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Experiences of cancer patients' return to work

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ABSTRACT

Purpose: This study explored the experiences of cancer survivors remaining in the workforce, or transitioning back into the workforce following treatment.

Methods: Using an exploratory qualitative design, eight individual interviews were conducted with participants undergoing treatment for various cancer diagnoses, all of whom were employed prior to their cancer diagnosis.

Findings: Participants revealed that work provided them with a sense of normalcy, purpose, and personal identity. All but one participant voiced the benefits of having a supportive work environment. Many also shared they had experienced financial burden and were unaware of where to seek financial assistance.

Conclusion: Future research needs to further explore how the healthcare team and employer can promote supportive work environments and increase cancer survivors' awareness and access to financial resources.

BACKGROUND

Recent Canadian Cancer Statistics (2019) estimate that "220,400 Canadians will be diagnosed with cancer and about one in two Canadians will develop cancer in their lifetime" (p. 6). Earlier diagnosis, developments in treatment, and follow-up care have led to an increase in survival rates of cancer patients (Bonnett & Smofsky, 2018; Van Muijen et al., 2013; Canadian Cancer Statistics, 2019) resulting in an increase in the number of cancer survivors in the workforce both during and after treatment. While many cancer survivors do well when they return to work, problems such as fatigue, pain, cognitive deficits, and anxiety may become chronic or persistent (Cooper, Hankins, Rixon, Eaton, & Grunfeld, 2013). In turn, these problems may compromise their ability to return to work (RTW) (Van Muijen et al., 2013).

Returning to work for patients has a significant impact for society, as well as for the individual. For society, there is potential financial loss related to work disruption and replacement costs (Bonnett & Smofsky, 2018). The ability to work is imperative for sustaining an individual's identity (Van Muijen

et al., 2013). RTW represents a return to normalcy (Steiner, Cavender, Main, & Bradley, 2004) and control (Kennedy, Haslam, Munir & Pryce, 2007); symbolizes recovery, raises self-esteem and helps to overcome the negative effects of treatment (Steiner et al., 2004; Sun, Shigaki, & Armer, 2017); and has a positive impact on physical and mental health (Marmot, 2015). Thus, being employed or being able to RTW contributes to quality of life (QOL) (Steiner et al., 2004). Half of all cancer survivors are in the prime of their working lives and while cancer survivors express a desire to work, they are 1.4 times more likely to be unemployed when compared to others without chronic or persistent health concerns (de Boer et al., 2008).

Support from subordinates, colleagues, supervisors, employers, and occupational physicians play an important facilitation role in RTW (Bonnett & Smofsky, 2018; Crawford et al., 2017; Stergiou-Kita et al., 2016; Tamminga, de Boer, Verbeek, & Frings-Dresen, 2012). Despite the importance of work and employment-related issues in cancer survivorship, there have been few attempts to investigate the return to work experiences of cancer survivors. The purpose of this qualitative exploratory study is to uncover the experiences of cancer survivors undergoing treatment while remaining in the workforce, or the experience of transitioning back into the workforce. This information will help identify factors that can facilitate and/or hinder return to work programs for cancer survivors and could lead to reviewing and modifying workplace practices. The findings can also be incorporated into best practices for supporting patients who are working while undergoing cancer treatment, as well as those who are returning to the workplace upon completion of their treatment.

METHOD

Design

An exploratory qualitative design (Gray, Grove, & Sutherland, 2017; Sandelowski, 2010) was utilized to uncover the experiences of cancer survivors remaining in the workforce, or the experience of transitioning back into the workforce while undergoing treatment. Inclusion criteria included age (30 to 62 years) and being employed prior to their cancer diagnosis. Patients with a terminal diagnosis, as defined in consultation with an oncologist at the cancer centre, were excluded.

Setting and Participants

Eight individual interviews were conducted with seven females and one male, over a seven-month period. The participants ranged in age from 45 to 62 years and were diagnosed with breast cancer (n=5), Hodgkin's stage 2 (n=1), Non-Hodgkin's (n=1), and bowel cancer (n=1). Seven participants held full-time positions and one participant worked part-time. One participant continued to work throughout treatment while the others were off work from four weeks to seven months. Six individuals had health insurance benefits and two did not.

AUTHOR NOTES

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Data Collection and Analysis

This research received ethics approval from the Research Ethics Board at the researchers' institution and the hospital where the cancer centre is located. Initially the clinic nurses were to approach potential participants for recruitment to the study. After three months of unsuccessful recruitment, a revised process was identified. A designated clinic nurse was identified to approach patients who met the inclusion criteria and provide them with information letters outlining the purpose and rationale for the study. If they were interested in participating in an interview, they provided contact information for follow-up by the researchers. Ongoing challenges arranging times for the interviews resulted in a prolonged recruitment period of seven months.

Interviews were audio-taped and transcribed verbatim by a professional transcriber. Interviews lasted from 60 minutes to 120 minutes and open-ended questions included:

- How do you feel that continuing to work or returning to work has impacted your quality of life?
- Can you tell me how you made the decision to continue to work while having treatment?
- Who assisted you in making your decision to return to work?
- Can you tell me what supports were available to you at your workplace?
- What recommendations would you suggest to make it easier for a cancer patient to remain working while undergoing treatment?

Participants selected pseudonyms to protect their anonymity. Transcripts were subjected to manifest and inductive content analysis, (Graneheim & Lundman, 2004) to identify the unique features of the experience of individuals who remained in the workforce while undergoing treatment for cancer and/or those who returned to the workforce upon completion of their treatment. The two researchers initially read the transcripts independently. Upon the second reading, open coding was completed with notes and headings written in the text to capture all meaningful content (Braun & Clarke, 2006). Code categories were then designed from data across all interviews and mutually agreed-upon themes were identified.

Criteria used to ensure the trustworthiness of the data included credibility, dependability, transferability, and confirmability (Cope, 2014; Graneheim & Lundman, 2004; LoBiondo-Wood, Haber, Cameron, & Singh, 2018). Credibility was supported through peer debriefing with colleagues who were not involved in this research. Dependability was established by having both researchers code the data and collect data until saturation was reached. Transferability was established as similar findings were found when compared to other related literature reporting on individuals who have returned to work after a cancer diagnosis (Fitch & Nicoll, 2019; Bonnett & Smofsky, 2018). Confirmability was established in the following two ways. At the end of each interview the researcher shared her interpretation of the participant's experiences to confirm that she captured the story accurately; direct quotes from participants were included to support the emerging themes. Both researchers engaged in ongoing discussion and reflectivity to address researcher bias.

FINDINGS

Emerging Themes

Individual interviews allowed cancer survivors to give voice to their unique experiences. When reflecting on their experiences of working during treatment or returning to work following treatment, the following themes emerged: normalcy, sense of purpose, personal identity/and supportive work environment.

Normalcy/Sense of Purpose

How do you feel that continuing to work or returning to work has impacted your quality of life?

The most common theme that emerged among participants was the feeling of wanting to return to their regular life of normalcy before treatment and regaining a sense of purpose in one's life. Participants commented that returning to work was a return to living a normal life. Melissa stated that, "the number one thing you want is things back to normal and quit thinking about cancer 24/7." For Agnes, returning to work was primarily for financial reasons, but "secondly, I wanted to live life as normal as possible...work actually helped me to get through it, to just be normal." Resuming a life as they knew it gave them a sense of being able to return to activities they did prior to their diagnosis. Returning to work represented a step in the direction of "normal" and was a sign of overcoming cancer. For some participants it allowed their family members to see them as they used to be, being "their old self," and doing what they saw as normal. Maria shared that, "I'm not a person to stay home... honestly, what I was thinking was I didn't want my kids to worry about me. So, I just wanted to live my life normal, so that's why I worked during my treatment." Joseph continued to work during treatment so that he would not dwell on the fear of being diagnosed with cancer. Continuing to work represented a normal life, a normal way of living and being productive: "I just didn't want that fear. I just wanted normal. Plus, what am I going to do at home... do nothing, watch television shows, read a book."

Maintaining Personal Identity

In response to the question, *Can you tell me how you made the decision to continue to work while having treatment*, all participants expressed the desire to maintain personal identity.

For individuals with cancer, the diagnosis not only brings a fear for one's life, but may also introduce a struggle for personal identity. Surviving cancer can affect how individuals feel about themselves, as a person, and how they believe others see them. Many of the participants expressed how returning to work was an important aspect of their identity. Returning to work allowed them to leave the sick role behind and return to their previously assigned roles. Personal identity encompassed the role of mother, regardless of the age of their children, and for others it was being a productive working member in society. Lisa, the mother of married, adult children, saw her role as being protector:

... the number one reason was because I wanted it for our family. I didn't want them worrying about me, seeing me in a sick way. I wanted to promote wellness... I never say the C word; never use the cancer word. When I did my treatment... I never said chemotherapy. I just said I'm going for treatment today. (Lisa)

For other participants, not being able to work negatively impacted how they viewed their role as a member of society. One woman spoke of the struggles she encountered with not comparing herself to others. She did not want her coworkers to perceive that she was not able to fulfill her work responsibilities.

Kelly commented that returning to work indicated that she still had the strength to resume her same work activities: "I am strong and I could not have gone through it without coming to work, honestly. I couldn't have gone through it without going to work... I would not be functioning as well as I did".

Having a sense of purpose allowed participants to maintain their identity of who they were with their assigned role prior to their diagnosis. It allowed them to reflect on the roles they performed prior to undergoing treatment for cancer. For Sarah, the need to not identify herself as a "cancer patient" resonated when she stated, "We all need purpose. Just taking chemo treatment, that's not really a good purpose." Jane voiced that returning to work while continuing treatment gave her a reason to look forward to the next day and not focus solely on her diagnosis: "... it gave me some purpose... the days would sometimes roll into the next day and the biggest decision was whether you were in the chair or lying in the couch."

The financial instability associated with the cancer experience had an impact on participants' personal identity, as the loss of income influenced their ability to provide for their families. The cost of being without a monthly income, as well as the cost incurred with expenses such as transportation, certain medications, childcare, home care, nutritional or food supplements, and medical supplies was a major stressor discussed during the interviews. If individuals did not have disability or health benefits, the financial impact of cancer was particularly difficult and significantly impacted their decision of returning to work: "Honestly, first it was money" (Agnes). Kelly also made the decision to return to work because of finances: "My husband was working, but only sometimes, not regular. So, I made the decision to go back to work."

Financial stress also contributes to the worry of being diagnosed with cancer. The stress can become overwhelming for individuals and lead to feelings of depression or anxiety (Amir, Wilson, Hennings, & Young, 2012). Joseph spoke of the anxiety he experienced when trying to submit healthcare records to his insurance company. He was told that this process would take approximately one month in order for the physician to complete the papers. As a single father he commented: "You have enough stress going on with your health and everything else... especially if you are the single breadwinner."

Cancer has a substantial impact on families, and challenges are intensified when both spouses/partners are ill at the same time. One participant's husband had a life-threatening illness and finances were a concern to the family. For her, returning to work was the only option, especially when her insurance company was challenging her healthcare benefits because of the amount of time and different time periods she needed to be away from work. In this case, she spoke of how her employer tried to navigate her through the process of insurance claims.

Maggie spoke of the financial hardships she faced and how it was not until she was talking with other survivors that she became aware of funding opportunities that were available.

"... there was not a person to help you navigate ...to come around financially and ask how you're navigating this...I have a Facebook of women who have gone through breast cancer, ovarian cancer, and finances is always a huge concern. I didn't know you can get that (funding) from this hospital." (Maggie)

Interwoven within the discussion of how participants decided to return to work, the question, *Who assisted you in making the decision to return to work*, was posited. Participants indicated that family and supportive colleagues were instrumental in their decision to return to work. As well, several credited their managers for encouraging their return to work. "I talked to my supervisors and they were comfortable with me giving it a try.....it was whatever I felt was best for my health" (Melissa). "My partner said go back to work...sitting at home is not good for you." (Joseph).

Supportive Work Environment

In response to the question, *Can you tell me what supports were available to you at your workplace*, all but one participant spoke of the support they received from managers and co-workers. Joseph expressed how supportive his supervisor was and commented: "...you have been through enough, don't lift...there are other people who can do that." For Melissa, Lisa and Maggie it was having the option to work modified hours that was perceived as supportive: "I was very blessed that where I work was very willing to work with me and I was thankful for that" (Melissa).

Participants also described the support they received from co-workers. "We all have that coworker who is our friend as well as our coworker...has figured out, yes you need to go home today." (Jane). "Everyone (staff) was so supportive when I came back to work...very encouraging." (Agnes).

While seven of the eight participants had supportive work environments, one participant did not. Holly, who was diagnosed with breast cancer, shared that she had a very unaccommodating work environment. She had overwhelming fatigue during her treatment and made the decision to go on disability and not work during treatment. Holly had to move back to her parents' home as she did not have the financial resources to support herself. Upon returning to work she was told that her position was given to another employee and that she would be given a new position with a decrease in pay. After beginning in this new position, she was told that there were complaints about her attitude, and she was terminated via an email. She had no recourse, as she was not a member of the union. In telling her story, Holly began to cry and stated: "I never cried this much over my diagnosis and treatment...going back to work and being so badly treated was worse than going through my breast cancer." She also revealed that the stress of returning to work "put me into a tailspin" and she questioned her future opportunities.

In response to the question, *What recommendations would you suggest to make it easier for cancer patients to remain working*

while undergoing treatment, participants focused on the importance of a workplace, be that through a colleague or supervisor, that allows for flexibility in accommodating the fluctuating health status while one undergoes cancer treatment. “And towards the end of the treatment, it (fatigue) is cumulative... tiredness at the end. That is when you need the modified hours.” (Lisa). Melissa emphasized the importance of being honest with your employer, “outlining what it is that you can do or not do.” (Melissa).

DISCUSSION

The purpose of this qualitative exploratory study was to discover the experiences of cancer survivors remaining in the workforce, or their experience of transitioning back into the workforce, while undergoing treatment. For the most part, the participants in this study who remained in, or returned to the workforce during their cancer treatment had a positive experience. Similar themes emerged when voicing their reasons for returning to or remaining in the workforce. The return to normalcy was the most common theme expressed by all of the participants. Other researchers have also suggested that returning to work during or following cancer treatment represents a return to normalcy and control over one's life; signifies recovery; promotes self-esteem; helps to alleviate the negative effects of treatment, and has a positive impact on physical and mental health (Bonnett & Smofsky, 2018; Kennedy et al., 2007; Marmot, 2015; Steiner, Cavender, Mains, & Bradley, 2004; Sun, Shigaki, & Armer, 2017). Consistent with the previous research, our participants stated that the sense of normalcy contributed to their quality of life.

While medical treatment is central to bringing normalcy back to cancer survivors' lives, of equal significance in survivorship is self-identity and social aspects of life (Ying Mak, Chaidaroon, Fan & Thalib, 2014). The effects of cancer and its treatments can have an impact psychologically and socially on individuals in a negative way. A meta-synthesis indicated that the ability to work not only re-established a sense of self for cancer survivors, but is essential for their sense of identity (Wells et al., 2013). Consistent with previous research (Ying Mak et al., 2014), the cancer survivors we interviewed chose to work in order to highlight for others and themselves their strength, competency, and independence. Many of these cancer survivors uncovered the theme of personal identity, expressing how being identified as a survivor or patient motivated their decision to return to work, because they viewed themselves as more than a label or diagnosis.

More than half of the participants articulated the psychological burden related to staying home, as well as the need to return to work because of the financial worry that accompanied cancer treatment. Studies have suggested that financial changes during cancer treatment are the main reason individuals return to the workplace (Van Muijen et al., 2013) and financial need can push survivors back to work before they feel that they are ready (McKay, Knott, & Delfabbro, 2013). Zafar et al. (2013) reported that 85% of patients experienced some degree of financial hardship from cancer-related expenses and, for 27% of patients, this burden was substantial. Research also

indicated that the risk of financial difficulty associated with cancer is higher among the working age population than among older adults (Banegas et al., 2016). Similarly, participants in our study consistently expressed the financial stresses incurred during their sick time from work that influenced their decisions to RTW. Most participants reported returning to work to support their families regardless of single or dual parent status.

IMPLICATIONS FOR PRACTICE AND RESEARCH

RTW for cancer survivors is multi-faceted, with roles being played by healthcare providers, employers, and caregivers. Specifically, oncology nurses have a pivotal role in providing education and information to assist cancer survivors in their re-entry to the workforce. The role of assisting cancer patients throughout the continuum of care, including their re-entry to the community, is highlighted in CANO/ACIO's Standards of Practice (#4) Navigating the System. Notably, “community of living includes home, work, school, circle of friends and family and community in which the individual lives” (CANO/ACIO, 2017, p. 3-4). Oncology nurses can liaison with workplaces so there is greater understanding of the unique needs of cancer survivors who wish to remain in the workplace, or return to work after their treatment. Caregivers, whether they are the cancer survivor's support person, or the employee, will need accommodating and flexible workplace policies that allow them to meet their care-giving role. As advocates, oncology nurses can raise awareness of available resources within the workplace and community, as well as legislated policies designed to support and protect workers.

Finances are often not readily discussed during cancer treatment and, for some individuals, there is a stigma attached to experiencing financial hardships, which makes it difficult to acknowledge issues (Amir et al., 2012; Canadian Cancer Action Network, 2012). Participants in our study voiced concerns about the financial burdens they faced and the lack of information regarding how and where to seek additional financial resources. Future research should explore the involvement of healthcare professionals in providing and explaining the available financial resources for cancer patients.

The benefits of a supportive work environment were expressed by all but one participant. An accommodating and supportive workplace culture, as well as individualized workplace adjustments are important for a successful return to work (Fitch & Nicoll, 2019; Stergiou et al., 2016). However, accommodations need to be customized and clearly related to survivors' specific job demands and available workplace supports (Crawford et al., 2017; Stergiou et al., 2016). When work adjustments are personalized to meet the needs of employees who have cancer, they are more likely to continue working or to return to work (Crawford et al., 2017). To provide a successful return to work, Crawford et al. (2017) suggested having an agreed-upon written plan for returning to work, including a gradual return to work to manage the workload, and planning regular discussions with the employer.

Although seven participants experienced a supportive work environment, one participant had a tragic return to

work where the employer was not accommodating. Cancer is enclosed under equality legislation, which requires employers to make reasonable adjustments (Crawford et al., 2017). For the one participant within this current study, her return to work was worse than the actual diagnosis of cancer itself, as her employer did not make realistic adjustments. This highlights the need to include labour legislation when planning return to work for cancer survivors. Future research needs to explore if, when, and how this information is provided to cancer patients.

CONCLUSION

This exploratory qualitative study provided an opportunity for cancer survivors to voice their experiences of remaining in the workforce while undergoing treatment or transitioning back to work upon completion of treatment. This research adds further support to the current body of knowledge around

RTW experiences of cancer survivors and reinforces the importance of normalcy, purpose, and personal identity for the individuals negotiating the decision to continue to work or return to work during or after treatment. The results also highlighted the financial burden associated with a cancer diagnosis. Employers must recognize the impact cancer has on individuals and provide the necessary accommodations for their employees. This study provides further evidence of the importance of a collaborative approach by all stakeholders to ensure a productive and successful return to work experience for cancer survivors.

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