



**UNIVERSITY *of* LIMERICK**

**O L L S C O I L L U I M N I G H**

**MSc Occupational Therapy**

***Exploration of the return to work experiences of  
breast cancer survivors in Ireland***

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## **Abstract**

### *Purpose:*

There has been an international increase in research concerning the recommencement of paid employment in cancer survivors. However, there is a lack of literature that captures the lived experiences of returning to work in Ireland, particularly for breast cancer survivors. This qualitative study aims to explore Irish breast cancer survivors' experiences of transitioning back to the workplace following treatment.

### *Methods:*

A qualitative approach using semi-structured interviews was employed to explore and gain insight into the work-related experiences of seven breast cancer survivors. The collected data was transcribed, entered into Nvivo software and analysed, using Braun & Clarke's (2006) six stages of thematic analysis.

### *Results:*

Six themes emerged from the data: The experience of financial support, inadequate professional advice received, emotional experience in anticipation of returning to work, experiences with employer, the transitional experience, and challenges experienced when back to work.

### *Conclusion:*

The results of the study are consistent with international studies exploring the experiences of returning to work post breast cancer. The employer's role in providing financial support and work role accommodations appear to be crucial factors in the transition of breast cancer survivors from sick leave to the workplace. Moreover, a lack of professional guidance about returning to work has also been found to affect breast cancer survivors' resumption of employment. The study's findings can contribute to occupational therapy oncology interventions and vocational rehabilitation services for people post breast cancer.

## **Introduction**

There is growing interest in research examining the impact of cancer diagnosis on work participation with at least 40% of cancer survivors in the working age range (Maddams *et al* 2009). Breast cancer (BC) is the most common diagnosis of cancer in Ireland, with 2400 new cases diagnosed annually (National Cancer Registry Ireland 2013; Breast Cancer Ireland 2016). In an Irish study of employment outcomes among cancer survivors, Sharp and Timmons (2011) identified that among those who had BC and had taken time off work following diagnosis, 62.9% had returned to work, 17.7% left the workplace and 19.5% hoped to resume work in the future. Previous research has predominately focused on identifying the positive and negative factors associated with work-place participation in cancer survivors. However, there is a lack of research exploring the work related experiences of BC survivors, specifically in the Irish context. Therefore, the focus of this study is to reveal the subjective accounts of BC survivors lived experiences of returning to work in Ireland.

## **Literature Review**

Work, as an occupation involving productivity, can yield satisfaction in some people and is essential to who we are as humans, and as occupational beings (Pierce 2003). Furthermore, there is a strong connection between unemployment and poorer physical and mental health mortality (Waddell & Burton 2006). Occupational Therapists can help cancer survivors return to work (RTW) by modifying activities, education on how to conserve energy, addressing body image, stress management and modifying their work environment (Vockins 2004). Additionally, vocational rehabilitation services aim to assist an individual with a health problem stay at, return to and remain in work (Waddell *et al* 2008).

According to a literature review by Spelten *et al* (2002), approximately 62% of cancer patients continue to RTW during or after treatment. However, literature suggests that they may experience a number of significant challenges such as medical leave, work expectations and side-effects of treatment (Braybrooke *et al* 2015; Blinder *et al* 2012). Consequently, these challenges can undermine the individual's ability to perform and fulfil their work role (Amir *et al* 2008). An important limitation identified by qualitative research, is the lack of advice from health professionals about when to RTW and the lack of guidance on work ability and sustainability (Bains *et al* 2012; Kennedy *et al* 2007; Main *et al* 2005).

Despite the many challenges faced by cancer survivors in their RTW, there are a number of motivators and enablers that aid in their ability to resume work. Literature has shown that the distraction from medical problems, relieving boredom and financial stress are the drivers pulling cancer survivors back to the work place (McKay *et al* 2013; Blinder *et al* 2012). Qualitative research with United Kingdom and American BC survivors identified that work role accommodations provided by employers, such as flexible hours, reducing workload and providing time off for medical appointments, are also important facilitators to help cancer survivors in their transition back to work (Kennedy *et al* 2007; Main *et al* 2005). It is against this background of literature that this qualitative study aims to investigate the RTW experience of individuals who had BC in Ireland.

## **Methodology**

### *Participants:*

Purposive recruitment was carried out through the 'Irish Cancer Society' who posted an advertisement of the research information on their Facebook and Twitter accounts. Following this, the BC support group 'Marie Keating Foundation' voluntarily re-shared the post on their social media pages. Inclusion criteria included; adults aged 18-65 years, who have had BC and who have returned to either full-time or part-time work in Ireland. Seven female participants were recruited. The profile of participants can be seen in Table 1.

### *Data Collection:*

Semi-structured audio-recorded interviews were conducted by a student researcher with seven participants. Interviews took approximately 60 minutes and were completed face-to-face in locations convenient to the participants. The interview involved open-ended questions to encourage full and meaningful subjective accounts of their work related experiences and feelings encountered. The interview schedule was designed to explore participants' experience of taking sick leave, communicating with employers and colleagues, sick pay, readiness to return, accommodations made by employer and challenges they experienced and supports received. The student researcher used probing and follow-up techniques in the interview to explore these topics in depth (Hennick *et al* 2011).

Table 1. Participant Profile Table

<b>Pseudonym:</b>	<b>Ann</b>	<b>Eileen</b>	<b>Geraldine</b>	<b>Josephine</b>	<b>Mary</b>	<b>Betty</b>	<b>Kathy</b>
<b>Age at Diagnosis:</b>	Not reported	Not reported	52	Not reported	35	27	42
<b>Area of employment at time of diagnosis:</b>	Dental Care	Palliative Care	Bank Clerk	Health Promotion	Teacher	Publishing Company	Kitchen Staff
<b>Current employment status:</b>	Returned to previous employment	Returned to previous employment	Has not yet returned to employment	Returned to previous employment	Unsuccessful in returning to previous employment	Returned to previous employment - changed job soon after	Returned to previous employment
<b>Length of sick leave:</b>	8 months	15 months	Currently still on sick leave	Not reported	12 months	16 months	Not reported

*Data Analysis:*

Data were analysed using Braun and Clarke's (2006) approach to thematic analysis. This form of analysis allows the researcher to discover emerging themes and concepts that are consistent throughout interviews. Each transcript was read several times to ensure familiarity with the data before initial codes were developed, organising the data into meaningful groups (Tuckett 2005). Transcripts were imported into NVIVO software where the researcher worked systematically through the transcripts, giving equal attention to each data item and identified interesting aspects that might form the basis of repeated patterns. Once the data had been coded and collated, codes were sorted into potential themes and sub-themes and combined to create possible overarching themes. The next stage involved refining and reviewing the themes to check for data that may have been missed during earlier coding stages (Braun and Clarke 2006). Themes were then named and identified and the student researcher conducted a detailed analysis of each theme, thus revealing the “story” that each theme told in relation to the work related experiences of BC survivors.

*Rigour/Trustworthiness:*

A number of guidelines were followed to achieve a rigorous analysis. An audit trail of an honest and clear account of the procedures used for analysing data is provided for the reader, adding transparency to the analysis so that procedures are clear for other academics to can follow. Additionally, the researcher used a reflexive approach, aiming to remove the potential bias that they may bring to data collection and analysis, ensuring the data is 'pure' and

untainted by personal perspectives and social values (Green and Thorogood 2014). Rigour was also supported in this research, by conducting interviews that were internally consistent, with a logical rationale, about the same topic, in the same interview and consistently following Braun and Clarke's (2006) six steps to thematically analysing data (Krefting 1991).

#### *Ethical Considerations:*

Ethical approval was obtained from the Education and Health Sciences Research Ethics Committee of University of Limerick (ethics number: 2015\_04\_21\_ehs). Voluntary participation was ensured and participants were provided with an information sheet giving sufficient and comprehensible details about the research study. Given the sensitive nature of the information, participants were provided with a list of support services available immediately following the interview, in case they would become distressed or require further support. Pseudonyms have been used to protect the participants' anonymity and confidentiality.

### **Findings**

The analysis revealed six themes: *The experience of financial support, inadequate professional advice received, emotional experience in anticipation of returning to work, experiences with employer, the transitional experience, and challenges experienced when back to work.*

#### ***The experience of financial support***

The provision of sick pay following diagnosis and during treatment was a significant factor affecting participant's time off from work and influencing their reasons to return.

With the majority of participants getting full pay for a number of months, followed by half pay for other months, participants considered themselves fortunate with the financial support they received.

*'I was so incredibly lucky with the company I worked for' (Betty).*

Their sick pay was considered to be supportive and comforting during their absence from work, as Josephine explained that bills and the mortgage: *'didn't enter my head'*.

The length of time participants were on sick leave varied, but many believe they were motivated to RTW once they were on half pay or when their sick pay was due to cease:

*'I was under pressure financially because I was going into no pay then'* (Ann).

The financial concern experienced during sick leave became a significant stressor for many participants. Mary was the only participant who did not receive any financial support:

*'The financial strain has been absolutely worse than having cancer itself'*.

The financial concern and the difficulty in regaining work forced Mary to take on another career:

*'I had to do something to try and make some more income because everything I had was just falling apart'*.

### ***Inadequate professional advice received***

Participants highlighted the lack of advice they received from health professionals post treatment about when to RTW. Participants experienced this as unhelpful and found the lack of advice to be unsupportive and difficult as they had to decide themselves when they were ready to RTW:

*'No advice at all, just if you feel fit to go back to work, go back to work'* (Eileen).

Ann received mixed reports, as nurses encouraged her to take more time off work and doctors advised that she was fit to RTW. Betty and Josephine reported that there should be more advice around the difficult transition that is returning to the workplace:

*'No one ever specifies.. so that was a difficult thing'* (Betty).

Participants were frustrated and disappointed from the unanswered important questions and lack of advice regarding how they might feel after returning to work. Josephine reported that GPs have a role to play in advising their patients as they *'know the pitfalls'* that returning to work too soon can involve.

Kathy and Betty also reported feeling uncertain and unsupported in the period between finishing treatment and returning to work:

*'When you're finished the chemo, it's like as though "yea off you go there now" and just get on with it' (Kathy).*

Betty described this lack of support as a period when she was depressed, as she struggled to manage the long term side-effects and *'psychologically get back to stuff'*.

### ***Emotional experience in anticipation of returning to work***

Participants highlighted an array of emotions they experienced before returning to work which influenced RTW decision-making, including a strive for normality, feelings of determination, disheartened with the lack of colleague support and fear of returning.

Eileen suggested that BC survivors should consider their emotional well-being in deciding to RTW:

*'Think long and hard and you might feel physically well to go back but they need to look within themselves from an emotional point of view to see where they're at'.*

For most participants, their readiness to RTW appeared to be driven by their desire for the routine of their old life and a desire for normality, as they missed their working role:

*'There is only so much golf you can play on a Monday to Sunday' (Eileen).*

Participants often had the perception that there was an expectation for them to RTW and this influenced their determination to return to their responsibilities:

*'I probably felt I should go back rather than felt I was ready to go back' (Betty).*

Many participants acknowledged the support they received from colleagues during their sick leave, but reported feeling let down, as some colleagues were not as supportive as they would have expected. Moreover, Geraldine described being fearful about the expectations involved in her post, reporting she would *'have to learn so much to return'*. This fear was heightened by the feeling of being put under pressure to return by the company and occupational physician.



### *Experiences with employer*

Participants reported on their experience with their employers when they returned to work post treatment.

#### Positive experiences:

Participants who had positive experiences with their employers commented on work role accommodations. Kathy reported:

*'I don't think they could have done much more for me. It was nice even to be told by HR that "if you have problems now, come to us so we can swap around your hours".'*

Betty reported that she felt supported and treated like a genuine person when she returned to work as her employer reduced her hours and provided a reduced workload. Furthermore, Ann reported on the benefits of occupational health support, which is part of her employer's policy for people returning to work from long term sick leave. This enabled her to have a phased transition to the workplace, which allowed her to manage the fatigue she was experiencing as a result of treatment.

#### Negative experiences:

Although many participants reported they found their immediate supervisors and managers supportive during their diagnosis and sick leave, many participants were disappointed in how higher management treated them on their return and how they adhered to impersonal policies. Mary was unhappy that there are no refresher courses for teachers out of work for long periods. This proved to be a challenge for Mary, as she was unsuccessful in gaining any teaching positions post treatment. Josephine worked as a line manager, but was disappointed when she did not receive the same support that she would usually provide for other employees, in terms of sick leave and occupational health support. Participants felt that once they returned to work, employers treated them as if nothing ever happened and provided no support in their transition:

*'I had gone through something physically and psychologically traumatic and yet it was like "oh your back to work, right great" (Josephine).'*

Participants made reference to how their employers followed strict policies which were enablers in their RTW, but they also considered these as impersonal and significant

challenges. Geraldine felt stressed and under pressure when her company's insurance policy sent her to occupational physicians for assessments and interviews. Josephine was disappointed with the implementation of impersonal policies when she was not granted time off work to get her wound dressed regularly and stated that:

*'They are going to offer one policy because it's easier for managers'.*

### ***The transition experience***

Participants reported a variety of emotions and factors that influenced their transition back to employment, including colleague support, the availability of flexible working conditions and the nature of the work tasks.

Kathy identified positive interactions with her colleagues and the support she received on her return as an important factor in helping her transition back to the workplace:

*'I remember thinking to myself "this is what I missed". It's not the actual work aspect of it, it's the social aspect, of actually having a bit of a skit as your working' (Kathy).*

Some participants found the initial RTW transition a significant challenge. Eileen reported finding it difficult to find her own way of coping once she returned and felt disheartened as she:

*'Expected them maybe to find me some office based work just to break me back in'.*

Moreover, Josephine's employer did not make any accommodations for her in terms of a supportive and phased transition:

*'I was told you're either well enough for work or not'.*

Josephine believes that a phased transition, in time and level of responsibility, is essential for enabling people post-treatment, to RTW successfully and that if this was built into the company policy this *'would eliminate a lot of the problems'*.

Anne found the nature of her work in management to be helpful during her transition, as she dealt with administration, could avoid tough situations and could roster herself to suit her needs. However, some participants struggled to readjust to their job role once they returned. Working in oncology, Eileen found it very difficult to be involved with patients in the terminal phase of their cancer and reported that it was *'too close to the bone'*. Furthermore, Betty's RTW transition came with a lot of learning and re-training, as she reported: *'the job*

*had changed. I wasn't happy with it*'. She felt stressed and uncomfortable throughout her transition, causing her to resign and gain employment elsewhere.

### ***Challenges experienced when back at work***

Participants reported a number of challenges they experienced when they returned to work post treatment, including memory difficulties, fatigue, co-morbid illnesses and wound healing issues.

The concept of 'chemo brain' was highlighted by many participants as a side effect they suffered when working:

*I found that quite difficult that I wouldn't have been as sharp as I was' (Betty).*

Most participants identified fatigue as a significant physical side effect experienced in the workplace, as they felt lethargic and flattened during the day. Working, after recently finishing radiotherapy treatment, also proved to be a difficult experience and caused further illnesses for Josephine. Additionally, difficulties with wound healing were reported by participants to be a negative experience when back at work. Betty also encountered complications, as surgery was needed for an encapsulated implant and additional time off work was required to recover. Although the participants reported many side-effects and complications that affected them when back at work, the majority believed this did not hinder their ability to carry out their work:

*I had loads of side-effects but there was nothing that I couldn't handle with the medication'*  
(Mary).

## **Discussion**

This study provides an in-depth exploration of the experiences of returning to work following BC in Ireland. Overall, the findings are consistent with international studies of work-related experiences of cancer survivors (Amir *et al* 2008; Taskila and Linbohm 2007). It is evident from the research findings that four key factors enhance our understanding of BC survivorship and employment; personal factors, employer factors, work-related factors and health professional factors.

The findings revealed a number of personal issues which affected participants' experiences of RTW such as their emotional influences to return and the side-effects of treatment. In line

with a literature review on employment and cancer survivors by Peteet (2000), the aspiration for moving forward and regaining control and normality of their lives was a significant driver to RTW for participants. Having strong will power and being determined to return were also reported to influence RTW decision-making, which coincides with characteristics identified in literature on experiences returning to work after a stroke (Vestling *et al* 2011; Gilworth *et al* 2008). A systematic review has also shown that physical limitations following cancer, such as fatigue and pain, significantly reduce strength and stamina in the workplace and memory deficits can affect work ability (Duijts *et al* 2014). Although participants of this study identified several physical and cognitive limitations when they returned to work, unlike previous studies, they reported the challenges were manageable and did not impact their work. Moreover, Sharp & Timmons (2011) identified factors associated with work resumption among cancer survivors in Ireland to include: completion of third-level education, not receiving chemotherapy, receiving sick pay and not having a medical card. This study is consistent with a proportion of Sharp & Timmons (2011) findings as six out of seven participants held professional roles which is indicative of tertiary education, six out of seven received sick pay from employers and the majority of participants did not receive chemotherapy. However, medical card status was not reported.

The participants of the study highlighted a number of factors relating to their employer that impacted their RTW experience. Similar to former qualitative studies of cancer survivors, those who received sick pay from employers were grateful, but the financial stress experienced when sick leave entitlement was expiring was considered to influence the decision to RTW (Amir *et al* 2008; Kennedy *et al* 2007). Participants who experienced a negative experience of RTW, reported a lack of collaboration with employer, implementation of strict policies with the impossibility of a phased RTW or being assigned easier duties. These findings are parallel to findings of a study by Tiedtke *et al* (2014), who demonstrated that employers perceive the return of an employee with BC as an intangible process, admitting to their tendency to follow their own judgement and be influenced by the nature and procedures within the organization. Moreover, this study's findings on employer factors are consistent with literature on RTW experiences of people with chronic back pain, with a gradual RTW and other work role accommodations identified as the crucial enablers to a successful RTW experience (Ryan *et al* 2014; Dionne *et al* 2012).

Keeping in line with previous qualitative research on cancer survivors, work-related factors such as the availability of a phased RTW, was identified in this study to help participants

manage better and allow for a successful transition (McKay *et al* 2013; Main *et al* 2005). This finding is also supported by Liddle *et al* (2008) who found that coping and acceptance must take place for a transition to be successful. Further work-related factors identified by this study include the social relationship with colleagues and the nature of the job as influencing participants RTW transition. Previous studies have highlighted that a supportive team of co-workers is a significant enabler, by keeping in contact while cancer patients are off from work for treatment and helping to ease them back to work (McKay *et al* 2013; Kennedy *et al* 2007). However, participants in this study identified a lack of colleague support during sick leave and only one participant commented on the social interaction of colleagues as an enabler in their RTW transition. According to Jonsson (2011), the transition experience varies for each individual, as one individual may perceive the outcomes of a transition as positive, while another may perceive a similar transition as negative. Interestingly, a participant who worked in management reported some benefits to the autonomy of her role in aiding her transition, while two other managers reported the high level of expectation in their role increased the challenge associated with RTW transition. Moreover, an integrative literature review exploring transition identified qualities of transition to be challenging, involving adaptation of roles and can be influenced by the environment (Crider *et al* 2015). This finding coincides with the accounts of the participants in this study, as the area and nature of their work proved to create a challenging transition back to the workplace which often involved difficulties coping, readapting to the role and a change in employment.

A small number of participants received occupational health support when they RTW post treatment. However, an important finding of this study, which concurs with international qualitative research, is the lack of advice provided by health professionals about when to RTW following cancer and the lack of guidance on work ability and sustainability (Bains *et al* 2012; Kennedy *et al* 2007; Main *et al* 2005). The findings extend previous research, as participants also reported a lack of support once they finished treatment and a lack of professional advice on how to deal with the side-effects and get back to their daily occupations. Furthermore, despite studies estimating that 62% of cancer patients RTW and the advances in cancer treatment and management, cancer survivors still experience an increased risk of unemployment due to challenges such as those identified in this study (deBoer *et al* 2009; Spelten *et al* 2002).

## **Study Limitations**

Although this study takes an important step forward in understanding the RTW experiences of BC survivors in Ireland, it is acknowledged that several limitations restrict conclusions that may be drawn. While interviewing the small sample size of seven participants provided in-depth insight, their accounts are not considered representative of all BC survivors' work-related experiences in Ireland. The study aimed to interview participants who have returned to work. However one participant had not returned to employment and another participant was unsuccessful and forced to find work elsewhere. With this in mind, a larger sample size with more specific inclusion criteria would contribute to a more comprehensive understanding of RTW experiences of this population. It is also important to acknowledge the limited experience of the student researcher in conducting qualitative interviews. Furthermore, the use of member checking may have enhanced the rigour and trustworthiness of the study (Babbie 2014).

## **Implications for Future Research**

Future research should involve a larger sample size in the form of a longitudinal study, as it would be interesting to explore the RTW experience of BC survivors at different stages, to understand it as a transitional process. Given the body of literature available on cancer survivors' experiences of returning to work, it is recommended that future research would focus on specific factors of RTW experiences, such as, the relationship with the employer or the financial experience of sick leave. As this research study used broad inclusion criteria, future research should focus on a more specific group to achieve a more comprehensive understanding of the RTW experience. It would be interesting if future studies explored the experience of people who: have had BC and who received particular treatment e.g. chemotherapy, experienced troublesome side-effects following treatment e.g. lymphedema, or male BC survivors RTW experiences. Moreover, inclusion criteria of a particular social class or type of job e.g. public or private employment, would also be an interesting advance on current literature on BC survivors. As employer support appears to be essential to creating good working conditions for BC survivors, it would also be beneficial to interview Irish employers, to gain their perspective on their roles and responsibility for employees RTW following BC.

## **Implications for Occupational Therapy Practice**

Within the discipline of occupational therapy, paid employment is considered an activity that is high in productivity, which means the activity is experienced for the outcome and goal dimension (Pierce 2003) which enhances one's physical and mental health (Waddell & Burton 2006). Employment can be beneficial for individuals by providing a sense of meaning in life and influencing their sense of identity, self-esteem and social status (Macmillan 2013). Désiron *et al* (2015) proposed that occupational therapists can effectively respond to BC survivors unmet needs regarding RTW, due to their skills in facilitating the rehabilitative transition from sick leave to the workplace. Although this study found that physical and cognitive side-effects did not impede participants ability to work, it is clear BC survivors still experience a number of challenges when they RTW. Therefore, it is recommended that occupational therapy interventions should have a holistic and client-centred approach, to provide BC survivors with education on coping strategies and prepare them emotionally and physically for the transition of RTW. Based on the study's finding that the level of support and flexible work conditions, provided by employers, are a significant factor of the RTW experience, occupational therapy interventions should involve workplace visits, advocating for the BC survivor, while advising and negotiating with employers on suitable work accommodations. The study also found there is a lack of professional advice to guide RTW decision-making for BC survivors. Occupational therapists have the skills to use goal setting to start up tailor made rehabilitation, linking assessment of abilities and work, to help with the decision to RTW (Désiron *et al* 2015). Therefore, based on international research and the challenges identified by participants in this study, occupational therapy is a recommended support for BC survivors to provide them with the necessary guidance in decision-making, coping skills and communicating with employers for appropriate working conditions, to resume work effectively.

## **Conclusion**

This paper aimed to explore the RTW experiences of BC survivors in Ireland. The themes that emerged from the data highlight aspects that influenced the transition; the provision of sick pay, the lack of advice from health professionals in supporting their RTW, their emotional readiness on deciding to return, the employer's pivotal role in providing a supportive transition and the side-effects of treatment experienced when back at work. As discussed above, these findings are in line with previous international studies on BC

survivors work-related experiences. However, this study enhances our understanding of BC survival and employment within the Irish context. Furthermore, this study shows there is a need for occupational therapy in vocational rehabilitation for BC survivors, to educate, advocate and advise on accommodations, to enhance their ability to return and remain in employment. The results of the study have the potential to guide future policy and provision of services to support BC survivors resuming work.



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