



## Return to work after breast cancer treatments: Rebuilding everything despite feeling “in-between”<sup>☆</sup>



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### ABSTRACT

**Purpose:** The aim of this longitudinal qualitative study is to describe the return-to-work (RTW) journey from the end of breast cancer (BC) treatments to RTW.

**Method:** Nine BC survivors were recruited in the province of Quebec (Canada). The participants, francophones between 30 and 60 years old, had received chemotherapy treatments and planned to RTW in the next six months. The interviews were performed at the end of cancer treatments (n = 9), one month before RTW (n = 9), and after RTW (n = 5). A content analysis was performed based on an iterative process.

**Results:** The first six months after the end of treatment was identified as an “in-between” period, during which participants questioned their ability to return to normal life due to the impact of side effects and a sense of withdrawal from health-care services. A three-stage journey similar to a rite of passage process (Van Gennep, 1969) was observed. 1) BC survivors became aware of feeling on the fringes of the workplace as they awaited RTW. 2) During that waiting period, BC survivors were rebuilding a “normal routine” and taking actions on their own in order to re-enter their workplace. 3) After RTW, they needed to make adjustments to maintain a work routine.

**Conclusion:** Support for BC survivors resuming their active lives needs to be optimized. BC survivors require support on side effect management, RTW decision-making, and resources for resuming daily activities. Nurses must be aware of the “in-between” period so that they can help BC survivors rebuild their confidence during this rite of passage process.

### 1. Introduction

Early screening and major advances in treatment are posing new challenges for people with breast cancer (BC) and for society (Burg et al., 2015; Knobf, 2015; Lorgelly and Neri, 2018). Studies on the experience of transitioning from living with cancer to life beyond cancer, i.e. the desire to return to a so-called “normal” life, are a recurring theme (Drageset et al., 2016; Nilsson et al., 2013a; Sun et al., 2016a; Wells et al., 2013). This passage includes going back to work with possible sequelae of cancer and cancer treatments, such as limitations in functional capacities or intense fatigue (Canadian Partnership Against Cancer, 2012; Jagasi et al., 2014; Mehnert and Koch, 2013). On top of these problems, there can be doubts regarding the ability to resume work due to the presence of late side effects of cancer that can affect returning to work and retaining the job (Duijts et al.,

2014), a sense of vulnerability (Tiedtke et al., 2012), and apprehension about reactions from people in the workplace (colleagues, supervisors) (Rusletto et al., 2018; Tamminga et al., 2012; Tiedtke et al., 2012). Despite these difficulties, survivors feel that work is important, as it helps them to maintain their social interactions, self-esteem, psychological well-being, and financial security (Nachreiner et al., 2007; Rasmussen and Elverdam, 2008; Wells et al., 2013). It is important to support the person through this episode, which can feel like a rite of passage marking cancer survival.

Some manuscripts have been written about cancer survival from the viewpoint of the rite of passage theory. According to Van Gennep (1969), the rite of passage consists of three successive stages: separation, liminality, and incorporation. Specifically, the experience of liminality has been documented in cancer survival (Bruce et al., 2014; Little et al., 1998). Liminality refers to a “space betwixt and between

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the normal day to day cultural and social states” (Turner, 1979, p. 94). Given that the survivor may feel “betwixt and between,” several authors recommend that the post-treatment period be better documented, based on specific intervals in time and especially, depending on the context of daily life in order to find out how survivors adapt to life again (Blows et al., 2012; Powers et al., 2016; Trusson et al., 2016). When this is applied to the experience of return to work (RTW) after cancer, it is possible to believe that an experience of liminality may take place. BC survivors transition from the status of patient to the status of survivor wishing to resume an active social life. An in-depth study of this period could provide a wealth of data to orient nursing interventions adapted to the reality of RTW.

RTW can be seen as a process made up of stages that include preparation, work re-entry, and work retention (Schultz and Gatchel, 2015; Steenstra et al., 2012). This complex process involves multi-factorial dimensions (physical health, social connections, functional capacity) and many different stakeholders (e.g. employer, insurers, health-care professionals) with varied, possibly competing interests (Denis et al., 2002). Available evidence on the RTW post-cancer journey provides information on the meaning attached to work (Brusletto et al., 2018.; Drageset et al., 2016; Nilsson et al., 2013a; Sun et al., 2016a), as well as strategies survivors deploy to retain their jobs (Barnard et al., 2016; Sun et al., 2016a). To foster RTW process, it is suggested to develop and implement multi-component interventions (e.g. educational, physical, vocational, psycho-educational activities) at various levels (survivor, health-care professionals, employer) (Bilodeau et al., 2017; de Boer et al., 2015; Greidanus et al., 2018; Stergiou-Kita et al., 2014; Sun et al., 2016b; Wells et al., 2013). However multi-component interventions remain “one-shot,” with highly variable activities (e.g. information brochures, counselling, physical activities), and at times of deployment (e.g. post-diagnosis, end of treatments) (Bilodeau et al., 2017). Despite acquired knowledge, it remains difficult to fully understand how survivors prepare to return to work and to determine how to accompany them through the experience of cancer survival.

The current state of knowledge shows how crucial it is to explore the RTW journey in some depth from the perspective of time. Documenting the journey of BC survivors who wish to RTW would enable us to better identify their needs and the best time to intervene. We propose targeting a turning point in the survival experience, i.e. the end of active cancer treatments. The goal of this study is therefore to describe the RTW journey of BC survivors from the end of active treatments through their return to work and job retention.

## 2. Method

We used the *Interpretative Description* method, a qualitative approach that lifts the veil on relevant experiential and subjective knowledge to research questions in professional disciplines (Thorne, 2016). This approach also makes it possible to use a reference framework to structure the study, in our case the *Arena of Work Disabilities* (Loisel, 2011).

### 2.1. Sample

A convenient sample was selected based on inclusion criteria: French-speaking, diagnosed with primary breast cancer, having or being on the point of finishing chemotherapy treatments, between the ages of 30 and 60, and planning to return to work over the next six months. Nine women who had been diagnosed with breast cancer were recruited, all from the same geographic region in Quebec (Canada) (Table 1). Women who had had a relapse of their breast cancer were excluded because they were unlikely to RTW (Canadian Partnership Against Cancer, 2012). The decision was made to restrict the sampling to women who had at least received chemotherapy treatments, because this is an indicator of delayed RTW (Hedayati et al., 2013; Jagsi et al., 2014; Johnsson et al., 2009; Peugniez et al., 2011; Taskila et al., 2012).

**Table 1**  
Patient characteristics.

Patient characteristics	N = 9
<i>Socio-demographic characteristics</i>	
Age, yrs.	
30-39	1
40-49	3
50-59	5
Civil status	
Married	1
Common law*	5
Separated	2
Divorced	1
Highest educational level	
High school	3
College	3
University	3
<i>Work-related characteristics</i>	
Sector of activities	
Health care and social assistance	1
Professional, scientific and technical services	4
Public administration	2
Educational services	1
Accommodation and food services	1
Work status before the diagnosis	
Permanent - full-time	6
Permanent - part-time	1
Contractual - part-time	1
Self-employed	1
Work status at the end of the study	
Permanent - full-time	2
Permanent - part-time	3
Ongoing progressive return to work	2
Awaiting for work re entry	1
Sick leave	1
Private insurance	
Yes	5
No	4
<i>Clinical characteristics</i>	
Type of cancer treatment	
Surgery, radiation therapy and chemotherapy	9
Ongoing hormone therapy	
Yes	7
No	2

\* living with a person who is not your spouse, but with whom you have a conjugal relationship.

### 2.2. Data collection

Data were collected longitudinally in order to document survivors' journeys and related challenges in real time. Twenty-three semi-directed interviews were conducted over a nine-month period after curative cancer treatments. The interviews took place one month after chemotherapy and radiation treatments (n = 9), one month before RTW (n = 9), and after RTW (n = 5). After the first interview, monthly follow-up was made with participants to determine better moments to conduct new interviews (before RTW, after RTW is done). The interviews, which were 22–58 min long, included questions on perspective of RTW (meaning, issues, and apprehension), description of contact/discussion with health-care professionals, supervisor/colleagues and insurer as well as efforts made to RTW. They were conducted over the telephone or in person in a location chosen by the participant. The collected data were recorded on digital audiotape. A logbook documented the experience of data collection and included methodological and interpretative notes, as well as details of the research process.

### 2.3. Analysis

Transcribed data underwent qualitative content analysis, consisting of an iterative process that included the following activities: condensation, presentation of data, and development and verification of

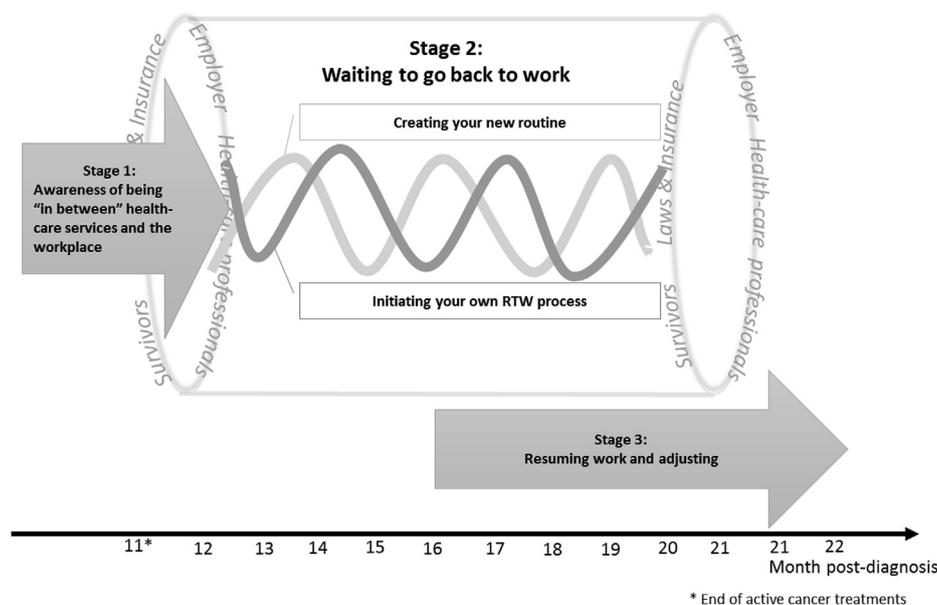


Fig. 1. Return to work journey after breast cancer treatments.

conclusions (Miles et al., 2014). An initial coding grid was developed, based on various systems (patient with BC, employer, health-care professionals, insurers) from the “Arena of work disability” (Loisel, 2011), and was enriched during the analysis. Data analysis involved several stages. Each participant transcript was processed individually. A first coding cycle, based on a procedural method (Miles et al., 2014), was performed to assign specific codes related to the theoretical framework to sections of the transcripts. A second cycle of inductive coding was then performed to provide a depth of information regarding each participant’s RTW journey. Subthemes that emerged from the analysis were organized in conceptual maps and tables. Then a transverse analysis was performed to elicit similarities and differences between participants. QDA Miner v.5.0.19 software was used to manage the qualitative data (Miles et al., 2014). The following measurements were taken by the investigators to ensure confirmability, reliability, credibility, and transferability (Miles et al., 2014): 1) a logbook was kept to document the data collection experience and to keep methodical and interpretative notes; 2) the interview transcriptions were validated against the digital audiotapes; 3) interviews were first coded by KB and recoded independently by a research professional to test the hypothesis, the conclusions were validated through feedback with the co-investigators and a research professional, as well as by rereading the data transcriptions and field notes; and 4) the context for the study was documented in detail.

#### 2.4. Ethical considerations

The study was approved by the Research Ethics Board of the Charles-LeMoine Hospital Research Centre (ref. Number AA-HCLM-15-016). All participants signed consent forms and were told that the data would remain confidential. They received a copy of the consent form.

### 3. Results

The nine participants were working in different spheres of employment. Six had permanent full-time positions, and two held part-time jobs. There was only one “self-employed” participant. Most of the participants had access to private insurance ( $n = 5$ ), but four participants did not (Table 1). At the end of the study, only one participant was still on sick leave because she was still feeling intense fatigue and was also waiting to have breast reconstruction surgery. Two

participants were on progressive RTW, and one was waiting to begin her work re-entry. Two had resumed full-time work, and three had gone back to work on a part-time basis. Of that number, two participants had voluntarily reduced their working hours. One participant had had to accept a part-time RTW temporarily (supernumerary position) because she was waiting to have breast reconstruction surgery and a new sick leave was imminent.

Participants were also experiencing recurring symptoms from the cancer and treatments, such as side effects of hormone therapy (e.g. pain, insomnia, fatigue) ( $n = 4$ ), radiation therapy-induced hypothyroidism ( $n = 1$ ), persistent fatigue ( $n = 6$ ), problems with upper limb mobility ( $n = 3$ ), and cognitive difficulties (e.g. loss of memory or concentration) ( $n = 3$ ). Participants were surprised by these symptoms and the impact the symptoms had on their lives after cancer and their work.

Overall, the participants who were recruited wanted to go back to work, as that event marked the end of their illness and a return to a more normal life. One participant even explained that going back to work meant “real life starting again.” The participants wanted to resume contact with their colleagues and break the isolation they had felt for the past year. As participant #8 explained:

“I can’t wait to see my colleagues. I can’t wait to be able to talk to them and go on to other things. Get out of the house a bit ... (...) I find the days rather long. When you’re sick and then you have chemo, the days pass quickly because you’re tired. But there ... I don’t know, it seems to me I’d rather do something else!” (Participant #8, interview #1)

As shown in Fig. 1, the RTW journey unfolds between 11 and 22 months after the cancer diagnosis. The duration fluctuates from participant to participant. Our data suggest that participants who did not have insurance had a shorter RTW journey due to concerns about earning a salary again because “like it or not, the longer it goes on, the less I have.” Stage 1, Awareness of being “in between” health-care services and the workplace, comes before Stage 2, Waiting to go back to work. During the waiting period, two simultaneous activities are intertwined: Creating your new routine and Initiating your own RTW process. Stage 3 covers Resuming work and adjusting. The influence of employers’ systems, legislation and insurance, survivors and health-care professionals is also felt throughout the RTW journey, creating positive conditions for RTW or not (see Table 2). In the next section, we take a detailed look at

**Table 2**  
Conditions that have an impact on RTW.

Systems	Positive conditions	Negative conditions
BC survivor	<ul style="list-style-type: none"> <li>● Ability to search for information on available resources (health-care services, community services, employer)</li> <li>● Few side effects from cancer</li> <li>● No real financial worries</li> </ul>	<ul style="list-style-type: none"> <li>● Financial worries</li> </ul>
Employer	<ul style="list-style-type: none"> <li>● Acceptance of progressive RTW</li> <li>● Flexible RTW conditions (duties, schedule, position)</li> <li>● Respectful attitude from superior and colleagues</li> <li>● Good relationships with co-workers</li> </ul>	<ul style="list-style-type: none"> <li>● Self-employment</li> <li>● Precarious employment</li> </ul>
Legislation and insurance	<ul style="list-style-type: none"> <li>● Sufficient insurance coverage</li> <li>● No pressure for RTW</li> <li>● Presence of RTW coordinator<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>● Insufficient or no insurance coverage</li> </ul>
Health-care professional	<ul style="list-style-type: none"> <li>● Latitude on decision-making re RTW</li> <li>● Progressive RTW a priority</li> </ul>	<ul style="list-style-type: none"> <li>● Limited resources for offering financial assistance</li> </ul>

<sup>a</sup> Person who coordinates the back-to-work process in the workplace (can also be provided by the insurer).

the stages in the RTW journey after BC.

### 3.1. Stage 1: awareness of being “in between” health-care services and the workplace

This stage takes place once active cancer treatments are finished. Most of the participants said that “*life will never be the same as it was before I was sick.*” During this period, they became aware of the impact the cancer and treatments were having on their lives, as well as their ability to resume “normal” life. Participant #4 explained:

“After radiation, I rested a lot because I was always tired. Then I stopped moving. It was like I had no confidence in myself physically or mentally any more, it was all the same. I had the impression I’d stepped down from the system (society).” (Participant #2, interview #2)

The participants were busy going to hospital appointments and treatments. At the end of the treatments, they felt “abandoned,” with few if any reference points. As one participant explained:

“When it’s over, it’s like it feels strange because it practically fills your life full-time, from the beginning to the end of treatments[...] So after that, I don’t know how to explain it. It’s a bit like ... You’re with yourself again, with what’s left [...] the symptoms that are still there. And then you have the impression oh, good! It’s over? It seems I’ve been cured, but ... I don’t know, it’s like an adjustment.” (Participant #9, interview #1)

The participants questioned their ability to resume activities in both their personal and professional lives. They felt disorganized as well, less reactive in terms of decision-making and taken aback as soon as anything unexpected happened. Two participants alluded to the fact of seeing the accumulation of tasks or activities as a “mountain.” Feeling they had trouble facing adversity led the participants to question their ability to RTW. They said they were “afraid.” They feared that they were no longer “competent” or “professional.” They said that for the most part, they were anxious when they remembered the “whirlpool” of the workplace. These fears were amplified due to the presence of fatigue and cognitive problems. They asked themselves so many questions:

“Will I be able to get back up to the same speed, the same ‘beat’ that’s required? Will I still be able to turn on a dime? (...) But then, with the illness, I hardly recognize myself. Will I be able to manage stress the same way? Will I be able to take on as much? Will I put my energies in the same place? Will I be as professional?” (Participant #6, interview #1)

Participants also noted that there was not much information on RTW from health-care professionals, employers or insurers. They would

like to have had a better understanding of when they could go back to work and what a gradual RTW would be like. Participant #8 explained her experience with health-care professionals:

“Every time I asked, ‘But what’s the norm? What’s the standard?’ it would be like, ‘There isn’t one.’ I can’t believe there is no standard. I understand that it’s case by case, but really, I think they’re able to evaluate my case, they can compare me, all the same. They can certainly see that I’m not 70. They really are able to judge my state of health and check with their norms. So, without insisting, I’d like to know their opinion at least.” (Participant #8, interview #1).

While analyzing the RTW journey, we made an interesting discovery about health-care professionals’, insurers’, and employers’ attitudes to certain participants. The participants reported that when they mentioned their desire to RTW, physicians, insurers, and employers told them to take their time. That sent an ambiguous message that could undermine participants’ wish to resume work. As participant #9 put it:

“My boss had already told me more than once to take my time because I saw him in the month of December. He’d already told me that, but I was still kind of waiting [for him to suggest that I stay on leave]. It still surprised me a little (...) If I went to see him when I was looking half-dead or very weak, he’d have said, ‘Oh, come on!’ But since I was in relatively good shape, I thought he should have said: She should come back to work.” (Participant #9, interview #1)

Some participants had the impression that their employers didn’t really want them to come back to work. Participant #7 said:

“I went to see the new boss and she told me: ‘Well, look, we can’t give you your job back because who knows ... how you’ll be ...’ So the impression I had when she spoke to me, it was as if I wasn’t good for anything?” (Participant #7, interview #1)

### 3.2. Stage 2: Waiting to go back to work

At this stage, participants were waiting to RTW. All of them had a positive attitude to RTW, saying that they “couldn’t wait” to go back to work and see their colleagues again. Participants said they were reassured and optimistic because their physicians had told them that they could RTW at their own pace and that employers had a positive view of progressive RTW. Participant #9 said:

“My boss told me: ‘These are major events, major life events, and all that ...’ Anyway, that reassured me, and I said to myself: ‘Ah, yes, that way I won’t get stressed out. If it doesn’t work out, well, that means plans will change [RTW plan].’” (Participant #9, interview #2)

Three participants perceived waiting anxiety-provoking due to financial problems. They had to postpone their RTW, regrettably, because

the doctor had extended their sick leave – a situation these participants hadn't wanted. They had tried to go back to work earlier by calling their clients and employer or sending out CVs. Here's one example:

“One time I asked to go back to work, because I was really desperate. (...) I asked the director of the company if I could go back, but she said, ‘But you're off work till January so you have to wait till then.’” (Participant #5, interview #1)

The “Waiting to go back to work” stage is typified by two activities participants engage in: “Creating your new routine” and “Initiating your own RTW process.”

**Creating your new routine.** Participants intuitively wanted to have a daily routine again. They felt that they had been inactive during their cancer treatments, engaging in very little physical activity and having very little involvement in domestic activities (e.g. preparing meals) or family activities (e.g. supervising children's homework). They felt the need to organize a schedule that would look more like a “normal” life. Participant #2 said:

“Basically, I think the secret is to know how to recreate a routine, to rebuild everything, finally, your bases for work, with the kids, food, everything, everything, everything. I think it's really a reorganization [laughing]. That's what you need to do, I think, to succeed.” (Participant #2, interview #2)

And so the participants reactivated themselves – in other words, they began to “*get in shape physically and get in shape psychologically.*” They mobilized their internal resources (knowledge, skills, attitudes) and their external resources (physical, human) to deal with problems that seemed to affect their ability to resume normal life or go back to work. They were able to find information, professionals, or activities that could help them. They searched for resources on the Internet, through oncology professionals and community organizations. Participants employed various measures: finding a support group (5/9), resuming physical activities (4/9), consulting a professional such as a physiotherapist or kinesiologist (4/9), seeking emergency financial assistance (e.g. applying to foundations or for social assistance from the government) (3/9). They also deliberately increased their domestic activities (e.g. household tasks, running errands) and reduced their rest time. All of these activities were intended to create a new everyday routine similar to the work routine. Participant #4 explained:

“At the same time, it kind of gave me a schedule. I had to get up in the morning, go to the gym, and do my exercises. For me, it was just as much of a job going to the gym as it was to go and sit in my office. It really helped me with that process. In any case, in all my experience, that was what really did me good.” (Participant #4, interview #3)

When it came to external resources, several participants tried to use resources from their oncology centre. However, the services offered for activities that addressed their post-cancer needs were limited or not available at the time. Several participants contacted non-profit organizations for patients diagnosed with cancer. Participants understood health-care professionals' roles and areas of expertise, which contributed to their wish to consult the professionals outside their oncology care team. Despite all the steps participants took, they observed that resources were scarce. Participant #4 stated:

“All the rehabilitation centres have programs for diabetics and all sorts of [other] diseases. But my physiotherapist told me: ‘I don't understand [why], for people who've had chemo or breast surgery, we have nothing, nothing at all.’ She made a few phone calls and referred me to someone who seemed to take an interest in my situation. But otherwise there was nothing. I even called a foundation for people with cancer, and there was nothing there either.” (Participant #4, interview #2)

**Initiating your own RTW process.** All the participants took steps

towards RTW with health-care professionals, employers, and insurers. They said they had some latitude in determining their RTW. Five of the participants were working in large public agencies or private corporations offering excellent working conditions. While they appreciated not being pressured to decide when they would RTW, on the other hand they sometimes felt they had been left to their own devices. As participant #6 explained:

“The fact that I could choose when to RTW meant I felt less pressured. However, the message you hear in another way is a bit like: ‘Well, look, you take care of your business, then ... you tell me when [you want to RTW]. I'll sign the papers.’” (Participant #6, interview #2)

Most of the participants contacted their employer soon just to “*take the pulse.*” They wanted to let their employer know when their treatments would be over and confirm that they wanted to resume work eventually. Participants also organized their RTW with their insurer. They contacted their employers again to discuss RTW conditions, informing them when they would RTW and how they were progressing. For the most part, they determined their own RTW sequence. Only one participant received advice from an RTW coordinator suggested by her insurer. They also discussed their workload with their employers, talking about duties, schedule, or work sector. Participant #4 explained:

“I had time to mull over my future return to work. Then in early March, I contacted my employer to say that I was ready to return, gently. So they gave me tasks that did not necessarily require me to be there every day to follow up on files, Then I started at one half-day per week, then two half-days.” (Participant #4, interview #3)

Three participants also wondered how the work team would regard their abilities. Since they felt different from the way they were before their cancer treatments, they were afraid their colleagues would perceive them as being less competent or their employer would decide to give them a pay cut if their duties were changed. Participant #4 put it this way:

“When we talked about my duties again, they would talk about me doing more routine things, saying that there were many things to do in the office, as if I wouldn't be capable of resuming the difficult duties I had before.” (Participant #4, interview #2)

### 3.3. Stage 3: Resuming work and adjusting

Five participants on this journey were interviewed after their work re-entry. They mentioned adjusting to their new energy level. They reviewed their routines to make it easier to retain their jobs, such as changing their schedule so they could sleep in longer in the morning or taking breaks during the work day (which they had not done before). The presence of fatigue also required re-evaluating their social and professional activities, as participant #3 explained:

“You learn to kind of master this new energy, which was not the same I had before. So I needed to adjust. As I said, there were some activities I dropped, but that I wasn't interested in resuming. I wasn't interested because I didn't feel strong enough to do them again anyway. I adjusted the activities that were ‘extra.’” (Participant #3, interview #3)

These participants expressed the desire not to be as “high-performance” at work as they had been before their cancer diagnosis. They now questioned the meaning of work and its importance in their life. They also accepted how others perceived them. Participant #4 shared this:

“I don't necessarily feel diminished by this [new assignment of temporary duties]. But I know that people may have a different

opinion than I do. They're not being mean, it's just reality. Perhaps they think I'm not necessarily as I was before. Well, I also think I'm not as I was before. So I'd rather that people think I'm not as I was before. That way, they'll pay more attention and not expect me to give 120%. Now, I just give 100% [laughing]!" (Participant #4, interview #3)

#### 4. Discussion

Our findings lift the veil on a largely undescribed period – from the end of treatments to the time of RTW, which is a transitional event in the post-cancer journey. To our knowledge, this is the first study to provide an in-depth description of how breast cancer survivors mobilize for their RTW during this period. The study adds further perspective to our understanding of the RTW experience after cancer – the experience of liminality after the end of active cancer treatments. In the sections below, we discuss our findings based on existing knowledge, from the rite of passage perspective.

##### 4.1. RTW in light of existing knowledge

Our findings suggest that the participants are forthcoming and proactive regarding their RTW despite being given very little guidance. The mobilization for the workplace observed in the study is consistent with other studies that provide a range of responses or motivations to explain this wish, including a desire for normalcy and the representation of work as an event that marks a “new beginning” (Brusletto et al., 2018; Drageset et al., 2016; Nilsson et al., 2013b; Sun et al., 2016a; Wells et al., 2013). In addition to this desire for normalcy, studies have documented cancer survivors' use of coping strategies, such as staying positive in the face of RTW or problem-solving (Barnard et al., 2016; Duijts et al., 2017). Some authors even suggest that RTW may in and of itself be a coping strategy. Going back to work may help keep survivors' minds occupied in order to attenuate negative emotions related to the illness (Drageset et al., 2016). Applied to the RTW context, scientific literature on self-regulation explains that representations of health and illness can serve as reference values and help the person to define her goals for her desired state of health (Leventhal et al., 2004; Scheier and Carver, 2003). The meaning attributed to work and to the illness may explain the individuals' rehabilitation trajectory (Coutu et al., 2011). Having a positive representation of their health (the return to normalcy) may have a positive effect on survivors' mobilization for their RTW, such as the use of coping strategies.

Our findings suggest that the RTW process is tinged by the influence of systems – the insurer's, the employer's, cancer survivors', and health-care professionals' systems (Loisel, 2011). Positive conditions were in place for several participants. Many studies have noted that the presence of certain conditions is conducive to RTW, such as support from the employer, a flexible schedule, gradual RTW, and the absence of pressure to RTW (Caron et al., 2018; Islam et al., 2014; Sun et al., 2016a; Wells et al., 2013). Negative conditions have also been documented, such as having a financial burden, more precarious employment, and no insurance. Some studies underline that blue-collar or self-employed cancer survivor as well as lack of income support (e.g. employment insurance benefits) are more at risk to experience diminished employment (Fitch and Nicoll, 2019; Mbengi et al., 2018; Wolvers et al., 2018). Also our documented conditions reduced the time devoted to the RTW experience for certain participants, who went back to work very soon. According to Stergiou-Kita et al. (2014), a too-rapid RTW can have a negative impact on job retention. There have been reports that it is better for survivors not to return to work too soon. This buffer period appears to reduce survivors' stress surrounding the RTW process and helps them to be emotionally prepared. According to our findings, postponing RTW increased these participants' stress and worries. For them, it was important to get back to work as soon as possible to reduce

the sensation of “burden.” In summary, the literature suggests that for survivors who keep working during their treatment or for self-employed workers, there should be support for returning to work or retaining their jobs while discussing their capacity and duties (Sun et al., 2016a; Torp et al., 2017).

##### 4.2. RTW seen as a rite of passage

Our findings on the RTW journey after BC could also be interpreted based on the “rites of passage” theory (Van Gennepp, 1969). Our participants felt “in between” health-care services and the workplace. They also questioned their abilities to resume an active life due to the impact of side effects. This is consistent with Frankenberg (1986), who suggests that the illness brings a period of rupture during which structures and routines are abandoned. This situation may represent the liminality stage, when participants feel they have “stepped down from the system.” A study exploring BC survivors' experience of liminality reported that they feel bereft of resources after treatments, but take the time to find their normal lives again. On the other hand, living with this uncertainty can be more difficult (Powers et al., 2016) and can cause some survivors to remain in an “in-between” state, not trying to move on to anything else (Bruce et al., 2014). Participants in our study did not remain in an “in-between” state, but rather took active steps to resume their normal lives. When applied to the context of RTW after a BC diagnosis, the rite of passage stages can be interpreted as follows: 1) separation of the individual from the group (announcement of the cancer diagnosis), 2) liminality (the feeling of being on the fringes of health-care services and the workplace), and 3) incorporation (RTW requiring some adjustment).

##### 4.3. Recommendations

Although the participants in our study seemed to be able to go back to their jobs on their own without needing much help, it is important to remember that several studies have shown that survivors have difficulty retaining their jobs (Canadian Partnership Against Cancer, 2012; Wells et al., 2013). Thus, our results show the important role of self-management of BC survivors during RTW process. In addition, when considering RTW a rite of passage it is important to look closely at the period of liminality during which survivors may feel on the fringes of the workplace and even on the fringes of society. Based on our findings, this period appears to occur at the end of active cancer treatments. As previously noted, this period, which can be difficult for certain survivors, requires special attention. In the light of our findings, it is important to discuss the resumption of a routine with the survivors and to explore with them various aspects that could help them maintain such a routine. In addition, our findings show that survivors already possess knowledge, have clear priorities, and are capable of identifying what needs to be set up in order to resume a routine and return to work. To make it easier to mobilize survivors for their RTW, we suggest initiating a discussion at the end of treatments about how they hope to resume active life and work. In the course of this discussion, it is important to rely on their strengths, their past experiences (e.g. previous daily routines) and their needs. It also seems wise to suggest that they establish a routine and resume activities of daily living and domestic activities gradually. In addition, information should be offered on the delayed effects of cancer treatments. Furthermore, nurses have to support RTW decision-making of patients across different sectors of the healthcare system (e.g. hospitals or specialized cancer centres, rehabilitation setting, primary care setting). It is an opportunity to foster inter-professional collaboration as well as intersectorial collaboration (e.g. RTW coordinator). Finally, it is crucial for regular health-care professional follow-up to be offered for three to six months after the end of treatments to see them through the transition and attenuate the experience of liminality.

Further studies are also needed to increase our understanding of the

population living with a financial burden after a cancer diagnosis. This situation may lead survivors to RTW too soon. The population who do not wish to RTW or who plan to postpone their RTW should also be the subject of further study to explore whether their journey differs. It is important to note as well that one aspect was not raised by participants in our study: social or family support. This aspect could not be integrated into the RTW journey, although there are papers emphasizing its importance (Wells et al., 2013). Continuing other studies of that component would improve our understanding of RTW after BC.

#### 4.4. Strengths/Limitations

What sets this study apart is the collection of longitudinal data. This approach produced unprecedented data on RTW journeys from the end of active cancer treatments through RTW. The use of repeated interviews to document the journey also enabled us to document RTW journeys in “real time.” This approach minimizes participants' memory bias. It should also be remembered that the criteria for inclusion in the study included wanting to return to work during the next six months. This criterion may have contributed to the selection of participants who were more inclined to resume work and especially those who had positive conditions in place (e.g. insurance). Thus, we did not have the perspectives of women who did not want to RTW. Repeated interviews with the principal investigator (KB) on preparation for RTW may also have influenced participants' interest in preparing for their RTW. Here again, the interviews may have had the effect of an intervention even though the investigator did not offer any support for RTW while conducting the study. It should be mentioned that the study was conducted in one semi-urban territory in the Canadian province of Quebec. The health-care system, labour legislation, and public policy on employment insurance for people with serious illnesses may differ for other industrialized countries. The findings should therefore only be interpreted in this specific context.

#### 5. Conclusion

The findings of this study expand our understanding of breast cancer survivors' RTW journey from the end of active treatments to the time of work re-entry. Based on the findings, we note that some BC survivors are capable of mobilizing their resources to resume a routine and take steps to prepare for RTW. In addition, the RTW process is like a rite of passage in cancer survival. When we look at these findings, we should remember that the Person, as seen in Nursing, has the power to act and is able to mobilize her resources. Nurses must be aware of their capacity to act and accompany the patient through her transitions, including the transition to RTW. Finally, nurses should recognize that surviving cancer can lead to an experience of liminality, especially when the survivor really wants to RTW.

#### Declarations of interest

The authors report no conflicts of interest in this work.

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#### References

Barnard, A., Clur, L., Joubert, Y., 2016. Returning to work: the cancer survivor's transformatory journey of adjustment and coping. *Int. J. Qual. Stud. Health Well-Being*

- 11, 32488.
- Bilodeau, K., Tremblay, D., Durand, M.-J., 2017. Exploration of return-to-work interventions for breast cancer patients: a scoping review. *Support. Care Canc.* 25, 1993–2007.
- Blows, E., Bird, L., Seymour, J., Cox, K., 2012. Liminality as a framework for understanding the experience of cancer survivorship: a literature review. *J. Adv. Nurs.* 68, 2155–2164.
- Bruce, A., Shields, L., Molzahn, A., Beuthin, R., Schick-Makaroff, K., Shermak, S., 2014. Stories of liminality: living with life-threatening illness. *J. Holist. Nurs.* 32, 35–43.
- Brusletto, B., Torp, S., Ihlebæk, C.M., Vinje, H.F., 2018. A five-phase process model describing the return to sustainable work of persons who survived cancer: a qualitative study. *Eur. J. Oncol. Nurs.* 34, 21–27.
- Burg, M.A., Adorno, G., Lopez, E.D., Loerzel, V., Stein, K., Wallace, C., Sharma, D.K.B., 2015. Current unmet needs of cancer survivors: analysis of open-ended responses to the American Cancer Society Study of Cancer Survivors II. *Cancer* 121, 623–630.
- Canadian Partnership Against Cancer, 2012. Return to Work Concerns Faced by People Dealing with Cancer and Caregivers: Literature Review and Consultation. Canadian Partnership Against Cancer, Toronto, pp. 169.
- Caron, M., Durand, M.J., Tremblay, D., 2018. Perceptions of breast cancer survivors on the supporting practices of their supervisors in the return-to-work process: a qualitative descriptive study. *J. Occup. Rehabil.* 28, 89–96.
- Coutu, M.-F., Baril, R., Durand, M.-J., Côté, D., Cadioux, G., 2011. Health and illness representations of workers with a musculoskeletal disorder-related work disability during work rehabilitation: a qualitative study. *J. Occup. Rehabil.* 21, 591–600.
- de Boer, A.G., Taskila, T.K., Tamminga, S.J., Feuerstein, M., Frings-Dresen, M.H., Verbeek, J.H., 2015. Interventions to Enhance Return-to-work for Cancer Patients. *The Cochrane Library*.
- Denis, J.-L., Hébert, Y., Langley, A., Lozeau, D., Trottier, L.-H., 2002. Explaining diffusion patterns for complex health care innovations. *Health Care Manag. Rev.* 27, 60–73.
- Drageset, S., Lindstrøm, T.C., Underlid, K., 2016. “I just have to move on”: women's coping experiences and reflections following their first year after primary breast cancer surgery. *Eur. J. Oncol. Nurs.* 21, 205–211.
- Duijts, S.F., van Egmond, M.P., Gits, M., van der Beek, A.J., Bleiker, E.M., 2017. Cancer survivors' perspectives and experiences regarding behavioral determinants of return to work and continuation of work. *Disabil. Rehabil.* 39, 2164–2172.
- Duijts, S.F.A., van Egmond, M.P., Spelten, E., van Muijen, P., Anema, J.R., van der Beek, A.J., 2014. Physical and psychosocial problems in cancer survivors beyond return to work: a systematic review. *Psycho Oncol.* 23, 481–492.
- Fitch, M.I., Nicoll, I., 2019. Returning to work after cancer: survivors', caregivers', and employers' perspectives. *Psycho Oncol.* 28, 792–798.
- Frankenberg, R., 1986. Sickness as cultural performance: drama, trajectory, and pilgrimage root metaphors and the making social of disease. *Int. J. Health Serv.* 16, 603–626.
- Greidanus, M., Boer, A., Rijk, A., Tiedtke, C., Dierckx de Casterlé, B., Frings-Dresen, M., Tamminga, S., 2018. Perceived employer-related barriers and facilitators for work participation of cancer survivors: a systematic review of employers' and survivors' perspectives. *Psycho Oncol.* 27, 725–733.
- Hedayati, E., Johnsson, A., Alinaghizadeh, H., Schedin, A., Nyman, H., Albertsson, M., 2013. Cognitive, psychosocial, somatic and treatment factors predicting return to work after breast cancer treatment. *Scand. J. Caring Sci.* 27, 380–387.
- Islam, T., Dahlui, M., Majid, H.A., Nahar, A.M., Mohd Taib, N.A., Su, T.T., 2014. Factors associated with return to work of breast cancer survivors: a systematic review. *BMC Public Health* 14, S8.
- Jagsi, R., Hawley, S.T., Abrahamse, P., Li, Y., Janz, N.K., Griggs, J.J., Bradley, C., Graff, J.J., Hamilton, A., Katz, S.J., 2014. Impact of adjuvant chemotherapy on long-term employment of survivors of early-stage breast cancer. *Cancer* 120, 1854–1862.
- Johnsson, A., Forander, T., Rutqvist, L., Vaez, M., Alexanderson, K., Olsson, M., 2009. Predictors of return to work ten months after primary breast cancer surgery. *Acta Oncol.* 48, 93–98.
- Knobf, M.T., 2015. The Transition Experience to Breast Cancer Survivorship. *Semin. Oncol. Nurs.* 31, 178–182.
- Leventhal, H., Halm, E., Horowitz, C., Leventhal, E.A., Ozakinci, G., 2004. Living with chronic illness: a contextualized, self-regulation approach. *Sage Handb. Health Psychol.* 197–240.
- Little, M., Jordens, C.F., Paul, K., Montgomery, K., Philipson, B., 1998. Liminality: a major category of the experience of cancer illness. *Soc. Sci. Med.* 47, 1485–1494.
- Loisel, P., 2011. Work Disability: it is not just the “lesion”. In: Feuerstein, M. (Ed.), *Work and Cancer Survivors*. Springer, New York, NY, pp. 93–103.
- Lorgelly, P.K., Neri, M., 2018. Survivorship burden for individuals, households and society: estimates and methodology. *J. Cancer Policy* 15 (Part B), 113–117.
- Mbengi, R.L.K., Nicolaie, A.M., Goetghebeur, E., Otter, R., Mortelmans, K., Missinne, S., Arbyn, M., Bouland, C., de Brouwer, C., 2018. Assessing factors associated with long-term work disability after cancer in Belgium: a population-based cohort study using competing risks analysis with a 7-year follow-up. *BMJ Open* 8, e014094.
- Mehmert, A., Koch, U., 2013. Predictors of employment among cancer survivors after medical rehabilitation—a prospective study. *Scand. J. Work. Environ. Health* 39, 76–87.
- Miles, M.B., Saldaña, J., Huberman, A.M., 2014. *Qualitative Data Analysis: a Methods Sourcebook*, third ed. SAGE Publications, Inc., Thousand Oaks, California.
- Nachreiner, N., Dagher, R., McGovern, P., Baker, B., Alexander, B., Gerberich, S., 2007. Successful return to work for cancer survivors. *AAOHN J.* 55, 290–295.
- Nilsson, M.I., Olsson, M., Wennman-Larsen, A., Petersson, L.M., Alexanderson, K., 2013a. Women's reflections and actions regarding working after breast cancer surgery - a focus group study. *Psycho Oncol.* 22, 1639–1644.
- Nilsson, M.I., Olsson, M., Wennman-Larsen, A., Petersson, L.M., Alexanderson, K., 2013b. Women's reflections and actions regarding working after breast cancer surgery—a

- focus group study. *Psycho Oncol.* 22, 1639–1644.
- Peugniez, C., Fantoni, S., Leroyer, A., Skrzypczak, J., Duprey, M., Bonnetterre, J., 2011. Return to work after treatment for breast cancer: single center experience in a cohort of 273 patients. *Bull. Canc.* 98, E69–E79.
- Powers, N., Gullifer, J., Shaw, R., 2016. When the treatment stops: a qualitative study of life post breast cancer treatment. *J. Health Psychol.* 21, 1371–1382.
- Rasmussen, D.M., Elverdam, B., 2008. The meaning of work and working life after cancer: an interview study. *Psycho Oncol.* 17, 1232–1238.
- Scheier, M.F., Carver, C.S., 2003. Goals and confidence as self-regulatory elements underlying health and illness behavior. *The self-regulation of health and illness behaviour* 17–41.
- Schultz, I.Z., Gatchel, R.J., 2015. *Handbook of Return to Work: from Research to Practice*. Springer.
- Steenstra, I., Lee, H., de Vroome, E., Busse, J., Hogg-Johnson, S., 2012. Comparing current definitions of return to work: a measurement approach. *J. Occup. Rehabil.* 22, 394–400.
- Stergiou-Kita, M., Grigorovich, A., Tseung, V., Milosevic, E., Hebert, D., Phan, S., Jones, J., 2014. Qualitative meta-synthesis of survivors' work experiences and the development of strategies to facilitate return to work. *J. Cancer* 1–14.
- Sun, W., Chen, K., Terhaar, A., Wiegmann, D.A., Heidrich, S.M., Tevaarwerk, A.J., Sesto, M.E., 2016a. Work-related barriers, facilitators, and strategies of breast cancer survivors working during curative treatment. *Work* 55, 783–795.
- Sun, Y., Shigaki, C.L., Armer, J.M., 2016b. Return to work among breast cancer survivors: a literature review. *Support. Care Canc.* 1–10.
- Tamminga, S.J., De Boer, A.G., Verbeek, J.H., Frings-Dresen, M.H., 2012. Breast cancer survivors' views of factors that influence the return-to-work process—a qualitative study. *Scand. J. Work. Environ. Health* 144–154.
- Taskila, T., Kuosma, E., Hietanen, P., Carlsen, K., Gudbergsson, S., Gunnarsdottir, H., 2012. Work ability of survivors of breast, prostate, and testicular cancer in Nordic countries: a NOCWO study. *J. Cancer* 6, 72–81.
- Thorne, S., 2016. *Interpretive Description: Qualitative Research for Applied Practice*. Routledge.
- Tiedtke, C., de Rijk, A., Donceel, P., Christiaens, M.R., de Casterle, B.D., 2012. Survived but feeling vulnerable and insecure: a qualitative study of the mental preparation for RTW after breast cancer treatment. *BMC Public Health* 12, 538.
- Torp, S., Syse, J., Paraonaris, A., Gudbergsson, S., 2017. Return to work among self-employed cancer survivors. *J. Cancer* 11, 189–200.
- Trusson, D., Pilnick, A., Roy, S., 2016. A new normal?: women's experiences of biographical disruption and liminality following treatment for early stage breast cancer. *Soc. Sci. Med.* 151, 121–129.
- Turner, V.W., 1979. *Process, Performance, and Pilgrimage: a Study in Comparative Symbology*. Concept Publishing Company, New Delhi.
- Van Gennep, A., 1969. *The Rites of Passage*. University of Chicago Press, Chicago.
- 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 Oncol.* 22, 1208–1219.
- Wolters, M., Leensen, M., Groeneveld, I., Frings-Dresen, M., De Boer, A., 2018. Predictors for earlier return to work of cancer patients. *J. Cancer* 12, 169–177.