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Composing hope through collage: A community-based intervention for cancer survivors living with lymphedema

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Abstract

Secondary lymphedema after cancer may result in distress, yet few interventions exist to support coping skills in this population. As part of a community-based intervention, we piloted the use of creative practices to promote active orientations to hope. A total of 19 participants completed the workshops; 11 collaged. The main themes address the collage processes as well as their content. The former addresses sub-themes such as selecting/composing. The latter includes sub-themes related to movement depicted in the collages. Collages and their associated discussions concretized hoping as an active and accessible process for participants living with two chronic illnesses.

Keywords

cancer, chronic illness, collage, distress, intervention

Introduction

Lymphedema is a chronic condition which cannot be cured. It commonly involves the swelling of one or more limbs. In North America, secondary lymphedema is most often associated with cancer and/or its treatments. In such cases, damage to the lymphatic vessels and/or nodes is a result of surgery or radiotherapy. Management involves compression using garments and/or bandaging, as well as manual lymph drainage. The swelling associated with lymphedema often results in pain and discomfort as well as physical and psychological morbidity (Lymphedema Framework, 2006).

International lymphedema best practice guidelines, along with recent systematic reviews, demonstrate that ensuing effects include functional impairment, as well as depression, anxiety, low self-esteem, and negative body image (Fu et al., 2013). Lymphedema also has implications for social domains, including problems within sexual, family, and other relationships, as well as paid and unpaid work, and leisure activities (Miedema et al., 2011). A lack of lymphedema awareness among health professionals often delays diagnosis and treatment, compounding the psychosocial impact ((Thomas and Hamilton, 2014)). Those who are living with lymphedema also face additional challenges related to cancer, an illness that is often associated with distress (Silver and Gilchrist, 2011). Since few psychosocial interventions have been developed for cancer survivors with lymphedema, individuals are ill-equipped to address the many issues that will be faced while living with two chronic illnesses.

Within cancer populations, hope-based interventions offer some promise (Duggleby et al., 2007; Herth, 2000; Rustoen et al., 1998). Hope is commonly defined as a "multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which to the hoping person is realistically possible and personally significant." (Dufault and Martocchio, 1985: 380). Hope can strengthen problem-solving skills and may help individuals cope with suffering (Rustoen et al., 1998). Previous literature has shown that hope can lessen despair and physical decline, while contributing to positive orientations to the future (Angell et al., 2003; Björneklett et al., 2012; Carmack et al., 2011; Duggleby et al., 2010a, 2010b, 2011; Fenlon and Foster, 2009; Herth, 1990, 1993; Oliffe et al., 2011; Sullivan, 1992), which may be complicated by chronic illnesses. Furthermore, the concept of hope is readily understood, used by both men and women, and has been

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shown to be enhanced with interventions (Duggleby et al., 2010a, 2010b, 2011).

Drawing on the work of Eliott and Olver (2007), our research conceptualizes hope as a verb or actions (Hamilton and Thomas, 2015). Experiencing hope as a verb (i.e. creating hope rather than viewing it as an external resource) involves orientation toward optimistic possibilities. Hoping can foster social engagement, a concentration on what is positive, and may enable individuals to improve quality of life while living with chronic or life-threatening conditions (Eliott and Olver, 2007). Similarly, others note that hope may incorporate "goals, pathways, and agency" (Snyder et al., 2005). Active conceptualizations of hope may therefore support those who are living with lymphedema, a condition in which symptoms may improve or worsen and during which hope can be expected to ebb and flow. There is also evidence that hoping during acute cancer care may need to be renegotiated when facing lymphedema post-treatment as the former is perceived as having an end, while the latter is incurable (Hamilton and Thomas, 2015). Health professionals may be able to provide support for this renegotiation process by orienting patients to hoping in order to move beyond hope as an object/noun. Indeed, leading hope scholars urge health professionals to consider how they might support expressions of hope throughout various illness trajectories (Eliott and Olver, 2009).

The overall purpose of our study was to test a hope-based intervention for men and women living with upper or lower limb lymphedema after cancer. Herth's hope intervention served as the basis for group workshops, but our approach was also consistent with established approaches to supportive care in chronic illnesses and lymphedema international best practice guidelines (Benzein and Berg, 2005; Cormier et al., 2010; Donavan et al., 2002; McDaniel and Rhodes, 1998; Patel, 1996; Roberts et al., 1992; Scherzer et al., 2001; Thomas-MacLean et al., 2008; Zaza et al., 2005). Our program followed Herth's theoretical foundations and goals (e.g. identifying support systems), while drawing upon coping enhancement techniques, such as cognitive reframing, problem-solving, and mindfulness (Beck, 1995; Benzein and Berg, 2005; Donavan et al., 2002; Hamilton et al., 2011; McDaniel and Rhodes, 1998; Moorey and Greer, 1989; Patel, 1996; Scherzer et al., 2001; Zaza et al., 2005). However, specific activities/content were developed and adapted in order to support participants in their efforts to create and foster hope. For instance, we included a return-to-work session led by an occupational therapist. As another example, we offered participants a choice of two creative practices—reflective writing and collage—to help them document and share their experiences. This component is grounded in a wide body of literature that has established the benefits of art-making for those with cancer (Collie et al., 2006; Lanceley et al., 2011; Rieger and Schultz, 2014). In this article, we focus on participants' creation and discussion of their collages.

Method

While this was a mixed methods pilot study of an intervention, our focus here is on the qualitative data. We used an interpretive description (Thorne, 2008) approach for the collection and analysis of these data which consisted of audio recordings of the workshops, as well as photographs of participants' collages, responses to open-ended questions on workshop evaluation forms, and notes from follow-up telephone interviews that were conducted after the workshops concluded.

Participants

Participants were recruited through posters displayed at a regional cancer survivorship center and a private physiotherapy clinic, a researcher's website, and word of mouth. Our intervention (i.e. workshops) was delivered to two separate groups in the Spring and Fall of 2013 in an urban center in Ontario, Canada. Each of the two workshop series occurred over three Saturdays. Workshops were scheduled 2 weeks apart during a 4-week period (i.e. every other Saturday). A total of 19 participants (16 women and three men) with either upper or lower limb lymphedema completed the workshops. The types of cancer represented were breast, prostate, melanoma, colorectal, and lymphoma. Participants had been living with lymphedema from 1–21 years. Ethics approval was obtained from the Research Ethics Board associated with the University of Ottawa.

Data analysis

Each workshop was audio-taped and sound files were then transcribed verbatim. Participants were invited to complete creative projects—either reflective writing or collage. Sixteen of the 19 participants completed and presented their creative projects at the workshops. Eleven women created and discussed a collage. Using a digital camera, several photographs of each participant's collage were taken. The photographs were then inserted into the transcripts at the points where they were being discussed. Workshop evaluations and interview notes were also transcribed. All transcripts and photographs were analyzed using NVivo 10.

A broad coding of hard copies of the workshop transcripts was followed by the development of a preliminary coding framework within NVivo 10. Each transcript was then coded line by line to further refine the themes and to develop analytical specificity. Nodes were then reviewed to identify overlap and generate comparisons to synthesize the data. We followed the same process in order to interpret the interview notes and comments provided in response to the open-ended questions from the workshop evaluations. Our process of verification was similar to the one described by Collie et al. (2006) which involves "theoretical thinking," establishing coherence with the research question, iterative

analysis, and revision of categories (p. 764). While workshop transcripts were not shared with participants, due to the length of the transcripts (~120 pages of single spaced text per workshop series), participants were invited to provide feedback on our analyses at a presentation. Nine of the participants attended this session and indicated the findings were congruent with their experiences. The response to the presentation was positive: there were neither any participants who disagreed with the themes presented nor were there any who indicated that the findings should be modified.

Results

The main nodes associated with the visual data address the overlapping themes of the *processes* connected to collaging and the *content* of the participants' work. The former addresses participants' discussions of *creating* which involved brainstorming, selecting images, and composition, and connecting the creation of collages to experiences of illness and hope. A second sub-theme associated with process addresses the *sharing* of each participant's collage and responses from the group. The second major theme (content) integrates sub-themes related to movement or progress depicted in the collages, reflecting a conceptualization of hope as action. The sub-themes related to the content of participants' work are: *beginning/reflecting backward*—to the diagnosis of cancer, its treatment, and the onset of lymphedema; and *fostering hope/future orientations*. Both the collage processes and content of the collages supported the expression of negative experiences, but also bolstered the visualization and concretization of hoping as an active process in which they could engage.

Process of collaging

Creating. Many of the participants initially approached collaging with some hesitation and trepidation. Visual arts activities were not generally a part of their everyday lives, as Shelley[1] noted: "Okay, I'm not an artsy person. Really, I didn't know what collage was. I decided to give this a shot, because I'd already written a couple of stories about my journey." From trepidation, participants moved toward a more positive orientation to the process:

> I really enjoyed making the collage. It was very therapeutic … Just to pull those pieces out and recognize them. The collage almost becomes an object of hope. It's really taking stock of "This is what lymphedema is and this is where I'm at, and this is what I'm looking forward to, what I want to work on." All of those pieces can come out in that one little page. (Jennifer)

In contrast to most of the other participants, Claudette had some experience with collage (Figure 1):



Figure 1. Respecting the process.

> I've done some collages at home because I've taken some classes on creative journaling … I knew what the process was. And I tried to respect the process. Not to make it pretty but to just to make it therapeutic. So all the pictures we grabbed last week, I tried to stick to those pictures, because that's the idea, is you know when you pick pictures you don't know why you're picking them, you just pick at them, you don't over think it. So I went home, and I had about 50 pictures.

Claudette was also more focused on the process than she was on the product. She continued,

> I started by just sifting through the magazines and pictures, like, "yes, no, yes, no." I'm going to keep some, and others, you don't know yet. And the fun is when you have all the pictures there, they're just a jumble, and then you just sit back and you just play with them … I think that the process is much more fun than the actual result. Because you feel good after. (Claudette)

Shelley expressed a similar response to the process, but with the added reflection about what the collage itself meant: "And every picture just hit me! Like it meant something from my journey." Similarly, Shadia drew connections between the process of collaging and its outcome:

> 'For an artist to see a living canvas, every day is incredible.'[2] So it is also incredible for us to see where we were and where we're at now, and what we went through. It's amazing. We've achieved something, and we did it. You know?

Another participant (Marie) wrote in her workshop evaluation that all future workshop participants should be encouraged to complete a collage, since "a picture is worth a thousand words." There was then widespread recognition of the value of collecting and sorting through images and their ability to convey experiences and emotions.



Figure 2. Words in white are background.

Nonetheless, there was also a general sense that pictures and the words/texts cut from magazines would not adequately express participants' experiences and reflections. Many of the participants added handwritten words to their collages. For example, Jennifer said that she wanted to direct attention to certain words (Figure 2):

> My idea was the white words fade a little more into the background, but they are always there. Lymphedema, cancer, pain, this is what life has become. Yeah, that's kind of always there. But these [words in black] are the more important things—to believe and to dream and to love and friends and 'enjoy every second' is in the centre of it all.

In summary, although a few participants approached collaging with some hesitation, they all conveyed positive benefits of the process and the outcome, with some placing more emphasis on the former.

Sharing and responding

All but one of the participants were willing to share their collage with the group. Individually, participants valued the opportunity to discuss their own thoughts and experiences. For example, one participant who described herself as being very introverted said,

> I've learned a lot. This was for me a big experience of learning many things. First, me talking about myself (laughs) and my emotions and sharing—that's new, actually. Because I keep things to myself. I don't share. I am very private with my life, but I just really felt comfortable around everybody, enough to talk, and express and say what I wanted to say.[3]

Other responses to the collage sharing were documented in the written workshop evaluations. In response to a question about which of the workshop components were the most valued, several participants mentioned the sharing of the collages. For example, one participant wrote: "Being able to share my reflections and photos was appreciated" (Bridget). Collaging provided participants with an opportunity to express their individual experiences, but the activity also benefited participants as they were able to learn from others.

The same participant who appreciated being able to share her experiences and reflections through collage also noted that there were benefits to listening to others discuss theirs: "Seeing and hearing the explanations and images created by others in the group was very helpful and inspiring" (Bridget). Similarly, another participant noted: "I appreciate the opportunity to work with a group of people with more or less the same problem, and getting to know their feelings and coping measures which will help me going forward" (Hannah). Responses to another workshop evaluation question about what was learned also revealed an added benefit of the collage discussions, namely a decreased sense of isolation. One participant noted that she learned: "I am not alone." Thus, the sharing of the collages then extended the benefits of the creative process to the group as a whole.

Observations about the benefits of sharing were not limited to the workshop evaluations, however. During one of the collage discussions, one participant said: "We are all in the same boat, right?" Another participant said,

> What I'm taking with me, is everyone's sharing their stories. They really meant something to me and the hope that maybe hope is there, but I never think about it. I don't lose hope, but I don't think about it this much.

Sharing the collages also provided opportunities for the group to provide feedback and support. For example, one participant mentioned gardening and limitations associated with this activity during her collage discussion. Another participant responded,

> I may have a solution for you … I got rid of all my flowerbeds in the back, and I had five of them. And what I did was replace them with big pots. So you never have to work hard. You just put them in, put them out, and it's very decorative. It's very nice and a lot less work. I love my pots. So, this I'm able to maintain, but it's been modified a lot.

Participants' suggestions for coping extended beyond functional limitations and provided openings for participants to discuss hope. While discussing her collage and the ways that it illustrated lymphedema experiences, one participant said: "Some days it's not half bad. You know, I think there's a lot worse that can happen." Another participant responded to this statement with a comment about being in "denial." The first participant corrected her:



Figure 3. Under the microscope.

> Well, no. I've seen worse working in a hospital where there's a lot of dramatic things. So you know, through all that. You start on your journey, you know. On the journey, there are these people in the desert. It's hard. It's a difficult environment, but you're going someplace. You're going on an adventure. You're in it and you're just moving ahead. So you learn more about stuff that I would never have learned about had I not had this. You know, it's a growth experience.

To summarize, the sharing of the collages provided opportunities for participants to discuss their experiences and reflections, while affording the realization that they were not alone in their experiences. The collages also fostered discussions of coping strategies to address the limitations associated with lymphedema as well as opportunities to reframe negative experiences.

Content

Along with discussing the processes of initiating and completing their collages, participants also spoke about the content of their collages which has been captured in two themes—Beginning/reflecting backward and Fostering hope/future orientations.

Beginning/reflecting backward

Several participants glued together more than one background piece of poster board in order to create collages with multiple panels (Figure 1). For these participants, each piece represented a phase of illness and provided an overarching narrative structure to the visual elements. For instance, Shelley shared her collage from left to right to correspond with the timing of her cancer diagnosis and to progress toward the present. In her first panel, she used an image of a woman with her hand held to her mouth, along with images of a microscope and binoculars to convey the following ideas about her cancer diagnosis: "So this is basically me questioning, you know, something is not right. Then you get the news, you're under the microscope, they're doing all the testing." (Figure 3) As she moved from left to right in her collage, she explained that she saw her experiences with illness in phases, referring to the image of a watch: "You see time here … The exploration, you're looking into everything, support groups, yoga, the deep breathing, visualization, healing tapes, all this. The 'discovery stage'. I call this the discovery stage."

Similarly, Claudette's collage incorporated panels with the first one on the left marking her cancer diagnosis as well:

> You start on your journey, you know. On the journey, these people in the desert, it's hard, it's a difficult environment, but you're going someplace. You're going on an adventure, you're in it for the horizon and you're just moving ahead. So you learn more about stuff that I would never have learned about had I not had this. You know, it's a growth experience. There's inspiration through that. So this is the start, and this is the direction I'm going.

In contrast to the collages described above, Marie's first panel was in (Figure 4) the shape of the sun and she indicated that she began her collage in a time of well-being that she experienced prior to her diagnosis: "This is my sun. This is my before life [before cancer] … I was very active, working full time. I did volunteer work at the hospital. I did a lot of things." After sharing experiences of her life before cancer, Marie discussed diagnosis and treatment and the ways in which these were represented by a narrow, middle panel (arrow shape) in her collage: "There's

a tunnel there." Marie continued: "I'm going to make it through. So then, of course, you go 'home again.' But to me, it was like crossing a bridge."

While participants reflected back to the time of their cancer diagnoses through the use of multiple panels, they shared other dimensions of those experiences through the use of color and images (Figure 5). Shadia said: "The pink [panel] represents my cancer. I went through that almost alone, like it was so difficult and this is the part [left side] where—I'll call it the darkness, the hard time." Shadia indicated that she had glued the black, green, and pink panels over other images. She said she started with images of

> a broken car and a good car and that was how I felt. I was in a good condition, then I was broken, and I'm working on my way to be better. So the second time when I worked on my collage, I said: Um, now, I'm not sure this is what I want.

Shadia said she replaced the image of the broken car with ones that she felt were more positive, but she retained the black panel to represent a dark time.

Another participant Carolyn also used dark images to convey her experiences, but she also used the overall structure of the collage to convey her experiences. Carolyn found it challenging to discuss her collage, one of only two that were three dimensional: "I went through the travel things. It's a bit of a dark bird. And these are more colorful birds. So what I was gonna do with this? It becomes like a handbasket to hang the birds from right?" (Figure 6) Later, Carolyn said her collage also represented feelings of "going to hell in a handbasket" that she associated with cancer and lymphedema.

Thus, several participants' collages captured the idea of a starting point or disruption, around the time of their cancer diagnoses. Participants used separate panels, as well as darker images, to depict the ways in which they reflected backward upon cancer experiences, while transitioning toward a discussion of present and future spaces in which they could create and maintain hope as they faced the challenges associated with chronic illness.



Figure 4. Crossing a bridge.



Figure 5. I was broken.



Figure 6. To hell in a handbasket.

Fostering hope/future orientations

The second theme related to the content of the collages contains ideas about transitions to cancer survivorship and learning to live with lymphedema. As shown previously, Claudette's collage and discussion began with a dark blue panel and her diagnosis. She later continued,

> So, it's yellow [right panel] (Figure 7). It's already better. 'Get your good going,' I like this phrase, because it's sort of talking about some of the affirmations, you know. You have to think, "I will succeed. Things will happen, but it'll be okay." So you have that in mind. There's a fortress here, or a house, I don't know what it is … at first I thought it was a lighthouse, but then I realized it's a fortress. Both are okay, because both are beneficial. So, through this, I've developed this treasure chest of nutrition talks, you know … And I have taken other workshops on improving your diet, on becoming more Zen, on doing some self-hypnosis, and mediating, and creative journaling. All these tools are in my treasure chest.

Claudette's use of the image of a treasure chest reflects her awareness of various coping skills or ways of maintaining hope that she has developed. Claudette continued her discussion of her (Figure 8) collage:

> I won! I've got the triumph, I've won, my 'wish' was 'granted.' This lady, if you look closely, she's got stitches everywhere. So she's like a rag doll that's put together, and some of them are around the breast. I thought, "Oh, this is good!" She's all mixed up and decked out and all dressed up and all fixed up and coloured up, you know, so she's victorious. So you know, life is fabulous and this was quite an experience. Through the pavement that I hit earlier, there's a flower that comes out and you know, life goes on.



Figure 7. It will be okay.

> So this lady is victorious, you know, like now what? There's a "second act," this is my future, and the arrow is going towards that …

Rana expressed similar ideas about transitions while discussing her collage: "We've all been through hell and back and here we are." She explained: "I started out with this flower and I said: How beautiful it is! It gives the thought of how beautiful life can be."

As with the participants' reflections backward, consideration of a more hopeful present and future was not only reflected in the structure or composition of the collages, but in the images used. Carolyn discussed her "hell in a handbasket collage" further:



Figure 8. Stitched but victorious.

> I've got sayings on dreaming. Pictures of your beach, 'find your beach.' A lot of things with birds. Also little, uh, little helpful sayings [laughs]. There's always hope, right? … Every year for me in the summertime, the lymphedema is horrible, but that's alright, life is good, and sometimes the leg is swollen so [laughs] … I don't know, but my collage has lots to do with birds and flying and spreading your wings and being in a good place.

Shadia who used black paper to convey negative experiences, also used color and images to convey hope:

> And the green is for hope, and life and 'mile end' is here to continue with, with my new life. A very important thing that I've learned is, love yourself. That is a big major thing … What we're going through here, actually made me think: "Okay, is this what I want? No. I, I really want to be positive."

She continued: "And this sentence really meant something to me: 'Distracted drivers are out and smart is in'. And this is when you make the right decisions." Shadia explained that she had been reluctant to disclose she had lymphedema and that one of her "right decisions" was to explain it to people and to talk openly about experiencing cancer.

In summary, participants' collages used composition and content to convey movement from past to present. Participants used dark/light images and panels, and most provided a narrative or temporal structure, to express their experiences of transitions from cancer diagnoses to a more hopeful present/future while incorporating discussions of the realities of living with lymphedema.

Discussion

While our previous research with men and women living with lymphedema after cancer shows that hope is a relevant concept, there are gaps in research on the development and implementation of hope interventions with this population. Participants in our study demonstrated experiences of loss and distress associated with the diagnosis of cancer and subsequent diagnoses of lymphedema, but the movement in collages demonstrates participants' attempts and abilities to alleviate some of the impacts of chronic illness while orienting positively to the future.

Hoping (hope as a verb) is an active process, not unlike the creative process associated with making a collage. Both require "intention." As one participant noted, she considered what she wanted to "work on." Participants also used words such as "process" and "transition" to describe collaging: these words and ideas are inherent to active conceptualizations of hope (Eliott and Olver, 2009; Hamilton and Thomas, 2015). In addition, within participants' accounts of the collaging process, there is evidence that they were actively orienting toward hope in order to create "an object of hope." While mention of an object of hope implies that hope was considered a noun, discussions of the creative practices associated with the collages indicate that participants viewed themselves as active creators of their work, and by extension, actively hoping.

With respect to the process, the collages also provided an opportunity and materials to prompt consideration of the past within the safe space of community-based workshops. At the same time, collaging prompted an orientation toward optimistic possibilities that also considered the realities of lymphedema self-management. Collaging and the sharing of the collages assisted with the development of coping strategies (e.g. adjustments to the leisure activities, such as gardening were shared) and the future-directed aspects of hope.

Hoping can foster a concentration on what is positive—the hands-on aspect of collage-making seemed to facilitate this focus, or at least some awareness that one can transition to hope, as conveyed by the composition of the collages. For instance, this transition was conveyed by one participant's reflection that there were worse experiences than cancer and lymphedema and that this was not evidence of denial. The awareness of the potential to transition to active hoping was also reflected in Shadia's editing of her collage from a focus on elements she felt were too negative to a collage that incorporated both negative and positive elements. This coincided with her decision to disclose her status as someone living with lymphedema and someone who had experienced cancer.

While this study illustrates the potential for a collage to foster an active orientation to hope, our research does have some limitations. Few men participated in the project as a whole and none of them chose to complete the collage activity. Further research is needed to determine whether or not a collage could be a meaningful way to engage men in hope interventions. The sample was also rather homogeneous, with most of the women reflecting dominant social

categories (e.g. completed post-secondary education). However, with its emphasis on images, a collage may be a suitable approach to engaging participants in hope interventions as a high level of literacy is not essential.

Our findings demonstrate that a collage, a low cost and accessible intervention component, shows promise in fostering hope for those living with chronic illnesses. In contrast, passive patient education may not provide those living with cancer and lymphedema with the same opportunities to identify sources of hope, hopeful activities, and positive orientations to the present and future. Participants' reflections on both the process and content of collages prompted discussions of numerous facets of hope and coping. Thus, our study shows that collaging is congruent with active and empowering orientations found within the existing hope literature and that future exploration of its potential impact is warranted.

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Notes

1. All participants were assigned pseudonyms.
2. Quotations from the collages (i.e. words that were selected and pasted onto the collage) are captured in single quotation marks to distinguish them from participants' own words as they discussed the collages.
3. As is common with focus group research, participants were not identifiable within the recordings of group discussions. Therefore, no pseudonyms/names appear in data excerpts from group discussions.

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