Conjoined bodies

ABSTRACT
Secondary lymphedema after cancer (SLC) lacks a strong presence within breast cancer survivorship discourses despite its notably high rates. Using arts-based research methods, an ethnodrama on SLC was developed with seven women living with SLC. We interviewed nine women with SLC about their responses to the ethnodrama in relation to their own experiences. Using a modified form of discourse analysis, we analysed parallel uses of metaphor within the ethnodrama and audience interviews, and argue for a discursive process of ‘conjoining bodies’, whereby SLC is constructed as a social body of suffering in order to combat marginalization within oncology. We suggest that these metaphors can have effects on the women’s practices of living with SLC and describe implications the ethnodrama and its reception have for wider recognition of SLC.

KEYWORDS
women
cancer
disability
metaphor
lymphedema
theatre

Woman B: Lymphedema is the cruel joke at the end of all this treatment.
Woman A: It’s permanent.
Woman C: We can put on a brave face.
Woman B: Wear our fake breasts.
Woman D: Have multiple surgeries to try to look normal.
Woman C: But our sexuality and our bodies have been compromised.
Woman B: People need to understand that.
Woman D: We need an audience that will hear us.
Woman C: And do something about it.
Woman A–D: (Holding hands). Together.

(From The New Normal: Living with Lymphedema).

INTRODUCTION

Lymphedema is a potentially disabling condition where the movement of lymphatic fluid is impeded or impaired and the fluid begins to flood local tissues (Rockson 2001). Secondary lymphedema after cancer (SLC) is a particularly common form of the condition seen to originate from oncological radiation and surgeries, often involving pain, impaired functioning, heightened risk of infection, and swelling of limbs proximal to treatment targets (Deng et al. 2011; Rockson 2001; Rockson and Rivera 2008).

Lymphedema in medical settings may be understood as an interrupted capillary action leading to the pooling of lymphatic liquid, but the term can possess much broader meanings within the discourses of people with SLC. Along with physical complications, people living with SLC report heightened psychosocial distress, intimacy and sexual difficulties, social isolation, and inability to participate in work and leisure activities (Fu et al. 2012; Miedema et al. 2008; Ostby et al. 2014; Quinlan et al. 2009). Despite the pervasiveness and compounding impacts of SLC among people with cancer, there is very little talk about SLC within medical professional discourses and, more broadly, public discussions of cancer survivorship (Thomas and Hamilton 2014). It is especially peculiar that a hyper-awareness of breast cancer, or ‘breast cancerization’ (Bell 2014), within North American cultural discourses has not produced more dialogue around common survivorship issues like SLC. The observable suffering and disability of people with SLC (e.g., being marked by bulky compression garments) as well as the historical lack of SLC representation within cancer discourses leads to an important paradox of being both visible and invisible at the same time (Thomas and Hamilton 2014).

The paradoxical (in)visibility of SLC can be situated within a two-pronged origin to illness and disability, observed by phenomenological philosopher Jean-Paul Sartre: ‘in one respect, illness is social ‘as’ society […] decides its sick and its dead. But in another respect, it is a certain manifestation – a particularly urgent one – of the material life, of needs, and of death’ ([1960] 1968: 103–04). In sum, illnesses like lymphedema take form through their physiological manifestations as well as their social constructions in language and practice. On the one hand, conditions like SLC are fiercely physical; medical philosopher Frederik Svenaeus wrote that ‘illness makes us feel our own bodies: it reveals the body to us in different ways, through making it heavy, stiff, hot, nauseated, plagued by pain, twists, jerks, shivers, etc.’ (2009: 59). On the other hand, how we experience our stiffness, pains and shivers depends upon their observation, (in)validation, and especially their naming with and by others. Appropriating a socially recognizable expression for one’s suffering, or ‘idiom of distress’, leads to many effects; sufferers are transformed into visible subjects within the available structures of care, situated within a shared community
and history of other sufferers, and qualified for certain kinds of intervention (Nichter 1981, 2010). In contrast, those who have lost or been bereft of an idiom, name, metaphor, or diagnosis, can experience marginalization which can lead to social and, in many cases, physical death (Good 1994; Kirmayer 1992; Scarry 1985). Thus, these two sides of illness are interdependent – physical suffering often instigates a need to speak, while discourses often transform how suffering is experienced.

There are times when bodily experiences and available languages are in tension, as seen among contested illnesses like chronic fatigue syndrome, where felt experiences of bodily distress are not legitimated by medical nosology (e.g. Banks and Prior 2001; Cohn 1999; Dumit 2006). The converse seems to occur in reports of overdiagnosis and overtreatment of breast cancer, where criteria for intervention may exceed the disease’s severity and potential for recurrence (for reviews on overdiagnosis, see Miller 2013; Puliti et al. 2012). To use an example, such practices as axillary dissection of lymph nodes – in response to sentinel nodes testing positive – can produce adverse outcomes (including lymphedema) in women with early breast cancer without having noticeable effects on survival (Galimberti et al. 2013; Giuliano et al. 2011). And yet, SLC is in some ways a contested disability in its own right, as research has shown that the diagnosis is often dismissed or disputed by health care professionals who might not be familiar with the term, might not reach a positive reading in their diagnostic toolkits, or might disregard patients’ idioms of distress (Ostby et al. 2014; Thomas and Hamilton 2014).

The (in)visibility of people with SLC seems to come from compounded social and physiological processes, most of which are working against them. On the one hand is the clinical relationship fraught with overtreatment of breast cancer and underdiagnosis of SLC, and on the other hand is the disrupted life of the lymphatic system resulting in intensities of pain, immobility, and anxiety. It is for these reasons that a ‘material-discursive’ analysis, attending to the interrelations between language and embodied experience, has been usefully applied to lymphedema after breast cancer (Thomas-Maclean and Miedema 2005).

Recent attempts to broaden recognition of SLC (e.g. advocacy groups, knowledge translation efforts) seek to close the gaps between the everyday material/bodily distresses of breast cancer survivors and their limited social/medical visibility. As knowledge of SLC is disseminated and appropriated into more and more women’s descriptions of their post-treatment bodies, their experiences of SLC might transform from individualized and marginalized forms of suffering into a collectively shared ‘social body’ (Schepers-Hughes and Lock 1987) among those living with SLC. As observed in support groups of breast cancer survivors (Mathews 2000), the work of social embodiment is to develop consensus around shared idioms and understandings of distress.

In this article, we explore the expanding social embodiment of SLC within the context of a theatre-based knowledge translation project with breast cancer survivors. Our specific research questions were: in what ways does the theatrical performance represent SLC; and in what ways do audience members with SLC talk about the effects of the ethnodrama on how they relate to others with SLC? These two queries touch upon social embodiment via the theatrical performance and audiences’ receptions of the play.
BACKGROUND OF THE NEW NORMAL THEATRE PROJECT

An interdisciplinary research team led by LQ formed in 2009 to study SLC. Founded upon longitudinal and qualitative studies of arm morbidity among breast cancer survivors, the team subsequently received a three-year knowledge translation grant from the Canadian Institutes of Health Research. We chose arts-based methods to explore life with lymphedema as well as disseminate knowledge in an accessible way to a wider audience. Seven women from a western Canadian province participated in the study (38–65 years old), all of whom were diagnosed with breast cancer within the last seven years and were currently living with SLC. The primary author (CH) joined in 2014 as a research assistant to support data analysis at the end of the project.

Among other expressive arts activities, the participants, researchers, and a scriptwriter developed a theatrical script around the women’s experiences with SLC, and four of the original participants later performed the script in front of several targeted audiences. Those involved created an ‘ethnodrama’ titled The New Normal: Living with Lymphedema after Breast Cancer, to achieve three objectives: (1) to raise awareness and encourage improvements in the care of SLC; (2) to cultivate empowerment among participants through expressive arts; and (3) to impact audiences’ knowledge base and attitudes around SLC. The opening quotation of this article shows these objectives in action, as the performers speak about SLC as an invisible condition needing more solidarity between those who suffer from it and more recognition from those who can treat it. Our present interest is regarding the responses of breast cancer survivors to this call for a widening social embodiment of SLC.

We chose ethnodrama as a medium because theatre can transform how people experience and act within their social worlds (see e.g. Turner 1981). Psychiatrist Fred Hickling described theatre as a powerful tool towards ‘education, consciousness-raising and demystification, as well as entertainment’, and his own ‘sociodrama’ programme in Jamaica in the late 1970s and early 1980s pursued the ‘social and ideological transformation of the oppressed and disenchanted’ (2004: 46–47). Although not new, the use of theatrical performances to explore and educate others about complex health and social issues is gaining a strong contemporary following (e.g. D’Alessandro and Frager 2014; Gray et al. 2000; Mitchell et al. 2011; Pleasant et al. 2014; Schneider et al. 2014). Performative arts are particularly appropriate for representing the entwined embodied and social sides of illness, as performances involve movement and multisensory activities in the witnessing presence of others. Ethnodrama is one of many forms of theatre-based research and knowledge translation practices (see Beck et al. 2011; Rossiter et al. 2008), in which researchers, participants, and often experts in theatre come together to create a script drawn from the words and themes of participant interviews, discussions, and observations (Saldana 2003).

The New Normal continues these theatrical traditions of intervention and empowerment. To date, the ethnodrama has been delivered live in six Canadian cities, in both French and English, to an estimated 300 people, including cancer survivors, their families, and health care professionals. The burgeoning availability of the Internet has extended its reach substantially; a performance was recorded and made available through a YouTube channel (https://www.youtube.com/channel/UCewEVF6CcTIEKYNcc8FWQ), and was issued to approximately 150 faculties of medicine and health sciences and over 50 breast cancer support groups across Canada.
METHODS AND ANALYSES

Among the live audiences, we surveyed 238 individuals on changes in their attitudes, knowledge, and practices regarding lymphedema as a result of watching the ethnodrama. We also conducted qualitative interviews with 32 audience members at four months and again at eight months post-performance. These audience members included nine women living with breast cancer (four of whom had a follow-up interview several months later); four were from Ontario, three from New Brunswick, and two from Saskatchewan. All interviewees reported having arm morbidity problems from breast cancer, although their experiences and knowledge of lymphedema varied greatly.

In this article, we focus on representations of SLC among sixteen women: the seven women who participated in the development of the ethnodrama and, in more detail, the nine women with SLC from the audience whom we interviewed. We have previously published a comparative analysis of surveys among different audience members (i.e. breast cancer survivors, healthcare professionals, and community members; Ahmed et al. 2015). We focus here on the qualitative data of women in the audience with SLC because we are interested in how the discourse of the ethnodrama was appropriated into their own representations of their bodies – an assembling social process we might refer to as ‘conjoining bodies’.

We approached the interviews from a biocultural perspective, interpreting people’s bodies as both social objects shaped by dominant discourses (e.g. medical nosologies) and social agents capable of disputing, resisting and producing new discourses (Becker 1997; Jenkins and Valiente 1994; Lyon and Barbalet 1994). This perspective also attends to language as an expression of both bodily experience and personal positioning within social discourses and relations (Gibbs and Franks 2002; Kirmayer 1992; Low 1994; So 2008).

Our methodology was adapted from discourse analysis, with some notable departures in focus and process. A discourse, broadly defined, is an interpretive framework composed of a series of statements about a subject (made through human expressions including language, gestures, performances, symbols/images, etc.; Potter et al. 1990). Discourses frame peoples’ experiences within selective structures of meaning (Ricoeur 1986; Todorov [1968] 1981), in a way ‘conjoining’ experiences into a unified social field. Discourses may be said to be both ‘constructed’ – pulling themselves together using an array of creative resources – and ‘constructive’ – giving actionable representation to peoples’ suffering (Potter 2003). Discourse analysis, in its various forms, works to decode the various strategies and effects of discourses (Jorgensen and Phillips 2002). We approached the work of decoding with attention to the poetics of metaphor, a particularly dominant mode of discourse used in the breast cancer survivors’ interviews. Among other formal features like genres and tropes, metaphors assist in structuring language into discourses (Fairclough 2003; Ricoeur 1986: 7–10; Todorov 1981: 16–19; Wood and Kroger 2000: 45–48). Metaphors produce relations of meaning by framing one thing in terms of another (Ricoeur 1977); in this way, metaphors can creatively conjoin disparate objects, people, experiences or events. As operands of discourses, metaphors serve as an ‘intermediate realm between body and society’ (Kirmayer 1993: 170), shaping how people think and act in their daily lives (Lakoff and Johnson 1980). The microcirculatory processes of SLC are not forgotten within assessments of metaphors, but rather are placed within embodied contexts of social (un)recognition and communication.
Our approach to discourse analysis is intentionally non-denominational; we depart from certain customary protocols both in being more selective in the modes of discourse we analysed and in choosing to cover a wide breadth of metaphors across different texts; this approach varies from more standard discourse analyses that interpret the unfolding situation of discursive acts within a text. In our interpretation of the ethnodrama and audience interviews, we remained sensitive to the metaphors participants used to represent SLC and their encounters with the ethnodrama. We gave equal attention to patterns and divergences in metaphors to account for both intersubjective and idiosyncratic aspects of discourse. We first identified metaphors – both common, everyday instances as well as novel instances – within an interview by their poetic framing of SLC in terms of other experiences and events; we then compared these metaphors across other interviews and with the ethnodrama. Our comparisons suggested a strong congruence in how participants metaphorically constructed SLC.

RESULTS: CONJOINING BODIES THROUGH EPIPHANIES AND UNITIES

To contextualize our interviewees’ responses in the post-performance interviews, we begin by briefly presenting the major metaphors of the ethnodrama itself, including abandonment and isolation, self-surveillance, and togetherness with other women with SLC. We then discuss two dominant metaphors within the interview transcripts, relating to receptions of the ethnodrama: (1) epiphanies – participants’ asserted realizations that they are part of a social body of suffering that is often invisible and (2) corroborations – participants’ claims that the play showed a social body within which they already lived. We briefly describe the conflicts between patient and professional discourses within which participants situate their social embodiment. We finish our analyses by considering some of the moral and practical implications raised by the metaphors of the ethnodrama and audience interviews. We use the term ‘moral’ here because metaphors of distress and healing have a ‘moral life’ (Kirmayer 1993) – they provide guidance for how to live, but sometimes this guidance can distort complex realities of illness experience (see Sontag 1978). Moralization is common within discourses of illness and might help some find direction while alienating others who take a different path (cf. Hyden 1995; Kleinman 1988; Zigon 2008).

The dominant metaphors of the ethnodrama

Emerging from the combined labours of the participants, researchers and scriptwriter, there are many different metaphors embedded within the script of the ethnodrama, not to mention the symbolism and poetics of the performers’ gestures, props and screen displays backgrounding the stage. The play’s many layers of imagery tend to locate lymphedema as a silent disability that maintains its power over women’s lives so long as it remains invisible, unnamable, and in isolated bodies. The dominant message in the ethnodrama script is to close the gaps between bodies, find a collective voice, and attract an audience that might appropriate its discourse; we break down this message into four moves.

The performance’s first two moves contribute to situating SLC as an alienating experience. The ethnodrama’s introduction frames SLC, first, within a
climate of social invisibility. The four performers walk onto an unlit stage and stand in a row facing the audience: ‘We’re in the dark’ (Woman A). ‘There’s no question about it’ (Woman B). ‘There’s so little information available’ (Woman C). ‘And most of it we’re not privy to’ (Woman D).

In this context, the performers speak of lymphedema as an invisible disease that keeps women silent, confused, and disconnected. They assert that not only is there a lack of knowledge, but also a lack of exchange regarding what knowledge exists (‘most of it we’re not privy to’). One of the women then steps forward onto centre stage and lights a single candle, and with it the stage lights brighten the room.

We may trace metaphors associating darkness with ignorance and light with knowledge as far as ancient Greece, to Plato’s parable of the cave in *The Republic*. Just as the cave dwellers are in chains, the women imply that they are in some sense kept in ‘the dark’ by a politics of knowledge. The women themselves must illuminate their experience, as expressed by the candle-lighting ceremony.

The ethnodrama typically targets physicians as obstacles to exiting the darkness. Onstage, a white coat is hanging on a wire frame, creating a hollow medical presence throughout the performance. It rests behind the women, shadowing them. When the women relay interactions with a medical professional, which are for the most part negative encounters, another woman steps behind the coat and delivers the doctor’s lines. The prop of the professional garment itself seems to create distance between professional and patient (as well as audience); concealed behind a puffy, elevated white coat, it is difficult just to see the performer playing the doctor’s part – we only really see a white coat with a talking head. The white coat, and the status and power differential it signifies, seems to create a barrier that prevents the women from acquiring the knowledge and support they seek. A later photo of a collage made by one of the performers shows a cartoon of a doctor holding an ear horn, with a cloud of thought bubbles expressing a dismissive attitude to what he is (not) hearing. We see later reiterations and expansions of these tensions with medicine in the interview transcripts.

In another instance, as Woman A relates a story of first feeling the symptoms of lymphedema, she frames life with SLC as a continual state of disorientation in no way assisted by her healthcare providers: ‘I’d just be lost, but kept going anyway […] when I started to think something was wrong and I asked for help I felt like this empty […] I felt like I was not seen’. Woman A continues her story and the other three performers unite in voice to authorize this as a familiar narrative among them:

Woman A: I felt like I would go down one road and try to get somebody to tell me something and […]
Woman B–D: Oh! Dead end.
Woman A: So I would go back down another avenue but there’s this big gaping hole […] incomplete and searching to find […] you know, the wholeness again.

Using a metaphor of paths taken and interrupted, Woman A juxtaposes her sense of personal agency in seeking care with the many false starts and misdirections she claims to have encountered. She then reframes her journey as a search for completion, a pursuit of ‘wholeness’ fraught with failure as the self in search encounters professional caregivers as roadblocks.
In a second discursive move, the ethnodrama locates an additional source of betrayal: the women’s own bodies. The performers position themselves as damaged and toxic bodies, having ‘felt broken’ (Woman A), ‘trapped in this body’ (Woman B), and accumulating lymphatic fluid metaphorized as ‘bodily sewage’ (Woman D) and ‘poison’ (Woman D). At one point, one of the performers says that ‘I’m fixated on my arm’, and all four women rub their affected arms. The women also take turns dropping items of their past lives into a bin at the front of the stage – golf clubs, clothing, baking sheets, and lotions that can no longer be worn or used. Over this next segment of the ethnodrama, images are projected onto a screen onstage and each image presents a tableau of items reflecting a new reality of troubled bodies. For example, one tableau contains pill bottles for managing symptoms, measuring tape for SLC assessments, and a watch symbolizing the finite ticking of time, among other items. Another image is a picture of a woman’s two arms parallel to each other, juxtaposing a thinner arm with a bracelet to a bare and swollen arm. These representations show bodies in conflict with themselves. Within these first two moves, the ethnodrama establishes the main sources of struggle.

In a third discursive move, the ethnodrama’s metaphors foster an internalized sense of personal responsibility for making SLC more socially recognizable and for getting their own bodies under control. Woman D highlights a sense of having no safety net, no backup should a health crisis arise: ‘What it is, is the panic, and it’s underscored by the fact that if it gets worse you have no recourse. You have nothing to turn to and that bothers you. You become hyper-vigilant’. The key metaphor here is of an absent space for bodies in crisis to find aid.

Stating that the ‘recourse’ of health care systems to recognize, understand, and treat disease often fails people with lymphedema, the performers anchor their actions in necessity: they must ‘turn’ to their own agency to monitor and treat their own swellings, pains, infections, and other complications that arise. Woman B says, ‘I feel like the only reason I get some answers is if I demand them’. This comment ties back to the symbolic candle lighting that initiates the performance – the performers signal that they feel they must take charge of their health, conduct the research themselves, and be their own advocates in order to see improvement in their symptoms.

Throughout the ethnodrama, the performers frequently confirm, console, and build upon each other’s frustrations – as in the above example of Women B–D completing Woman A’s sentence. There are reflections of solidarity throughout the performance, as when the women all come onstage at the beginning each wearing lymphedema sleeves; the sleeve is a source of contention for women with SLC as it makes their condition visible, and wearing this garment together in public symbolizes unity in the shared struggle to be seen. However, we interpret this solidarity as a fourth discursive move, as it finds its pinnacle in the final moments of the play (provided in this article’s introduction). The finishing assertion ‘Together’ in unison, with hands clasped together, accomplishes the process of conjoining bodies, that is, discovery of one voice and one body to bring the women out of the shadows. In this way, the ethnodrama delivers a communal narrative of women losing each other by means of lacking understanding of their shared condition (‘We are in the dark’) and finding each other again in the effort to make their shared experiences visible ‘Together’.

The above metaphors of abandonment, self-governance, and togetherness frame experiences of SLC within a forlorn history of medical (un)recognition,
but projected into a hopeful future of unified discourse and action. We found similar metaphors with comparable effects used by women living with SLC who watched the ethnodrama.

**Dominant metaphors of audience members with SLC**

There was remarkable consistency in the patterning of metaphors among the audience interviewees. Most of them talked about SLC and the effect of the ethnodrama as either an epiphany of an invisible social embodiment of suffering and/or a corroboration of the social embodiment they already knew. These metaphors of conjoined bodies included moral action in the forms of advocacy and self-management practices. These patterns of metaphors and their implications suggest the ethnodrama’s metaphors had important formative effects on how their audiences of breast cancer survivors talk about and act on their post-treatment bodies.

(1) **Epiphanies**

The first metaphor of epiphany tells a compressed story, or ‘kernel narrative’ (Teucher 2003), of coming to understand SLC as a social experience. According to the survey, 75 per cent of breast cancer survivors watching the ethnodrama agreed that the performance was effective in changing their understanding of SLC (Ahmed et al. 2015). Until encountering the ethnodrama, about half of the interviewed women with SLC said they understood SLC as an individuating, isolating disability. They described their epiphanies as discoveries of the shared pain, frustration, and struggle among women with lymphedema. For example, one woman we will name Josee said she was ‘fairly new to lymphedema’ and valued having ‘a chance to talk to other people that have the same issues’ at the ethnodrama. She constructed the performance as ‘very moving’ and situated the ethnodrama as a revelation of bodies suffering together: ‘everybody’s going through this, it’s not just me and my body that aren’t letting me forget I have had cancer’. She fortified the significance of her revelation with claims to its consoling effects: ‘[I left] with that good feeling, to know that I wasn’t the only one who sort of struggled with the emotions’.

Josee’s metaphor of epiphany found repetition in other women’s interviews. Karen said of the ethnodrama that ‘it made a big difference, it touched me’. Although Josee’s metaphor was kinaesthetic (‘moving’) and Karen’s was somatosensory (‘touched’), they both constructed the impact of the ethnodrama as affecting them in an embodied way and relating to others in a different way. This double meaning to their metaphors emerges from the ethnodrama’s own categorizations of distress around SLC, that is, of bodily betrayal and social marginalization. In other words, we found traces of the dramatically constructed framework of SLC lived experience in the audience’s responses.

A third woman, Beth, used a visual metaphor to define the ethnodrama as an epiphany. She described it as ‘an eye opener’, revealing a hidden, behind-the-scenes world of SLC. She compared it to day-in-the-life videos she has seen on television, which seem to display the ‘authentic’ lives of those filmed:

I thought it was real and I just enjoyed the personal […] it was like reality TV […] even though it was like a drama, it was real life experiences, it was like, it brought tears to my eyes, it was emotional.
She presented the performance as a public display of the ‘real’ lives of the performers, even as the event was scripted and choreographed. Beth’s ‘reality TV’ simile and ‘eye opener’ imagery both tell a story of her witnessing an invisible truth (i.e. the everyday bodies and lives of people with SLC) becoming more visible.

While the women above talked in nuanced ways about their receptions of the ethnodrama, their metaphors all seemed to converge upon an image of epiphany. Metaphor usage is a discursive act that creates as much as describes experiences, and in this context the metaphors of epiphany created a shared sense of suffering among women with SLC. In other words, their metaphors of discovering a social body of SLC enacted that very discovery through language.

(2) Corroborations

Roughly half of the interviewees situated the ethnodrama not as a defining moment but rather a corroboration of pre-existing perceptions of SLC as a social experience of distress. In contrast to metaphors of epiphanies, the conjoining of lymphedema bodies was already presumed under this imagery of validations. However, the two sets of metaphors were not mutually exclusive, as evidenced by Karen’s interview. Although she reported the ethnodrama ‘touched’ her and made ‘a big difference’, she stated earlier in the interview, ‘I can’t say that for myself it changed anything in my life’. These two statements seem contradictory, but Karen’s changing discourse might reflect tensions people with SLC talk about between being visible and invisible at the same time; in this case, perhaps she was implying that while the ethnodrama made SLC sufferers more evident to each other, they still remained hidden as a community. She suggested as much at the very beginning of her interview, which was significantly reminiscent of the first lines of the ethnodrama: ‘We are the forgotten people’.

Within this discourse of validation, interviewees evaluated the ethnodrama in terms of its congruence with what they identified as the social reality of SLC – a performance that mirrors the social dramas happening offstage. For instance, Pam said that the portrayal of SLC was ‘right on the mark’ and the performers ‘spoke to the real issue of lymphedema’. Her review seemed to assess the performance’s verisimilitude against the audiences’ experiences: ‘I know with the people that I sat with […] the reaction was “Oh, my goodness, they’re telling my story”’. She positioned herself as privy to the ‘true’ representation of SLC, first with her evaluative metaphor ‘right on the mark’ and then by shifting metaphors to suggest that most women (like those discussed in the previous section) would encounter the ethnodrama as ‘a real awakening’. In this way, she constructed herself as a proper arbitrator to determine the play’s veracity.

All of the metaphors in the audience interviews parallel the discursive moves of the ethnodrama, with the exception of one dominant metaphor. The metaphor of dragon boating was nowhere to be found within the ethnodrama, but it was one of the most frequent and potent images used to depict the process of conjoining bodies. Dragon boating has become, over the last twenty years, an internationally popular activity for women living with breast cancer and is often hailed as an effective treatment for its physical, psychosocial and existential difficulties – lymphedema among them (McKenzie 1998; Parry 2008). The activities of the dragon boat are rife with social embodiment
symbolism – women ‘in the same boat’ who must synchronize their movements in order to reach a common destination. In fact, lymph is the Latin word for ‘water’, and in dragon boating women with SLC might be seen to paddle against two currents of water.

Although we might be accused of reading into the metaphors of dragon boating, several interviewees talked about the dragon boat as a practice of unifying women’s bodies and a few also applied dragon boating metaphors to what they saw as the accomplishments of the ethnodrama. Sara praised dragon boating for her recovery from SLC: ‘all over the world you’ve got breast cancer survivors paddling dragon boats, and we paddle each other […] that’s the big thing I did with my lymphedema’. The dragon boat, in this case, served as an embodied metaphor of togetherness; the dragon boat team paddles together and ‘paddle each other’ against common difficulties.

Deborah spoke the most about dragon boating, at one point describing it as building ‘camaraderie’. Her use of metaphors was quite telling, for instance, when she talked about the global reach of this activity: ‘It’s really snowballed […] we just had an international festival a couple years ago’. Her ‘snowball’ image shapes dragon boating practices into a single body growing in size, momentum and geographical reach. Deborah then applied a dragon boating metaphor to her evaluation of the ethnodrama:

It’s nice to see you’re not the only one paddling through this terrible time […] I think that’s a good sign for some of the people to see because when you’re going through it, you really feel like you’re the only one.

By her assessment, the ethnodrama’s merits were not exactly in its mirror of reality (as others had measured it) but in its ability to situate SLC sufferers within a boat of others ‘paddling through’ it as well. Some audience members, then, evaluated the ethnodrama against the dragon boat, which is perhaps the quintessential activity and metaphor for conjoining the bodies of breast cancer survivors.

In sum, several women claimed they already understood SLC as a socially marginalized illness prior to attending the performance and used a variety of metaphors to establish this discourse. They talked about the ethnodrama in terms of its ability to adequately represent the social body of SLC, to reveal the ‘forgotten people’, and to show audiences they are not ‘paddling’ alone. Women with SLC introduced the metaphor of dragon boating into their interviews as relevant to the intentions of the ethnodrama by way of its embodied symbolism of togetherness.

**Moral and practical implications of the dominant metaphors**

Bodies may join together by performing a set of shared practices deemed morally and practically relevant to a social experience. We include discursive practices within this set, including the appropriation and reuse of familiar metaphors; we have shown some of the repetition in representation among women with SLC, but we now turn to two other major practices that emerged from the encounters between the ethnodrama and audience interviews: group campaigning and individual self-management. The ethnodrama and audience interviews defined these practices as resistance towards what the women presented as an all-too-common medical narrative of SLC – that swelling and pain in limbs are temporary reactions to treatment and will go away with minimal intervention.
First, through their metaphors of being the ‘forgotten people’ left ‘in the dark’, the ethnodrama and the interviews delivered a call for wider social visibility of SLC within survivorship care, through such practices as advocacy campaigns, appeals to medical insurance for coverage of standard treatments, and educating doctors who seem unfamiliar with SLC. All interviewees endorsed the efforts of the ethnodrama to encourage collective action (i.e. social embodiment in motion). For example, Beth said that the ethnodrama revealed there needs to be ‘more research, more awareness […] I’m just happy [about the ethnodrama] for the continuing awareness of it’. Several people situated the ethnodrama as a tool for helping to unify the cause and build a social network between people affected by SLC.

The interviewees also discussed self-management practices at length. Along with dragon boating, several women recommended Nordic walking, wearing compression garments, self-massaging, and low-impact exercising. Discourses of self-management for cancer survivorship can be problematic, as they tend to place disproportional expectations upon patients to control their bodies (Bell 2010; Ignatieff 1988; Stacey 1997: 209–17). For example, using metaphors of manual labour, Karen insinuated that every person with SLC needs to carry themselves in order to move forward together:

*I will not pull people who, who are not willing to help themselves out of the mud, that takes too much energy on my part […] There are people who feel sorry for themselves and sit on their hands […] The ‘poor me’ syndrome. There’s no such thing as a ‘poor me’ syndrome and it takes a lot of energy to pull them up and I would like to be in studies and I would like to talk to people who are doers.*

This quote illustrates a counterpoint to conjoining bodies, that is, people with SLC are not always united in their struggles and might judge their peers harshly for not meeting the call for self-management. The paradox within Karen’s comments is that although self-management practices tend to individualize distress and disability as a matter of personal will, they may also promote the social body of SLC.

Despite the dangers of self-management discourses, they might still be productive for women with SLC. With the exception of the above quote, Karen constructed the individualization of SLC care as a solution to abandonment, rather than a tool for isolating bodies from each other. The performance spoke of women with lymphedema as currently ‘on their own’ (until such time they can come ‘together’) due to what was defined as a void of knowledge and practical information within oncology, and an unwillingness to legitimize lymphedema. Audience members gave examples of healthcare providers telling them they were fat and had to lose weight, and refused to provide signatures that would aid in gaining coverage for their sleeves. The ethnodrama and interviewees emphasized taking charge of one’s health and well-being in lieu of supportive healthcare structures.

Many of the women in this study talked about the ethnodrama as a facilitator of self-management, as we noted in our analysis of the ethnodrama’s main metaphors. For instance, Connie said that she became proactive in her SLC management immediately after the ethnodrama: ‘[It] certainly told me about the hazards of [SLC] and I didn’t want to experience that so I thought “Okay, I’m going to see what I can do” and I did it’. She explained the ethnodrama showed her that ‘you are responsible and you can’t sit around and wait
for somebody to tell you what to do about it’. Beth also said the ethnodrama encouraged her to do more research on SLC management: ‘It was good to hear that information out and it motivates you to wanna go and research and be aware of the resources, potential risks, and what to look for’. Beth’s talk of doing one’s own research instructs SLC patients to be active investigators. This claim to agency might empower some, as it seems to have done for Beth, but it also has a double edge of assuming patients have the time, resources, and access to gather the information they need within a medical culture that is clearly criticized for not conducting or sharing research on SLC.

Although not without their limitations, the practices of advocacy and self-management offered productive avenues for the women with SLC. In particular, they provided direction through which alienated bodies come together as conjoined bodies, as depicted within the unfolding narrative of the ethnodrama.

**CONCLUSION: ETHNODRAMA AS THE DISSEMINATION OF BODIES**

The women in this study located their experiences within a collective vehicle of women’s bodies, trekking forward to a future hope of widespread recognition, acceptance, and care. The ethnodrama metaphorized the embodiment of SLC as abandonment leading towards self-governance first and togetherness eventually. Breast cancer survivors who attended the ethnodrama negotiated these metaphors as they provided their own narratives of ‘discovering’ the social body of SLC and engaging in practices legitimated within it.

We have described this process as conjoining bodies, in which discourses bring bodies together into assemblies of meaning and action. Theatre-based knowledge translations like the *The New Normal* ethnodrama – events intended to make lymphedema or other health concerns more visible through performative arts – seem to do a great deal more than just disseminate information about a condition; they disseminate bodies that can pull audiences’ disparate experiences together into organizing metaphors with moral and practical significance.

What, then, does this feature of ethnodramas to initiate social embodiment mean for recognition of diverse bodies and experiences of illness? On the one hand, the conjoining of bodies around lymphedema is predicated upon acknowledgement that women’s bodies, and breast cancer survivors’ bodies in particular, are not all the same. The ethnodrama’s purpose of broadening visibility of SLC is itself a call for recognition of ignored and marginalized bodies. In this sense, the discursive fusion of bodies through metaphor may be a path towards empowerment among alienated women and a tool for raising visibility of hidden illness experiences.

On the other hand, as bodies unite their voices begin to speak in harmony – slotted into standardized metaphors and narratives – and this standardization may push the potential diversity of experiences and knowledges within the social body to the periphery. Awareness campaigns, for example, can minimize divergent viewpoints in order to get a single, unified ‘message’ out – however it might be defined. Self-management discourses, for their part, can take women’s bodies out of local contexts in which they must negotiate various (dis)abilities, responsibilities, expectations and practices. Social embodiment can, in such ways, instigate further loss of recognition.

Although we emphasized the conjoining of bodies within this article, there are few indications of an enduring impact of the ethnodrama discourse.
on audiences’ embodiment. Indeed, as some critical analyses of embodiment have suggested, bodies continually assemble into and disassemble out of collectivities (e.g. Deleuze and Guattari 1980) and might never stay still long enough to become composed (individual or collective) entities (e.g. Manning 2014).

In our analyses of the ethnodrama and interview transcripts, alongside conjoining bodies we also observed clashing, contradicting, and resisting bodies – in particular, bodies in negotiation and movement between different knowledges of SLC associated with medicine, allied health sciences, and patients’ lived experiences. Within the participant interviews, like the ethnodrama, medical professionals were cast as typically reluctant and hostile towards sharing power/knowledge, while allied professions were most likely to validate their patients’ embodiment. In Deborah’s case, for instance, she found recognition from her massage therapist, who acknowledged her lymphedema but whose discipline was not licensed to do arm measurements. Medical knowledge and practice often served as the gatekeeper for accessing services and receiving insurance coverage, which performers and audiences alike found problematic because, among their medical professionals, lymphedema was an absent knowledge or non-discourse. However, women in the audience with SLC reported a wider variation of experience with healthcare professionals than the ethnodrama. They provided exceptions in which medical professionals recognized their own power to erase and overrule the embodiment of lymphedema; Josee, as an example, reported that, ‘[my GP] said “Over the phone I wouldn’t have taken you as seriously as I have with you sitting in the office and showing it to me”’. Although the audience presented more collaborative constructions of SLC than the performance, there was agreement all around that living with SLC involves an ongoing negotiation of embodiment with the people in charge of their care.

For contested illnesses such as lymphedema, there will continue to be a large liminal space created by clinicians’ power to withhold legitimacy to discourses originating outside their practice. Arts-based forms of knowledge translation, such as the ethnodrama explored here, demonstrate a power to subvert dominant medical discourses to construct a social body of suffering. We must therefore understand conjoining bodies as one of many important social and political processes of exchange that can occur within contexts of knowledge translation.

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**SUGGESTED CITATION**


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