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Changes in employment status, barriers to, and facilitators of (return to) work in breast cancer survivors 5–10 years after diagnosis

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ABSTRACT

Purpose: To qualitatively investigate changes in employment status, barriers to and facilitators of (return to) work in breast cancer survivors 5–10 years after diagnosis.

Materials and methods: Women were eligible to participate in the focus groups if they were younger than 55 years and were employed at time of diagnosis. Data were analysed by two independent researchers using thematic content analysis.

Results: Nineteen women participated in three semi-structured focus groups, of whom 18 reported a change in employment status 5–10 years after diagnosis. Perceived barriers to (return to) work shortly after breast cancer diagnosis tended to be disease- and treatment-related, while 5–10 years later, they were personal- and work-related. Participants recommended open communication and support at the workplace, and comprehensive information from (occupational) health care professionals to facilitate dealing with breast cancer at work.

Conclusions: Breast cancer survivors still experience changes in employment status 5–10 years after diagnosis. (Occupational) health care professionals should be alert that perceived barriers for returning to work change over time. Future research should focus on increasing awareness (at work) of breast cancer survivors' needs, providing adequate information and support to all involved, and developing interventions to sustain survivors' work ability at the long term.

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► IMPLICATIONS FOR REHABILITATION


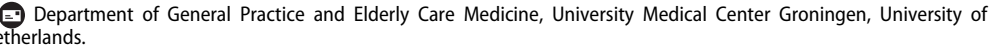
- Even long after diagnosis and treatment, a sizeable number of breast cancer survivors report a change in employment status, such as job loss.
- (Occupational) health care professionals should be alert that barriers for returning to work and retaining work change over time.
- There is a lack of awareness and a shortage of interventions regarding work-related issues for breast cancer survivors at long-term follow-up.

Introduction

Yearly, approximately 15 000 women in the Netherlands are diagnosed with breast cancer [1], of whom about 40% are of working age at time of diagnosis [2,3]. Due to earlier diagnosis and improvements in treatment, breast cancer patients currently have a 5-year survival of about 85% [4]. While almost 90% of cancer patients are able to (partially) return to work (RTW), within the first 2 years after diagnosis [5], the risk of becoming unemployed after breast cancer treatment is still higher compared to general population rates (RR 1.28; CI: 1.1–1.5) [6]. Long-term sequelae of breast cancer and its treatment, including fatigue, depression, and cognitive impairments, may not only hinder the RTW process, but also work performance [7,8]. Conversely, social support from family, friends, and occupational health services, and adequate workplace accommodations may positively affect RTW [9]. Job

flexibility and job security are examples of work-related factors that motivate women to RTW [10].

To date, most studies exploring changes in employment status in cancer survivors and barriers and facilitators regarding RTW have been conducted shortly after diagnosis, i.e., within the first 2 years. For example, in a focus group study by Tamminga et al., breast cancer survivors who were 2 years post-diagnosis reported physical impairments due to treatment as a barrier for their RTW [11]. Johnsson et al. reported that a change in the meaning of work was a barrier for RTW one year after diagnosis [12]. Furthermore, when it comes to changes in employment status of breast cancer survivors, Bradley et al. reported that six months after diagnosis, women were less likely to work and those who remained employed, generally worked less hours [13].

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Little information is available about changes in employment status and barriers and facilitators regarding RTW, beyond these first 2 years after diagnosis. Therefore, we conducted three focus group interviews within the framework of a recent cross-sectional quantitative study, the JOBS-study, which focused on employment status of breast cancer survivors 5–10 years after diagnosis. The aim of this study was to get a more detailed and comprehensive view on experiences of breast cancer survivors regarding change in employment status 5–10 years after diagnosis, and to identify perceived barriers and facilitators regarding RTW and retaining work, both in the short and the long term.

Materials and methods

Design and recruitment procedure

Focus group interviews were conducted with breast cancer survivors 5–10 years after diagnosis [14]. Participants for the focus groups were recruited through the JOBS-study, a quantitative study conducted in 2013, in which questionnaires were sent to women treated for breast cancer at the Netherlands Cancer Institute in the years 2003–2008. All eligible women were younger than 55 years of age, employed at time of diagnosis, and 5–10 years post-breast cancer diagnosis at time of questionnaire completion. Women with active disease or disease recurrence, and women who were not able to speak or understand the Dutch language, were excluded. In all, 1974 women received a questionnaire of whom 1159 responded with a signed informed consent form. Participants could indicate in the JOBS-questionnaire whether they were willing to participate in a focus group.

Focus groups

From all women willing to participate in the focus groups, a sample was drawn that reflected heterogeneity in terms of age, educational level, type of breast cancer treatment, and current employment status. In order to reach saturation, three focus groups were conducted, each with 6–8 participants. All participants signed an informed consent form at the start of the focus group interview. The institutional review board of the Netherlands Cancer Institute waived the requirement of medical ethical approval.

Focus groups were led by the JOBS-study coordinator (CP), who functioned as the moderator. She was supported by one or two research assistants (PvM and/or MG), who kept notes. The focus groups were semi-structured, using a predetermined topic list and started with an introduction by the moderator, explaining the JOBS-study and the objective of the focus group. Subsequently, each participant in the group was invited to describe if and how her work had changed shortly after being diagnosed with breast cancer and at present. Next, the list of prepared topics was discussed with the participants (Table 1). The moderator used these topics merely as a guidance for the interview and not as an exclusive set of themes. Data saturation was

reached when no new themes came up in the discussions in the third focus group interview. The focus groups were audio-recorded and subsequently transcribed verbatim. Participant names were replaced by numbers in the transcripts of the focus groups. All meetings took place in the Antoni van Leeuwenhoek hospital in Amsterdam.

Analysis

Sociodemographics, disease- and treatment-related, and work-related characteristics of the participants were extracted from the JOBS-questionnaires and are reported descriptively. In the analysis, the data transcripts were the primary data source, complemented by field notes taken by the research assistant(s).

Two researchers (PvM and MS) separately performed a standardised thematic analysis, consisting of six phases [14]. In Phase 1, the data were studied by reading and re-reading the transcripts, noting possible patterns and ideas for codes. In Phase 2, initial codes were assigned to create a base of repeated patterns (themes). In Phase 3, the initial codes were sorted and merged in order to produce overarching (sub) themes. In Phase 4, the (sub) themes were reviewed to check whether the data from the merged codes still corresponded to the potential theme that was assigned to it. Next, the assigned themes were considered in relation to the entire dataset, to consider the validity of individual themes in relation to the dataset and to check whether the potential themes accurately reflected the meanings evident in the dataset as a whole. In Phase 5, the two researchers discussed the results of their analyses and refined the themes until consensus was reached. If there were any discrepancies, final decisions were made by a third researcher (SD). In Phase 6, the data were analysed using Atlas.ti version 7.2 software [15].

Results

The results of this study are reported in accordance with the consolidated criteria for qualitative research (COREQ) [16].

Recruitment and participant characteristics

Of the 1159 women who responded to the JOBS-questionnaire, 489 indicated their willingness to participate in a focus group. Approximately 50 of them were contacted to compose the intended three groups. In total, two focus groups with seven women and one with five women were formed. The focus group interviews lasted approximately 1 h and 45 min each. After the third focus group, no new results came forward and data saturation was reached at a satisfactory level, based on the notes taken.

The participants' age ranged from 39 to 59 years, 11 were married or living together with their partner, and all but one were moderate to highly educated (Table 2). Almost all had had radiotherapy ($n=18$) and the majority had undergone chemotherapy ($n=12$). At diagnosis, 13 participants had a white-collar job,

Table 1. Overview of interview topics.

Topics
1. Experiences regarding change in employment status
2. Barriers for RTW after diagnosis and at present
3. Facilitators for RTW after diagnosis and at present
4. Control of barriers and facilitators which influenced (return to) work
5. Meaning of work
6. Social support of stakeholders and their involvement in the process of return to or retaining work
7. Participation in a supportive intervention program
8. Opinion about a potential supportive work-related intervention

Table 2. Characteristics of the breast cancer survivors included in the focus groups.

P ^a	Age	Educational level	Marital status ^b	Treatment ^c	Type of job ^d	Working hours per week at time of diagnosis (h)	Employment status at time of the focus group interview	Interventions ^e
P1.1	55	High	Married	S; R; C; H	White collar	24	Unemployed	Yes
P1.2	52	High	Divorced	S; R; C; H	White collar	38	Unemployed	Yes
P1.3	50	Moderate	Married	S; R	White collar	24	Unemployed (volunteer)	Yes
P1.4	39	High	Unmarried	S; R; C; H	Self-employed	30/40	Employed (hours unknown)	Yes
P1.5	59	High	Married	S; R; C; H	White collar	22	Employed (12 h); partial disability benefits	Yes
P1.6	59	Moderate	Married	S; R	Healthcare worker	40	Employed (40 h)	No
P1.7	51	Moderate	LAT	R; C	Healthcare worker	25	Employed (32 h)	No
P2.1	55	Moderate	Married	R	Self-employed	50	Unemployed (volunteer)	No
P2.2	55	High	Divorced	S; R; C	White collar	40	Unemployed; partial disability benefits	Yes
P2.3	55	High	Divorced	S; R	White collar	40	Employed (50/60 h)	Yes
P2.4	58	High	Married	S; R; C	White collar	18	Unemployed (volunteer)	Yes
P2.5	40	Moderate	Married	S; R; C	White collar	32	Unemployed (volunteer); full disability benefits	No
P2.6	45	Low	Divorced	S; R; C	Blue collar	40	Unemployed; partial disability benefits	Yes
P2.7	42	High	Married	S; R; C; H	White collar	24	Employed (24 h); partial disability benefits	Yes
P3.1	57	Moderate	Married	S; R; C; H	White collar	15	Employed (24 h)	Yes
P3.2	55	Moderate	Divorced	S	White collar	28	Unemployed (volunteer); full disability benefits	No
P3.3	43	Moderate	Married	S; R; C; H	White collar	16	Employed (24 h)	Yes
P3.4	53	High	Divorced	S; R	White collar	24	Unemployed	Yes
P3.5	55	Moderate	Married	S; R; H	Self-employed	45/50	Employed (24 h)	No

^aParticipant number.^bLAT: living apart together.^cMultiple answers were possible; S: surgery; R: radiotherapy; C: chemotherapy; H: hormone therapy.^dAt time of diagnosis.^eParticipated in supportive interventions at time of questionnaire completion.

working between 15 and 50 h per week (median: 28 h). At time of the focus groups, nine participants had returned to work, working 12–40 h per week (median: 24 h). Two participants who had returned to work received partial disability benefits. Four of the participants who were not currently working received partial or full disability benefits. Five of the currently unemployed women were involved in volunteer work. Two-third of the participants had followed a supportive intervention, e.g., exercise or psycho-education during or after their treatment for breast cancer.

Experiences regarding change in employment status

Eighteen women were able to RTW shortly after diagnosis and treatment; one woman (P2.5) could not RTW because of comorbidities. Some women continued to work or even felt obliged to work (e.g., for financial reasons) during treatment ($n = 5$). Of those who returned to work, 15 returned to their former job and gradually expanded the number of working hours during their reintegration (e.g., P3.1), while others had to change jobs because their employment contract was not renewed. One woman said: "I was still undergoing treatment, just before my contract ended. They sent me a letter explaining that my contract would not be renewed. They wished me good luck with finding a new job." (P2.7)

At time of the focus groups, ten participants were unemployed, due to a reorganisation (e.g., P2.2), because of a conflict at work (P1.1), high job demands (P1.3) or concentration problems (P2.4), while others voluntarily resigned. Five women had switched jobs, for example, because their temporary employment contract was not renewed, because their job was physically too demanding (e.g., P1.4), or because of disagreements with their employer. Two women worked more hours than before breast cancer diagnosis because of financial reasons. One of them explained: "I needed to RTW, because of financial necessities. But

I was very tired." (P1.7) Conversely, one woman who received partial disability benefits decreased her working hours (P1.5).

Barriers for RTW

The experienced barriers for RTW could be subdivided into (1) work-, (2) disease- and treatment-related, and (3) personal barriers. Directly after diagnosis, work-related barriers, such as the type of job (e.g., blue-collar work), little flexibility in working hours, high workload, and high expectations from the employer, negatively influenced the RTW process the most. One woman (P1.3) said: "The amount of work I had to do was too much for a part-time job. I could not handle this work load, so I resigned." Women often mentioned that fatigue, concentration, and memory problems (especially those who received hormonal therapy and/or chemotherapy), and depression affected their work ability shortly after diagnosis ($n = 6$). Further, two women experienced the need to take care of family members or relationship-related issues as a barrier for RTW.

At the time of the focus groups, women were more likely to consider societal and economic circumstances as major work-related barriers, i.e., the recession made it difficult for them to find a job. Nine participants also mentioned work as being exhausting, as one of them explained: "If I do too much in a day, I can barely do my job the next day. This was not the case before my disease and treatment." (P1.5) Moreover, four women experienced their age as a personal barrier when applying for a new job.

Facilitators of RTW

Women indicated that, shortly after diagnosis, the support of colleagues and/or the employer was an important facilitator for RTW or to remain working. One participant (P1.6) said: "I continued

working during treatment and received a lot of assistance from my colleagues, which was really helpful." Further, receiving a good prognosis stimulated them to RTW.

Many years later, women experienced support from their employer, ongoing flexibility in working hours and regaining responsibility for specific work tasks continued to facilitate their work ability. Also, they described work as a distraction from their chronic, (potentially) treatment-induced complaints. One woman reported: "Because I am working, I am not aware of the pain that is still there." (P1.5)

Control of the RTW process

Only a few women ($n=4$) felt that they were in control of their RTW process at time of diagnosis and these women were generally self-employed. Others did not feel in control at all or felt pressured by their employer or occupational physician (OP), as this woman (P1.5) said: "My employer told me to reduce my working hours after I was diagnosed. However, I wanted to stay in control and preferred to decide about my working hours myself."

Women mentioned that, over the years, they learned to stand up for themselves, which they experienced as a sense of control. A participant explained: "I have learned to say 'this is where I draw the line.'" (P1.4)

Meaning of work

Being able to work during treatment was important for the participants, because it gave a sense of normalcy; it helped them to move on with their lives and to feel less like a patient. It was also important because it provided an important source of income (especially for the self-employed). But overall, work was not the major priority around the time of diagnosis and treatment.

Regarding the current situation, women described work as having both social and financial significance. One woman explained: "I still receive unemployment benefits, which I believe is a problem, because I do not want to depend on my husband's salary, but be financially independent." (P1.1)

Social support and involvement of stakeholders

Shortly after diagnosis, participants most often received social support from their family and friends, but also from their employer and colleagues. Work-related support from occupational health services was variable. Several women reported having felt pressured by their OP to RTW, while others did not feel stimulated, or even felt inhibited from RTW by their OP. In general, support from (para) medical staff and psychologists was highly appreciated.

At time of the focus groups, employers and colleagues still offered support to many survivors and were receptive to issues concerning their health. However, a few women mentioned feeling that their social environment disregarded their breast cancer history and the continuous impact of the diagnosis and treatment on their lives. Others admitted that they did not want their colleagues to talk about it anymore. With regard to the involvement of the Dutch Social Security Agency (SSA), of those who received (partial) disability benefits, some felt supported by this agency, while others experienced poor communication, a lack of interest, and a continuous pressure – even up to 10 years after diagnosis – to RTW. As one woman said: "They did not bother to prepare the conversation or to show empathy regarding my situation." (P2.7)

Participation in a supportive intervention

Thirteen women participated in some form of a supportive intervention program, such as a physical rehabilitation program, directly after diagnosis. None of the women took part in an intervention specifically focused on RTW. However, one participant explained that "work" was discussed during the intervention in which she took part. Overall, they experienced these interventions as useful, because of the social element (i.e., contact with peers), increased trust in their bodily functions and appearance, and improved general well-being. One woman explained: "The intervention [which focused on mental and physical aspects after cancer] helped me to gain self-confidence and reduce my anger and frustration." (P2.3) Six women did not participate in any supportive intervention program, because they did not experience the need to participate, were not aware of the existence of such programs or could not afford them, or because their health insurance did not cover the expenses for participating in such an intervention.

At time of the focus groups, none of the women were participating in supportive intervention programs, but a few explicitly mentioned that they continued to work on remaining physically and mentally fit on their own.

Additional topics

Several participants indicated that they concealed their breast cancer history and the related period of sickness absence, and did not talk about it when applying for a new job. One woman said: "I stopped noting dates on my CV, in order to cover up the period I was treated for breast cancer." (P2.7) Also, some women stated that they wished they had received oral and written information regarding the RTW process, for themselves and their employers, both at an early stage and long after they had returned to work.

Discussion

Main findings

The findings of this qualitative study indicate that, while most women were able to RTW in the first years after breast cancer diagnosis, the majority had experienced a change in employment status 5–10 years after diagnosis. Further, perceived barriers to RTW or retaining work changed from being primarily disease- and treatment-related, shortly after diagnosis, to be more personal and work-related at longer follow-up. Support from family, friends, the employer, and colleagues regarding work was most often present early on, but was still highly appreciated later in their follow-up. Finally, open communication and detailed information about how to deal with breast cancer in the workplace, for both patients and the employer, was often lacking according to the participants.

Interpretation of findings

Almost all of the women in our study had experienced a change in their work status (often loss or a significant reduction in work) 5–10 years after breast cancer diagnosis. It could be argued, though, that these changes also occur in a cancer-free population. However, results from previous studies support our findings. For example, Carlsen et al. found that 5 years after diagnosis, self-reported work ability of breast cancer survivors was low compared to non-cancer controls [17] and Paalman et al. observed

that breast cancer patients had a higher risk of becoming unemployed 5–10 years after diagnosis in comparison with healthy controls [18]. Shortly after diagnosis, breast cancer survivors in the Netherlands are supported by Dutch legislation to return to their former job [19]. However, finding a new job longer after breast cancer diagnosis may be more problematic because employers may be concerned with illness episodes or disability leave due to cancer recurrence or long-term side effects. Fatigue and memory problems – especially those receiving (maintenance) hormonal therapy or received, which was also found in previous research [20–22] – may influence their work performance.

Women indicated that social support from the employer and colleagues was one of the main facilitators for RTW shortly after diagnosis. However, at longer-term follow-up, flexibility of the employer, and accommodations at the workplace were reported to be highly beneficial for continuation of work. Our findings are in line with a previous review in patients diagnosed with breast cancer, which indicated that perceived social support from the women's employer/supervisor and her colleagues are the most important factors facilitating RTW [10]. The type of support patients in the focus groups experienced changed over time from predominantly social support, shortly after diagnosis, to mainly practical support longer-term after diagnosis. This may be explained by the shift in outlook of the disease. That is, being diagnosed with cancer can significantly affect someone's emotional life and that of people in their direct environment [23,24]. At longer term, women may still experience health issues, but due to the absence of an acute treat, practical help, e.g., adjusted tasks at work because of long-term fatigue, is particularly recognised as an important facilitator.

Social support from friends, family, employer, OP, and colleagues was present and appreciated in the beginning, however, less obvious and sometimes even less valued later in time (e.g., in case women did not want to talk about their history of breast cancer anymore). Shortly after diagnosis, women sometimes felt pressured by their OP to RTW. At longer-term follow-up, most women who received (partial) disability benefits reported poor communication and lack of interest by the SSA. Previous research investigating the experiences of cancer patients on sick leave with the SSA indicated, in line with our findings, that better communication and guidance from SSA employees is needed [25,26]. The fact that women in our study felt unsupported might be explained by the study of Van Muijen et al., stating that insurance physicians often have difficulty in estimating a cancer patients' (physical and psychological) health and subsequently their work (dis)ability [26]. As a result, patients might be confused themselves, as they are in need of clear guidance and support. Regarding the long-term support of family and friends, it is known from other studies that former cancer patients struggle with still needing help on the one hand, and no longer wanting to be treated as a patient, on the other hand [27].

Most participants reported that their employer and OP were more or less in control of their RTW process shortly after diagnosis, while at longer-term follow-up, they regained more control of their own work situation. Self-management literature supports these findings. An interview study following chronically-ill patients over time showed that it is difficult to execute self-management behaviour when routines are challenged [28]. It is not surprising that women felt less in control directly after diagnosis, when the medical team has an important position and responsibility in regaining health, while the employer and OP have an important responsibility in supporting work re-integration. Because of this, self-management skills might be employed to a lesser extent,

especially in the first period after diagnosis, as shown in an earlier study in breast cancer patients [29].

The meaning of work also changed over time for the women in our focus groups. Shortly after diagnosis, for many participating women, being able to work meant not only being a patient, but also being an employee again. At long-term follow-up though, work often had the same status as it had before diagnosis (i.e., a social and financial meaning). In a previous study by Isaksson et al., patients with head and neck cancer reported that, up to 24 months after diagnosis, work gave them a sense of normalcy, and a goal in life contributing to their identity. Interestingly, patients in this study who felt forced to retire within 2 years after diagnosis, e.g., because they were too tired to work, more often experienced a lack of social contacts, loneliness and financial problems [30]. In another related study, cancer survivors experienced a need to find other activities to keep them occupied and to structure their day [31]. Similarly, in our study, we found that the majority of the women who were not working at the time of the focus group interviews, were engaged in volunteer work to sustain social interactions and to give meaning to their daily life.

Strikingly, some women who were unemployed at time of the focus group interviews reported that they concealed their breast cancer history to (potentially new) employers and even colleagues. A previous study, investigating disclosure of breast cancer 2 years after diagnosis, showed that most survivors are relatively comfortable with being open about their diagnosis, not only to family and friends, but also toward people at work. Still, occasionally, women experience negative consequences at work after disclosure [32]. Correspondingly, in our study, women explained that they were afraid of negative consequences if they were to be honest about their disease history when applying for a new job.

Many of the women in our study indicated that they would have liked to have received more information early on about work-related consequences of their disease and treatment, and to have been offered supportive, work-related programs. In a previous study, several difficulties regarding information provision were reported though, especially in situations where high levels of emotional distress are present. Because of this, remembering information might be problematic [33]. However, even though women might be overwhelmed by the amount of information regarding diagnosis and treatment, that does not mean that work-related issues should not (repeatedly) be discussed.

Strengths and limitations

This study is, to the best of our knowledge, the first qualitative exploration focused on changes in employment status, barriers to and facilitators of RTW and retaining work in the period 5–10 years after breast cancer diagnosis. However, as only breast cancer survivors treated at the Antoni van Leeuwenhoek hospital (a specialised cancer research hospital) were included, our results may not be representative of the larger population of breast cancer survivors. In particular, patients treated in this hospital tend to be better educated than those treated in community hospitals, and thus may also have been more proactive when it comes to dealing with problems at work. Moreover, since only breast cancer survivors participated in this study, we caution against generalising the results to patients with other tumour types. Finally, the findings of our study should be interpreted in the light of Dutch social security legislation. By law, cancer survivors with an employment contract who is on sick leave or who is (partially) disabled receive employment benefits from their employer for 2 years

(amounting to about 70% of their annual salary) [34]. This may have affected our observed RTW rates (i.e., may have influenced/delayed the transition toward RTW) [10].

Implications for research and practice

Changes in employment status still occur 5–10 years after breast cancer diagnosis and therefore, we recommend development and evaluation of supportive interventions for longer-term survivors. Future research should take into account the fact that barriers to and facilitators of RTW may change over time, which implies the need for early, ongoing and more tailored interventions that fit the needs of women at different stages of their survivorship experience. Various stakeholders, including breast cancer survivors, rehabilitation specialists, employers and OPs, should be involved in the development of these interventions.

In clinical practice, breast cancer survivors should be better informed that work-related changes can occur, even years after treatment has been completed. Consequently, it is important that (occupational) health care professionals and other stakeholders communicate openly about potential barriers that might be experienced during the whole RTW trajectory. Employers should be supported by the government when hiring employees with a history of (breast) cancer, even long-term after diagnosis. If so, employers will not solely carry the financial risk in case a survivor needs to take up sick leave again, and survivors will have a higher change to regain employment.

Conclusion

Breast cancer survivors still experience changes in employment status 5–10 years after diagnosis. Barriers and facilitators that are hampering or supporting these survivors to RTW or continue working change over time. These findings should be taken into account when developing future innovative interventions, as there is a need among breast cancer survivors for long-term work-related support.

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