BCRL. However, for our participants, the ramifications of BCRL extended well beyond the women's personal domains, thereby illustrating the intersection of the personal and the political, or the nature of what it means to be embodied.

Wendell writes that: "Much of the world is...structured as though everyone is physically strong...as though everyone can work and play at a pace that is not compatible with any kind of illness or pain" (1989, 111). Many of the women in this study found both paid and unpaid labour to be challenging as a result of BCRL. The difficulties associated with work, and loss or reduction of income, are indicative of the materiality of the women's experiences, but the challenges they faced are also a result of the ways in which work is organized, which may be understood to be a discursive representation of social values. The social construction of disability means that little attention is paid to the ways in which occupations are framed within an ableist

social context. This means that alternative ways of organizing or conceptualizing work are largely non-existent. For one participant, a nurse, the physical demands of the profession meant she had to change her employment status. This raises the question of what is essential to work and how professions might be modified to invite more extensive participation from those with disabilities. While the modification of working conditions might affect the materiality of women's lives, the recognition of the need to modify work is a discursive practice.

Given the social value of work, the inability to perform one's job is also indicative of the disabling nature of BCRL. Work is very much connected to one's identity. To alter or terminate one's employment because of illness provides further illustration of the intersection of the social, the material and the physical. This in turn may enhance understanding of what it means to be embodied, i.e., to experience the intersection of these dimensions of experience.

Further, BCRL may affect certain segments of the labour force to a greater extent than others. Participants with low incomes reported difficulty in gaining access to physiotherapists and affording to purchase compression garments. Given that women are disproportionately represented in part-time work and the service industry, it is reasonable to assume that being underpaid or without private health care could contribute to an exacerbation of BCRL symptoms, which could in turn reinforce poor employment status. Ferri and Gregg report that "women with disabilities are less likely to be employed outside the home after completing...rehabilitation programs" (1998, 430). Unfortunately, little research has been conducted into women's experiences with work after breast cancer (Maunsell et al 1999). This is an important area for feminist research, as Garland-Thomson writes that "[d]isability is an identity category that anyone can enter at any time, and we will all join it if we live long

enough." Changes to appearance, work patterns and the pursuit of sports and hobbies may all be disrupted by disabling conditions such as BCRL. Thus, the ways in which the "body perpetually metamorphoses" thus requires further study (Garland-Thomson 2002, 20).

Participants also showed that women's experiences of unpaid labour are extremely complex. While feminists have documented the ways in which unpaid labour may be experienced as a source of oppression or subordination, our participants spoke with a sense of loss at being unable to perform tasks that they had previously taken for granted. Using a discursive lens, we may interpret the women's sense of loss as being indicative of the construction of femininity and women's association with domestic labour. We wonder if participants' sense of loss is directly related to society's values of domesticity that further perpetuate women's subordination. Yet, we would also argue, as Margaret Lloyd does, that a feminist perspective of disability needs to incorporate recognition that caring for others "is something that women might want to do, or at the very least, would not want someone else to do" (2001, 722) and that regardless of discourse, these feelings ought to be recognized as legitimate.

However, despite the limitations inherent to BCRL, participants also suggested that they were able to remain positive. These accounts of BCRL are difficult to interpret. On the one hand, as Celia Kitzinger writes, "thinking positive" has evolved as a means of supposedly being able to control cancer and that this idea has not been critically examined. Kitzinger argues that literature advocating positive thinking must be critiqued as apolitical and victim-blaming (2000, 122). Ferri and Gregg (1998) write that the "media is replete with patronizing portrayals of the person with a disability achieving 'against the odds'" (432). Likewise, C. Thomas Couser (1997) is critical of portrayals of extreme heroism with respect to people with disabilities.

Positive thinking may serve as a prescriptive discourse for surviving illness. Overcoming disability may be read as a means by which discourse asserts its power over the sharing of narratives of illness and disability. Thus, it may be argued that participants' accounts are reflective of survivorship discourse and they represent an uncritical assumption of a positive thinking imperative. However, such readings must be balanced with our participants' accounts which seem to suggest that BCRL and disability are not entirely negative experiences, while simultaneously acknowledging that participants may have felt obliged to be positive, given that the interviewer is not disabled. Thus, there is more than one possible reading of the participants' accounts of living with BCRL.

Yet, participants came forward as a result of the publicity of our study and were not recruited through direct methods, which suggests that the women felt comfortable with the possibility of sharing their experiences in their entirety. The women were also asked detailed questions about everyday routines. While this would never completely mitigate the effects of survivorship discourse and cultural imperatives to think positively, we do believe that there is an element of authenticity in participants' suggestions that BCRL is not an entirely negative experience. In fact, feminist humour lends some support to this assertion by providing a vehicle by which negative experiences can be re-framed. This points to the importance of recognizing the complexity of embodiment and disability and what various interpretations of disability experiences may offer to the expanding feminist literature addressing the body. Such work may then lead to new queries into the "unsteady construction of normal" (Ferri and Gregg 1998, 435).

Conclusion

Bordo argues that while ableism does not completely constrict agency, it does "remain strongly

normalizing within our culture" (1993, 299). Similarly, our participants show that "disability is a culturally fabricated narrative of the body" (Garland-Thomson 2002, 5). Further, their accounts provide empirical evidence for dimensions of disability that have been theoretically outlined by feminist scholars such as Garland-Thomson, who has argued that disability illustrates "bodily variations," the connection between body and social context, "a set of practices," and "the inherent instability of the embodied self" (2002, 5). Marrying theories of disability with research such as ours points to the complex task involved with increasing understanding of feminist theories, embodiment and disability. Ultimately, as Ferri and Gregg (1998) note, this task rests on creating dialogue with women, such as our participants, who have direct experiences of disabilities.

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