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Impact of employers on the return to work experience of breast cancer survivors in Ireland

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Abstract

Background:

In Ireland, one in ten women will develop breast cancer (BCA). It is estimated that 85% survive BCA. Return to work (RTW) can be an important goal for many survivors on their recovery journey. Employers are key stakeholders in the RTW experience of cancer survivors. There is little research completed in Ireland evaluating the perspective of employees on the role of the employer in RTW. This study seeks to address this gap in research, with a focus on how BCA survivors experienced the role of their employer in facilitating and/or hindering their RTW experience.

Method

The study adopted a qualitative methodology. Seven semi-structured one to one interviews were completed with BCA survivors who had experienced RTW in Ireland.

Findings

Through thematic analysis, four themes were identified. These include: employers don't participate in the RTW decision; the quality of the employee/employer relationship influenced the RTW experience; employers' enactment of organisational policies impacts RTW experiences and the employer management of reintegration back into the workplace impacts on RTW experience.

Conclusion

This study suggests that the employer plays a primary role in the RTW experience of BCA survivors. Findings indicate that employers facilitate the RTW experience to some extent, but they hinder the experience to a much greater extent. Findings of this study do not reflect employer best practice guidelines for supporting employees RTW following sick leave. The findings combined with existing literature suggest that there is a need for vocational supports for BCA survivors and that employers can and should be an integral part of this process.

Introduction

In Ireland, 2,600 individuals, both male and female, are diagnosed with breast cancer annual (Irish Cancer Society 2015). The five- year relative survival rate for breast cancer (BCA) survivors was 85% during the period of 2008-2010 (NCRI 2014). This high percentage of survival indicates that following recovery, return to work (RTW) is an important goal for many survivors (Amir *et al* 2008). Employers are key stakeholders in the RTW experience of cancer survivors. This study explores the RTW experiences of BCA survivors with a focus on understanding how the employer hinders and facilitates this transition.

Literature Review

According to the World Health Organization BCA is the most prevalent malignancy among women globally. The WHO reports that there are approximately 1.38 million new cancer cases each year (Ferlay *et al* 2010). In Ireland, one in four women will develop a form of cancer once in their lifetime (NCRI 2014), with one in ten of these women developing BCA. The figures collected by the National Cancer Registry Ireland, highlight the growing number of individuals diagnosed with BCA. While the figures indicate a cause for concern and increased awareness of the condition, the 85% five-year relative survival rate for BCA patients (NCRI 2014) provides many with hope after diagnosis.

For many survivors one occupation that is meaningful and important is paid employment (Amir *et al* 2008, Bains *et al* 2012, Mehnert and Koch 2013). It is of social and economical importance that we understand the lived experiences of BCA survivors to provide them with a positive transition back into the workplace. Whether paid or unpaid, work provides individuals with financial security, social interactions and a good quality of life (Waddell and Burton 2006). Positive health and well-being is associated with individuals' engagement in employment as an occupation (Wilcock 2006).

Vocational Rehabilitation (VR) is identified as a successful support system that helps individuals with illness or disability to remain in employment or transition back to work following leave of absence (Ekholm and Schüldt Ekholm 2009, Waddell *et al* 2008, Sinclair *et al* 2014). Cancer can disrupt work engagement for individuals (Peteet 2000, Mehnert and Koch 2013). Occupational Therapists working in VR bring specialist knowledge to the occupational performance patterns of individuals and their engagement in work (Frost *et al*

2013). Many BCA survivors do not RTW following treatment (De Boer 2009). A quantitative study, representative of 346 breast and prostate cancer survivors in Ireland found that 16% did not intend on returning to employment following cancer treatment (Sharp and Timmons 2010). The implications of not returning to the workforce can lead to a weakened sense of identity and belonging (Amir *et al* 2008, Rasmussen and Elverdam 2008). Unemployment among cancer survivors was found to increase the risk of decline in individuals physical and mental health (Carlsen *et al* 2008).

The transition back into the workplace can be challenging for many BCA survivors. The employer plays a primary role in influencing the RTW experience of cancer survivors (MacMillan 2013). A positive relationship shared between an employer and the employee can ease the work rehabilitation process (Amir *et al* 2008, Mehnert and Koch 2013). Employers who demonstrate flexibility with duties of work and offer a phased RTW are regarded as facilitators in the RTW process for cancer survivors (Spelten *et al* 2003, Amir *et al* 2008, Islam *et al* 2014). In contrast, employers who do not make such accommodations to employee workload or do not offer a phased RTW are identified as hindering the RTW experience (MacMillan 2013).

It is highlighted by Peteet (2000) and Amir *et al* (2008) that there is a need to further research the role of the employer in the transition process of RTW for cancer survivors. This research study contributes to filling this gap with specific focus on BCA survivors.

Study Aim

This study aims to identify how employers facilitate and/or hinder the RTW experience for BCA survivors in Ireland.

Methodology

A qualitative approach was selected as the most appropriate for this study as it facilitated the researcher to obtain a valuable understanding of the lived experiences from the viewpoint of BCA survivors. Qualitative methods are chosen by researchers when they value exploring people's life history or everyday experiences (Silverman 2000). Qualitative research is widely regarded as an appropriate methodology approach in obtaining meaningful and rich data on personal or sensitive subjects (Denzon and Lincoln 1994, Holloway 2004).

Participants

Purposeful sampling was utilized with participants recruited through a social media advertisement on the Irish Cancer Society Facebook and Twitter accounts. The recruitment strategy was extended to members of the public and a BCA specific organisation 'The Marie Keating Foundation' voluntarily sharing the advertisement on their Twitter and Facebook accounts. The inclusion criteria were men and women, aged over 18 years, who have had BCA and have experienced RTW. In total seven participants voluntarily agreed to partake in interviews (see table 1). All participants were female. Participants came from various backgrounds of employment with four public sector employees and three private sector employees.

Table 1: Participants

Name	Employer	Employment Area	Current Employment Status
Una	Public	Health and Social Care	Returned to Work
Mary	Private	Private Industry	RTW after BCA and then subsequently on sick leave again at time of interview
Diane	Public	Health and Social Care	Returned to Work
Lucy	Public	Health and Social Care	Returned to Work
Sarah	Public	Education	Self-employment and actively seeking employment
Claire	Private	Private Industry	Returned to Work
Amy	Private	Health and Social Care	Returned to Work

Data Collection

Data was collected through in - depth semi structured face to face interviews. These types of interviews empower participants to lead the conversation through the flexibility and adaptation of questions throughout the natural flow of the interview (Stein *et al* 2013). Interviews ranged from 25 minute to 60-minute duration. Interviews were audio recorded using a dictaphone.

The researcher followed a set of guiding questions and introduced follow up techniques. Qualitative interviews acknowledge that the participant is the expert in their own lived experiences and the researcher is the learner (Hennink *et al* 2011). The interview schedule opened with overview questions in relation to the participants' work history and led on to participants' diagnosis of BCA. The interviewer then asked specific questions on the factors that influenced the RTW experience. The interviewer concluded by inviting participants to input any advice they would give to employers or other BCA survivors on RTW. Interviews were transcribed verbatim by the author, using pseudonyms to maintain participant anonymity.

Data Analysis

Data was organised and analyzed using Nvivo software. Thematic analysis (Braun and Clarke 2006) was chosen to systematically organize, analyse and describe the findings of the data set. Thematic analysis is regarded as a flexible research tool that facilitates the researcher to obtain a detailed analysis and account, representative of the original data (Braun and Clarke 2006). The researcher completed data analysis adhering to Braun and Clarke's six stage guide (see table 2).

Table 2: Braun and Clarkes' Six Stage Guide for thematic analysis

1. Becoming familiar with the data.	Multiple readings of the transcripts was completed
2. Generating initial codes.	Nvivo software was used to code data. Coding was completed with identification of key words, identifying repetitive patterns of meaning in the data.
3. Searching for themes.	Codes were categorised with consideration to patterns identified in data set. Emerging themes were identified from these categories and codes. Four themes were developed as representative of the data findings.
4. Reviewing themes	Themes were reviewed with consideration to all codes generated and categories organised in keeping with participants' experiences.
5. Defining and naming themes.	Four themes were titled to reflect main findings of all interviews
6. Producing the report.	The researcher wrote up findings report according to the four themes identified.

Rigour

The principles of credibility, transferability, dependability and conformability are key considerations to ensure the trustworthiness of qualitative studies (Guba and Lincoln 1989). Credibility was addressed in the transcribing of audio interviews verbatim. Transferability, dependability and conformability of this study were all addressed in the keeping of an audit trail. The audit trail provides detailed information on the researchers' actions and decisions at all stages of the research process (Guba and Lincoln 1989). To address reflectivity, the researcher maintained a reflective journal, identifying any prejudgments and an awareness of any personal bias they may bring to the study (Hennink *et al* 2011).

Ethical Considerations

This research study received ethical approval from the Faculty of Education and Health Sciences Research Ethics Committee (University of Limerick). The qualitative approach to this study required the researcher to adopt measures that addressed all ethical principles: informed consent, self determination, minimization of harm, anonymity and confidentiality (Hennink *et al* 2011).

All participants were provided with an information sheet outlining background and purpose of the study. Informed consent was obtained by inviting participants to voluntarily sign a consent form prior to interviews. Participants were informed of their option to withdraw from the study at any time without any consequences. Participant confidentiality was maintained using pseudonyms. The researcher endeavored to ensure no harm came to the participants during the research process. Participants were provided with a list of available support services following completion of the interviews. Interview recordings were stored on a password-protected computer, and following transcription the recordings were deleted. Access to the research data was limited to the relevant research parties only. Transcripts will be stored in a secure office at the University of Limerick for seven years, after which they will be destroyed.

Findings

Six of the participants that took part in this study returned to work following their treatment while one participants' (Sarah) journey is still developing. Sarah's differing experience is attributed to the nature of her employment contract prior to cancer diagnosis. The contract ceased upon sick leave and she returned to self employed work on a part time basis. The findings from the seven interviews completed are presented through four themes.

Theme 1: Employers don't participate in the RTW decision

Overall, participants reported that employers don't participate in the RTW decision. Six of the participants reported that their employer played no direct role in the decision making process to RTW and reported that the decision to RTW was self initiated;

"I just went to my team manager and she said to me 'are you sure'? and I said I don't know, I won't know until I'm back, so I said I'll just have to go with it.....no advice at all, just if you feel fit to go back to work, go back to work"

(Una)

One participant was the exception as she received employer input. Mary describes her experience to which her employer did play an active role in the RTW decision. The employer input into this decision was negatively experienced by Mary, who explains further;

"I was put under a lot of pressure to return to work, I was put through an awful ringer then, which I think the company are embarrassed by now ..I was sent for mental assessments, actually, which was very harsh I felt at the time..I was sent to an occupational physician.....he said that I would be able to return on reduced hours"

(Mary)

Theme 2: The quality of the employee/employer relationship influenced RTW

The quality of the relationship held between employees and their employers was reported to be influential in RTW experience. Participants collectively reported positive and negative experiences of this relationship. Employer policy and employer personal characteristics were reported to influence the quality of the relationship.

Six of the participants identified having some form of contact with their employer when on sick leave. Four of these participants recalled how this contact was linked to employer policy on sick leave;

“So there is a matter that the boss has to make contact with anyone who is on long term sickness leave,.. so there was regular enough contact.....Texts, phone-calls and eh causal call out.”

(Diane)

Participants who held a close working relationship with their employer prior to going on sick leave felt more supported during the RTW process;

“You know we have a very close working relationship here in that our manager at the time...he was like ‘ok just keep me informed and whatever we need to do and that’s fine”

(Lucy)

The close relationship Amy held with her supervisor influenced how she experienced a positive phased transition back into the workplace;

“I mean I worked with her for the last (number) of years...so we were close.... so what (supervisor) had suggested that time was she said "I think what we'll do is, we'll start you on two days and a day's holiday for the first few weeks and see how you go"

(Amy)

Some participants reported that their employer’s personality impacted on the RTW experience, as described by Mary;

“she did, she did (support),.. em’ but I think, how will this sound..in her personality, I think she liked the drama of supporting someone who had breast cancer, so whether her support was as genuine as an ordinary person might have been? .. She liked the drama to be able to flag to people senior to her”

(Mary)

Claire also reports on employer’s personality in her experience;

“My particular team leader, she’s a lovely woman but she had not much tact..she’d come over and.....(say) like ‘oh I was watching this programme on cancer’so I think that

was one of the reasons I wanted to leave as well because I didn't want to always be that person that had cancer”.

(Claire)

Theme 3: Employers enactment of organisational policies impacts RTW

The enactment of organisational policies was reported by all participants to have had an impact on their RTW experience. Employer policies impacted financial supports and on the terms and conditions associated with RTW.

Six participants received some form of financial support from their employer while on sick leave. Three of the participants who worked within the public sector shared similar experiences;

“pay was got for 6 months - full pay, then got 6 months half pay”

(Una)

In contrast, three of the private sector participants reported that the amount of financial support and duration for them was slightly lower;

“so for the first three months you get full pay, for the next three months you get 75%.... altogether you can get a year like, so the further 6 months then goes into 50% as in half pay”

(Amy)

One participant had a very a different experience, who due to lack of employer policy protection was reliant on state support in the form of social welfare payments while on sick leave;

“when you're out you don't get paid because you were never permanent so there's the snag.....Nothing I received nothing (from employer) ... I had disability benefit so I did....and that's a big massive let down to come from a salary to that welfare payment”

(Sarah)

Despite financial supports from their employer or state, the majority of the participants reported feeling dissatisfied with the level of financial support and the timeframe. This contributed to the pressure felt by participants to RTW for financial reasons;

“(satisfied) Oh absolutely not! sure that's why all the financial strain has been absolutely worse than having cancer itself”

(Sarah)

The enactment of employer policy extended to impacting on the terms and conditions of how participants RTW after their sick leave. Three participants reported employer policy as rigid and not flexible.

“so while they have really good sick leave policies there are very rigid you know, there is no flexibility to look at each”

(Lucy)

This rigidity and inflexibility is further explained through Lucy’s narrative when she sought accommodations to attend clinic appointments in the mornings;

“because I went to them and said look I just need some time everyday to go, they said well you know, you have to either take annual leave or..build up that time and you owed it back. I thought that was really unsupportive in the situation I was in”

(Lucy)

Theme 4: Employers management of reintegration back into the workplace impacts on the RTW experience

The management of reintegration was reported to have an impact on participants RTW experience. Employers management included provision of accommodation, phased return, and workload management.

Four participants describe their experience of not receiving accommodations to ease the transition back to work. Una described her expectations about RTW;

“I would have expected management... maybe to have found me some office based work just to break me in”

(Una)

One participant described previous experience (prior to current employment) of RTW after cancer where accommodations were not provided;

“I had to be slightly re-trained because the job had changed.. So the retraining didn't really happen so I kind of never.. I always felt long footed because I felt that I had never been fully

trained in the new work flow. So that was another reason why I was not happy there and I wanted to leave”

(Claire)

The option to RTW on a phased basis was a preference highlighted by the majority of participants. Despite this, three participants reported that their employer did not give them the option for a phased return. Lucy describes her experience;

“I remember having a conversation with HR, I rang them and I said ‘is there a possibility of me coming back say mornings only’ because I feel like what I need is phased in ...going back full time Monday morning, it’s a big leap...and I don’t think that does any service to your job or you as an employee”

(Lucy)

Lucy’s request was declined and she went on to say;

“I had gone through something physically and psychologically traumatic and yet it was like ‘oh your back to work, right great!’, ...I felt like I was treated like someone... I was no different to someone who had the flu”

(Lucy)

Four participants reported that their employer made no accommodations in reducing their level of workload. The expectation to perform to a high level was identified;

“there would have been an expectation that I would deliver the same kind of performance, and however everyone would say we’ll ease her back gently,.. the reality is I’m a ranked official and there is an expectation that I’d be able to deliver to the level I used to”

(Mary)

In contrast to the majority, one participant recalled how she felt supported and reassured in the accommodations made for her in RTW on a phased basis as recommended by her employer;

“I don’t think they could have done much more for me. It was nice even to be told by HR when she said like ‘if you have problems now come to us so we can swap around your hours’.

(Amy)

Discussion

This study sought to understand how employers facilitate and/or hinder RTW for people with BCA in Ireland. The findings of this study have reported that for the majority of participants, the employer hindered on RTW experiences rather than facilitated. The employer role was identified through four themes;

- Employers don't participate in the RTW decision.
- The quality of the employee/employer relationship influenced the RTW experience.
- Employers enactment of organisational policies impacts RTW experiences.
- The employer management of reintegration back into the workplace impacts on RTW experience.

It is clear that current employer practice as detailed in the participants' experiences in this study is not aligning with best practice guideline recommendations. The NICE best practice guidelines (2009) on the management of 'Workplace Health: Long Term Sickness Absence and Incapacity to Work' propose that a multi agency approach should be adapted when supporting individuals on sick leave re integrate back into the workplace. This approach was not found in the majority of the participant's experiences.

A lack of employer understanding on the supports required for BCA survivors is identified in the findings of this study. Similarly, a mixed method research study in the United Kingdom (Kennedy *et al.*2007) found that insufficient RTW support was attributed to a lack of employer awareness of the needs of cancer survivors. An employer work assessment with an employee prior to RTW is recommended under the NICE (2009) guidelines. Assessment would consider individuals physical and mental health, the employees perceived confidence and ability to RTW successfully. Findings of this study indicate the need to adapt similar assessments for BCA survivors in order for them to receive appropriate and necessary accommodations in their RTW experience.

There was widespread diversity noted in the flexibility of employers to offer accommodations; support in the RTW decision, reduced workloads and offering a phased return. Interestingly, four participants, all employees of the public system reported a negative rigidity and inflexibility in the implementation of large scale organisational policy. These

participants reported feeling overwhelmed and challenged by workload demands upon RTW. In contrast, two participants, both employees in the private sector, reported on more flexible employer policies where phased return and reduced workload were an option. One would question the level of individual consideration taken when implementing organisational policies to those returning after cancer treatment.

Employer policies on provision of financial support and the time limits for receipt of sick pay was reported as contributing to a pressure felt by participants to RTW early. These findings are consistent with those of (Kennedy *et al* 2007, Sharp and Timmons 2010) who also reported on pressure felt by cancer survivors to RTW early due to financial concerns. In Ireland, a study undertaken by Sharp and Timmons (2010), reports that 31% of 364 participants found that their household income had decreased during sick leave for cancer treatment. Reasons for the decrease in income was linked to the continuous reduction in employer sick pay over the course of their absence from work.

It is evident from participant experiences that there is an inconsistency in how employers manage RTW of BCA survivors in Ireland. The Irish Congress of Trade Unions (2014) published guidelines for assisting workers with BCA in the workplace. This guiding document outlines best practice guidelines to which the employee themselves or a trade union representative will negotiate with the employer on sick leave and RTW conditions. The guide proposes the development of an individual 'Time Off Work Plan' which would outline agreed employer accommodations to work regimes. No participants of this study made reference to utilising a trade union representative. It is therefore questionable as to what extent these guidelines from the ITCU are being implemented.

Parallel with the findings of Amir *et al* (2008) study, the quality of the employer/employee relationship was found to facilitate but also hinder the RTW experience. Holding a positive relationship with employers facilitated RTW experience for cancer survivors. The participants of Aas *et al* (2008) study, describe a valued employer, as somebody who holds qualities of supporting an employee RTW. These qualities include the ability to make contact, being considerate, understanding, empathetic and appreciative. From this study, the findings indicate that employers can hinder RTW experiences as the participants' employers did not demonstrate such qualities in the majority of experiences.

Implications for Professional Practice

The findings of this study add to the limited literature available in an Irish context on the experience of BCA survivors RTW. The findings collectively suggest that there is a need for a RTW transition programme for cancer survivors in Ireland. A programme would aim to bridge the imbalance between employee expectations and employer practice. In line with best practice guidelines (NICE 2009, ITCU 2014), such a programme should adopt a multi agency approach to optimise the best potential for successful RTW for BCA survivors. Evidence suggests that vocational rehabilitation (VR) is an appropriate response system that can meet the needs identified (Désiron *et al* 2015, Hoving *et al* 2009).

According to (Sinclair *et al* 2014), VR is concerned with matching an individual's limitations with their abilities to meet the demands of their job and participation within their work environment. VR involves working closely with the employee and their employer (Waddell *et al* 2008). Occupational Therapists hold the appropriate skills to effectively meet the needs of BCA survivors RTW (Désiron *et al* 2015). An Occupational Therapist understands an individual's functional abilities in relation to their medical condition (Stuckey 1997) and is regarded as an appropriate clinician to be working in VR. Occupational Therapists bring specialist knowledge to the occupational performance patterns of individuals in VR (Frost *et al* 2013).

Occupational Therapists consider all factors that influence an individual's re engagement in employment following an illness, including the individual's physical and mental health. The Occupational Therapist working within VR takes on an intermediary role between the employee and the employer, supporting both parties to effectively achieve a positive RTW experience. This study found that the majority of participants did not have the support of a third party advocating for appropriate supports and work accommodations prior to their RTW. As highlighted in the work of (Frost *et al* 2013) an Occupational Therapist in VR aims to explain the employees' perspective to the employer. With consideration to the findings of this study, an Occupational Therapist could provide advice to the employer on how best to grade RTW transitions for the employee, grade employee work duties and adapt the workplace environment according to the needs of both parties.

VR programs have proved successful in meeting the RTW needs of many individuals with rheumatic diseases (Allaire *et al* 2003) and musculoskeletal problems (Selander *et al* 2006). As identified in the work of (Desiron *et al* 2015) VR has the potential to extend its practice to support BCA survivors RTW.

This study and its findings encourages us to consider all options available to positively support individuals with breast cancer RTW. The findings of this study also indicate that employers may not be aware of employee needs and how best to support their transition. VR is considered an appropriate option in meeting the needs of all involved in the RTW experience.

Study Limitations

This study was conducted with seven female participants. The experiences of male BCA survivors were not obtained as no males volunteered. Four participants were employees of the public sector and three from the private sector. The imbalance lends itself to the over representation of public sector workers and findings should be interpreted with this awareness. Given the voluntary nature of recruitment, participants may have felt more strongly about their experience than other BCA survivors. The researcher acknowledges that the findings may not be representative of typical RTW experiences from a generalized population of BCA survivors.

Identification of future areas for development and research

This study captured the experiences of RTW for a small number of BCA survivors, all of which were female. A similar research approach to a larger sample of mixed gender participants is recommended. Nevertheless, the experiences of this study's participants has highlighted the diversity in how employers manage the RTW of employees following leave for cancer treatment. It has been made clear that a more universal and multi agency approach is warranted for the delivery of RTW supports to all employees regardless of their employer. It is with this in mind that advocating for policy change on a national level is required to ensure all cancer survivors receive the same level of support and accommodations. Additionally, employers need to become more aware of the said or unsaid needs of supporting an employee RTW following BCA. Further research into Irish employers current understanding would be of benefit.

Conclusion

This study provided a platform for individuals who had BCA to share their perspective on RTW with a focus to how their employer hindered and/or facilitated the transition. Findings indicate that employers facilitate but to a greater extent they hinder the RTW experience of BCA survivors. Challenges met by the participants included; lack of advice from employers in making the decision to RTW; no option to RTW on a phased basis due to policy restrictions; and overall a lack of accommodations made by the employer in reducing workload demands of the employee.

Despite the workplace challenges encountered by the participants, the majority reported that work was a valued and meaningful occupation in their lives. Work provides opportunity for financial security, social interactions and positive health and well being (Waddell and Burton 2006). BCA survivors deserve the opportunity to re join a workforce that appropriately meets their occupational needs. The findings of this study combined with existing literature suggest that there is a need for vocational supports for BCA survivors and that employers can and should be an integral part of this process.

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