

Review

Experiences and concerns about ‘returning to work’ for women breast cancer survivors: a literature review

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Abstract

Objective: To explore how female breast cancer patients experience work incapacity during the treatment and return-to-work phases and how interactions between patients and stakeholders affect this experience.

Method: Database search for full text articles published between January 1995 and January 2008 that focused on employed female breast cancer patients, factors related to work incapacity, and returning to work. Only results based on self-report data were included. Studies focusing on treatment, financial factors, rate of return, or absence were excluded.

Results: Six articles met the inclusion criteria. Women with breast cancer receive varied reactions but little advice about returning to work. Women were primarily concerned with disclosing the diagnosis to their employer and to relatives. Uncertainties about physical appearance, ability to work, and possible job loss affected the women’s decisions about working during the treatment phase. After treatment, most women wanted to regain their ‘normal life’, but concentration and arm or fatigue problems potentially interfered. Although supportive work environments were helpful, the individual needs of women differed. Employers and employees need to find a balance in defining accommodating work. Many women received favourable support, but some reported feeling discriminated against. Many women re-evaluated the role of work in their lives after being confronted with breast cancer.

Conclusion: Work adjustments could help women to keep their jobs during illness and recovery. To resolve women’s concerns about returning to work, employers, physicians, and insurance institutions should consider increasing and improving communication with breast cancer patients and playing a more active and supportive role.

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Introduction

Receiving a breast cancer diagnosis is a major life event for many women, as it is the most prevalent malignancy among women in the industrialised world [1]. Breast cancer and its treatment have an immediate and striking impact on a patient’s daily life. Furthermore, many questions arise regarding prognosis, possible long-term physical and mental problems, and many aspects of personal life, including professional activities. Although a minority of women with breast cancer want to continue working during treatment, most must interrupt their working life temporarily. The greatest reduction in work hours occurs 6 months after diagnosis, during which surgery and adjuvant treatment take

place. In many cases, women make decisions about working and how treatment may influence their work without obtaining medical advice from their physician. Doctors also tend to assume that patients can decide for themselves how treatment and recovery may affect their work [2]. However, decisions made during the treatment period ‘may impact the quality of survivorship and the patient’s economic well-being for many years to come’ [[2], p. 47].

Although several studies have emphasised the importance of a supportive environment—including work environment—after cancer [3–5], little is known about women’s perceptions, experiences, and concerns about returning to work, and how these might influence their return to work. In an

overview of studies of cancer survivors, Spelten *et al.* [3] distinguished three categories of factors—work-related factors, disease- and treatment-related factors, and person-related factors—that influence whether survivors will return to work. Emotional or practical support and job flexibility, which allows returnees to schedule their work and to choose specific work activities, can improve return-to-work experiences [4,5]. Lack of supportive interactions coupled with co-worker and employer ignorance may hinder returning to work or make it more stressful [4,5]. We assume that experiences and interactions with the environment (e.g. family, physicians, employers, and colleagues) differ widely and may or may not be helpful.

This review explores how work incapacity during the treatment and return-to-work phases are experienced by female breast cancer patients and how interactions and relationships with caregivers, employers, insurance institutions, and personal environment affect this experience, which was assessed by self-reports.

Methods

Search strategy

Our search (Table 1) was confined to the electronic databases PUBMED, PSYCHINFO, EMBASE, and Web of Science (ISI Web of Knowledge). We used the search terms 'breast cancer (survivors)' AND 'return to work' or 'breast cancer (survivors)' AND 'employment', and limited our search to full text articles published between January 1995 and January 2008. To be considered as a candidate article for review, the terms 'breast cancer', 'experience', and 'work' or 'employment' had to be stated in the title or abstract. Studies were included in our review if they focused on employed, female breast cancer patients or survivors and on factors related to work incapacity or returning to the workplace. Because we were interested in women's perceptions, results had to be based on self-report data. We excluded studies that mainly focused on medical treatment-related factors or financial factors and cohort studies primarily examining the rate of return or absence. We also inspected the reference lists of the included papers to identify any possible additional studies that might have been missed during the database searches.

Search outcome

The search yielded six candidate publications, which are briefly described in Table 2. Three studies were classified as qualitative and three as quantitative. The ages of the women in the six studies varied from 20 to 88 years. Three studies were completed in Canada [8,10,11]; two in the

Table 1. Search strategy

Stage 1: initial search	
Keywords	Breast cancer AND return to work OR employment
Results	55737
Keywords	Breast cancer survivors AND return to work OR employment
Results	10275
Keywords	Breast cancer AND return to work OR breast cancer AND employment
Results	360
Stage 2: screening	
Filter	Breast cancer AND return to work OR breast cancer and employment/Field: Title/Abstract/1995–2008/Full text articles
Results	159
Filter	Breast cancer survivors AND return to work OR breast cancer survivors AND employment/Field: Title/Abstract/1995–2008/Full text articles
Results	27
Filter	Title/Abstract/'Related articles' examined for relevance
Results	12 and 8 'related'
Filter inclusion/exclusion criteria	Articles examined for relevance. 'Related articles' of relevant articles examined for relevance. Manual searching in bibliographies of relevant articles. Consultation of experts
Results	6
Criteria	
Inclusion	Focus on employed, female breast cancer patients and on factors related to work incapacity or returning to the workplace. Results based on self-report data
Exclusion	Focus on medical treatment-related factors/financial factors. Cohort studies primarily examining the rate of return/absence

United States of America (USA) [6,9]; and one in the United Kingdom (UK) [7]. Data for these studies were collected by using individual, focus group, or telephone interviews, except for Stewart *et al.* [11], who used a questionnaire.

Appraisal

There is little consensus on how to appraise a collection of qualitative and quantitative articles [12]. Quantitative studies are judged in terms of reliability and validity, whereas evaluative criteria of qualitative studies are based on trustworthiness [13]. Thus, we used some general points of interest, as presented by Dixon-Woods *et al.* [14] and Kearney [15], to evaluate the rigour of the included studies.

The three qualitative studies gave a detailed description of sampling, data collection, and analysis procedures. The study population varied from 13 French-speaking subjects [8] and 29 [7] to 102 subjects of various ethnicities [6]. Maunsell *et al.* [8] restricted their study to women who spontaneously reported their work-related problems to a nurse or physician. By contrast, in

Table 2. Studies included in the literature review

Author, origin	Design	Sample	Data collection	Employment variables/themes	Analysis
Ashing-Giwa <i>et al.</i> [6] USA	Qualitative, explorative	102 breast cancer survivors	Focus group interviews	Health beliefs, health socialization, relationships, quality of care, socio-economic status, socio-ecological factors	Thematic content analysis, comparative analysis through ethnic groups
Kennedy <i>et al.</i> [7] UK	Qualitative, explorative	29 participants having received a cancer diagnosis in the last ten years, 24 with breast cancer	Semi-structured interview ($n = 19$), focus groups ($n = 4$, $n = 6$)	Experience of work after cancer, support and adjustment at work, attitudes about work, individuals' reasons for returning, any problems or difficulties, advice from health professionals, support at work, and work adjustments that helped or would have helped	Thematic analysis
Maunsell <i>et al.</i> [8] Canada	Qualitative, explorative	13 breast cancer survivors who had paid employment at diagnosis	Individual interviews	Diagnosis and effect on co-workers, physician's approach to work issues, apprehensions about returning to work, unwanted changes in work situation, changes in work capacity and attitude to work	Thematic content analysis
Bouknight <i>et al.</i> [9] USA	Quantitative, retrospective	416 employed women with newly diagnosed breast cancer	Telephone interview	Type of occupation, full-time employment, self-employment, presence or absence of sick leave and health insurance, job involvement, job tasks, perceived employer accommodation, perceived employer discrimination	Univariate analyses, logistic regression
Maunsell <i>et al.</i> [10] Canada	Quantitative, retrospective	646 survivors 3 years after diagnosis 890 women comparison group	Telephone interview	Changes in work situation, reasons for stopping work, changes in working conditions	Descriptive statistics, binominal regression
Stewart [11] Canada	Quantitative, retrospective	378 survivors, disease-free for 2–47 years	Questionnaire (anonymous)	Confidentiality, disclosure, career change, early retirement, work ability, perceived discrimination	Descriptive statistics

Ashing-Giwa *et al.* [6] and Kennedy *et al.* [7] participants were recruited from cancer support groups. Because of the various ethnicities, Ashing-Giwa *et al.* [6] employed experienced and trained bilingual research assistants. Except for Kennedy *et al.* [7], the studies used informed consent and obtained approval from an ethical committee.

The research questions that were asked were suitable for qualitative research: all the studies searched for experiences of work after cancer and obtained information directly from women who had a breast cancer diagnosis, either through focus groups or through in-depth interviews, using semi-structured or open-ended questions. No description of how the qualitative studies guaranteed trustworthiness was given, except for the stated use of audiotaped and transcribed interviews. One study used thematic analysis [7], two studies used content and theme analysis [6,8].

Regarding the quantitative studies, detailed information was given about the study population ($n = 378$, $n = 416$, $n = 646$); design (retrospective); and recruitment procedures. Participants were identified from Cancer Registry Systems or support

groups, and approval was obtained from an ethical committee. Maunsell *et al.* [10] assessed whether there was evidence of work discrimination associated with breast cancer diagnosis; Bouknight *et al.* [9] examined the impact of demographic, clinical, and employment characteristics on returning to work; and Stewart *et al.* [11] examined the experiences of breast cancer survivors and determined how cancer affected confidentiality, work, and insurance. All quantitative studies also used self-reported data: an anonymous questionnaire in the case of the Stewart *et al.* [11] study and telephone interviews in the Maunsell *et al.* [10] and Bouknight *et al.* [9] studies. To increase validity, the latter studies implemented questionnaire scales that were extracted from existing or widely used questionnaires [9] or pre-tested among survivors and comparison groups [10].

Data abstraction and synthesis

All included studies described survivor's experiences towards disability and returning to work. To

compare the qualitative and quantitative findings, the reviewer (CT) isolated and categorised 'experience' findings and summarised them into relevant themes (thematic analysis): disclosure, privacy, fear, anxiety, needs, expectations, attitudes about work, advice, support, discrimination, work adjustments, work situation. Subsequently, the in-depth qualitative and the complementary quantitative findings from questionnaires were integrated and divided into 'women experiences' and 'environmental reactions'. This process of abstraction and synthesis was also discussed with the co-authors [16,17].

Results

Patient experiences

Experiences about disclosure and privacy

Receiving the cancer diagnosis appeared to be an important moment that influenced the patients' interactions with others. Women feared that this personal news might affect relationships and their job or career [11]. In Stewart *et al.* [11], two-thirds (total $n = 378$) of the women disclosed their illness to family and friends, and one-half disclosed their illness to employers and co-workers. Some ($n = 13$) were forced to do so when receiving the diagnosis by telephone at work [8,11]. One reason for not revealing the cancer diagnosis was that the women felt uncomfortable embarrassing or upsetting others, and for some they reported that it would be too personal an experience. Women also feared disclosure because they did not want to be the subject of gossip, and some were worried about the stigma that might be attached to such a diagnosis [11]. Nevertheless, women perceived that they could not hide this information from their employers, because of the time-off needed for appointments, surgery, and treatment [7,8]. Some women, however, chose to stop working to avoid disclosure, or did not attend all treatments to avoid losing their jobs [6].

When sharing the cancer diagnosis, women received different reactions from the environment. A majority felt that disclosure had positive effects, including receiving more support and advice [7,11]. More than half of the women felt closer to the people they talked to about their diagnosis. However, for some women, disclosure was an uncomfortable experience because of the inadequate reaction of their supervisor or co-workers. Some even felt pressured to leave their job [6,11].

After disclosing the diagnosis, most women expected some privacy, but employers did not always keep the information confidential. Colleagues, hospital staff, family, and neighbours seemed

to respect their privacy more. Some women were not concerned about confidentiality at all [8,11].

Experiences about recovery and returning to work

The majority of patients reported some support from their workplace [7,11]. Still, the cancer and its treatment caused uncomfortable feelings, which were particularly felt during the weeks before patients returned to work. Women were especially concerned about their appearance, productivity, disappointing the employer, and job loss. Most women were anxious about their physical appearance and felt that colleagues were staring at their body; this was particularly the case with those that had undergone a mastectomy [8]. Some were concerned about hair loss or wearing a wig. Although women were informed about the consequences of chemotherapy, Kennedy *et al.* [7] found that hair loss was experienced by patients as one of the worst things that could happen.

A concern was the fear of being less competent in carrying out their job duties compared to before the illness. This stressful apprehension led women to work harder after returning to work. They feared disappointing employers and colleagues and losing their positions [8]. Because women felt responsibility and loyalty towards their employers, the feeling of being less competent was experienced as if they were letting the company down; this was especially the case in smaller companies that struggled to cope with the extra workload during their absence [7].

The practical organisation of ongoing appointments with specialists was a specific point of concern. Some women needed to take unpaid time off, whereas others were allowed to attend their appointments during work hours [7]. In a study of breast cancer patients of different ethnicities, some Latina women did not comply with their treatment in order to avoid job termination; they worried about losing their job and being unable to financially support their families [6]. Once having lost their job, women were concerned about finding new employment after having had cancer. They felt that new employers would question their recovery and work capacity [8].

Several factors influenced women's decisions about returning to work. Some women felt ready and wanted to return to normality, some used work as a distraction from their illness, while others were under financial pressure to return to work. Women had to find a balance: they did not want to be labelled as a cancer patient, but they also needed some support and needed to be given some allowances [7]. Workplace modifications were requested and obtained, but in some cases the employer denied these requests. Women experiencing fatigue or arm problems and difficulties with concentration, especially in stressful jobs, indicated

they had conflicting feelings of responsibility and loyalty towards their employer. These factors led to a demotion or reduced productivity, and women were uncertain to what extent this result was due to the illness [7,8].

Women experienced recovery as a long process that might take years instead of months. Some women felt family pressure or expectations about re-entering work [6]. Some referred to expectations they felt from their employer and workmates once they returned to work, especially when they looked well. Women feared they might mislead employers and colleagues into thinking that they had completely recovered [7]. Even if the women look well, they still felt vulnerable. Thus, in a way, offsetting cancer-related changes in a woman's appearance could lead to reduced support.

Attitudes about work

Work became less important in the women's lives after they received their cancer diagnosis. Four of the studies found that participants changed their perception of work. Survivors felt that they valued work less than before. Motivation and priorities changed over time, and some women became more goal focused. The relevance of work in their lives was re-evaluated [7,8,10,11].

Stewart *et al.* [11] found that many women felt that cancer did not affect their work or career, while nearly just as many women felt that cancer actually altered their work priorities and ambitions. After a time, some women stopped working; some conveyed that this was their own decision [10,11]. Reasons for stopping work were health related (e.g. new cancer events), or work related (e.g. put less value on work, unsatisfying work, or difficult work) [10]. In some cases, participants retired early as a result of the cancer. They felt unable to fulfil their duties or felt too ill to continue working [11]. Many women did not have the option to stop working: Kennedy *et al.* [7] found that for half of the women ($n = 29$) financial pressure was a primary reason for returning to work.

Impact of the environment

Advice about returning to work

After receiving the breast cancer diagnosis, women followed their own intuition, knowing that dealing with cancer would be difficult, and that the only option would be to temporarily discontinue working [8]. They had to inform their employer because of the time-off needed for treatment, and from that time forward women tried to cope with the illness and needed time to recover [7,8]. Obviously, priority could not be given to work: The cancer diagnosis suddenly required all of their attention.

After the initial treatment, employees need to decide about returning to work. Maunsell *et al.* [8]

and Kennedy *et al.* [7] concluded that breast cancer survivors discussed work issues very little with treating physicians. In particular, possible exposure to infection at work seemed to be an important topic for discussion, but patients were not even sure if their doctor knew whether they were working or not. In appointments with insurance or company doctors, the main discussion point was the length of sick leave, and in many cases doctors followed the patient's wishes [8]. Only a few treatment doctors gave specific advice about returning to work; however, some women indicated that more information would have helped in their decision-making. Most doctors let patients decide for themselves about returning to work. Many patients understood that it was difficult for doctors to give advice, because individuals react differently with treatment [7].

Support and adjustments

A supportive work environment helped women to adapt to challenges related to their illness. Women who perceived that their employer accommodated them and their cancer treatment were more likely to return to work [9]. Especially during the first months, women felt supported when colleagues took over some responsibilities; for example, finishing some detailed tasks at times of reduced office work load [7].

The majority of women discussed what defines high-quality support and alluded to the possibility that larger employers offer more services and support. Adjustments based on flexibility, gradual assimilation, and changes in tasks were usually offered automatically but were not always sufficient [7]. In some cases, the women had to take the initiative and ask for these adjustments. The minority of women described negative reactions from the workplace. One woman reduced her work schedule to fewer days a week, but the office sent her phone calls and faxes on her time-off days. Some women reported a lack of support and understanding from employers and colleagues. Others enjoyed the social network at their workplace and felt emotionally better off at work, even while undergoing chemotherapy [7].

In a study of various ethnicities, Ashing-Giwa *et al.* [6] found that the majority of Asian and African American women received support after disclosing their illness. By contrast, several Latina women lost their position or jobs as a result of treatment-related absences at work. In the USA, accommodations are obligatory because the Americans with Disabilities Act requires companies with fifteen or more employees to accommodate persons with disabilities [9].

Discrimination

In a large cohort study of survivors and a comparison group, Maunsell *et al.* [10] found no

significant differences in working hours and earnings, having a second job, or working part-time, except in women that had experienced new breast cancer events. A portion of the women, however, felt discriminated against as a result of the cancer, and therefore actually felt unable to work [6,11]. Others felt annoyed by colleagues' questions, heard hurtful remarks, or experienced awkward moments of social silence. Changes in work situation such as task modifications, job loss, or altered relations with co-workers and employers were also considered to be discrimination. Some women attributed most of the unwanted changes to a 'difficult employer' rather than to the illness [6, p. 470]. Perceived employer discrimination, however, hindered women from returning to work after the initial treatment, which in general lasts 12 months [9].

Discussion

In the present review, we discuss the findings of six studies that assess the experiences of female breast cancer survivors as they dealt with work-related issues and returning to work. We found that women with breast cancer in general receive little advice about returning to work. They cope with many uncertainties about physical appearance, ability to work, and possible job loss. The individual needs of women differed, but a supportive work environment seems to be of paramount importance.

The results of this review need to be interpreted with some caution, as none of the studies described the entire range of experiences. However, our review does reveal that women encounter many difficulties in handling the illness. Breast cancer diagnoses cause sudden and complete life changes. Women's actions tend to be moulded by their new circumstances. Adding to the confusion caused by the diagnosis is the confusion stemming from deciding with whom to share this shocking news. Handling the cancer diagnosis is difficult enough. Women, at the same time, also need to think about disclosing the cancer diagnosis to family, friends, and colleagues. Some women even choose to stop working to avoid disclosure.

Treatment is required; thus, women fear that personal and professional relationships may change over time because time off is needed for cancer treatment and recovery. Work incapacity will last for some time and work perception may change over time. Initial reactions of the employer seem to be crucial, as these reactions represent the start of supporting the employee or discriminating against the employee. As cancer treatment often affects patients' appearance and abilities, returning to work can magnify these changes, causing patients to experience appearance and ability

problems and to fear prejudice and losing their position. As a result, some women tend to make decisions at the expense of their health, such as avoiding treatment, which is a frightening and disturbing finding.

Some evidence indicates that a supportive work environment could help women to return to work with less difficulty. Nonetheless, attitudes about work still change over time. One issue that has emerged from our current findings is the lack of communication between women and their employers and physicians about returning to work. Communication in advance could reveal the diverse needs of women. Although support from family and friends was mentioned, we found very little information on how the personal environment influences work issues.

Bouknight *et al.*'s [9] findings supported the idea that women, who perceived that their employer would accommodate their illness, were more likely to return to work. The role of employers seems to be evident, but questions regarding accommodation and discrimination were subject to women's interpretation.

Almost 90% of the participants in the Bouknight *et al.* [9] study ($n=416$) were qualified for work-related accommodations, according to the Americans with Disabilities Act, which mandates the role of employers towards disabled employees. The wide range of worker-related legislation across countries should not be underestimated. Employers will act differently if they are legally obliged to accommodate disabled employees and are prohibited from 'taking revenge' on employees because of their disability. The liberal welfare systems of the UK and the USA differ from the social security systems of Northern and Western Europe. The former relies more on antidiscrimination principles, while the latter relies more on public income insurance systems [18]. In 2005, the Disability Discrimination Act was legally established in the UK. Thus, the women interviewed in the Kennedy *et al.* study [7] may have already benefited from this legislation [19].

We only identified a few studies that helped us to understand how women with breast cancer experience work incapacity and returning to work. All but one study [6] were retrospective. None of the studies reported experiences that were recorded close to or at the time they occurred. Maunsell *et al.*'s 13 interviews, for example, were conducted in 1994 [8].

Synthesising the findings from the reviewed studies was precarious, because they differed widely in design, number of participants ($n=13$ to $n=646$), and employment variables examined. Moreover, the age of the participants varied from 20 to 88 years. As a serious health problem may cause most women 55 years and older to decide not to return to work or to retire from work early, the

findings of the reviewed papers may be biased towards women younger than 55. In addition, the interval varied between the time subjects received their diagnoses and time the subjects participated in one of the reviewed studies: In Kennedy *et al.*'s study [7], for example, this interval ranged from 11 to 118 months. Stewart *et al.*'s [11] results were based on questionnaire responses from participants who had received their diagnosis, on average, 9 years before. Thus, findings are most likely to be based on patients' memory, possibly explaining why cancer did not affect work for half of the women questioned in the Stewart *et al.* study [11]. Nevertheless, cancer did alter work-related priorities and ambitions, and many of the women changed careers or stopped working [7,8,10,11].

We still lack convincing information on how a woman's environment influences her ability to work as well as how this environment affects her experiences in returning to work. Moreover, we do not know how, with whom, and when women communicate and decide about returning to work.

Conclusion

An understanding, supportive, and cordial work environment during and after breast cancer diagnosis and treatment can help and encourage survivors, facilitating their work resumption. Modified working hours, duties, or other forms of flexibility can support the re-integration process. For some women, staying professionally active during the treatment phase offers social and emotional support.

Employers need to be aware of women's concerns and difficulties during work incapacity, treatment, and also after returning to work. Appropriate communication from employers, human resource management, and insurance or company doctors can be very helpful. Particular points of attention are appearance and uncertainty about work ability after treatment.

Women seem to go through a complex decision process before deciding on whether to return to work. Thus, they will need correct information that is adjusted to their medical and professional situation. Physical uncertainty and mixed feelings about the work environment may raise a woman's vulnerability. In some cases, this can slow down the return-to-work process, or even lead to job loss. Caregivers and insurance institutions have to increase their awareness of problems regarding work incapacity and workplace re-integration, and should become more involved in a supportive way. More qualitative research on work incapacity and returning to work from the perspective of women with breast cancer will be helpful.

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