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Survivors' experiences of return to work following cancer: A photovoice study

Expériences vécues par des survivantes à un cancer face à leur retour au travail : Une étude photovoice

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Key words: Cancer survivorship; Neoplasms; Return to work; Vocational rehabilitation; Work reintegration.

Mots clés : néoplasmes; réadaptation professionnelle; réintégration au travail; retour au travail; survie au cancer.

Abstract

Background. For many working-age cancer survivors, return to work represents a quality-of-life indicator. However, there is currently a lack of resources to assist survivors with navigating this process. **Purpose.** As a first step toward informing resources to address this gap, 10 female survivors' return-to-work experiences were explored. **Method.** Photovoice methods were combined with interviews. Photographs and text were analyzed to identify key themes. **Findings.** Return to work was psychosocially motivated. Survivors independently decided if they would take leave and, if so, when they would return to work. Successful work reintegration was characterized as respectful, collaborative, and customized to each survivor's ongoing limitations and variable recovery. **Implications.** The findings underscore a holistic, client-centred, and collaborative approach to successful return to work with cancer survivors. Occupational therapists, with their vocational rehabilitation knowledge and responsive practice philosophy, are well positioned to address this gap in survivorship support.

Abrégé

Description. Pour de nombreuses personnes en âge de travailler ayant survécu à un cancer, le retour au travail représente un indicateur de la qualité de vie. Cependant, on constate actuellement un manque de ressources pour accompagner les survivants tout au long de ce processus. **But.** Dans une première étape visant à orienter les ressources en vue d'aborder cette lacune, les expériences vécues par 10 survivantes face à leur retour au travail ont été explorées. **Méthodologie.** Des méthodes photovoice ont été combinées à des entrevues, puis des photographies et des textes ont été analysés en vue de dégager les principaux thèmes. **Résultats.** Le retour au travail a été influencé par des facteurs psychosociaux. Les survivantes avaient décidé de manière autonome si elles souhaitaient s'absenter du travail, et si c'était le cas, elles aussi avaient décidé du moment où elles retourneraient au travail. La réintégration au travail réussie était décrite comme étant respectueuse, axée sur la collaboration et adaptée aux limitations et au rythme de rétablissement variable de chaque survivante. **Conséquences.** Les résultats mettent en évidence l'importance d'offrir une approche globale, collaborative et centrée sur la personne pour favoriser la réintégration au travail des survivants d'un cancer. Compte tenu de leurs connaissances sur la réadaptation professionnelle et de leur philosophie de la pratique adaptée aux besoins de la personne, les ergothérapeutes sont dans une position idéale pour aborder le manque de soutien aux survivants d'un cancer.

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Although the Canadian Cancer Society (2013) estimates that two in every five Canadians will be diagnosed with cancer during their lifetime; currently 63% will survive at least 5 years following diagnosis. There are even higher 5-year survivorship rates in the most prevalent forms of cancer, including 88% for women diagnosed with breast cancer and 96% for men diagnosed with prostate cancer (Canadian Cancer Society, 2013). For people under 65 years of age, an indicator of working age, the overall survival rate is 70% (Neary, 2011). As a result, attention is now turning to issues inherent to surviving cancer and its associated treatment.

Cancer survivorship is now recognized as a chronic condition with physical (e.g., fatigue, pain), emotional (e.g., depression, distress), and cognitive (e.g., impaired memory, concentration) implications that impact survivors' quality of life (Sesto & Simmonds, 2011; Sullivan, Simmonds, Butler, Shalliwani, & Hamidzadeh, 2011; Veramonti & Meyers, 2011). For many working-age cancer survivors, the ability and choice to return to work (RTW) "is [about] much more than paid employment" (Wells et al., 2013, p. 1210). Employment offers a normalizing structure, social identity, financial security, a sense of productivity, and fulfillment (Maytal & Peteet, 2011). Wells et al. (2013) recently developed a heuristic model that draws these interrelated and dynamic considerations together into a four-element model describing the experience of work following cancer: self-identity (e.g., sense of former self, ability, appearance), meaning and significance of work (e.g., structure, sense of purpose, distraction from illness), family and financial context (e.g., financial necessity, health benefits), and work performance and environment (e.g., organizational and interpersonal support).

Statistics show that many cancer survivors who wish to RTW are able to manage the return. For example, in their review across heterogeneous cancers, Spelten, Sprangers, and Verbeek (2002) found a mean RTW rate of 62%, ranging between 30% and 93%. Statistics, however, do not tell the whole story. In the face of chronic disease and treatment sequellae, survivors experience trepidation with diagnosis disclosure, altered appearance, work performance, and possible job loss (Tiedtke, de Rijk, Dierckx de Casterlé, Christiaens, & Donceel, 2010). Furthermore, most survivors report having to navigate decisions regarding work (e.g., working through treatment versus taking leave, when to return) in a void of advice from health care professionals (Nitkin, Parkinson, & Schultz, 2011; Wells et al., 2013). Verbeek, de Boer, and Taskila (2011) suggest that some survivors are off work unnecessarily. Thus, they encourage health care providers to enter into a conversation with the patient to determine the value of work to the patient's identity and normalcy; financial implications of being off work; emotional, cognitive, and physical demands of the patient's work tasks; and nature of the relationship with the supervisor.

In addition to limited advice from health care providers, existing specific support programs designed to facilitate survivors' RTW are sparse, available only once treatment has been completed, and focused upon RTW to the exclusion of work maintenance (Canadian Partnership Against Cancer [The Partnership], 2012a). Consequently, survivors are commonly left to navigate their RTW independently. Many experience apprehension due to lost confidence and fear of disappointing others (Tiedtke et al., 2010). Employers have also expressed related trepidation. For example, employers have expressed concern about survivors' level of productivity, their own lack of knowledge regarding management of chronic health conditions, and the need for support in establishing appropriate workplace accommodations (Amir, Strauser, & Chan, 2011).

The inadequacy of advice and programs can be explained by the gaps in research on work following cancer. While studies have demonstrated that survivors are more likely to RTW if they are younger, have higher education, are male, have less physical demands, and have an employer willing to provide accommodations (Mehnert, 2011), the process of returning and maintaining work is not fully understood. There is a need to improve the evidence base for the guidance and evaluation of interventions to support survivors' RTW. In fact, The Partnership (2012b) outlined the need to develop more robust accommodation strategies for cancer survivors' work reintegration and the need to focus past the initial return to include work maintenance. They further recommend pilot projects to test interventions that involve all stakeholders, including survivors, health care professionals, and employers.

Purpose of Study

As the first step in a larger research portfolio, this current study endeavours to elucidate, in a provocative manner, the lived experiences of cancer survivors related to both their work return and maintenance. Photovoice methods allowed participants to communicate their idiosyncratic experiences of RTW and work maintenance through powerful images intended to destabilize. The overarching goals of photovoice, a participatory action research methodology, are to emancipate participants and influence policies by raising consciousness (Wang, 1999; Wang, Burris, & Ping, 1996), both ultimate objectives of the current portfolio of research. In this case, images reflective of survivors' experiences of work after cancer are combined with narrative descriptions to provide intriguing case-based examples often reflective of themes previously identified in existing literature. The unique contribution of this study is the combination of images and words that contextualize each other in forming different representations than either alone can accomplish (Pink, 2007). The findings informed the development of vignettes to be used in future stages of related inquiry.

Method

As an occupational therapist with two decades of experience helping injured individuals with their vocational return, an appreciation has been gleaned of the multifaceted and idiosyncratically defined importance of work. Each individual's valuation of work is shaped by dynamically influencing factors at the micro, meso, and macro levels. Despite this contextual conceptualization being reflexively held, the experiences of work reintegration and maintenance for cancer survivors was a new area of learning for this therapist. The researcher thus approached the study as a "learner" with the intention of being shaped by the cancer survivors' perspectives (Brooks, Poudrier, & Thomas-MacLean, 2008). In this study, participants used cameras to capture images relevant to their experience of work following cancer. These images were later interpreted via dialogue to reveal their lived experiences. Participants' explanations enhanced the meaningfulness and contextualization of the photographs.

Participants

Upon receipt of approval from the University of Ottawa Health Sciences and Science Research Ethics Board (reference H10-12-01), purposive sampling was used to solicit participation of 10 cancer survivors. An e-mail blast including a poster describing the study was distributed widely through professional and personal contacts. Posters were also displayed at various professional locations, including physiotherapy clinics. Interested participants contacted the first author directly, at which time the participation requirements were reviewed in detail. This conversation also permitted the verification that the participant met the inclusion criteria: (a) working at the time of cancer diagnosis, (b) 18 years of age or older, (c) able to provide consent, (d) able to communicate fluently in English, and (e) interested and felt able to take photographs reflective of their experiences and participate in two audio-recorded interviews. Eligible participants were invited to participate in the study on a first-come/first-served basis as per the date and time of their initial contact with the researcher. The objective was to recruit up to 10 participants, a recommended sample size given the nature of the study (Wang, 1999). The first 10 participants to contact the researcher were all women (see Table 1). Some participants had completed treatment and returned to work years prior and therefore recalled their past experiences from within their current life situation, whereas others were at various stages of treatment and work reintegration. The variable time since experience permitted different perspectives and insights to be shared.

Table 1
Participant Demographics by Number of Participants

Variable	*n*
Age (years)	
40–49	3
50–59	5
60–69	2
Ethnicity	
White	9
Asian	1
Type of cancer	
Breast	7
Pancreatic	1
Colorectal	1
Hematological	1
Post-cancer reduction in family income	
Insignificant reduction, or family income remained above $100,000	8
Less than $20,000 reduction	0
$20,000–29,999 reduction	1
$30,000–39,999 reduction	0
$40,000–49,999 reduction	1
Education level	
College	6
University	
Bachelor's	3
Doctorate	1
Vocational sector	
Food industry	1
Professional/white collar	9
Time with employer prior to cancer	
<2 years	1
2–5 years	4
6–10 years	1
11–25 years	4

Data Collection

An introductory meeting between the first author and participant occurred at a time and location of convenience to the participant (e.g., at the university, participant's home or workplace). The study details, including participatory requirements, were again reviewed, as was the consent form. Participants were provided the opportunity to reveal themselves (i.e., in photographs, by first name) or remain anonymous by not appearing in any photographs and using a pseudonym. Following consent, the following were completed: (a) a demographic survey, (b) an interview concerning the participant's experience of cancer and health impacts as well as the participant's worker role and related social considerations, (c) an orientation to photovoice methods using examples from another study, (d) training concerning the use of the digital camera should it have been loaned (participants had the option of using their own camera), (e) a review of ethics/safety of photography and the use of a third-party release form for other identifiable individuals captured in photographs, and (f) instructions to take approximately 10 photographs that hold some personal meaning of work return/maintenance following cancer prior to a second interview. Ten photographs were suggested to ensure that data remained manageable. Participants produced a range of 1 to 12 photographs. The two-phase approach was purposefully intended to encourage a reflective process between interviews (Mueller, 2006). Both interviews were audio recorded and transcribed verbatim.

The second interview occurred approximately 1 month later, during which the participants discussed the intended meaning of each photograph. When an identifiable third party was included in a photograph, a signed consent was sought to ensure that the third party permitted use of the image. In cases when these were not completed, identifying aspects were pixilated to maintain anonymity.

Data Analysis

During the second interview, participants selected, contextualized, and codified their photographs (Wang, 1999). The participants' selected photographs were transferred to a laptop computer and displayed one at a time in the participant's preferred order. The contextualization of each photograph was facilitated using the following commonly used, root-cause questioning identified by the mnemonic SHOWED (Wang, 1999): (a) What do you *see* here? (b) What is really *happening* here? (c) How does this relate to *our* lives (your work return/maintenance)? (d) *Why* does this concern/situation/strength exist? (e) How can we become *empowered* through our new understanding? (f) What can we *do* about it? Participants then interpreted the photograph by reflecting on the "issues, themes and theories that arise from their photographs" (Wang, 1999, p. 188).

A layered approach to data analysis was undertaken composed of *preview*, *review*, *cross-photo comparison*, and *theorizing*, as outlined by Oliffe, Bottorff, Kelly, and Halpin (2008). Each interview was transcribed verbatim. The generated photographs were inserted into the second transcript for each participant, allowing the participant's own words and attributed meaning to be closely tied to each photograph. A line-by-line review of each transcript identified key phrases that were highlighted. The content of the photographs was not the focus of the analysis but, rather, the participant-attributed meaning given the relevance to the topic (Pink, 2007). Using NVivo 10, photographs and highlighted text were coded into nodes representing similar or repeating ideas (e.g., work's representation of normalcy). Some photographs and text were coded to more than one node reflective of the number of ideas presented. Related nodes were grouped together to create preliminary themes. For example, there were 14 nodes (e.g., distraction, return to normalcy, a demonstration of resiliency) grouped together in a theme pertaining to survivors' motivations for returning to work. This is the first theme of this manuscript, presented below.

Enhancing Credibility and Trustworthiness

Several efforts were undertaken to enhance the credibility of this study, including strategies outlined by Shenton (2004). These strategies included the adoption of established research methods, the developed familiarity with the topic through the first author's clinical experience and as represented in her reflective commentary, efforts to ensure honesty (e.g., consistency between interviews), triangulation between images and narratives, frequent debriefing sessions, and an examination of previous research findings. Steps were also taken to ensure that the presented findings were grounded in the participants' experiences and ideas as evidenced by their photographs with directly linked narratives. Although the procedures deviated from the original conceptualization of photovoice methodology (see Wang, 1999; e.g., no focus group was used to enhance feasibility of participant participation), the utilized methods have been well established in previous studies (e.g., see Oliffe et al., 2008). The interviewer had extensive knowledge of work reintegration, which was briefly described to participants to explain the interest in the topic yet the desire to learn from their experiences in a new area of learning (i.e., cancer survivorship). Prior to the second interview, the first interview's content was freshly reviewed by the interviewer. Questions and reflections that arose from the first transcript were addressed during the second interview, and any changes in the story being told were questioned to seek a deeper understanding of the shifts in how the participant's subjective experiences were conveyed. For some participants, reflection between the first and second interview shaped their presentation during the second interview. Any detected changes were openly discussed to achieve a fuller understanding. The images displayed in the photographs and their descriptions also represented a form of triangulation between visual image and narrative description. As the study evolved, debriefing sessions occurred with the first author's supervisor to check findings and interpretations and to challenge the evolving themes identified by the first author. Last, the findings that emerged were compared to previous research findings to assess their congruence.

To enhance the dependability of the findings, an auditing process was used (Tobin & Begley, 2004). The auditor (in this case, the postdoctoral supervisor), while involved in the research design, was not involved in data collection or the fundamental data analysis. Rather, she functioned exclusively at arm's length. Once the initial data analysis had been completed by the first author, the supervisor examined both the process of data analysis as well as the findings and provided additional input. This was facilitated by use of the audit trail (e.g., memos and reflective remarks) that had been maintained while engaging in the coding process. Only once the initial analysis had been completed did the auditor examine the conceptual coherence and validity of the findings at each step of the analytic procedure, beginning with the initial data coding through to the generated themes. She verified that there was sufficient evidence to support the claims presented. Feedback received from the auditor was considered and appropriate revisions made. Last, all 10 participants are included in the findings herein, demonstrating authenticity through a range of different realities (Tobin & Begley, 2004).

Findings

Three key findings of this study are presented below, including the reason why participants returned to work, the timing of their return, and the experienced process of returning to work.

Reasons Why Survivors RTW

There was a variety of reasons why these participants returned to work. Overwhelmingly, participants returned to work because it symbolized a return to normalcy: "The reason I went back to work and wanted to go back to work as quickly [as possible] was to maintain that sense of normalcy in my own life" (Lynn); "I was so proud of myself, like I can, I had cancer, I had it, it's gone and then you know I go to work" (Aliciya); "To get back into that work force, I wanted to do something. I wanted life to be the way it was before" (Melanie). For many, this return to normal was synonymous with a return to health and well-being:

> You know that look good, feel better thing? You have to ascribe to it a little bit in that when you go in and people say,

> "I think you look amazing" and that kind of stuff and "You're looking great." It makes you feel better, you release endorphins, and then you just keep going. (Lisa)

For some, returning to work symbolized resilience. Alyson noted, "I have this expectation that I should be able to [RTW] because I'm tough." The demonstration of strength was also discussed as a reason for resuming work by Mary. She explained that one of her competitors had attempted to claim Mary's customer base in the face of Mary's cancer:

> One of my competitors had called all my clients and so I made the decision.... I spent the whole weekend calling all my customers...[and] said it was going to be business as usual.... Four or 5 days post-surgery when I still had the drains in place I went to my first...meeting with one of my clients.... Nobody knew.

Other reasons cited for returning to work included a sense of being valued at work, meaningfulness of work, distraction from cancer, social connectedness, love of the job, and sense of identity. The financial incentive of work was not frequently mentioned as a reason for returning, and if it was cited, it was never the predominant reason. For example, Kathy noted, "Work has always been a big part of who I am...I need the work because of who I am," but when specifically asked if she needed the financial benefits, Kathy replied, "It helps, it helps." Returning to work held idiosyncratic meaning for the participants, each underscoring important considerations for the individual recovery processes.

The Timing of RTW

Some participants took minimal time off work, whereas others took 1 to 2 years off work. For those who took time off work, they received little concrete assistance in deciding when to return. As previously described, Mary took off work only the required time for surgery and returned to work with drainage tubes still affixed. Aliciya explained, "I had the surgery and I came back from the hospital and you know, like nothing happened. I just went back to my computer." Aliciya worked part-time from home for 3 months before returning to full-time work. Lynn returned to work following surgery:

> I took literally 6 weeks off. I think I probably could have come back after 5, to tell you the truth, but I had plans for that final week, lunches, meeting up with friends that you don't normally [do] when you're working, so I came back at 6 weeks.

Lynn's chemotherapy was then scheduled to occur at the end of every second Thursday. Lynn was thus required to take every second Friday off for 3 to 4 months and then was back at work full-time throughout her radiation treatments.

In comparison, many participants took leave from work entirely until their treatment for cancer was completed. There were physical (e.g., fatigue, illness) repercussions that hindered their work return, but there was also psychosocial and emotional healing that they wanted to address before returning to work. Josée described the process of weighing these aspects when she independently decided on a suitable date (see Figure 1) for her RTW:

Figure 1. August 1st. Josée presented an image of a calendar date for August 1st to convey the date she decided to return to work.

> What was significant [about my RTW] was selection of the date.... I was taking care of my mental health but I felt like I was more on vacation and I started to feel uncomfortable...so I was debating July too early, September too late, so first of August.

Over the next few months, Josée returned to work gradually. Similarly, Carol used a gradual RTW schedule process:

> I was thinking about going back to work the first time and then I delayed it. I felt like I had a huge weight on my shoulder [see Figure 2].... Once I spoke to the owner, he was totally okay with me delaying coming back and I felt like that weight [was lifted].... It was really a phew!

When Carol returned to work approximately 6 months later, she explained, "There was a difference physically, yeah and I was more prepared mentally."

Any advice from health care professionals regarding the timing of RTW was perceived as cautionary: "Everybody told me, 'Don't rush, take it gradually.' My physiotherapist kept telling me, 'Don't go too hard, go gradually'" (Josée). Lynn's oncologist suggested, "What's your hurry? Don't rush back. Take time for yourself." Similarly, Kathy had the impression that the timing of her RTW was largely self-determined:

> They asked me after initial diagnosis will I be able to go off or will I have to continue to work? .... Basically the sense I got from each of the doctors that I saw was you have to do what you have to do.

Figure 2. Heavy burden. Carol presented this image of a dumbbell to represent the huge weight that she felt when deciding on the timing of her return to work.

Survivors were often left to decide if they would take leave, how much leave, and when and how to RTW. There was a lack of concrete counsel from their health care providers beyond cautionary advice.

The RTW Process

With the limited advice and resources available to assist survivors with their RTW, significant issues can present. Fortunately, with supportive collaboration, some individuals, like Lisa and Melanie, are able to implement successful strategies effectively; however, other barriers, such as social discrimination, are more difficult to navigate. In Lynn's situation, despite working for an employer with a focus on disability management, when Lynn lost her hair during chemotherapy treatments, her employer removed her from her usual duties, thereby eliminating Lynn's interaction with the company's clients. Lynn explained to a supervisor, "Please understand that this [RTW] is as demoralizing as the disease." Lynn noted the irony that "our whole work is dealing with people who have been injured or disabled, and our whole focus, apparently, is to get them back to work, but not one of our own." She described her employer's lack of support as metaphorically attempting to cross a bridge (see Figure 3):

> I was at the foot of the bridge and I had no idea how long or how to get to the other side given the obstacles that were in my path.... I would have been very happy had [my employer] been prepared to go across the bridge. With me. Follow me... across the bridge.... I would have been very, very happy to have led them across the bridge too but they didn't show up.

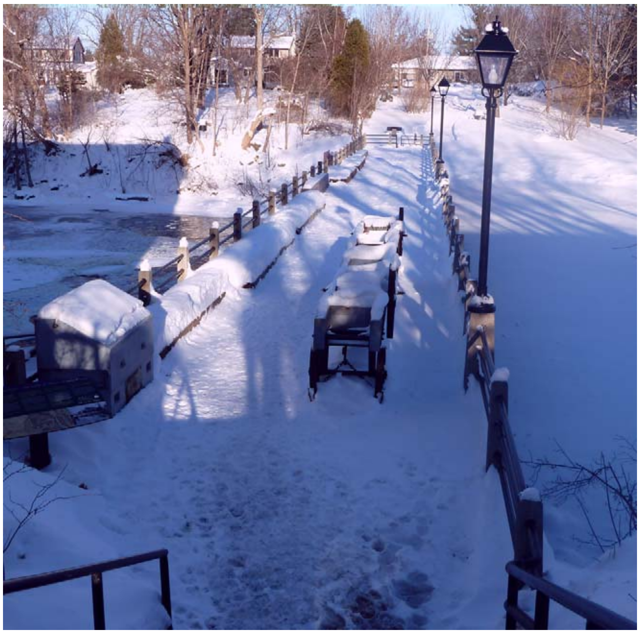

Figure 3. The bridge. Lynn presented this image of a bridge to depict her difficult return-to-work experience.

In contrast, upon hearing of Lisa's diagnosis, her employer immediately sought to understand her plan and facilitated her continued working during her treatment. Her fatigue and depleted immune system were of concern. Lisa described how her smart card (see Figure 4) represented her employer's willingness to accommodate her needs:

> This is my smart card and smart card reader.... This really is the marriage of my [computer at home] to the machine at work.... There is an implication there that my employer has made financially. Of course it's a temporary expense because as soon as I come back they can just allocate the machine to somebody else who comes along. It's just the idea of being able to be flexible enough... it's not a cookie-cutter approach.... [It's] customized.

Melanie received support from a long-term disability insurer who facilitated communication and planning with Melanie's large employer. Melanie reflected on her needs and identified accommodations necessary to optimize her successful return. Melanie purchased a couch (see Figure 5) and had it installed in her office before she returned. In addition to the construct of customized accommodations, Melanie also raised the issue that RTW is best approached as a transitionary phase:

> This is my couch here in my office.... when I'm really exhausted and I just can't move anymore I lock my door and I pull this out and I sleep.... Without that I could not have returned to work.... The symbol here [the couch] is a new phase of being able to [RTW]... a transitionary phase. It's not black and white. Wouldn't it be wonderful if when a cancer patient came back if [the employer] sat down beforehand with them and said, "How can we make your space workable for you? Why don't we take an office that's not being used or a broom closet, why don't we put a coat of paint on there and someone will bring in a poster... we can sit in there and have lunch, you can go in there, we'll put a little 'do not disturb' sign. If you need a nap, you go in there." Just thinking a little

Figure 4. My smart card. Lisa presented this image of a smart card to represent her employer's willingness to accommodate her needs by setting her up to work from home.

Figure 5. Work return: A customized transitionary phase. Melanie presented this image of her office couch to represent her transitionary needs for her successful return to work.

> bit about how we can accommodate different types of needs. We already do that a lot for disabilities.

An effective RTW process requires personal insight and self-advocacy. Patricia realized that the staff management duties were too energy-consuming and "mind clogging.... I wanted to be free in my mind." Thus, prior to returning to work, she negotiated with her employer the elimination of those duties, to which he immediately agreed. Alyson, who had been treated for non-Hodgkins lymphoma, presented with ongoing pervasive fatigue, cognitive limitations, and anxiety; she described how the image of a stop sign (see Figure 6) helped her RTW planning:

> Slow down, stop, think.... Like I say to my family and my husband... I'll try it. If I can do it, I do it. If I don't, I don't. I stop. That's it.... [This image] is helping me out a lot.... It's just that [snaps fingers] little picture that you have in your brain that helps you out [in] two ways: (a) Like stop, don't go, slow down and think about it, and (b) stop and go and try it.

In the void of informed support, many participants were forced to use a trial-and-error approach to their RTW. Many participants came to embrace their RTW as a fluid process within their overall recovery, moving beyond a merely defined date and percentage of hours or duties reclaimed. Melanie described this ebb-and-flow process:

> But the reality of cancer is that you take a step up and then you take a step down. There's never a clear path to the door; there's always obstacles. I wanted to kind of represent that in a picture [see Figure 7] and I chose my front steps.... [Now] I'm standing on the final step going on to the platform. I'm getting there.

In the void of informed support, survivors were left to independently navigate hurdles inherent to their RTW. These hurdles included discrimination, reasonable accommodations, and the management of long-term disease and treatment sequellae in the process of returning to work.

Discussion

The participants of this study experienced physical, cognitive, and emotional repercussions as a result of cancer, which for many were long-term sequellae. Despite the variable constellation of symptoms, for these women, the ability to work was important to their recovery process. Rarely did the financial benefits of employment factor into their reasons for returning to work, and when it did, it was never the primary reason, which may be a reflection of the high levels of education and family incomes across this sample. For these women, work held psychosocial importance, including a symbolic return to normalcy and health; a sense of meaning, identity, and being valued; and the social support inherent in the work setting. This is consistent with previous findings (e.g., Spelten et al., 2002; Wells et al., 2013) and in agreement with the first- (self-identity) and second-order (meaning and significance of work) elements of the model proposed by Wells et al. (2013).

The results of this study highlight the extent to which survivors are left to decide on the timing of RTW as well as suitable accommodations in the void of specific advice from health care providers. Some women took only the bare necessity of time off work, whereas others took a formal block of time off work to focus on their health and well-being. Although there may be a concern that some used work as a distraction from cancer or even a denial mechanism, this may again point to the

Figure 6. Stop the anxiety. Alyson presented this image of a stop sign that she found particularly helpful during planning for her return to work.

Figure 7. Return to work is a process, not a date. Melanie presented this set of stairs as representative of her experience of the ebb-and-flow process of returning to work.

lack of support programs available to individuals to work through such issues (The Partnership, 2012a). Distraction or denial did not, however, appear to be present for all survivors who took no time off work. Rather, for some, RTW appeared to reflect a healthy coping mechanism by reclaiming a normal and productive occupational routine as soon as their health permitted. For these individuals, support should focus on ensuring an effective balance between occupational demands and the requirements of holistic health. For those who did take some time off work, the timing of their RTW was almost exclusively determined by the survivor herself. While providers may have intended their cautionary advice as support of individual decisions, survivors were left with too little concrete considerations to guide their decisions. While this is consistent with previous findings (see Nitkin et al., 2011; Tiedtke et al., 2010; Wells et al., 2013), the result of this study highlighted the role of a disability insurer in addressing this gap in specific advice. This finding was not found in the literature. The few survivors who described specific RTW assistance received it from a long-term disability insurer. In these cases, the insurer assisted with determining a suitable time to RTW and advocated for a gradual return schedule and other accommodations. Even so, these participants reported that they were in the position of having to self-assess their own physical, cognitive, and emotional preparedness to RTW as there was no professional assessment assistance. This finding again highlights a gap in survivorship support and a concern that this advice may not be based upon holistic health considerations of the long-term sequellae of cancer and its treatment. Rather, the mandate of a disability insurer may be counterintuitive to identifying and addressing survivors' holistic needs. Customized assessment, indicated treatment (e.g., cognitive, emotional. or physical remediation), and worksite intervention (e.g., accommodations, negotiations, education) by multidisciplinary health care professionals well informed in the multifaceted consequences of cancer are direly needed. Such services should also address the required employer support (Amir et al., 2011). By proactively supporting and educating employers about their duty to accommodate, such as proposed in the Accessibility for Ontarians With Disabilities Act (2005), discriminatory practices such as that experienced by Lynn can be avoided.

Clearly, the current haphazard process of cancer survivors' work return and maintenance would be improved with the involvement of informed health care providers and resources. Support needs to be available from the point of diagnosis and to consider individual characteristics, abilities and limitations, and disease and treatment ramifications as well as the nature of the work, employer characteristics, and social and physical environmental issues (The Partnership, 2012a). These recommendations are not unlike RTW support needs of other disability groups, but consideration must be given to the complex and chronic constellation of disease and treatment ramifications specific to cancer. Survivors also need assistance navigating many questions, including existential questions, such as why and if returning to work is important in the face of potentially life-threatening cancer, if and how to disclose their diagnosis, when to RTW and at what pace, and what accommodations will facilitate their return. Group and web-based programming may be effective for some, but individualized support attending to the holistic (e.g., physical, cognitive, emotional, financial) needs of each survivor in our study considering her defined employment requirements with her specific employer would be most beneficial. Thus, this is not a cookie-cutter approach. Rather, a client-centred approach that considers the survivors' holistic needs necessitates a creative approach to those accommodations required to optimize success. Occupational therapists are undoubtedly well suited to provide leadership in delivering this type of intervention and are encouraged to work proactively to develop and deliver these client-centred services ideally within interdisciplinary teams able to address the complex web of cancer survivorship sequellae. As detailed below, a pilot test of an educational intervention is an intended future stage of the first author's research. The intervention will be adapted based, in part, on the findings described herein.

Limitations

There are limitations to this study. The first 10 participants who expressed an interest in participating in the study were all women. As a result, although the study permits a deep understanding of these women's experiences, there is no understanding of men's experiences. To this end, further research is currently under way with men. The current sample represented well-educated women with a high family income who worked almost exclusively in professional positions; returning to work was often not a financial necessity, and work was not physically demanding. Future studies should target inclusion of participants from lower socioeconomic classes, less educated workers, and those from various employment sectors. The variability in time since cancer and work return permitted different representations of experience. While this breadth of representation may represent a strength of the study (e.g., variable forms of knowledge in time), it did reflect a lack of consistency across the sample. Further, the participant sample does not represent survivors who were unable to RTW.

While the postdoctoral supervisor remained at arm's length from the data collection, she was involved in overseeing the research design. An external auditor may have differently impacted the results. The first author's clinical vocational rehabilitation experience and contextual conceptualization described above provided participants with reassurance of a background of related knowledge and interest. Given that the study's objective was the novel exploration of survivors' experiences of work following cancer, the researcher's previous experience unrelated to cancer is not considered to have materially influenced the findings. Some participants struggled with capturing specific experiences in images. During the second interview, participants were asked to reflect and share those items or concepts that they had wished to capture in an image but were unable either due to access or conceptualization. There was thus an effort to capture experiences through both images and narrative, but some data may have been lost due to the methodology.

Future Directions

While the findings of this study both support and extend the existing literature, a significant and unique contribution has been the use of visual methods. The person-centred understanding and empathetic response elicited through photovoice methods can invoke action by influential people (Wang & Burris, 1997). Action is a goal of this program of research. In keeping with The Partnership's (2012b) recommendations for variable stakeholder involvement, the provocative photographs combined with survivors' own words have informed the development of vignettes to be presented to physicians (Phase 2) and industry professionals (e.g., disability insurers, employers; Phase 3). The purpose of those inquiries is to understand their customary management of work return and maintenance issues with cancer survivors. Shaped by the insights gleaned through the first three phases and again consistent with the recommendations of The Partnership (2012a), the culmination will be the piloting of purposefully crafted interventions intended to address the current gap in support for cancer survivors.

Conclusion

Cancer survivorship support services are limited in the area of work return and maintenance, which are important to quality of life. In the void of supports and specific advice from health care providers, survivors are currently often left to navigate work reintegration and maintenance independently, including whether to take leave and when and how to RTW. Given the complex and layered implications of cancer and its treatment, occupational therapists, with their client-centred, holistic approach and vocational expertise, are well suited to provide leadership in addressing this gap.

Key Messages

- In the void of return-to-work support, cancer survivors are left to independently navigate the complex decisions and processes involved in work return and maintenance. For many, working is an important quality-of-life indicator.
- Occupational therapists are well positioned to address this gap by using a holistic, client-centred approach informed by individual survivors' ongoing limitations and the contextual considerations specific to each client-occupation-environment situation.

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References

Accessibility for Ontarians with Disabilities Act. (2005). S. O. 2005, c. 11, s. 10. Ontario Regulation 191/11, Integrated Accessibility Standard. Retrieved from http://www.e-laws.gov.on.ca/html/regs/english/elaws_regs_110191_e.htm

Amir, Z., Strauser, D. R., & Chan, F. (2011). Employers' and survivors' perspectives. In M. Feuerstein (Ed.), *Work and cancer survivors* (pp. 73–89). New York, NY: Springer.

Brooks, C., Poudrier, J., & Thomas-MacLean, R. (2008). Creating collaborative visions with aboriginal women: A photovoice project. In P. Liamputtong (Ed.), *Doing cross-cultural research: Ethical and* *methodological perspectives* (pp. 193–211). Dordrecht, Netherlands: Springer.

Canadian Cancer Society. (2013). *Canadian cancer statistics 2013: Special topic liver cancer*. Retrieved from http://www.cancer.ca/~/media/cancer.ca/CW/cancer%20information/cancer%20101/Canadian%20cancer%20statistics/canadian-cancer-statistics-2013-EN.pdf

Canadian Partnership Against Cancer. (2012a). *Programs and resources to facilitate return to work for people with cancer or other chronic diseases: Environmental scan*. Retrieved from http://www.cancerview.ca/idc/groups/public/documents/webcontent/rtw_environmental_scan.pdf

Canadian Partnership Against Cancer. (2012b). *Research related to workplace support for cancer survivors: Perspectives of employers*. Retrieved from http://www.cancerview.ca/idc/groups/public/documents/webcontent/rtw_workplace_support.pdf

Maytal, G., & Peteet, J. (2011). The meaning of work. In M. Feuerstein (Ed.), *Work and cancer survivors* (pp. 105–119). New York, NY: Springer.

Mehnert, A. (2011). Employer and work-related issues in cancer survivors. *Critical Reviews in Oncology/Hematology*, *77*, 109–130. doi:10.1016/j.critrevonc.2010.01.004

Mueller, C. (2006). Creating a joint partnership: Including Qallunaat teacher voices within Nanavik education policy. *International Journal of Inclusive Education*, *10*, 429–447. doi:10.1080/13603110600578281

Neary, D. (2011). Epidemiology. In M. Feuerstein (Ed.), *Work and cancer survivors* (pp. 3–23). New York, NY: Springer.

Nitkin, P., Parkinson, M., & Schultz, I. Z. (2011). *Cancer and work: A Canadian perspective*. Retrieved from http://www.capo.ca/pdf/CancerandWork-ACanadianPerspective.pdf

Oliffe, J. L., Bottorff, J. L., Kelly, M., & Halpin, M. (2008). Analyzing participant produced photographs from an ethnographic study of fatherhood and smoking. *Research in Nursing and Health*, *31*, 529–539. doi:10.1002/nur.20269

Pink, S. (2007). *Doing visual ethnography* (2nd ed.). Thousand Oaks, CA: Sage.

Sesto, M. E., & Simmonds, M. J. (2011). Fatigue, pain and physical function. In M. Feuerstein (Ed.), *Work and cancer survivors* (pp. 123–145). New York, NY: Springer.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*, 63–75.

Spelten, E. R., Sprangers, M. A. G., & Verbeek, J. H. A. M. (2002). Factors reported to influence the return to work of cancer survivors: A literature review. *Psycho-Oncology*, *11*, 124–131. doi:10.1002/pon.585

Sullivan, M. J. L., Simmonds, M., Butler, D., Shalliwani, S., & Hamidzadeh, M. (2011). Rehabilitation. In M. Feuerstein (Ed.), *Work and cancer survivors* (pp. 211–232). New York, NY: Springer.

Tiedtke, C., de Rijk, A., Dierckx de Casterlé, B., Christiaens, M.-R., & Donceel, P. (2010). Experiences and concerns about "returning to work" for women breast cancer survivors: A literature review. *Psycho-Oncology*, *19*, 677–683. doi:10.1002/pon.1633

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*, 388–396. doi:10.1111/j.1365-2648.2004.03207.x

Veramonti, T., & Meyers, C. (2011). Cognitive limitations. In M. Feuerstein (Ed.), *Work and cancer survivors* (pp. 147–162). New York, NY: Springer.

Verbeek, J., de Boer, A., & Taskila, T. (2011). Primary and occupational health care providers. In M. Feuerstein (Ed.), *Work and cancer survivors* (pp. 191–209). New York, NY: Springer.

Wang, C. C. (1999). Photovoice: A participatory action research strategy applied to women's health. *Journal of Women's Health*, *8*, 185–192. doi:10.1089/jwh.1999.8.185

Wang, C. C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education and Behavior*, *24*, 369–387. doi:10.1177/109019819702400309

Wang, C., Burris, M. A., & Ping, X. Y. (1996). Chinese village women as visual anthropologists: A participatory approach to reaching policymakers. *Social Science and Medicine*, *42*, 1391–1400. doi:10.1016/0277-9536(95)00287-1

Wells, M., Williams, B., Firnigl, D., Lang, H., Coyle, J., Kroll, T., & MacGillivray, S. (2013). Supporting "work-related goals" rather than "return to work" after cancer? A systematic review and meta-synthesis of 25 qualitative studies. *Psycho-Oncology*, *22*, 1208–1219. doi:10.1002/pon.3148

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