
10-29-2018

A Critical Analysis of the Delivery of a Psychosocial Workshop for Cancer Survivors with Lymphedema

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Recommended APA Citation

Hamilton, R., Thomas, R., Anisimowicz, Y., Piers, M., & Matte, R. (2018). A Critical Analysis of the Delivery of a Psychosocial Workshop for Cancer Survivors with Lymphedema. *The Qualitative Report*, 23(10), 2586-2602. <https://doi.org/10.46743/2160-3715/2018.3497>

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Abstract

Secondary lymphedema is a chronic condition that can develop after the treatment of cancer and can often lead to negative psychological and social impairments. When dealing with chronic illness, hoping and coping are interdependent. Previous research has assessed the outcomes of workshops designed to enhance hope but has not examined the workshop itself to determine how those outcomes were achieved. This study deconstructs the Living Hopefully with Lymphedema workshop to identify (1) what aspects of the workshop facilitated or interfered with therapeutic progress, (2) key aspects of facilitation that contributed to the functioning of the workshop, and (3) how participants responded to the workshop. Two three-day workshops were attended by a total of 19 participants. All sessions were audio taped and the recordings analyzed. Theoretical coding revealed a central theme focused on the importance of a safe environment within the workshop. Facilitators and participants worked together to co-create, maintain, and protect a safe space in which to engage in therapy. Findings are discussed in relation to key aspects of facilitation and the participants' response to the workshops. Recommendations for future workshop development are presented.

Keywords

Cancer, Survivorship, Coping, Intervention, Workshop, Group Facilitation, Interpretive Description

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Acknowledgements

This research was funded in part by a New Brunswick Health Research Foundation Bridge Grant. This research was undertaken, in part, thanks to funding from the Canada Research Chairs program.

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Secondary lymphedema is a chronic condition that can develop after the treatment of cancer and can often lead to negative psychological and social impairments. When dealing with chronic illness, hoping and coping are interdependent. Previous research has assessed the outcomes of workshops designed to enhance hope but has not examined the workshop itself to determine how those outcomes were achieved. This study deconstructs the Living Hopefully with Lymphedema workshop to identify (1) what aspects of the workshop facilitated or interfered with therapeutic progress, (2) key aspects of facilitation that contributed to the functioning of the workshop, and (3) how participants responded to the workshop. Two three-day workshops were attended by a total of 19 participants. All sessions were audio taped and the recordings analyzed. Theoretical coding revealed a central theme focused on the importance of a safe environment within the workshop. Facilitators and participants worked together to co-create, maintain, and protect a safe space in which to engage in therapy. Findings are discussed in relation to key aspects of facilitation and the participants' response to the workshops. Recommendations for future workshop development are presented. Keywords: Cancer, Survivorship, Coping, Intervention, Workshop, Group Facilitation, Interpretive Description

Introduction

As survival rates increase for many forms of cancer (Canadian Cancer Society, 2015), there is a growing need to understand the experiences of cancer survivors and the many challenges and quality of life issues they may encounter. One potential complication is the development of secondary lymphedema, a chronic condition that can develop as a result of lymphatic trauma and the obstruction or disruption of the lymphatic system (Cormier et al., 2010), which can occur as a result of surgical or radiotherapeutic interventions for cancer (Rockson & Rivera, 2008). The presence of lymphedema is often accompanied by a host of social, physical, and psychological impairments; as a result individuals with lymphedema can face substantial challenges to daily life that are not always apparent, but that have a profound psychosocial impact.

Since lymphedema is a prevalent part of cancer survivorship, it is increasingly important that we understand how to cope with the consequences of lymphedema. Previous cancer survivorship research has demonstrated a relationship between coping and hope (Felder 2004; Folkman, 2010; Hamilton & Thomas, 2016). In cases of prolonged stress, such as living

with a chronic condition like lymphedema, hoping and coping work interdependently, with coping mechanisms increasing levels of hope when they are depleted, and the process of hoping providing a reason for which to engage in coping mechanisms (Folkman, 2010). Although there have been several studies analyzing the relationship between hope and cancer (Duggleby, Ghosh, Cooper, & Dwernychuk, 2013; Elliott & Olver, 2007; Felder, 2004; Folkman, 2010; Herth, 2000), little research on hope has been conducted specifically in regard to lymphedema. Hope-based intervention programs have been found to be effective in increasing hope and quality of life in individuals with a first recurrence of cancer (Herth, 2000), but little is known about how these workshops are experienced by participants, or how to create the ideal environment to maximize their potential benefits. Moreover, most research focuses on outcomes of workshops and interventions, rather than examining the process of delivery and facilitation.

The purpose of this study is to identify what elements inhibit or facilitate therapy for cancer survivors living with lymphedema by analyzing transcripts resulting from two *Living Hopefully with Lymphedema* workshops. This research will increase our understanding of how participants experience skills-building workshops and enhance our knowledge of how to construct and present workshops for the greatest therapeutic impact.

Lymphedema

As many as 30% of cancer survivors may develop lymphedema, depending on the type and location of the cancer as well as what type of treatment they underwent (Cormier et al., 2010). Cancer patients are often given little information about or preparation for the possible onset of lymphedema, as members of the medical community tend to exhibit a general lack of knowledge about the condition (Cal & Bahar, 2016; Fu & Rosedale, 2009; Maree & Beckmann, 2016). This lack of knowledge limits the mental preparation of cancer survivors for the possible lymphedema diagnosis and hinders the support they could receive from medical professionals (Fu & Rosedale, 2009; Maree & Beckmann, 2016).

Lymphedema can present multiple symptoms through the day, including continual pain and discomfort such as stabbing pain, burning, heaviness, and swelling, which can create perpetual distress and anxiety (Fu & Rosedale, 2009). Due to the dangers of infection, increased swelling, and worsening of the disorder, individuals must always be cautious of their bodies and any possible risks to which they may be exposed (Radina, 2009). This cautiousness creates a constant awareness of the disorder and the heightened potential for death from infections, as well as serving as a reminder of the cancer they endured and the possibility of recurrence (Radina, 2009). When living with lymphedema, it becomes increasingly difficult to forget or completely move on from the experience of cancer. Other qualitative studies we have conducted involving individuals living with lymphedema indicate this is in part because management is demanding, and compression garments are quite visible (Hamilton & Thomas, 2016; Thomas & Hamilton, 2014).

There are several therapeutic techniques designed to decrease pain and prevent the worsening of lymphedema (Shah & Vicini, 2011). Individuals with lymphedema often wear compression bandages or garments that provide pressure to affected limbs while mobilizing the lymph fluid and engage in therapeutic exercises that aid lymph flow through repeated contraction and relaxation of the muscles (Shah & Vicini, 2011). Complex decongestive physiotherapy (CDP) is an intensive combination therapy which, in addition to compression devices and therapeutic exercises, also includes proper skin and nail care and manual lymphatic drainage, which is often done through self-massaging at home (Karadibak, Yavuzsen, & Saydam, 2008).

Although compression garments and swollen limbs are visible indicators of the condition, the emotional and psychological consequences are often invisible. Individuals living with lymphedema may face restrictions that can limit their independence and influence their self-identity (Cal & Bahar, 2016; Thomas & Hamilton, 2014). Clothing must sometimes be chosen not as a means of self-expression but to accommodate compression garments or a swollen limb (Fu & Rosedale, 2009). Restrictions against heavy lifting and repetitive motions can limit activities in every aspect of a person's life, including recreation, career, and the tasks of daily living (Cal & Bahar, 2016; Radina & Armer, 2001; Thomas et al., 2015). Managing the symptoms of lymphedema can also be expensive and time-consuming (Fu et al., 2011; Maree & Beckmann, 2016), and can create difficulties within sexual relationships (Heppner et al., 2009; Winch et al., 2016). Overall, lymphedema can be a source of psychological distress and can have a negative impact on quality of life among cancer survivors (Chachaj et al., 2010; Teo, Fingeret, Liu, & Chang, 2016).

Coping and Hope

In instances of chronic illness, such as lymphedema, hope serves as a psychological resource that allows for coping to take place (Folkman, 2010). Hope in cancer patients has been examined (Elliott & Olver, 2007), and hope-based interventions have been successful (Duggleby et al., 2007; Herth, 2000). Work has also been done to enhance the coping skills of cancer survivors (Hamilton, Miedema, MacIntyre, & Easley, 2011).

Coping. Cancer survivors who have lymphedema engage in a multitude of coping strategies in order to decrease the negative psychological and social impairments resulting from their diagnosis. These strategies generally fall into two categories: problem-focused coping, which is about trying to remove or mitigate stressors, and emotion-focused coping, which is about trying to manage our response to stressors (Lazarus, 1993). Problem-focused coping strategies involve actively seeking information on the condition and the treatment options, including learning various physical strategies to manage the condition, such as engaging in self-massage (Heppner et al., 2009). Emotion-focused coping strategies include focusing on acceptance of limitations and having a positive outlook on life, finding solace in spiritual/religious activity, and being open and helping educate others about lymphedema (Heppner et al., 2009).

Research shows that several social supports and social resources can help people cope with lymphedema. Reliable support from a partner, reliable support from individuals other than a partner, and concern and support from practitioners and other health care providers are important social resources (Cal & Bahar, 2016; Heppner et al., 2009; Maree & Beckmann, 2016). An additional source of coping resources appears to be the opportunity to nurture others (Heppner et al., 2009). This can include friends and family, but also includes nurturing other cancer patients and cancer survivors through disseminating information about lymphedema. By sharing their personal experience, it is believed that others will gain knowledge on how to cope with the lymphedema diagnosis and reduce the related symptoms (Heppner et al., 2009).

Hope. Complementary to coping is the presence of hope. A hope to avoid exacerbating lymphedema symptoms can encourage engaging in coping activities designed to meet that hope, such as wearing compression garments (Hamilton & Thomas, 2016). Hope has been associated with increased sense of self, feelings of control, improved relationships with others, and increased quality of life (Duggleby et al., 2012). Hope is not a stable trait, however, and can be influenced by internal and external conditions (Duggleby et al., 2012; Folkman, 2010). Care providers' understanding of the role of hope in the coping process is very important, as

cancer patients have identified that hope is often determined by the way the diagnosis and possible treatments are presented (Elliott & Olver, 2007).

Hope also involves the process of positive reappraisal in which patients with chronic conditions may acknowledge and accept that their hopes must often change (Duggleby et al., 2012). Thus, it is possible that hope could aid in the process of redefining oneself in the context of a chronic condition. For cancer survivors, their experience has already given them practice applying hope in the context of seeking a cure; cancer survivors diagnosed with lymphedema must engage in the process of renegotiating their understanding of hope, shifting their focus away from purely cure-based hopes (Hamilton & Thomas, 2016).

Hope-Based Intervention

The *Living Hopefully with Lymphedema* workshops employed in the present study were designed to foster hope and develop coping skills for cancer survivors who had been diagnosed with lymphedema. The workshop was based upon and included an expansion of Herth's Hope Intervention Program (Herth, 2000). This approach combined the hope-enhancing interventions found to be effective for cancer patients (from Herth) with the unique psychosocial needs of people with lymphedema. In sum, the workshops consisted of group-based cognitive behavioural interventions, creative expression, hope-based intervention, introduction to occupational therapy, a session with a physiotherapist specializing in lymphedema care, mindfulness and acceptance training, and the sharing of personal stories and creative work. Participants had access to a multidisciplinary team of facilitators that included a psychologist, sociologist, occupational therapist, and physiotherapist.

According to Campbell and colleagues (2007), "understanding context is crucial not only when designing interventions but also when assessing whether an intervention that was effective in one setting might work in others" (p. 455). Although the effectiveness of hope-enhancing workshops has been evaluated (Duggleby et al., 2007), there has been little analysis into deeper aspects of intervention programs beyond outcome-based assessments. Therefore, this study will attempt to fill this gap by deconstructing the *Living Hopefully with Lymphedema* workshops to identify (1) what aspects of the workshops facilitated or interfered with therapeutic progress, (2) key aspects of facilitation that contributed to the functioning of the workshops, and (3) how participants responded to the workshops. Critically analyzing the workshops will provide greater knowledge on the ways to construct and present workshops more effectively and provide better experiences and outcomes for participants. Before describing the method employed in this study, it is important to describe who each of the researchers are to enable readers to reflect on how the researcher's context may have influenced the execution and analysis of this study. Ryan Hamilton is an associate professor of psychology with an extensive background in sport and exercise psychology. Ryan's research and consulting work are primarily focused on the implementation and analysis of group-mediated cognitive behavioural interventions. Roanne Thomas is a sociologist working in rehabilitation. She has been working with cancer survivors for 25 years and with people living with lymphedema for much of that time. Having worked on a number of descriptive studies, her work now focuses on exploring creative practices that may enhance well-being given the lack of psychosocial and community-based supports for those living with chronic illness. Yvonne Anisimowicz is a PhD student in experimental psychology whose research focuses on cancer survivorship. Marquelle Piers is a post-graduate student studying social work and led the coding of this project. Renee Matte is a PhD candidate in experimental psychology whose research focuses on psycho-social aspects of sport and exercise.

Method

We used an interpretive description design for the study. With an emphasis on the intersections of context (ethnography), experience (phenomenology), and process (grounded theory), this methodology addresses the complexity associated with developing an understanding of both the outcomes and the processes of our workshops. In addition, interpretive description provides space for the integration of researchers' experience and expertise in health care to inform all phases of the research process, including analysis (Hunt, 2009). This methodology was also suited to our research as it emphasizes the application of research to practice. In the following section, we describe key aspects of the workshops, participants, data collection, and data analysis.

Delivery of the Workshops

Two separate *Living Hopefully with Lymphedema* workshops took place in the spring and fall of 2013 in Ottawa, Canada. The workshops took place over a total of three days, occurring every other Saturday at the Ottawa Regional Cancer Foundation (ORCF), a community-based centre that offers cancer survivorship wellness programs (e.g., coaching, exercise and nutrition programs) from diagnosis forward. ORCF programs and infrastructure ensure that the space is not clinical or reminiscent of a hospital setting: the ORCF space includes a conference room, lounges, a craft room, and a full kitchen, along with ample parking.

Facilitators. Facilitators (who included two of the researchers, RH and RT) were a practicing sport/exercise psychologist with training in group-based cognitive-behavioural techniques, a sociologist with expertise in cancer survivorship and lymphedema, an occupational therapist specializing in return-to-work issues for cancer survivors, and a physiotherapist with a private practice focused on lymphedema care. The inclusion of the two health professionals reflects the emphasis on providing local support/care in the hope intervention.

Developing Complex Interventions

The present intervention was tailored to the unique needs of cancer survivors with lymphedema. Many pedagogical approaches were used for content delivery, including group discussions, anecdotes, PowerPoint presentations, collaging and creative writing, workbook completion, and humour and self-disclosure by facilitators and participants. The major components of the workshop included: a) teaching coping skills such as relaxation, cognitive restructuring, and mindfulness; b) completing activities in being hopeful; c) creative expression (collage and creative writing); and d) building resources through presentations by a lymphedema physiotherapist and an occupational therapist.

Participants. The two workshops were comprised of a total of 19 participants (16 women, 3 men) with either upper or lower limb lymphedema. Several different cancer diagnoses were represented in the group, including breast, prostate, melanoma, colorectal, and lymphoma. The length of time participants had experienced lymphedema ranged from 1-21 years. Participants were recruited via online and physical advertisements at relevant online (lymphedema websites) and offline (physiotherapy clinics) locations. Participation was completely voluntary, and all aspects of the study were in compliance with ethical principles as overseen by the University of Ottawa research ethics board who granted approval for the project.

Data Collection and Analysis

The workshop facilitators audio taped each 8-hour workshop session, producing 24 hours of content per workshop for a total of approximately 48 hours of recordings (workshop delivered on two occasions). All aspects of the workshops were recorded including presentations from facilitators, facilitator-led discussions, conversations during creative work, and presentations of creative work. Recording was paused during lunch to provide an “off the record” opportunity for participants to interact. A researcher who was not involved in delivering the intervention transcribed the recordings verbatim and inspected every aspect of the intervention for therapeutic moments (i.e., instances where therapy was either enhanced or hindered), with the goal of critically examining the intervention process. Simply put, our analysis involved a continual return to the key interpretive question raised by Thorne, Reimer-Kirkham, and O’Flynn-Magee (2004): “What is happening here?” During the transcription process, several rough categories emerged from the data that appeared to facilitate or interfere with the therapeutic process. A preliminary coding framework was developed within QSR NVivo 10 utilizing these categories. Each workshop was then coded line-by-line to identify codes that resonated with the workshop participants (Krippendorff, 2013). Theoretical coding was then used to help theorize how the focused codes related to one another and fit into particular themes. Upon completion of line-by-line coding, the meaning units were refined to account for any overlap that had occurred between nodes. The key meaning units were then organized in a variety of ways to represent the data effectively and identify the emergent themes upon which the units were centred. A final revision of the coding framework occurred as similar key codes were identified and organized into themes related to workshop delivery; codes that proved irrelevant to the research question and were unrepresentative of the data were discarded.

Findings

Our analysis of the workshop transcripts identified moments where therapy was enhanced or hindered. An interpretive description of the themes that emerged from theoretical coding of the therapeutic moments are presented in these findings.

Therapeutic Moments

Beyond the activities of the workshop and the skills fostered by their implementation, a central theme focused on the importance of a safe environment within the workshop became evident. The nodes were organized in terms of their relation to this safe environment and were categorized into three main themes that were classified as: (1) creating a safe space, (2) maintaining the safe space, and (3) protecting the safe space.

1. Creating a safe space. The creation of a safe and accepting space enabled participants to disclose personal information and respond to the therapy from a place of emotional vulnerability. A safe space is not inherent in the dynamics of a group, however, and the positive environment was not present naturally from the beginning of the workshop. Often participants enter a workshop with little knowledge as to who the facilitators or fellow participants will be, and without a clear understanding of what will be asked of them. This can lead to apprehension, reticence, or reservations when it comes to sharing deep emotional experiences. Thus, a safe space must be cultivated by the facilitators in order to overcome the apprehensions and reservations that are often transported into therapy by participants. This was evidenced in one participant’s response to facilitators asking for feedback:

You set a place for us that is open [...] and accepting and safe. [...] I think from what we said the first time, we did come with some worries or trepidations or you know, what were we going to hear, what were we going to say about ourselves, were we going to have to reveal huge things, and [...] I feel as if we've all really come to reveal a lot, [...] but you set the stage for that. (Female P, Spring Workshop)

The creation of the safe space was accomplished in part through the structure of the workshop and the participatory, non-didactic communication style of the facilitators. One aspect of communication that participants appreciated was the emotional stance taken by facilitators. "But you're sympathetic, not empathetic. You haven't put yourself in their [cancer survivors'] place because you haven't experienced it [cancer]." (Female P, Fall workshop)

Having multiple facilitators with different approaches was considered by participants to be a positive aspect of the workshop. One participant said:

And the two of you are so very different in your approaches to things. This is not news to either of you, and that's the funny thing is, because it worked so well and is so beneficial for facilitating for so many different people and different kinds of things. Because of that diversity that the two of you together can present. (Female P, Spring Workshop)

Differing experiences with cancer were also considered a positive aspect of the workshop. Participants indicated they felt there were some benefits of having the outside perspective of facilitators who themselves had not been diagnosed with cancer.

I think that, as a cancer survivor, I would rather have somebody who has never had cancer give me your side of life, and your side of coping skills and positive thinking. Because then it makes it more real, in life. You know? It's just another thing we have to cope with. Everybody has stuff to cope with. We all have to find the way. [...] And I think if we had people [facilitators] who had cancer, we wouldn't get that perspective. (Female P, Fall Workshop)

The safe space created in the workshop was not solely the result of the facilitators' efforts, as the participants also contributed. Participants openly and warmly greeted one another, gave time for fellow participants to explore and express their thoughts and feelings, and reinforced the sharing of others as varied and distinct as it was at times. One facilitator mentioned to participants that "you also created an environment where everyone would feel safe and comfortable" (Facilitator 2, Spring Workshop). Thus, it is evident that the creation of a safe and accepting space is not inherent to the design of a workshop, but rather is co-created through the combined efforts of both the facilitators and participants.

Creating a safe space was accomplished through (a) modelling open and supportive behaviour, (b) using storytelling, humour, and self-disclosure, and (c) fostering participant engagement and connections.

Modelling open and supportive behaviour. One of the ways the facilitators "set the stage" for an open, accepting, and safe environment was through the ways they related to each other and to the participants, and in the way they delivered the various components of the workshops. Facilitators created an environment in which it was acceptable and encouraging for participants to express their honest opinions about their experience with the workshop: the

material, lymphedema, and the members of the workshop. Facilitators did so by modelling this behaviour themselves. For example, when asking participants for feedback on the previous session, the facilitators stressed that any criticism, whether directed at the material or even at their own personal communication style, was welcome.

But you all don't have to say nice things about [Facilitator 1], you can say bad things [laughing]. We shared an office 10 years ago and I think there might have been a time when I threw a book at him. Yeah, he can really push your buttons sometimes. (Facilitator 2, Spring Workshop)

Participants also modelled supporting and encouraging behaviour throughout the workshops, and therefore may have been less fearful of judgement from their fellow participants if they were to disclose something personal. Instead, they were met with encouragement and praise for being honest and open. When one participant acknowledged the strain that lymphedema had placed on his relationships and the difficulties surrounding sexual intimacy, a fellow participant responded by saying, "Good for you for bringing that up! It's not always discussed" (Female P, Fall Workshop). This allowed participants to be vulnerable, as they could expect to receive the same empathy and support that they and their fellow participants had already given to others within the workshop.

Using storytelling, humour, and self-disclosure. The facilitators made the therapy accessible to the average individual entering a workshop by interweaving stories and personal disclosure to illustrate points and express how to apply the various interventions to everyday life. By revealing personal stories pertaining to the various intervention strategies and using humour, often aimed at their own misfortune, the facilitators also made the therapy more memorable: "The depth that he goes into, the lessons learned out of them, you remember them" (Female P, Spring Workshop). The facilitators did not focus on their own position of expertise in comparison to the rest of the room, but instead presented themselves as fellow individuals learning to hope and cope with the challenges of life.

It's your method of, teaching us by, through stories that was very commendable it's not, you didn't tell us, you showed us, which is, and you gave us examples of people in adversity and here they are surviving and accomplishing and uh, it helps us to feel we can do all of that too. I know we are trying, because we all had to try to be here at this point in time, and but it reinforces that even if we were trying thinking, forgetting or forgetting, whatever, it reinforces that you know, you can, we can, we all can. (Female P, Spring Workshop)

Storytelling not only offered new information but also offered participants the opportunity to consider known information from a different perspective. One participant noted:

You brought us information in a way that was understandable and helped us get there. And probably, I think I've certainly heard a lot of what the things that you have pointed out, but you presented them in another way. Like, similar messages, but in a very important way through the storytelling, through you know, just the way you've done it. (Female P, Spring Workshop)

As facilitators called upon participants to share examples from their own life during the workshop, participants often chose to draw upon personal experiences, sometimes becoming emotionally vulnerable, to encourage those around them and to situate their hardships and

experiences in the light of a greater context. Just as the facilitators used storytelling, humour, and self-disclosure to create an open and safe environment, so did the participants. Humour allowed an alternate way to frame the very serious and real consequences of cancer and lymphedema.

Swimming is no longer easy. You need another boob to put in there! You just don't go and say, "I'm going to go swimming." All of a sudden you decide to go swimming, you say, "I forgot that boob at home!" [Laughter]. (Female P, Fall Workshop)

Though this experience had impacted the participant's life and had altered her access to an activity she had previously engaged in regularly, she chose to use the experience as a way to make the other participants comfortable and to see a negative situation through a lens of humour. Using humour allowed participants to discuss very emotional topics and experiences in a different light and helped to contribute to the creation of a safe and accepting space.

Fostering participant engagement and connections. The facilitators ensured that participants were not passive observers and listeners in the session but instead encouraged them to contribute and interact with each other. One technique to prompt this behaviour was to invite participants to contribute responses to other participants' questions, instead of having facilitators provide an immediate response or solution. For example, when one participant asked how to hope with a terminal illness, Facilitator 1 responded by saying, "Does anyone have any experience with this? Strategies that they've used? Or do you want me to just speak to it?" (Fall Workshop) The facilitator allowed room for participants to partake in active solution engagement and provide various strategies they have learned to deal with the impairments of lymphedema. Participants were apt to pass out any tips they had learned throughout their journey or any information they believed could benefit others in the group. By allowing unstructured conversations to emerge and by focusing much of the intervention on the discussion of personal examples from the participants, the facilitators enabled participants to relate to each other in ways that drew them together through their shared personal experiences. As one participant noted: "That's the power of a session like this, [...] that you're with people going through the same thing you are" (Female P, Fall Workshop).

Through the discussions prompted by the facilitators, participants shared common experiences across a wide range of topics. Sharing these common experiences normalized the various psychosocial impairments they had faced and helped create the safe space. As the workshop progressed, participants began to explain their experiences using words such as "we" when telling stories about lymphedema and the challenges they faced as a unified group of individuals with a common condition. "We've been through this. We've had a death sentence, but we survived it" (Female P, Fall Workshop).

The effectiveness of storytelling in the Living Hopefully with Lymphedema workshops supports previous findings that narrative communication can be an effective way to facilitate engagement and bonding, and help individuals find meaning in their experiences of chronic illness (Gucciardi, Jean-Pierre, Karam, & Sidani, 2016). Sharing personal experiences also did help our participants learn from each other how to manage and cope with their lymphedema, as was found by Heppner and colleagues (2009).

The existence of the safe space was vital to providing a therapeutic environment, and to the overall functioning of the workshop. The openness and supportiveness of facilitators and participants provided the foundation upon which the safe space was created. However, creating the safe space was only the beginning of the work for facilitators and a transition was evident in the codes that work also had to be done to maintain that safe space.

2. Maintaining the safe space. Once the safe space had been created, the facilitators were tasked with maintaining it for the duration of the workshop. Maintaining a safe space was accomplished through the facilitators' management of the workshop and the ways in which they meet the needs of the participants. This included soliciting feedback, modifying the workshop, and tactfully guiding the conversation forward as necessary.

Soliciting feedback. Facilitators regularly asked for feedback in regard to the structure, content, and style of the workshop, emphasizing that the participants' thoughts and opinions were important and even crucial for the success of the workshop. This helped maintain the safe space as it taught participants that if there was something threatening their personal safety within the workshop, they were encouraged to comment on it. Not only could they point out these threats, but they could see something being done about them as a result. This openness and encouragement of free expression allowed for participants to safely express their opinions about the workshop, even if they were framed in terms of disappointment.

I will say I'm, kind of expected to hear a little bit more on the physical from an occupational therapist, you know, like [...] occupational therapist deals more with the things you actually do and how to do them, and that's a piece that I heard from coming out today, is, it's how you move and that kind of thing. So I'm a little bit disappointed in that. (Female P, Spring Workshop)

The solicitation of feedback from participants throughout the workshop helped reinforce the safe space that had been created.

Modifying the workshop. Through the facilitators being responsive and accommodating requests made throughout the workshop, participants learned that their suggestions were valued and that the facilitators would work to meet their specific needs. In response to the comment presented from the participant in the spring workshop who wanted more from an occupational therapist, the facilitators arranged for a short presentation from the occupational therapist, adjusting the planned schedule as needed; the fall workshop was also revised before delivery to incorporate the requested content. In addition, the facilitators noted that the change and the request came from participants themselves:

So at the end of the last workshop a few of us stayed and we were chatting, you know, just sort of informally and I asked participants what else they wanted to do, and [Participant] mentioned that she wanted to hear more from the OT, and what she might do, so [Facilitator 3] has prepared just a little talk about what OTs do. (Facilitator 2, Spring Workshop)

By calling attention to ways the workshop was modified to meet the needs participants addressed, the facilitators were inviting others to voice their opinions, thus enabling the safe space to be maintained. The participant who wanted more information about occupational therapists also supported the safe space by stating, "I'm really glad that you got to explain [about OTs] today, and I'm really glad I asked" (Female P, Spring Workshop).

Guiding the conversation. Facilitators also maintained the safe space by sensitively managing the conversation when it got off topic or when they felt enough time had been spent on a particular topic. A balance had to be struck between allowing the participants to express the things that concerned them the most while still meeting the objectives of the workshop. One way this guidance was accomplished was by refocusing the participants when the

conversation strayed off track: “So that’s great! But back to the point” (Facilitator 2, Fall Workshop). This ensured that the workshop progressed through the various examples and exercises at an efficient pace: “So again, I don’t want to cut this short, you have some really great suggestions, but I want to get to some of the materials that we prepared for you” (Facilitator 2, Fall Workshop). This relates to the safe space that was nurtured throughout the workshop, as facilitators typically embraced the comments and feedback then would often use humour as a way to control the conversation without appearing harsh:

So, listen, I’m gonna be, speaking of tyranny, when it comes to the agenda after lunch, there will be a tyranny imposed. No, I’m just kidding [laughing]. But we will keep moving the needle along. (Facilitator 1, Fall Workshop)

The facilitators did not reprimand participants for getting off topic or taking too long to answer questions, but instead expressed the need to switch topics or move swiftly through the examples by making the participants laugh and turning the situation into a joke.

Participant: Oh, oh, oh, I guess I should write something down, eh?
Facilitator 1: Work first, chitter chatter second!
(Spring Workshop)

3. Protecting the safe space. Although participants helped create a safe space for their fellows by giving support, normalizing experiences, and partaking in solution engagement, at times they also threatened the safety of the environment and the ability of participants to benefit fully from the interventions. This occurred when participants disagreed with facilitators concerning the content of the therapy and the structure of the workshop, disagreed and invalidated the experience of fellow participants, and complained excessively about the lack of services available to lymphedema patients.

Disagreement with facilitators. Conflict and differences of opinion threatened the supportive environment and the trust that had been developed between facilitators and participants, and among the participant group as a whole. One participant disagreed with a facilitator’s specific viewpoint and resisted a particular intervention strategy, voicing disagreement on several occasions and attempting to undercut the effectiveness of the model when certain strategies or activities were suggested, despite facilitators explaining its effectiveness and the justification for using the specific technique.

I have a problem with this kind of cognitive behavioural model that’s the only one that’s ever researched, and therefore it’s the best. Because that’s the only research frame people are using. And it doesn’t mention the body, and there are so many more different therapies, like mindfulness and somatic experiencing.
(Female P, Fall Workshop)

The participant continued to offer criticism even after the facilitator explained that the cognitive aspect being discussed was only one of many that would be explored throughout the workshop, including the mindfulness piece.

Participant: I did mention that I found that script, sort of CBT model problematic, because it’s all focused on your thoughts. And there are variations of that that exist, you know, there’s a mindfulness based, cognitive behavioural therapy now [...].

Facilitator: Right. And there is a breathing exercise in your workbook, and you can find more breathing exercises online, you can find meditation CDs...

Participant: In terms of that presentation, I think it could be harmful for people that have cancer.

(Fall Workshop)

The dialogue continued with the participant diverting the conversation to their preferred approaches, despite the facilitator acknowledging the participant's point of view while pointing out that some of the other techniques were already part of the activities scheduled for later in the workshop. This undermined both the facilitators and the participants who had had positive experiences with the methods being disparaged. The conversation evolved into a lengthy digression on the risks and benefits of particular physical exercises, which the facilitator eventually was able to guide into an informative discussion rather than a disruptive one.

Invalidating the experiences of others. Some participants disagreed with each other to the extent that they were unable to agree to disagree, and instead ended up invalidating the opinions and experiences other participants were trying to share. This can hinder participants' willingness to be emotionally vulnerable and threaten the safe space that had been built and maintained. One specific disagreement that began with a conflict between a participant and a facilitator turned into a larger disagreement among many of the participants.

Participant 1: Okay, one thing you just said about hope... Okay, we're talking about, we were talking about someone who is terminal. Okay. They know they're not going to beat this. They can have as much whatever... there is no hope. Let's call a spade a spade.

Facilitator 1: There's no hope for what?

Participant 1: There's no hope for a cure. They are going to die. Okay. I had a girlfriend, who it will be two years Christmas day, who had a seizure, and she had brain cancer. She died in May. There was never any hope for her.

Participant 2: But you have hope to die peacefully...

Participant 1: Well this is what I'm getting at—

Participant 3: There are different kinds of hope.

Participant 1: [hostile tone] Just let me finish this, please, because this is one thing that I've learned. And I think it's something that a lot of people need to learn. There was never any hope.

(Fall Workshop)

In this conversation exploring the idea that there are many things to hope *for*, one participant was adamant that hope only meant hope of survival and would not consider anything else, including co-participants' experiences of hope. Not only did this conversation derail the progression of the workshop and undermine the purpose, but the disagreement also threatened the safe space as participants may not have been as willing to open up or share their opinions with the group for fear of being judged or causing another disagreement.

Excessive complaining. When participants would complain at length without any interference from facilitators, the safe space of the workshop was threatened. Although in some cases complaining allowed participants to bond over shared experiences, it also sometimes led to hostility among the participants, as not all frustrations were shared: "If you're not satisfied? Do something about it! You know? Don't just sit there bitching about it, just go do something! Or find out somebody else maybe could help you, or whatever" (Male P, Fall Workshop). In

summary, some participants noted the lack of services available for lymphedema and that not all treatment costs are covered by the public healthcare system, so although there was consensus that lymphedema patients experience challenges with respect to healthcare, some participants were also concerned that repeated discussion was unhelpful. When the comments become unproductive to learning about hope and coping, such as when the complaints are not about the workshop or are about topics the facilitators have no control over, the environment is threatened as the discussion loses focus and becomes ineffective. In those moments, instead of coping with the difficulties of lymphedema and finding hope amidst these struggles, participants were dwelling on their own frustrations. Having the group become mired in unproductive discussions interfered with and directly opposed the directive of the workshop, which was to teach hope-enhancing strategies. This is especially problematic since optimism has been found to aid in the process of transcendence, which provides a sense of meaning and purpose and allows for individuals to evaluate and prioritize hope amidst adverse environmental factors such as chronic illness (Duggleby et al., 2012). Having a positive outlook on life and accepting one's limitations has also been found to be an effective strategy for coping and decreasing the negative psychological and social impairments connected to the condition (Heppner et al., 2009).

Discussion

Throughout the Living Hopefully with Lymphedema workshops, facilitators and participants co-created a safe space in which to engage in therapy and worked together to maintain and protect that safe space. The use of an interpretive description design allowed us to discern the often-intertwined roles and contributions of participants and facilitators in these processes throughout the intervention. Because interpretive description incorporates qualitative approaches from a variety of disciplines, it was ideally suited to analyzing these types of complex relationships and experiences (Thorne et al., 2004). Furthermore, interpretive description allows for the study of process and context, which is well-suited to fulfilling our goal of capturing the "how" of a workshop. This research is unique in that we are investigating the ways in which desirable intervention outcomes are achieved, rather than focusing solely on what the outcomes were.

Facilitation/Management

The key aspects of facilitation in the Living Hopefully with Lymphedema workshops were (1) being accessible, (2) fostering participant engagement, and (3) being responsive to participant feedback and needs. Facilitators were honest and accepting with each other and with the participants; they modelled open and supportive behaviour that helped create the safe space for participants to engage in therapeutic activity. They used storytelling, humour, and self-disclosure to make therapy more accessible and memorable, also making it more likely that participants would take the lessons home and apply them. One important way that facilitators demonstrated all three aspects at once was by soliciting honest feedback and modifying the workshop according to participants' responses.

Participant Response

Participant response to the workshop was overall very positive. They were particularly receptive to therapeutic intervention through storytelling, humour, and self-disclosure, from facilitators and from other participants. The stories helped make the lessons memorable and place the facilitators in a more accessible, friendly position as opposed to feeling as if they

were raised up as experts. When participants engaged in this type of sharing with each other, it normalized their experiences, and the support and encouragement they gave and received helped the group bond over their common experiences and create an atmosphere of “we” and “us” that reinforced the safe space. Participants noticed when facilitators modified the workshop in direct response to participant feedback and were pleased that they could share their needs and have them met.

Recommendations for Workshop Development

Workshop designers and facilitators should be aware of the problems identified herein and establish how they will be addressed prior to future workshop development. Strategies to manage issues should be in place before they arise so that facilitators are better prepared to deal with or diffuse them. In particular, facilitators need training and tools to handle hostile or aggressive situations, techniques to redirect or reframe the conversation when participants invalidate the experiences of others, and to anticipate complaining and be able to identify when it stops being a method of group bonding and becomes detrimental to the experience.

Facilitators could manage participants’ disagreement with their strategies or with the workshop by strategically marking when to ask for feedback. Solicitation of feedback can be presented in a constructive light, providing an avenue for participants to disagree with facilitators in a constructive way that does not threaten the environment. To manage situations where participants invalidate the experiences of others, facilitators could avoid being drawn into disagreements, and encourage participants to respectfully acknowledge that others have different perspectives without invalidating them. They could also consider using these situations as an opportunity to discuss how individual experiences help shape differing perspectives (Krueger, 1998). Finally, facilitators could manage the excessive complaining by controlling the conversation in a way that allowed for participants to normalize their experience and bond over their shared frustrations, while minimizing the possibility of creating a negative and hostile environment. For instance, this could have been accomplished by prompting participants to once again partake in solution-focused activities. Since complaining in some instances did allow for participants to bond over shared experiences, it is suggested that further workshops anticipate complaining to a greater extent and incorporate any issues or complaints into exercises within the workshop to maximize the positive aspects gleaned from complaining while still protecting the safe space.

Designers and facilitators should build flexibility into the workshop wherever possible, structuring them so the format can accommodate changes based on participant feedback and needs. This was an important component of the Living Hopefully with Lymphedema workshops, as it allowed participants to tell facilitators what they needed from the experience, and when facilitators made the effort to meet those needs, it contributed to building the trust that is so vital to the therapeutic experience.

Limitations

Our findings regarding what helps and hinders the therapeutic process of a workshop or intervention were based on a sample of cancer survivors with secondary lymphedema and may not be transferable to workshops focusing on other conditions. In addition, the participants of the Living Hopefully with Lymphedema workshops were primarily Canadians of European descent; individuals from non-Western sociocultural groups may not respond the same way to the techniques identified in this study. The majority of participants were women, so the experiences of men may not be fully represented in this study. Finally, participants self-selected into the study, potentially creating a bias for individuals in greater need of an intervention, and,

conversely, for individuals physically and mentally well enough to attend. We acknowledge these limitations and hope that future studies will be better situated to explore how these findings might be applied in different contexts (see Campbell et al., 2007).

Conclusion

Setting the stage for a safe space was a crucial element to the success of this workshop. The safe space was co-created by facilitators and participants through the use of storytelling, humour, and self-disclosure; and by modelling open and supportive behaviour in their interactions. Successful facilitation involved being accessible, soliciting feedback, and responding to participant needs. Overall, participants responded positively to the workshop, supporting each other and bonding as a group over shared experiences. It is recommended that future workshop designs incorporate strategies to manage antagonistic or disrespectful situations and unproductive complaining.

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This research was funded in part by a New Brunswick Health Research Foundation Bridge Grant. This research was undertaken, in part, thanks to funding from the Canada Research Chairs program.

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Article Citation

Hamilton, R., Thomas, R., Anisimowicz, Y., Piers, M., & Matte, R. (2018). A critical analysis of the delivery of a psychosocial workshop for cancer survivors with lymphedema. *The Qualitative Report*, 23(10), 2586-2602. Retrieved from <https://nsuworks.nova.edu/tqr/vol23/iss10/20>
