

# **The Role of Job Changes in Sustainable Return to Work for Breast Cancer Survivors – Patterns of Interpretation and Coping Strategies**

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**List of abbreviations**

B-CARE: Breast cancer patients' return to work

N-MALE: Male breast cancer: patients' needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care

PIAT: Strengthening patient competence—breast cancer patients' information and training needs

RTW: Return to work

## 1. Abstract

Thus far, research on return to work (RTW) after breast cancer has focused on objective outcomes such as return rates. Moreover, a strong emphasis on the initial RTW can be observed in the literature. However, knowledge on the evolution of work participation over time in the aftermath of RTW, which can be referred to as the sustainability of RTW, is scarce. The aim of this doctoral thesis was to investigate breast cancer survivors' perspective on job changes as an indicator of the sustainability of RTW using Parsons' concept of the *sick role* and the *conceptual model of the experience of cancer and work* as a theoretical basis. The following research questions were addressed: How do breast cancer survivors experience their RTW and the phase afterward? How do breast cancer survivors experience and evaluate job changes after their RTW? How and why do job changes occur in breast cancer survivors after their RTW? This cumulative dissertation comprises five publications. (1) The first original article focuses on the experiences of 14 male breast cancer patients through their RTW and its aftermath using data from the N-MALE project (Male breast cancer: patients' needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care). (2) The letter to the editor answers questions regarding the first original article and discusses further research needs related to RTW and male breast cancer. (3) The study protocol describes the methodological approach of the mixed methods B-CARE project (Breast cancer patients' return to work), which aimed to investigate the rehabilitation and RTW of breast cancer survivors 5–6 years post-diagnosis. (4) The second original article employs regression analyses with B-CARE survey data from 184 breast cancer survivors to investigate the involuntariness of job changes and their association with occupational development satisfaction. (5) A qualitative grounded theory approach based on the interview data of the B-CARE study with 26 female breast cancer survivors was applied in this original article to explore rehabilitation processes of long-term breast cancer survivors. Overall, the findings show that breast cancer survivors were naturally motivated to return to work. Experiences were primarily positive, although male survivors reported stigmatization in the work context. Job changes after the return were welcomed, although financially disadvantageous (e.g., early retirement). It was found that the involuntariness of job changes

is negatively associated with occupational development satisfaction. The *grounded theory of incompatibilities in the areas of life*, newly developed in this dissertation, explains that (involuntary) job changes may occur due to interviewees' struggles to balance the demands of different areas of life (family, work, household, leisure time, and disease). As a consequence, prioritization of single areas, particularly areas other than work, occurred. These findings add new aspects to the conceptual model of the experience of cancer and work and support it by identifying the rehabilitation process after breast cancer as a continuous, non-linear process that can continue 5–6 years after diagnosis. In contrast to Parsons' concept of health, the breast cancer survivors apparently had not yet regained their "optimum capacity" to perform their daily roles. The results indicate the existence of support needs in long-term cancer survivors in order to prevent job changes that pose a risk to the sustainability of RTW.

## 2. Introduction and aims

With nearly 70,000 new cases per annum, breast cancer is among the most common cancer sites in Germany (Robert Koch-Institut 2019). Recent 5-year survival rates of male (77 %) and female (87 %) patients with breast cancer stress the need for successful rehabilitation (Robert Koch-Institut 2019). Patients with breast cancer often undergo intense multimodal treatment, which can last up to several months. Only a small number are able to continue their normal life during this period, which is why rehabilitation plays an important role in the social reintegration of cancer patients. Reintegration into work after surviving such a severe disease, often referred to as return to work (RTW), is an essential aim of the rehabilitation process for cancer patients of working age. Work is an enabler of social participation, allows financial independence, restores normalcy, and is part of one's personal identity (Rasmussen and Elverdam 2008; Peteet 2000). Due to the various functions of work, it is important that cancer survivors (i.e., cancer patients from the moment of diagnosis through the balance of their lives (Denlinger et al. 2014)) benefit from work in the long run. Thus, not only should the initial RTW be investigated, but the evolution of work participation over time in the aftermath of the RTW (e.g., in terms of long-term work performance), which can be referred to as the sustainability of RTW, should be investigated as well. Thus, some scholars encourage understanding RTW as a phase rather than a singular event (Wells et al. 2013; Stergiou-Kita et al. 2014).

RTW after cancer received academic attention in the 1970s and 1980s. Early interventional studies targeting RTW in breast cancer survivors were conducted in the late 1970s, as a review by Hoving et al. (2009) shows. For instance, Clark and Landis (1989) presented their work re-entry program to help breast cancer patients to return to work. In recent years, studies reported country-specific RTW rates for breast cancer survivors, with the highest rates in the United States (80 %) and lower in Germany (59 %) (Rick et al. 2012). A more recent study from Germany found a RTW rate of 70 % in breast cancer survivors on average 8.3 years into survival (Arndt et al. 2019). Extensive quantitative research has identified sociodemographic, psychosocial, work-, treatment-, and disease-related determinants associated with RTW in cancer survivors (Paltrinieri et al. 2018; Sun et al. 2017). Among

others, extensive treatment (e.g., receiving chemotherapy), a poorer state of health (e.g., depression, fatigue, arm morbidity, cognitive impairments), a lower socioeconomic status (e.g., education), and insufficient social support (e.g., in the work and private environments) were associated with negative outcomes in RTW (Sun et al. 2017). Qualitative studies indicated that personal, environmental, and occupational aspects were associated with RTW (Stergiou-Kita et al. 2014). Disease- and treatment-related barriers seem to be more pronounced shortly after diagnosis, but personal and work-related barriers gain importance 5–10 years after diagnosis (van Maarschalkerweerd et al. 2019).

Whereas most earlier studies focused on the initial point of re-entry into work, recently, research has begun to investigate the sustainability of RTW by exploring the work participation and trajectories over the following years, for instance, in terms of work performance. A significantly higher sick leave rate was found for 5-year cancer survivors compared to cancer-free controls in all years following diagnosis (Torp et al. 2012). A review showed that impaired physical functioning of breast cancer survivors was associated with negative work outcomes like leaving the workforce or being unemployed (Bijker et al. 2018). Another important indicator for the sustainability of RTW that has received increasing attention in recent years is the occurrence of job changes, meaning alterations of the employment situation. In a study with cancer survivors from Denmark, Finland, Iceland, and Norway, about 17 % of the participants reported job changes 2–6 years after diagnosis and treatment (Gudbergsson et al. 2008). About 67 % of cancer survivors experienced at least one change in work characteristics in the study from the United States; 57 % reduced their working hours two years after the diagnosis, and 81 % of these attributed the reduction to the cancer disease (Steiner et al. 2008). According to a European multi-country study, 6–37 % of employed cancer survivors reported an occupational change within periods ranging from 1 to 6 years after diagnosis (Torp et al. 2019). Work changes were moderately correlated with work ability (Gudbergsson et al. 2008). Moreover, cancer survivors who experienced work changes were more often female, more comorbid, had poorer work ability and quality of life, worked fewer hours per week, and showed more neuroticism, compared to survivors without changes (Gudbergsson et al. 2008). Mols et al. (2009) found that older age,



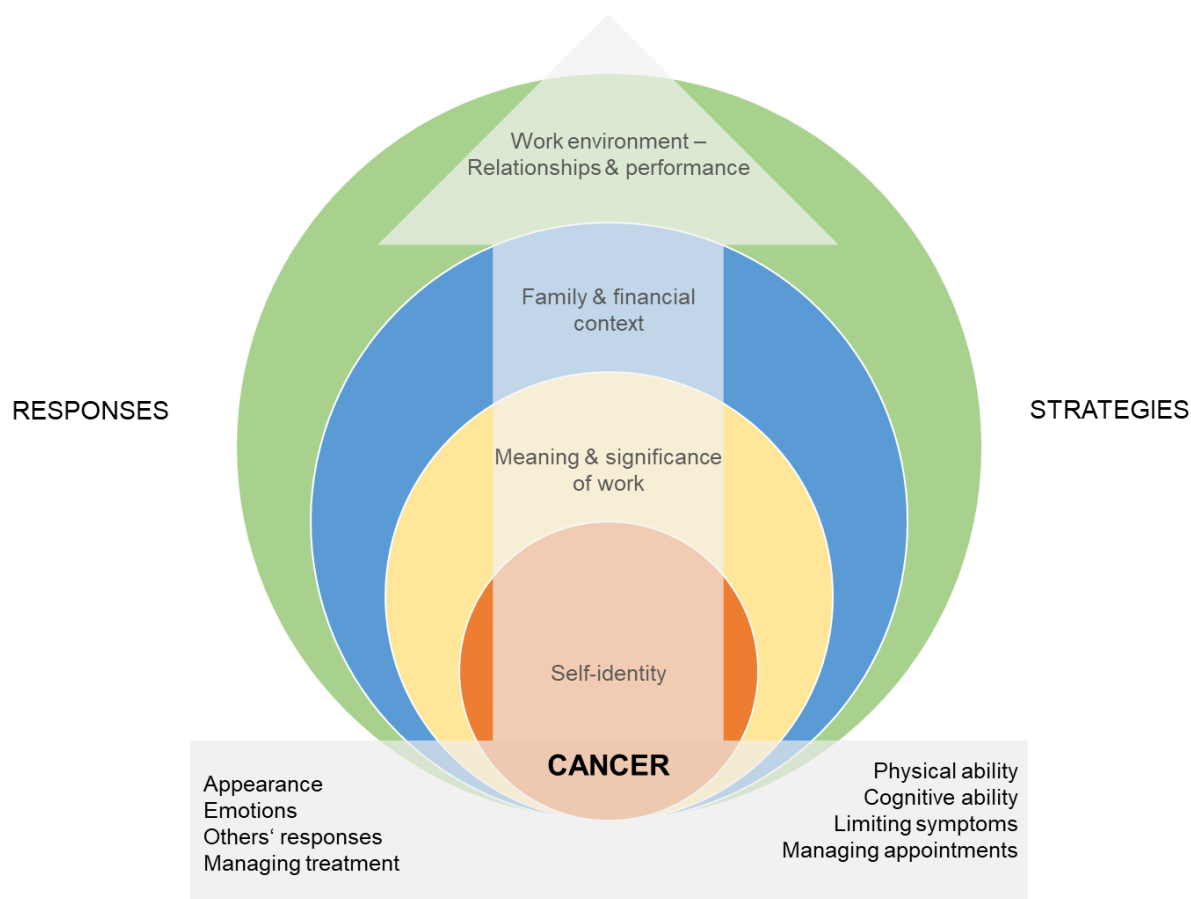
chemotherapy, and disease progression were also associated with experiencing job changes. These results suggest that job changes can be associated with social inequalities. Job changes can exacerbate disparities, for example, when they lead to income losses due to a reduction of working time. In addition to causing financial hardship for individuals, job changes represent a burden for social welfare systems with a redistributive structure when they are accompanied by reduced contributions or costs (e.g., reduced working hours, reduced or earning-capacity pension).

Against this background, it is important to understand the occurrence of job changes in cancer survivors as an indicator for the sustainability of the RTW. However, current knowledge is limited. While job changes are known to occur, how breast cancer survivors interpret and evaluate these job changes in terms of their long-term work outcomes and what they see as the reasons for these job changes is unclear. This knowledge is crucial for adapting survivorship care such that burdensome work outcomes and social inequalities in breast cancer survivors are successfully prevented or, at a minimum, reduced. This dissertation seeks to contribute to closing this research gap, focusing empirically on Germany. Germany is a relevant case due to its re-distributive healthcare system with a needs-based provision of rehabilitative measures that are provided free of charge and aimed at social participation following the principle “rehabilitation before pension.” Provided rehabilitative measures include, among others, multidisciplinary in-patient rehabilitation, gradual reintegration into work, and workplace adjustments. In Section 2.1, the theoretical framework of this dissertation is explained. Specifically, this doctoral thesis draws on the concept of the *sick role* introduced by Talcott Parsons (1972; Parsons and Smelser 2012) and the *conceptual model of the experience of cancer and work* developed by Wells and colleagues (2013) to understand the phenomenon of job changes in breast cancer patients. In Section 2.2, the research aims of this doctoral thesis are described.

## 2.1 Theoretical framework

The discipline of medical sociology applies concepts, methods, and theories from general sociology to phenomena of health and disease (Siegrist 2005). A key objective of medical sociology is the understanding of rehabilitation processes, which include the work re-integration after a disease, as it enables social participation. In this discipline, an understanding of health is characterized by the ability to perform social roles. Accordingly, in his popular definition, Talcott Parsons (1972, p. 117) refers to health as “the state of optimum *capacity* [emphasis in original] of an individual for the effective performance of the roles and tasks for which he has been socialized”. Based on this definition, illness is characterized by the incapacity to perform roles and the tasks that come along with these roles (Parsons 1972). While healthy individuals exercise their usual roles (e.g., in the areas of work and family), ill individuals occupy the sick role. Depending on the nature and severity of the condition, the sick role is accompanied by role expectations, for example, being obliged to try to get well, seek competent help, and cooperate with medical professionals (Parsons and Smelser 2012). In return, the sick individual is exempt from typical social roles, is not held responsible for his/her condition, and has the right to be taken care of (Parsons and Smelser 2012).

Long-term breast cancer survivors exercise the roles of healthy individuals, for instance, in their families as partners and parents or at work as employees. A conceptual model, which reflects this co-existence of roles in cancer survivors, was developed by Wells et al. (2013). The conceptual model of the experience of cancer and work, shown in Figure 1, results from a meta-synthesis of 25 qualitative studies.



**Figure 1.** The conceptual model of the experience of cancer and work; own figure based on Wells et al. 2013, p. 2011

According to the model, a cancer survivor's relationship with work is represented by four inter-related elements: *self-identity*, *meaning and significance of work*, *family and financial context*, and *work environment*. The self-identity element refers to work as a contributing factor to restore cancer survivors' identities and get back to their former self. Meaning and significance of work includes the idea that work represents normality for cancer survivors, for instance, through the association of not being ill, having routines, and social interactions. Family and financial context considers financial hardship experienced due to the cancer disease. Moreover, the attitudes of family members can promote or hinder work after cancer. The work environment element refers to cancer survivors' work experiences, for example, depending on provided organizational and intrapersonal support, as well as work characteristics.

Implications of the cancer experience (such as psychological or physical effects) are super-imposed on these four elements, potentially causing uncertainties and the need for adjustments in the already complex system of elements. Certain strategies, namely communication and negotiation with employers, accepting changed capabilities, managing symptoms, and working smarter, helped cancer survivors return to work. The four elements resemble the roles that healthy individuals occupy in different life domains such as work, family, and self-actualization, while the super-imposed cancer disease of the model resembles Parsons' (1972; Parsons and Smelser 2012) sick role. Wells and colleagues (2013) described the cancer experience as a dynamic process with individual differences, for example, regarding the importance of certain elements or their relationships. While the theoretical concept of the sick role is more general, the conceptual model of the experience of cancer and work specifically refers to work in cancer survivors. Parsons' conceptions of health and sickness suggest that breast cancer survivors have an exclusive status of either sick or healthy. However, the empirical model of Wells and colleagues implies that the sick and healthy roles can be exercised simultaneously. These role concepts help clarify the recovery processes of breast cancer survivors and the role of work in this process. Hence, either the transition from sick to healthy or an interplay of the work role with cancer are assumed to influence the sustainability of RTW as well as job changes as an indicator of it. The concepts of the sick role and the conceptual model of the experience of cancer and work were the foundation for the empirical analyses of this dissertation and are used as a background against which the results are interpreted and discussed.

## **2.2 Aims**

The present doctoral thesis aims to expand knowledge regarding the sustainability of RTW by contributing to closing the existing research gap in relation to breast cancer survivors' perspective on job changes in the aftermath of their RTW. With Parsons' concept of the sick role and the model of the experience of cancer and work in mind (Parsons 1972; Parsons and Smelser 2012; Wells et al. 2013), this dissertation has the aim of exploring whether

recovery processes resemble a transition from sick to healthy or whether an interplay of roles occurs. For these purposes, the following research questions were addressed:

- (1) How do breast cancer survivors experience their RTW and the phase afterward?
- (2) How do breast cancer survivors experience and evaluate job changes after their RTW?
- (3) How and why do job changes occur in breast cancer survivors after their RTW?

The research questions are addressed in five publications presented in Section 3. In Section 4, the findings of the publications and the arising implications are discussed, and strengths and limitations of the present work are outlined.

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### 3. Publications

This cumulative doctoral thesis comprises three original articles (1,4, and 5 below), one letter to the editor related to one of the original articles (2), and one study protocol (3), each published as first author in international peer-reviewed journals listed in PubMed. Personal contributions to the publications are explained in Section 6. Table 1 provides an overview of the publications of this doctoral thesis.

**Table 1.** The publications of this doctoral thesis

	Title	Data source	Article type	Published in
(1)	Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study	N–MALE project (Midding and Halbach 2016)	Original article	European Journal of Cancer Care
(2)	Response to “Response to ‘Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study.’”	N–MALE project (Midding and Halbach 2016)	Letter to the editor	European Journal of Cancer Care
(3)	Breast cancer patients’ return to work (B–CARE): Protocol of a longitudinal mixed-methods study aiming to explore medical and occupational rehabilitation of patients with breast cancer in Germany	B–CARE project (Hiltrop et al. 2019)	Study protocol	BMJ Open
(4)	Involuntariness of job changes is related to less satisfaction with occupational development in long-term breast cancer survivors	PIAT project (Schmidt et al. 2015), B–CARE project (Hiltrop et al. 2019)	Original article	Journal of Cancer Survivorship
(5)	Conflicting demands, coping, and adjustment: A grounded theory to understand rehabilitation processes in long-term breast cancer survivors	B–CARE project (Hiltrop et al. 2019)	Original article	Psycho-Oncology

Notes: N–MALE: Male breast cancer: patients’ needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care; B–CARE: Breast cancer patients’ return to work; PIAT: Strengthening patient competence—breast cancer patients’ information and training needs.



(1) *Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study*

For the first original article (see Section 3.1) (Hiltrop et al. 2021c), data from semi-structured interviews with male breast cancer patients were used. The interviews were part of the mixed-methods N–MALE study (Midding and Halbach 2016). A qualitative content analysis was carried out to investigate RTW patterns and explore experiences from male breast cancer patients' perspective on their RTW and the aftermath.

(2) *Response to 'Response to "Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study."'*

This letter to the editor (see Section 3.2) (Hiltrop and Ernstmann 2021) is a response to a letter concerning the first publication (1) written by Kobayashi and colleagues (2021). In their letter, the authors question the sample size and discuss the differing occupational status of the interviewees and the role of gradual return options for cancer survivors (Kobayashi et al. 2021). The response letter (2) (Hiltrop and Ernstmann 2021) responds to their questions concerning the original article (1) (Hiltrop et al. 2021c), points out future research needs related to RTW, and raises awareness of male breast cancer.

(3) *Breast cancer patients' return to work (B–CARE): Protocol of a longitudinal mixed-methods study aiming to explore medical and occupational rehabilitation of patients with breast cancer in Germany*

This study protocol explains the methodological approach of the mixed-methods B–CARE study (see Section 3.3) (Hiltrop et al. 2019). The study combined various data sources and linked primary data with previously collected survey data from the PIAT project (Strengthening patient competence: Breast cancer patients' information and training needs) (Schmidt et al. 2015) to make primary data from four measurement time points throughout the cancer journey available for female breast cancer survivors. The aim was to investigate

long-term breast cancer survivors' rehabilitation and RTW. The author collected the B-CARE survey data and conducted the interviews with colleagues. Data from the B-CARE project (Breast cancer patients' return to work) were used for publications (4) and (5) of this doctoral thesis.

*(4) Involuntariness of job changes is related to less satisfaction with occupational development in long-term breast cancer survivors*

For this study (see Section 3.4) (Hiltrop et al. 2021a), survey data from 184 female breast cancer survivors were drawn from the B-CARE project. Data were linked to previously collected survey data resulting in four measurement time points from hospitalization to 5–6 years into survival. Descriptive analyses and stepwise linear regression modelling were used to examine involuntary job changes and explore the association between job changes, involuntariness, and occupational development satisfaction in female breast cancer survivors 5–6 years after diagnosis.

*(5) Conflicting demands, coping, and adjustment: A grounded theory to understand rehabilitation processes in long-term breast cancer survivors*

The third original study (see Section 3.5) (Hiltrop et al. 2021b) uses a qualitative grounded theory approach based on the interview data of the B-CARE study with 26 female breast cancer survivors. By analyzing causes, contexts, and consequences of decisions related to medical and occupational rehabilitation, the aim was to explore the rehabilitation processes of long-term breast cancer survivors.

**3.1 Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study**



## ORIGINAL ARTICLE

# Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study

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## ABSTRACT

**Objective:** Knowledge regarding the occupational rehabilitation of male breast cancer patients (MBCPs) is currently scarce; however, there may exist unmet needs of men affected by this rare disease. Therefore, this exploratory study investigated the experiences of MBCPs in their return to work (RTW).

**Methods:** Interview data from 14 men with a breast cancer diagnosis were used for qualitative content analysis. Data were collected within the mixed-methods N-MALE project (*Male breast cancer: patients' needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care*), conducted in Germany from 2016 to 2018.

**Results:** The eight identified motives for RTW were desire for normalcy, distraction, need for activity, social contacts, work as a source of pleasure, financial considerations, lack of self-perception of illness, and having a job requiring low physical effort. The participants reported positive experiences with their workplaces from diagnosis through RTW. However, stigmatisation occurred. The aftermath of the disease and treatment led to changes in the interviewees' productivity, for instance due to fatigue.

**Conclusion:** The findings of this study contribute to a better understanding of RTW processes, as new insights were gained about motives and experiences particular to MBCPs. Support needs after return were apparent and may help to reduce long-term effects that limit productivity.

## KEYWORDS

content analysis, employment, male breast cancer, occupational rehabilitation, qualitative research, return to work

## 1 | INTRODUCTION

While breast cancer is the most common cancer among women (Bray et al., 2018), it is considered a rare disease among men as only 1% of patients are male (Giordano, 2018). This inequality

in prevalence exposes male breast cancer patients (MBCPs) to particular disadvantages such as diagnosis delays, treatment deficits, and stigmatisation due to the perception of breast cancer as a 'women's disease' (da Silva, 2016; Halbach et al., 2020; Midding et al., 2018). Furthermore, male patients

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are underrepresented in research, although initial studies focussing on MBCP diagnosis, treatment, and medical rehabilitation have been initiated in recent years both in Germany (MALE, Registerstudie Mammakarzinom des Mannes, BRECA-Male-Study) and internationally (EORTC 10085/TBCRC/BIG/NABCG International Male Breast Cancer Program) (Cardoso et al., 2018; Vermeulen et al., 2017). Moreover, studies have also investigated the social support and psychological strain experienced by male patients with breast cancer (Kipling et al., 2014; Midding et al., 2019). Existing unmet needs in terms of care (Halbach et al., 2020; Nguyen et al., 2020) and information (Bootsma et al., 2020; Iredale et al., 2007; Pituskin et al., 2007) have also been investigated. One study included work-related problems in a quantitative questionnaire used to research unmet information needs in male patients with breast cancer (Bootsma et al., 2020). Their results suggested that unmet needs regarding physical and cognitive long-term symptoms were more prominent compared with work-related problems.

Thus, little is known about occupational rehabilitation in MBCPs, even though work is an important part of the life of affected working-age men. Work can be a critical aspect of identity and help to restore a sense of normalcy and control after surviving such an impactful disease (Rasmussen & Elverdam, 2008). In the short term, the work ability of MBCPs may be influenced by the disease due to complex and time-consuming treatment, resulting in periods of absence from work. Applied therapies can further lead to long-term side effects that may also affect work ability in the aftermath of treatment (Duijts et al., 2014). Patients report, *inter alia*, cognitive and physical difficulties such as fatigue, which can last up to 15 years after treatment (Gernier et al., 2020). Such reports stress the need to understand return-to-work (RTW) processes to support successful long-term occupational rehabilitation for cancer patients.

Recent quantitative studies have focused on RTW determinants and timing (Islam et al., 2014; Paltrinieri et al., 2018; Sun et al., 2017; van Muijen et al., 2013). The qualitative findings regarding the motives for occupational rehabilitation among (female breast) cancer patients indicate that work provides normalcy, distraction from the disease, and both social and financial support (Amir et al., 2008; Main et al., 2005; Wells et al., 2013). Furthermore, work helps to structure life and is missed when absent (Lilliehorn et al., 2013). Patients mostly evaluate RTW as a positive experience, despite some negative situations, for example with co-workers (Maunsell et al., 1999).

Current knowledge on occupational rehabilitation is derived from studies including various cancer types or female breast cancer patients only, although research suggests that RTW-related problems vary by cancer type (Kiasuwa Mbengi et al., 2016) and predict gender-specific work-related outcomes after cancer (Ullrich et al., 2012), which underscores the necessity to investigate the specific RTW experiences of MBPCs.

This study applied an explorative qualitative approach to investigate the RTW experiences of MBCPs. Exploration of RTW

procedures and experiences can reveal the specific needs of breast cancer patients. The following research questions were addressed in the present study: (a) What kind of RTW patterns exist among MBCPs? (b) What motivates MBCPs to return to work? (c) How do MBCPs experience their RTW? (d) How does the disease influence their work after RTW?

## 2 | METHODS

### 2.1 | Study design

The present study was based on the mixed-methods N-MALE project (Male breast cancer: patients' needs in prevention, diagnosis, treatment, rehabilitation, and follow-up care), which was conducted in Germany from 2016 to 2018. Quantitative and qualitative data were collected to study the medical and psychosocial needs of MBCPs from diagnosis to aftercare and rehabilitation. The N-MALE project was described in Midding et al. (2018).

The present study emphasised qualitative data obtained from semi-structured interviews conducted based on an interview guide with open-ended stimuli and complemented by further narrative-generating questions (Helfferich, 2011). The topics of the guide addressed the participants' needs and experiences with the healthcare system during diagnosis, active treatment, aftercare, and rehabilitation as well as social support and coping. All measures were developed by the multidisciplinary N-MALE project team (health economics, sociology, and psychology). To assure comprehensibility, the interview guide was pretested in three interviews.

The interviews were conducted by two female (one male was present once) research fellows (PhD candidates) who were first trained in interviewing and prepared for potentially sensitive topics (e.g. sexuality, emotional reactions) by a psychotherapist. By using different trained interviewers and an interview guide, biases attributed to the interviewer and their characteristics were reduced.

The Ethics Committee of the Medical Faculty of the University of Bonn approved the N-MALE project (reference number 087/16).

### 2.2 | Recruitment

A sample of 100 men with breast cancer completed the quantitative survey after being recruited through certified breast cancer centres, the Men with Breast Cancer Network (Netzwerk Männer mit Brustkrebs e. V.), and invitations published in press releases and short articles. A subsample of 27 participants was selected using purposeful sampling (Corbin & Strauss, 2015). The sampling strategy aimed to include contrasting cases with characteristics considered relevant to the research topic. Information from the quantitative survey was used to select interviewees with different

sociodemographic characteristics (e.g. age, marital status, having children, education, place of residence, working status), disease- and treatment-related characteristics (time since diagnosis, cancer stage, relapse, place and kind of treatment, positive or negative experiences with treatment), and participation in self-help groups. The sampling process continued until data saturation was reached (Corbin & Strauss, 2015).

The inclusion criteria were male gender, a confirmed breast cancer diagnosis (10th revision of the International Statistical Classification of Diseases and Related Health Problems [ICD-10] C50.x or D05.x), written informed consent, and sufficient knowledge of the German language. Patients were excluded from the interviews if they did not provide consent or if participation was impossible due to health constraints (e.g. deafness) or insufficient knowledge of the German language.

### 2.3 | Data collection and analysis

After being selected for an interview, the participants were contacted to set an appointment. The interviewees were informed about the procedure (audio recording, data use) before providing consent. Face-to-face interviews were carried out in the participants' preferred locations (in most cases, their homes) and lasted for a maximum of two hours. To prevent interruptions, only the interviewer and interviewee were present (upon request, interviewees' spouses also attended). All interviews were audio-recorded, transcribed verbatim, and pseudonymised before analysis.

The analysis consisted of three steps: first, all 27 transcripts were read; then, the transcripts were analysed for work- and return-related content (some interviews did not cover the topic of occupational rehabilitation because the questions were only asked to participants of working age or when the interviewees themselves brought up the topic). Finally, 14 transcripts with relevant content were included in the qualitative content analysis (Mayring, 2014). Similar to Mayring's summarising content analysis, the content was first paraphrased. Then, more general code titles were assigned to the paraphrased text segments to summarise these text passages under more general code names and group similar codes to categories. KH (coding, discussion of material), PH (coding, discussion of material), and NE (discussion of material) participated in this process. Data management was performed using MAXQDA 2018. The coding process was both deductive and inductive, with codes derived from existing literature and complemented by new codes based on the data. To ensure the reliability of the analysis, the data were coded by two scientists. Any differences in coding were discussed until consent was reached.

The results are presented as quotes representing the typical interview responses translated into English. To facilitate understanding, these quotes were modified, for example by omitting filler words (marked with [...]) or by adding information in square brackets.

## 3 | RESULTS

### 3.1 | Sample characteristics

Fourteen of the 27 interviews containing work- or return-related content were analysed in this study. While the 100 participating MBCPs had a mean age of 66.9 years at the time of data collection, the subsample of 14 participants was younger (mean age, 58.6 years). The interviewees received their first diagnosis an average of 4 years before participating in the study (range: 0–17 years). For most participants, the breast cancer diagnosis was their first diagnosis. In the subsample, eight patients worked full- or part-time, while six were retired or on sick leave at the time of data collection. The interviewees had varying levels of education and the participants underwent multimodal treatment. Chemotherapy and radiation therapy were applied more often among the subsample of 14 interviewees. Table 1 presents the sample characteristics.

### 3.2 | RTW patterns

The RTW patterns were described using four events: working during therapy, participation in medical rehabilitation, occurrence and type of RTW, and job changes after RTW. The patterns and events were used to distinguish and determined from inductive derivation of the interviews. Since some of the 14 participants exhibited the same RTW patterns, a total of 11 patterns were analysed, as shown in Table 2. Patterns 5 and 6 were experienced by more than one participant.

The results showed that the participants commonly worked during treatment as four patterns were identified in which they worked while receiving chemotherapy and/or radiation therapy.

Most patterns were characterised by participation in medical rehabilitation. In particular, interviewees who were not working while receiving treatment participated in medical rehabilitation programmes.

The interviewees tended to return to work non-gradually. Particularly, participants who worked during therapy waived the option to return gradually. Four patterns did not include RTW because they led to retirement after sick leave, occupational reintegration was forthcoming at the time of the interview, or RTW was not defined in the data.

The reported changes after RTW included reduced working hours, altered tasks, entry into retirement, and uptake of a side job. The interviewed MBCPs viewed such changes positively, for instance one participant preferred early retirement with its associated improved quality of life over the financial advantages:

And so, now I'm going to retire. Because well, [...] should I suffer through it for another year and a half and then retire without any reductions or can I afford the year and a half with a few percentage points less? And I think I can afford it [...]. And then I have, let's say, maybe already an attitude to life [...].

(P32, 61 years of age)<sup>1</sup>

<sup>1</sup>“P” is the abbreviation for participant, the number is a randomly assigned pseudonym.

**TABLE 1** Sociodemographic and disease-related characteristics of the whole sample (N = 100) compared with the subsample of the present study (n = 14)

	N = 100				n = 14			
	Abs	Ø	Min	Max	Abs	Ø	Min	Max
Age at time of interview (in years)		66.9 <sup>a</sup>	39 <sup>a</sup>	89 <sup>a</sup>		58.6	42	75
<b>Family status</b>								
Married	76				12			
Single	8				1			
Divorced	7				1			
Widowed	7				0			
Missing	2				0			
<b>Education<sup>c</sup></b>								
No school certificate	1				0			
Lower school certificate	36				6			
Intermediate school certificate	24				3			
University entrance certificate	35				5			
Other	2				0			
Missing	2				0			
<b>Occupation</b>								
Full-time	24				7			
Part-time	4				1			
Retired	54				5			
Occupational rehabilitation	2				0			
On sick leave	12				1			
Unemployed	1				0			
Missing	3				0			
Time since first diagnosis (in years)		3.6 <sup>b</sup>	<1 <sup>b</sup>	20 <sup>b</sup>		3.8	<1	17
<b>First diagnosis</b>								
Yes	92				11			
No	4				1			
Missing	4				2			
<b>Existence of metastases</b>								
Yes	7				0			
No	81				13			
Do not know	3				0			
Missing	9				1			
<b>Treatment (multiple choice)</b>								
Surgery	97				14			
Chemotherapy	56				11			
Radiation therapy	65				10			
Hormone therapy	75				12			
Do not know	2				1			

<sup>a</sup>Calculation based on n = 98 (two missing values).

<sup>b</sup>Calculation based on n = 95 (five missing values).

<sup>c</sup>Education levels: lower school certificate  $\pm$  8–9 years of schooling, intermediate school certificate  $\pm$  10 years of schooling, university entrance certificate  $\pm$  12–13 years of schooling.

Two patterns showed reduced working hours, in which the persons worked during therapy and did not return gradually. Changes in task occurred after a gradual RTW and were

followed by early retirement. Retirement entry was observed both among persons who returned gradually and those who did not.

TABLE 2 Return to work (RTW) patterns ( $n = 14$  male breast cancer patients)

Pattern No.	Worked during therapy	Participation medical rehabilitation (at least one) <sup>a</sup>	Occurrence/type of RTW	Job changes after RTW	<i>n</i>
1	X	X	Non-gradual	Reduced working hours, retirement, uptake of side job	1
2	X	X	Non-gradual	Partial retirement programme	1
3	X	–	Non-gradual	Reduced working hours	1
4	X	–	Non-gradual	Early retirement	1
5	–	X	Non-gradual	–	2
6	–	X	Gradual	–	3
7	–	X	Gradual	Changes in task, early retirement	1
8	–	X	Pending	–	1
9	–	X	–	Reduced earning capacity pension	1
10	–	X	Undefined	–	1
11	–	–	Undefined	Retirement	1

<sup>a</sup>Most cancer patients in Germany are entitled to at least 3 weeks of inpatient medical rehabilitation covered by the German statutory pension insurance scheme; each row of the table shows an RTW pattern. RTW patterns are defined by the following events (shown in columns): work during therapy; participation in at least one medical rehabilitation programme; occurrence and type of RTW, as well as job changes after RTW. An 'X' indicates that an event was reported; '–' means that it was not reported.

TABLE 3 Coding scheme of the qualitative content analysis ( $n = 14$  male breast cancer patients)

	<i>n</i>
Motives to RTW	
Normalcy	3
Distraction	4
Need for activity	3
Social contacts	2
Job not requiring physical effort facilitating return	2
Not perceiving yourself as sick	1
Passion for work	4
Financial considerations	3
Handling cancer disease in the workplace	
Telling about cancer disease at work	10
Keeping contact with work environment during sick leave	2
Not desiring contact with work environment during sick leave	1
Support by colleagues/supervisors	10
Negative experiences with colleagues/supervisors	5
Changes in productivity after RTW	
Fatigue	5
Forgetfulness	1
'Pulling oneself together' with clients	1
Emotional distress through work	1
Working time being restricted due to aftercare	1
Aftercare being restricted due to working time	1

RTW, return to work.

### 3.3 | Motives

A total of eight motives to return to work were analysed, as illustrated in Table 3. None of the participants considered not going back to work and some worked while receiving treatment. This impression of RTW being a 'natural thing to do' was supported by their wish to regain normalcy by going back to work:

And of course, that has been my dream for months by now because when you have been in this situation once, then normalcy is of course already ideal. So, teaching up there again, fully able-bodied, that would be really, really good, right?.

(P53, 55 years of age)

Besides the factor of regaining normalcy, resuming work functioned as a distraction from the disease. The following quote illustrates how the urge for distraction could prevail over negative consequences such as participants' limited performance capability:

On the one hand, I was totally exhausted, but I always did want some distraction, right? [...] And in the evenings, I was [...] tired, pale. And later without hair. But Jeez, I would say, I could bear it, yeah.

(P16, 66 years of age)

Some interviewees were motivated to resume working by a need for activity. This need became evident, for instance when other family members continued their daily routines (including work), as the following quote shows:



I can't just be home, can't just ride around on my race bike. I was in great shape, but then I, my wife works, and then I thought in winter or when it was raining, what are you gonna do now, right?

(P14, 71 years of age)

Some participants described missing social contacts. For them, work represented a way to increase social involvement.

Another factor motivating the return was the perception of cancer. One person did not consider himself, but rather the cancer tissue, as sick. The removal of the sick part from his body left him with the feeling of being healed and ready to work again:

I am not sick. It's not a disease. A disease is a cold, flu, that's a disease, a sick part, but it has been cut out after all. That's why I'm no longer sick [...].

(P14, 71 years of age)

In addition, the perception of the job and the effort it required was potentially motivating. Participants with jobs requiring little physical effort were motivated to resume work.

A passion for work and the resulting joy were other motives for interviewees to resume work. One participant expressed his passion for his 'dream job,' which enabled him 'to draw on all of his knowledge and experience' (P10, 63 years of age).

Financial reasons also played a role in the decision to return. A self-employed part-time worker expressed financial strain in the case of long-term absence, leading to income losses:

[...] [Y]ou start to receive only sickness benefits and when all of a sudden, you have over 500 euro less, you have to first see how you manage with that. And for me [...] it was even more because I only have a 60% part-time job and work as a freelancer on the side. And that I couldn't do any longer either.

(P42, 51 years of age)

### 3.4 | Handling cancer disease in the workplace

Most participants told their colleagues and supervisors about the disease. Some preferred to disclose it to a few people only or to delay providing this information until their return. The following quote shows how openness about the disease was used as a strategy to avoid rumours and gossip:

And in my life, I have generally gotten into the habit of going on the offensive right away and putting all my cards on the table. This is because nothing is more boring than yesterday's rumour. If you try to fiddle or cover things up, they will keep asking: 'Well, what do you have? What's that? And why isn't he showing up now?' [...] So I wrote an email and took the big

distribution list, everyone I could think of [...] and sent it off.

(P53, 55 years of age)

Some participants kept in contact with their work environment during their absence. The form of desired interaction differed: while some appreciated meeting colleagues while on sick leave, others restricted contact with organisational matters.

Most interviewees spoke about the support received, for example emotional support from co-workers who had experienced cancer or organisational support, allowing a more flexible schedule. However, some participants reported situations characterised by a lack of support. Some colleagues were uncertain about how to interact with their co-worker after learning about the disease, sometimes leading to insufficient or excessive understanding and attention, as the following quotes show:

After the reintegration, you're suddenly back in working life. It's like turning a switch. You simply have to function again. Your colleagues quickly forget that you were gone for eleven months, not long ago. Actually, expect a lot of understanding, but offer little themselves. You always have to show understanding for them and their situation, always.

(P12, 55 years of age)

Later, I was tired of it too, because people asked: 'How are you?' And so I always wrote the same text [...] 30, 40, 50 times, with a few changes. At some point, I didn't want to talk about it anymore, I was tired of always explaining it.

(P53, 55 years of age)

Another example of negative experiences in the workplace was the reported stigmatisation by colleagues because the individual was suffering from 'a typical women's disease.' One participant described his colleague addressing him as 'Miss' instead of 'Mister':

I have a colleague who still makes life a bit difficult for me by generally addressing me as 'Ms. Jones<sup>2</sup>, right? [...] I simply told them once that [...] at the hospital, in the discharge letter [...] it always [says] 'Ms. Jones' right?

(P54, 61 years of age)

### 3.5 | Changes in productivity after RTW

Interviewees reported perceiving changes in their productivity after cancer treatment compared with their previous levels of

<sup>2</sup>Name has been changed.

performance. In particular, those who worked during treatment reported limitations.

Changes in cognitive functions, such as forgetfulness, were mentioned.

The associated fatigue limited participants' productivity at work, leading one participant to take naps in the office to be 'fit again' (P67, 62 years of age) and make it through a working day.

Furthermore, an interviewee mentioned that he felt like he had to 'pull himself together' (P10, 63 years of age) when clients were present.

The participants also reported mental state changes because being reminded of the cancer disease triggered emotional distress. A physician described treating cancer patients immediately after his RTW as 'emotionally very burdening' (P10, 63 years of age).

In the aftercare phase, the interviewed MBCPs expressed that either their working time was restricted due to aftercare appointments or vice versa, and sometimes both scenarios.

And the first workday would have been the same day as my first follow-up appointment, right? But I already told my boss: 'I can't come in then, that's when I have my follow-up appointment,' right?

*(P54, 61 years of age)*

In the beginning, oncology had actually wanted [physical therapy] five times a week. [...] And now because I also travel for work, I do three times a week. And I simply don't have time for more either.

*(P54, 61 years of age)*

## 4 | DISCUSSION

### 4.1 | RTW patterns

The results showed that the RTW patterns of the participating MBCPs were individual and diverse. Analysis of the experiences of 14 participants revealed 11 different return patterns based on the events of working during therapy, participation in medical rehabilitation, occurrence and type of RTW, and changes after the return.

Overall, the interviewees in this study tended to resume work non-gradually, in some cases despite limited productivity. The participants were willing to accept negative outcomes (e.g. fatigue) in exchange for the expected positive effects of RTW. Nevertheless, the limited productivity caused problems for those affected, possibly indicating a need for further support after RTW. Thus, RTW may be more appropriately considered a process rather than a single event.

The results suggested that participants who worked while receiving therapy were less likely to participate in medical rehabilitation or to use supportive measures such as gradual return. These participants may have been in a better state of health and, therefore, had a low need for support. However, early returning interviewees also experienced physical problems. Hence, waiving support measures

could also indicate a lack of information about these measures, unavailability of outpatient offers to avoid further interrupting the work routine, or a repressive coping style characterised by an attempt to avoid confronting the disease by resuming work (supported by the RTW motive of 'regaining normalcy').

Previous studies reported that cancer patients are at risk of early retirement and interpreted reduced hours after RTW partly as discrimination (Maunsell et al., 1999; Mehnert, 2011). However, our results showed that the interviewees interpreted changes positively and welcomed them. Decreasing work hours helped those affected to reacquaint themselves with the work requirements, and early retirement was seen as a sign of re-evaluating work as a priority in life. This re-evaluation of priorities was also reported in previous studies of cancer patients (Amir et al., 2008; Kennedy et al., 2007; Main et al., 2005).

### 4.2 | Motives

Previous studies have analysed the desire for normalcy, distraction and maintenance of social contacts; the need for activity; financial pressures; missing work; and work not requiring physical effort as motivating factors for RTW (Amir et al., 2008; Johnsson et al., 2010; Kennedy et al., 2007; Lilliehorn et al., 2013; Main et al., 2005). The present study additionally found motives such as joy at work and not perceiving oneself as sick that may be unique among MBCPs. Work as a source of joy may be one reason for the motive 'missing work' described by Lilliehorn et al. (2013).

The motivators identified in the present study suggested that the participants were mainly driven by internal factors to resume work. Nevertheless, external motivators such as financial aspects were also observed. Single, part-time and self-employed participants mentioning financial pressure as a motive might indicate the need for special support among these jobholders.

### 4.3 | Handling cancer disease in the workplace

Nearly all interviewees informed their work environments of their diagnosis. They were also transparent about having breast cancer, even though men with this 'typical women's disease' were at risk for stigmatisation (Midding et al., 2018). In addition, participants in the present study reported negative stigmatising experiences specific to MBCPs, for example being called Miss instead of Mister by a colleague. In general and consistent with previous findings, the participants in the present study mainly reported positive experiences concerning RTW (Amir et al., 2008; Kennedy et al., 2007; Main et al., 2005; Maunsell et al., 1999). Openness about the disease was even reported as beneficial since an interviewee thought it prevented rumours and helped his coping.

Regarding staying in contact with the work environment, participants' preferences differed, with some restricting contact with organisational matters and others appreciating meeting colleagues

while on sick leave. The results of a qualitative study with female breast cancer patients suggested that contact with at least a supervisor is helpful, for example to structure the return (Caron et al., 2018).

#### 4.4 | Changes in productivity after RTW

The consequences of the disease and its treatment led to various physical and psychological changes in productivity at work. Our results supported previous findings showing that fatigue in cancer patients limited their efficiency after RTW (Amir et al., 2008; Kennedy et al., 2007; Main et al., 2005; Maunsell et al., 1999).

#### 4.5 | Practical implications

The results of the present study showed that both restoring and maintaining work ability long term were important to the MBCPs. Therefore, the cancer care system should focus on long-term health outcomes that challenge the productivity of survivors and offer suitable support measures. Consequences such as early retirement may also be reduced.

Even though a reduction in working hours and early retirement seemed to be deliberately chosen, they are accompanied by financial losses to the welfare system and individuals. Hence, it should be determined whether modifying the work conditions could prevent MBCPs from dropping out of work or reducing hours since they are highly motivated to RTW. Qualitative findings have suggested that flexibility in the work schedule for a certain time facilitated RTW (Caron et al., 2018).

MBCPs face stigmatisation, indicating that further education is necessary to alter the image of breast cancer as a 'women's disease' and facilitate the occupational rehabilitation of male patients.

#### 4.6 | Research implications

Since some participants declined support measures (medical rehabilitation or gradual return), future research is needed to investigate their reasons for waiving such options to develop strategies to efficiently reach these groups. Initial studies among cancer patients have identified family-related and personal reasons that prevent patients from participating in medical rehabilitation (Deck et al., 2019; Deck & Walther, 2017; Miedema & Easley, 2012).

Future studies should focus on patients who are unable to successfully RTW and explore their motivations and experiences to understand obstacles preventing RTW. Since most MBCPs in this sample resumed working, it was not possible to investigate potential barriers.

In the context of rare diseases associated with stigmatisation, interventional studies would be useful to explore the roles of

supervisors and colleagues in the process of occupational reintegration. Moreover, MBCPs' needs regarding communication and frequency of contact with the workplace should be considered.

#### 4.7 | Strengths and limitations

The analysis of qualitative data from semi-structured interviews in the present study permitted in-depth insights into RTW experiences from the MBCPs' perspectives. The results provided a better understanding of the processes by revealing internal motivating factors as well as interpretations of and reasons for work-related behaviour regarding RTW after a breast cancer diagnosis.

Due to the exploratory nature of this study, the results can be used to develop further studies. Despite analysing 14 interviews in-depth, the sample showed great variation. RTW decisions are made in different healthcare settings, implying different support opportunities for cancer survivors. These differing conditions influence RTW rates and patterns. In Germany, the healthcare system provides the opportunity for at least three weeks of inpatient medical rehabilitation, covering gradual return options and support measures enabling participation in working life (e.g. vocational retraining). Therefore, the results may be country-specific.

On average, the interviews took place 4 years after the participants received their initial diagnosis, potentially resulting in memory bias. However, this time span also provided information on the years after RTW.

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#### CONFLICT OF INTEREST

CK is employee of the German Cancer Society (DKG). All other authors declare no conflicts of interest.

#### DATA AVAILABILITY STATEMENT

Research data are not shared. According to the patient consent form, data are not available for scientific use by others than the project group members.

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**3.2 Response to ‘Response to “Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study.”’**

## LETTER TO THE EDITOR

## Response to ‘Response to “Occupational rehabilitation of male breast cancer patients: Return patterns, motives, experiences, and implications—A qualitative study.”’

Male breast cancer (MBC) is rare as only 1% of patients are male. Studies showed that male patients are confronted with delayed diagnoses, treatment deficits and stigmatisation (da Silva, 2016). Hence, it is important to investigate experiences of male breast cancer patients (MBCPs) throughout their whole cancer journey. Return to work (RTW) after cancer is a key factor of the recovery process ensuring social participation. We appreciate that RTW experiences of MBCPs receive attention and gladly share our thoughts on the points outlined in the authors' letter.

First, the authors stress the relevance of sample sizes and question why data from 14 of 27 participants were analysed. A purposeful sample of 27 MBCPs, collected during the N-MALE study, was subject to the present analysis. The occupational status was one sampling criterion. Some interviews did not cover the topic of RTW because participants were asked to this when they were of working age or the interviewees brought it up. Thus, screening for work-related content led to 14 interviews, which were included in the following steps of the analysis. Our study created valuable first insights. As Malterud et al., (2016, p. 1759) put it '[f]or an exploratory study, we do not head for a complete description of all aspects of the phenomenon we study'. In line with the authors, we think that more research on RTW experiences of MBCPs is required and that our exploratory results can serve as a base. We encourage that upcoming research includes larger samples. Given that MBC is rare, international collaborations should be pursued to reach larger cohorts.

Second, the authors point out participants' different occupational status and question whether their experiences could be influenced by a forthcoming or fulfilled RTW. When RTW was forthcoming, participants were able to contribute by talking about their desire to return, their motives and how the disease was handled at work so far. Participants were not asked to elaborate on future experiences, wherefore the narrations were not influenced by the RTW status.

Third, the authors discuss gradual RTW options and ask for factors associated with waiving gradual reintegration. Participants who were working while receiving therapy were seemingly less likely to return gradually; therefore, we discussed a better health status as a potential barrier. Moreover, unavailability of outpatient offers to avoid interrupting the work routine, a repressive coping style or lack of information about such measures were interpreted as possible

barriers in the manuscript. We agree with the authors that knowledge on barriers to use support measures (e.g. gradual return) is valuable to design patient-centred, need-oriented interventions and that (gradual) RTW planning could be important for a successful RTW. Additionally, interventions targeting employers or caretakers could be beneficial when aiming for satisfying RTW outcomes due to specialists' lacking knowledge (Lamort-Bouché et al., 2020) and different communication needs of patients with the workplace (Hiltrop et al., 2021).

Our research showed that experiencing MBC is likely to be associated with health professionals' uncertainty and unmet needs (Halbach et al., 2020; Hiltrop et al., 2021; Midding et al., 2018, 2019). We thank the authors for the critical debate and appraisal of our study. We welcome exchange and collaborations with other researchers that raise the awareness for MBC and contribute to a better understanding of MBCPs' needs in the future.

**KEYWORDS**

content analysis, employment, male breast cancer, occupational rehabilitation, qualitative research, return to work

**FUNDING INFORMATION**

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**CONFLICT OF INTEREST**


None.

**ETHICAL APPROVAL**

The Ethics Committee of the Medical Faculty of the University of Bonn approved the N-MALE project (reference number 087/16).

**DATA AVAILABILITY STATEMENT**

Research data are not shared. According to the patient consent form, data are not available for scientific use by others than the project group members.

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**3.3 Breast cancer patients' return to work (B-CARE): Protocol of a longitudinal mixed-methods study aiming to explore medical and occupational rehabilitation of patients with breast cancer in Germany**

# BMJ Open Breast cancer patients' return to work (B-CARE): protocol of a longitudinal mixed-methods study aiming to explore medical and occupational rehabilitation of patients with breast cancer in Germany

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## ABSTRACT

**Introduction** In recent years, research has been done on determinants of return to work (RTW) in cancer survivors and their long-term work outcomes. Nevertheless, little is known about the survivors' evaluation of these outcomes in terms of job satisfaction and voluntariness. Hence, B-CARE aims at filling the research gap by providing a longitudinal cohort study investigating medical and occupational rehabilitation including an evaluation by breast cancer survivors.

**Methods and analysis** A mixed-methods approach, combining a quantitative survey with qualitative semi-structured interviews, is used to study breast cancer survivors 5–6 years after diagnosis. These data will be linked to data from prior waves of patients during hospitalisation and 10 and 40 weeks after hospital discharge as well as routine data from the German Statutory Pension Insurance Scheme and German Cancer Society if available. The actual survey focuses on determinants of medical rehabilitation use, RTW, subsequent employment patterns post care as well as the voluntariness of and satisfaction with job changes.

**Ethics and dissemination** A positive vote from the ethics committee of the Medical Faculty of the University of Bonn has been obtained. Data protection regulations will be adhered to for all handled data. Personal identifiers of participants will be pseudonymised. Dissemination strategies include a workshop to discuss results among stakeholders such as representatives of the German Statutory Pension Insurance Scheme, social workers and self-help groups.

**Trial registration number** German Clinical Trials Register (DRKS00016982); Pre-results.

## INTRODUCTION

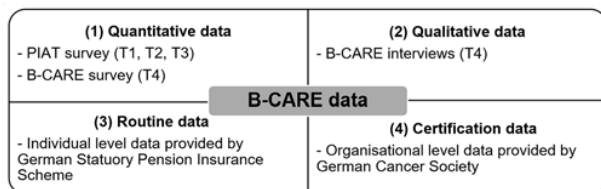
Breast cancer is the most common type of cancer among women, with around 70 000 newly diagnosed cases per year in Germany.<sup>1</sup> Around 30% of affected women are under 55 years of age.<sup>2</sup> In combination with decreasing mortality rates due to therapeutic success

## Strengths and limitations of this study

- First German study to investigate factors influencing the use of medical rehabilitation and return to work with patients from a representative sample of certified German breast cancer centres.
- Diverse data sources and plan to link primary data (survey and interview data) and secondary data (routine and certification data).
- Primary data allow for longitudinal analyses as they were collected at multiple time points, ranging from shortly after breast cancer diagnosis to the survival phase 5–6 years later.
- Some measures could be affected by recall bias; however, all instruments will be pretested to check if participants are able to answer the questions.
- Due to the sample consisting of women with (breast) cancer, the results may not translate to men with (breast) cancer.

and early detection through screening programme,<sup>2</sup> this makes successful medical and occupational rehabilitation to ensure patients' social participation after survival increasingly important.

Although patients with cancer in Germany are entitled to at least 3 weeks of inpatient rehabilitation after completing primary care, current numbers show that only around 60–70% of patients with breast cancer make use of this opportunity offered by the German Statutory Pension Insurance Scheme,<sup>3–5</sup> and the rates are declining.<sup>6</sup> The available research on barriers to the use of medical rehabilitation among patients with cancer is scarce.<sup>7</sup> Its results suggest that barriers are diverse, ranging from personal, family-related and occupational reasons to system-related reasons.<sup>8,9</sup> For example, being away from the



**Figure 1** Data sources of the B-CARE project. PIAT, ‘Strengthening patient competence: Breast cancer patients’ information and training needs’ study.

family, financial pressure to return to work soon, fear of exposure to other affected persons being a negative influence and a lack of outpatient rehabilitation options hinder cancer patients’ use of rehabilitation. Cancer stage, age, psychological strain and information available on rehabilitation are considered to predict participation in medical rehabilitation.<sup>7</sup> However, sociodemographic factors have a rather small predictive power regarding use of rehabilitation measures.<sup>10</sup>

Since it is supposed to enable occupational rehabilitation, medical rehabilitation is important for the growing number of patients with breast cancer of working age. That is why the German Statutory Pension Insurance Scheme offers a variety of measures to encourage patients’ return to work (RTW) based on the ‘rehabilitation before retirement’ principle.<sup>11</sup> Particularly in recent years attempts were made to intensify work-related content in medical rehabilitation.<sup>12</sup> Still, RTW rates are comparatively low in Germany: while 80% of patients with breast cancer in the United States return to work, only 59% of them do so in Germany.<sup>13</sup>

To understand the RTW of cancer survivors, national and international studies conducted in recent years investigated its determinants and timing and found that disease, treatment and work related as well as sociodemographic and psychosocial factors influence RTW.<sup>14–19</sup>

In addition to initial RTW, studies investigated the occurrence of job changes, unemployment and other long-term work outcomes in cancer survivors up to 10 years post diagnosis.<sup>3 5 20 21</sup> Inter alia, it was found that perceived barriers to resuming work seem to change over time<sup>20</sup> and that cancer survivors may suffer financial burdens due to reduced working hours 5 years post diagnosis.<sup>5</sup>

While long-term work outcomes have been analysed, little is known about how cancer survivors evaluate these outcomes in terms of job satisfaction and the voluntary nature of their employment development.<sup>22</sup> Hence, more longitudinal studies exploring RTW,<sup>23</sup> its long-term outcomes and their evaluation from the cancer survivors’ perspective are needed, as work contributes to the social and psychological well-being of cancer survivors.<sup>21 24</sup>

### Aims of the study

B-CARE aims at filling the research gap by providing a longitudinal cohort study investigating breast cancer survivors’ rehabilitation use, RTW and subsequent

employment patterns post care in Germany considering disease, treatment and work related as well as sociodemographic and psychosocial information using a mixed-methods approach. The results may contribute to the development of specific measures to increase the number of patients in medical rehabilitation and to have an understanding of cancer survivors’ long-term work-related needs.

## METHODS AND ANALYSIS

### Study design

B-CARE is a multicentre, non-interventional, mixed-methods cohort study combining several data sources, which are illustrated in figure 1. Quantitative survey data as well as qualitative data from semi-structured interviews will be used. Routine data on the individual and organisational level are intended to be included. The use of diverse data sources enables generating a holistic understanding of the research topic by balancing weaknesses and strengths of each individual data source,<sup>25</sup> for example, eliminating possible biases based on self-reported measures by the addition of more objective routine data. The project will be conducted between May 2018 and December 2020.

### Recruitment & Sample

For ‘Strengthening patient competence: Breast cancer patients’ information and training needs’ (PIAT) study, a representative sample of n=1359 patients with breast cancer was recruited in n=60 breast cancer centres throughout Germany in 2013/2014. The n=60 participating breast cancer centres were part of a random sample of n=98 German Cancer Society-certified breast cancer centres. Participants came from 15 out of 16 federal states in Germany. The breast cancer centres included all patients who had their initial breast cancer diagnosis and surgery between 1 February and 31 August 2013. Surveys were conducted at three time points: during hospitalisation, 10 weeks after hospital discharge and 40 weeks after hospital discharge (T1: n=1359; T2: n=1248; T3: n=1202). Further information on the recruitment and sampling of the PIAT study can be found in Schmidt *et al*.<sup>26</sup>

B-CARE is based on a subsample of the PIAT sample. The subsample includes n=530 patients with a breast cancer diagnosis (C50.x or D05.x) and sufficient German language skills who worked prior to this diagnosis and gave consent to be recontacted in case of a follow-up. B-CARE carries out this follow-up 5–6 years after the patients’ hospital discharge. The sample of n=530 possible participants will be invited by mail. Additionally, some of the survey participants who gave consent to be re-contacted will take part in a semi-structured interview (around n=30). Participants will be selected through theoretical sampling aiming at maximising the heterogeneity of the sample. The sample shall vary with respect to sociodemographic factors (eg, age, number of children, marital status) and psychosocial factors (eg, health literacy) as

**Table 1** Central elements of the quantitative PIAT and B-CARE questionnaires

	PIAT T1	PIAT T2	PIAT T3	B- CARE T4
<b>Disease and treatment-related variables</b>				
Treatment process/after care	x	x	x	x
Comorbidities	x			x
<b>Psychosocial variables</b>				
(Psycho)social support	x	x	x	x
Fear and depression			x	x
Fear of progression	x		x	x
Self-efficacy				x
Health literacy	x	x	x	x
Quality of life		x	x	x
Coping				x
<b>Information needs and sources variables</b>				
Information needs, sources and use	x	x	x	x
<b>Rehabilitation-related variables</b>				
Medical rehabilitation use		x	x	x
Evaluation of medical rehabilitation				x
Occupational rehabilitation			x	x
Evaluation of occupational rehabilitation				x
<b>Sociodemographic variables</b>				
	x	x	x	x

PIAT, 'Strengthening patient competence: Breast cancer patients' information and training needs' study.

well as based on rehabilitation process characteristics (use of medical rehabilitation, RTW process). Participants who give written consent and fill in the survey will be included in the study.

## Measures

### Quantitative data

The quantitative PIAT and B-CARE questionnaires consist of validated scales and self-developed measures. The self-developed measures are in line with standards of survey question development.<sup>27</sup> Table 1 illustrates the central contents of both questionnaires.

The PIAT questionnaire was designed to investigate information needs among recently diagnosed patients with breast cancer. The questionnaire included, among others, questions on participants' disease and course of treatment, measures of psychosocial and sociodemographic characteristics, and questions on information needs, sources and their use (eg, regarding treatment, support measures, financial issues).

The B-CARE questionnaire aims at measuring determinants of use of medical rehabilitation, RTW and subsequent employment patterns post care. Therefore, the questionnaire contains, inter alia, questions on the participants' aftercare, psychosocial and sociodemographic measures and questions on information needs, now focused on rehabilitation.

Disease and treatment-related variables include questions regarding the frequency and type of aftercare examinations, cancer recurrence and existing comorbidities. Psychosocial variables comprise questions on the need for and use of (psycho)social support as well as validated scales to measure fear and depression (HADS-D<sup>28</sup>), fear of progression (PA-F-KF<sup>29</sup>), self-efficacy (ASKU<sup>30</sup>), health literacy (HLS-EU-Q16<sup>31</sup>), quality of life (EORTC QLQ-C30,<sup>32</sup> SF36<sup>33</sup>) and coping (FKV<sup>34</sup>). Information needs and sources are assessed based on the CaPIN scale.<sup>35</sup> Rehabilitation-related variables include questions on the frequency and evaluation of medical rehabilitation. With regard to occupational rehabilitation, patients may, among other things, be asked about their current work status, occurrence and timing of job changes, desirability of and satisfaction with changes as well as overall satisfaction with their employment development since surviving cancer. Sociodemographic variables cover sex, year of birth, first language, school-leaving qualification, vocational training, cohabitation with partner, marital status, number of children, number of children in the household, occupational status, main earner in the household and household income.

The outcome 'use of rehabilitation' is measured by the number of rehabilitation programme used because of participants' breast cancer since diagnosis. RTW is measured dichotomously. Additionally, the type and amount of work changes are assessed in combination with voluntariness and contentment.

### Qualitative data

The qualitative interview guide contains open-ended stimulus questions, complemented by further narrative-generating questions.<sup>36</sup> These interviews provide the opportunity to analyse breast cancer patients' experiences with medical and occupational rehabilitation in a more detailed way than the quantitative survey. The aim is to investigate promoters and barriers to both medical and occupational rehabilitation as well as to create an understanding of job changes. Possible gaps and shortcomings regarding the long-term support of breast cancer survivors can be made visible. The interview guide covers questions on expectations and experiences regarding processes in medical and occupational rehabilitation as well as decision regret.

In order to assure the comprehensibility of all scales and measures used, cognitive pretests will be performed according to research standards, and adjustments will be made if necessary.<sup>37</sup> Both the written questionnaire and the interview guide are developed with the help of existing literature and the input of an expert group



including researchers as well as representatives of the German Statutory Pension Insurance Scheme, social workers and self-help groups.

#### Routine data

Individual routine data from the German Statutory Pension Insurance Scheme will be accessed for the purposes of matching with the survey and interview data if available. Routine data provide retrospective longitudinal information about the use and benefits of medical and vocational rehabilitation without the risk of recall bias. Routine data may cover the participants' employment pattern post care as well as applications for and use of rehabilitation measures.

#### Certification data

German Cancer Society certification data on the organisational level of breast cancer centres allow analyses on the impact of centres' structural characteristics on the use of rehabilitation measures and the RTW rate. Variables such as recommended and provided therapies, number of mastectomies or psycho-oncological support will be matched with patients' individual-level data.

#### Data collection

Persons will be contacted by mail and receive the study information, a consent form, a survey questionnaire to fill in at home and two stamped envelopes in which to return the documents to the research centre (the consent form and questionnaire are to be sent separately). Filling in the survey will take up to 60 min. Before participating, patients will be informed about the study and asked to provide written consent for data collection and processing as well as pseudonymised analysis. In line with the Dillman's Total Design Method for surveys, two reminders will be sent in order to increase the response rate.<sup>38</sup>

For the qualitative interviews, participants will be chosen using theoretical sampling in order to increase the heterogeneity of the sample.<sup>39 40</sup> They will be recontacted via mail or phone to set an appointment for the interview. The qualitative semi-structured interviews will be carried out via telephone or face-to-face. Face-to-face interviews will take place in the participants' preferred location (at home or at the research centre). The interviews will last no longer than 90 min. All interviews will be documented by audio recordings and interviewers' memory protocols.<sup>39 40</sup> Consent for audio recording and analysis of the pseudonymised data will be obtained from participants before the interview. Throughout the interviewing process, the interview guide may be altered in accordance with qualitative research standards.<sup>39</sup> The sampling process will continue until theoretical saturation is reached, that is, to the point at which further cases will not generate more knowledge regarding the research topic.<sup>40</sup>

The quantitative and qualitative data collection will run concurrently.<sup>25</sup>

## Data analysis

### Quantitative data

The quantitative B-CARE survey data will be digitalised using the Teleform data capturing software and checked regarding plausibility. Data will be used according to the coding manuals after testing their psychometric properties. All personal data that allow identification will be deleted before merging data files and analysis. Therefore, the research team will match pseudonymised routine and survey data into one data set. This longitudinal data set will comprise quantitative data from PIAT (T1-T3), B-CARE (T4), if available routine data from the German Statutory Pension Insurance Scheme as well as aggregated certification data from the German Cancer Society on the breast cancer centres where participants were treated. Quantitative data will be analysed with the IBM SPSS V.25 statistical software. Multivariate and multilevel regression models will be estimated to investigate disease, treatment and work related as well as sociodemographic and psychosocial determinants of medical rehabilitation use and RTW as well as the subsequent employment patterns post care of cancer survivors under consideration of qualitative and quantitative data from hospitalisation until 5–6 years post diagnosis.

### Qualitative data

Audio records of the qualitative interview data will be transcribed verbatim and analysed using the grounded theory method.<sup>39</sup> At least two researchers will analyse the data independently with the help of MAXQDA software. Categories will be derived from existing literature and complemented with categories based on the data in order to include all relevant aspects regarding the research issue.<sup>39 40</sup> The data will be subsequently interpreted by a group of researchers.

### Triangulation

All data sources will be matched to a mixed-methods data matrix in order to be able to comparatively analyse quantitative and qualitative findings.<sup>41</sup> The matrix will be created so that each row represents data of one participant, while the columns contain quantitative and qualitative data collected for each case. This procedure allows studying (1) participants, taking into consideration different data types, as well as (2) patterns across different participants.<sup>41</sup>

### Patient and public involvement statement

Representatives of self-help groups and social workers are cooperation partners of the B-CARE project. Support will be received regarding the design of the study, development of instruments and discussion of results.

## ETHICS AND DISSEMINATION

### Ethical considerations

Data protection regulations will be adhered to for all handled data. While developing the data protection concept, special attention has been paid to ensure data

security as data from several sources will be matched on an individual level. A positive vote of the ethics committee of the Medical Faculty of the University Bonn has been obtained. All participants will be informed about the study's procedure and aims, with study information being provided before participants give written consent to collect, save and analyse their pseudonymised data.

### Dissemination plan

The results will be discussed in a workshop among stakeholders (German Statutory Pension Insurance Scheme, breast cancer centres, social workers and self-help groups). A results report for stakeholders will be prepared. In order to disseminate the findings among the health services research community, scientific publications and presentations at conferences are planned.

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**Competing interests** CK is employed by the German Cancer Society (DKG). All other authors declare no conflicts of interest.

**Patient consent for publication** Not required.

**Ethics approval** A positive vote of the ethics committee of the Medical Faculty of the University Bonn has been obtained.

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**3.4 Involuntariness of job changes is related to less satisfaction with occupational development in long-term breast cancer survivors**





# Involuntariness of job changes is related to less satisfaction with occupational development in long-term breast cancer survivors

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## Abstract

**Purpose** Considering that breast cancer survivors (BCSs) have been dealing with unwanted job changes after diagnosis, this study aimed to investigate involuntary job changes (unwanted modifications in employment since diagnosis) and explore the association between job changes, involuntariness, and occupational development satisfaction in BCSs 5–6 years after diagnosis.

**Methods** Data were drawn from the mixed-methods breast cancer patients' return to work (B-CARE) study. We surveyed 184 female BCSs who were working at the time of study enrollment during hospitalization (T1), 10 weeks after discharge (T2), 40 weeks after discharge (T3), and 5–6 years after diagnosis (T4) and used descriptive measures and stepwise linear regression models for data analysis.

**Results** The mean age of BCSs was 57 years. A total of 105 participants reported 410 job changes, of which 16.1% were reportedly (rather) involuntary. The most commonly reported involuntary changes were increased workload (15.2%) and increased scope of work (15.2%). In the final model, significant predictors of satisfaction with occupational development 5–6 years after diagnosis were age, state of health  $\Delta T2$ – $T3$ , state of health  $\Delta T3$ – $T4$ , and involuntariness of job changes.

**Conclusions** Although the number of job changes alone is not substantially associated with BCSs' satisfaction with occupational development, experiencing involuntary job changes is. Sociodemographic, disease-related, and work(place)-related factors may influence occupational satisfaction among BCSs.

**Implications for Cancer Survivors** The findings indicate the importance of strengthening one's ability to work as desired to prevent involuntary job changes and enable desired work participation in long-term support. The significance of workplace characteristics highlights the need for employers to encourage satisfying work participation.

**Trial registration number** German Clinical Trials Register (DRKS00016982), 12 April 2019

**Keywords** Breast cancer · Return to work · Occupational development · Involuntariness · Job changes · Social capital

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## Introduction

In Germany, approximately 492,000 new cancer cases were diagnosed in 2016 [1]. The most common cancer type among females is breast cancer, with almost 70,000 newly diagnosed cases per year [1]. Screening programs and therapy improvements contribute to a 5-year survival rate of 88% among female patients with breast cancer [2]. Furthermore, a significant proportion of affected women (30%) are younger than 55 years old when diagnosed [3].

Work-related outcomes are especially important for working-age breast cancer survivors (BCSs), considering that work can give meaning, provide financial security, allow social participation [4], and positively influence their quality of life [5]. In recent years, work-related outcomes, such as the timing and determinants of return to work (RTW), of cancer survivors have been extensively researched [6–10]. Disease-, treatment-, and work-related aspects as well as sociodemographic and psychosocial aspects influence RTW [6–10]. Objective long-term work-related outcomes such as work performance, absenteeism, and job changes in cancer survivors have also been studied [11–13]. Bijker et al. [11] found that an improved general functional status is associated with less absence, higher productivity, and slightly higher chances of RTW among cancer survivors. According to a systematic review, cancer survivors within 5 years after diagnosis have higher absenteeism than nonaffected individuals [12]. Regarding job changes, more than half of cancer survivor participants reported at least one change 2 years after diagnosis [13]. A multicountry study by Torp et al. [14] described that 6–37% of employed cancer survivors underwent occupational changes up to 6 years following diagnosis, and given that changes in working time were analyzed separately, approximately one-quarter of these respondents reduced their working hours after diagnosis. Moreover, cancer survivors partially attributed changes such as reduced working hours, changed tasks, and changed employers to cancer disease experience [13, 14]. Older age, presence of comorbidities, treatment with chemotherapy, and disease progression were reportedly predictors of experiencing job changes [15]. Reduced physical and mental work abilities were associated with work changes [16].

The insight on how BCSs perceive and evaluate objective work-related outcomes, such as job changes, remains largely unknown. Although using more subjective measures is necessary to determine BCSs' perspectives, only few studies exist. Mehnert and Koch [17] reported that work satisfaction is associated with sociodemographic characteristics such as older age, higher income, and health-related quality of life. Furthermore, lower levels of satisfaction with the vocational situation could predict

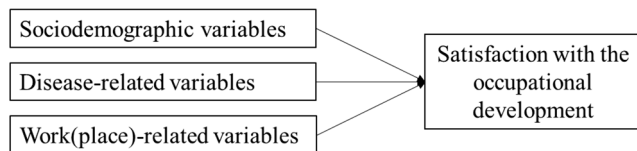
no RTW among BCSs [18]. More research on BCSs' evaluation of work-related outcomes is needed to (1) understand if experienced work-related outcomes are evaluated as burdensome and disadvantageous and to (2) determine the need for support from or improvements in the healthcare and social systems.

One aspect that might explain how disadvantageous work-related outcomes are for cancer survivors is probably their involuntariness. In the context of life-event research, stressful work-related events, particularly unintended job disruptions, directly and indirectly (mediated by coping and supportive resources) decrease mental health among working-age adult participants [19]. Currently, the association of involuntary job changes with work-related outcomes among cancer survivors has remained insufficiently researched. Initial studies reported the existence of unwanted job changes, such as demotion and changes in tasks and earnings, in BCSs after diagnosis [20]. However, the extent of experiencing involuntary work-related outcomes and the association of involuntariness with subjective work-related outcomes in cancer survivors are still unknown. Hence, this study aimed to (1) describe involuntary job changes and (2) explore the association between job changes, involuntariness, and satisfaction with the occupational development 5–6 years following a breast cancer diagnosis after controlling for sociodemographic, disease-related, and work(place)-related variables (Fig. 1).

## Methods

### Study design, sample, and data collection

In this “breast cancer patients' return to work” (B-CARE) study with mixed methods, we used BCSs' longitudinal data that were collected at four measurement time points: during hospitalization, 10 weeks after discharge, 40 weeks after discharge, and 5–6 years after discharge (T1:  $n = 1359$ ; T2:  $n = 1248$ ; T3:  $n = 1202$ ; T4:  $n = 184$ , respectively). Figure 2 illustrates the flow of participants. Data from the first three measurement time points were acquired from the PIAT study (“Strengthening patient competence: Breast cancer patients' information and training needs”). The PIAT study was conducted in Germany from 2013 to 2014 and recruited a representative sample of breast cancer patients from 60 randomly selected certified breast cancer centers. These breast cancer centers invited all patients who had their initial breast cancer diagnosis (C50.x or D05.x) and surgery between February 2013 and August 2013. After written consent was obtained, participants answered the first paper-and-pencil survey during hospitalization (T1). The same patients received two more



**Fig. 1** Research model

surveys via post in the follow-up treatment phase approximately 10 weeks after hospital discharge (T2) and in the post-treatment phase 40 weeks after hospital discharge (T3). For the mixed-methods B-CARE project, 530 PIAT participants who were employed during their breast cancer diagnosis and who gave consent to be recontacted in case of a follow-up were invited by post to complete another survey (response rate, 35%). Medical, psychosocial, and sociodemographic characteristics (e.g., UICC TNM stage, number of comorbidities, level of fear of progression, and age) did not significantly differ between responders and nonresponders at T4 (analyses not shown). Some of the participants underwent semistructured interviews. All postal mailings were conducted following the total design method to enhance the response rate [21]. Detailed information on the study design and sampling

process can be found elsewhere [22, 23]. The Ethics Committees of the Medical Faculty of the University of Cologne approved the PIAT study and the Ethics Committee of the Medical Faculty of the University of Bonn approved the B-CARE study.

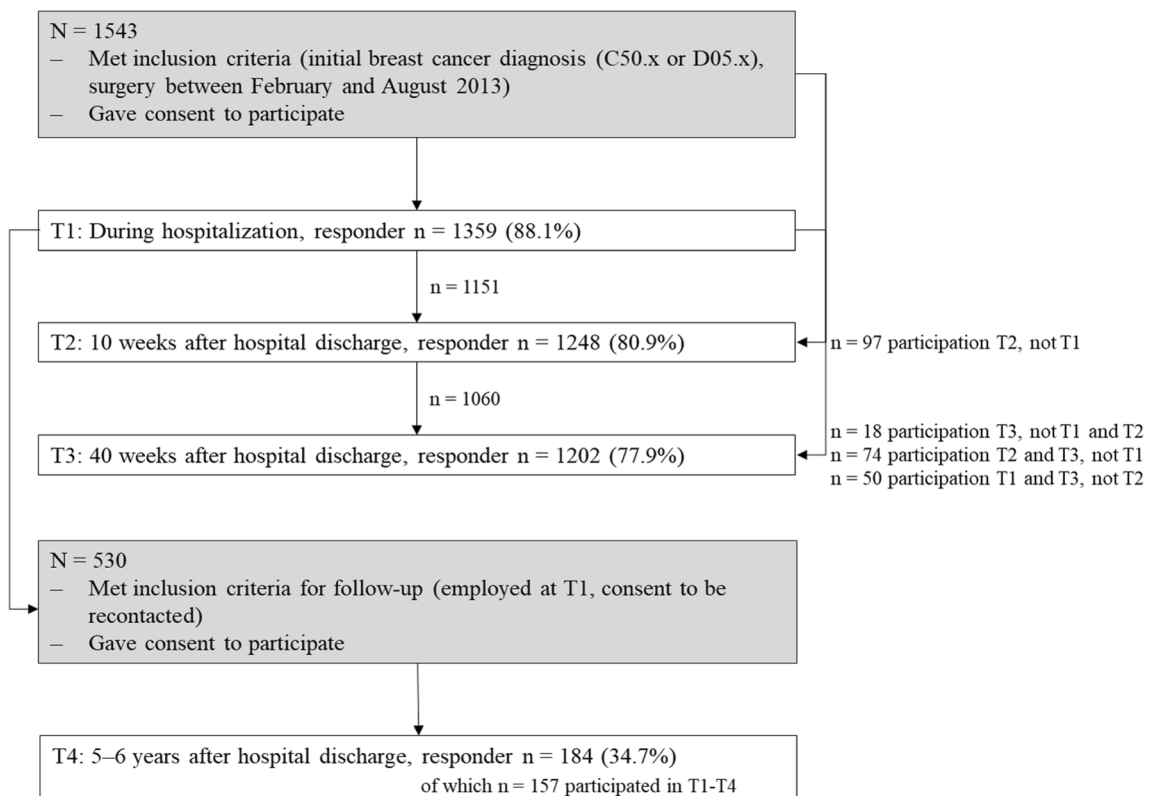
## Measurements

### Satisfaction with occupational development

Satisfaction with occupational development at T4 was the dependent variable. It was measured with the item “Overall, how satisfied are you with your occupational development since your first breast cancer diagnosis?” on a 5-point Likert scale; the higher the values, the higher the level of satisfaction (1, dissatisfied; 2, rather dissatisfied; 3, partly; 4, rather satisfied; 5, satisfied).

### Involuntariness of job changes

The respondents reported job changes that occurred since their diagnosis. These job changes were the following: increased/decreased working time, increased/decreased



**Fig. 2** Flow of participants. Note: Respondents consisted of breast cancer survivors who consecutively participated in every survey wave and those who participated at least once. Dropouts occurred because of nonresponse, death, or unverifiable addresses

scope of work, increased/decreased workload, increased/decreased payment, change of employer, change within employer, and retirement entry (caused by age, early retirement, or reduced earning capacity). Considering that job changes can occur several times within 5–6 years, the questionnaire allowed us to chronologically indicate which of these job changes had occurred up to six occasions (Table S1 shows an excerpt from the questionnaire). For every occasion, the participants were asked the same questions. They were asked to report changes that occurred at that point in time (multiple choices from the aforementioned changes), rate the involuntariness of the chosen changes, and specify the point in time (month, year). The total score of reported changes was calculated using the dichotomous variables for all changes at all time points, possibly ranging from 0 to 66. The respondents were also asked to evaluate the voluntariness of the job changes on every occasion on a 5-point Likert scale (1, voluntary; 2, rather voluntary; 3, partly; 4, rather involuntary; 5, involuntary); the higher the values, the higher the level of involuntariness. Then, we calculated the average of the maximum six involuntariness ratings. The sum of job changes and their averaged involuntariness were measured at T4 and used as independent variables.

### Sociodemographic, disease-related, and work(place)-related variables

Sociodemographic variables such as age at T4 (continuous), marital status at T4 (“single/divorced/widowed,” reference: “married”), number of children at T4 (continuous), and vocational training at T1 (“lower vocational training,” reference: “higher vocational training”) served as independent variables. Lower vocational training included participants who did (not or not yet) complete vocational training, whereas higher vocational training included participants who completed university (of applied sciences) or master craftsman training.

Disease-related variables were recurrence since diagnosis at T4 (“yes”, reference: “no”) and a subjective evaluation of the state of health (1, bad; 2, less good; 3, good; 4, very good; 5, excellent) measured at T2, T3, and T4 according to an item of the SF-36 Health Survey questionnaire [24]. Changes in self-reported state of health from  $\Delta T2$ –T3 and  $\Delta T3$ –T4 were calculated. Furthermore, the Union for International Cancer Control (UICC) TNM staging [25] added by clinical personnel at T1 was included.

The work(place)-related variable social capital (T4) was defined in this study as “features of social organizations such as networks, norms, and social trust that facilitate coordination and cooperation for mutual benefit” [26] and can be measured in workplaces. The social capital of the workplace where the participants returned to

was measured using the SOCAPO-E instrument [27]. The instrument has six items that measure different social capital elements: warm circle, mutual understanding, trust, common values, “we”-feeling, and mutual help and reciprocity (“In my workplace, the willingness to help one another is great.”). The items were scored on a 4-point Likert scale (1, strongly disagree; 2, somewhat disagree; 3, somewhat agree; 4, strongly agree) and then averaged.

All measures were pretested in interviews or focus groups, as described elsewhere [22].

### Analysis

The quantitative survey data were digitalized using the data-capturing software Teleform version 16 and checked for plausibility. The pseudonymized PIAT (T1–T3) and B-CARE (T4) data sets were merged into one data set according to the study ID of each participant.

Missing values of the metric variables were imputed with the expectation maximization (EM) algorithm prior to the main analyses, namely, health status (T2, T3, T4), age (T4), involuntariness of work changes ratings (T4), and satisfaction with occupational development (T4). If a variable or instrument has more than 30% of missing values, imputation was not applied [28]. The EM algorithm estimates missing data according to an iterative maximum-likelihood process and is recommended for preventing biases caused by not completely at random missing data processes [29, 30].

Missing data in the categorical and ordinal variables used for calculating the UICC TNM stage (T1), recurrence since diagnosis (T4), and vocational training (T1) were replaced with modal values [31]. Meanwhile, the remaining missing data were deleted listwise.

Initially, we analyzed the frequencies of job changes and their involuntariness descriptively. Next, the associations between job changes, their involuntariness, and satisfaction with the occupational development of BCSs 5–6 years after diagnosis were investigated using three linear regression models with stepwise addition of variables. The first model M1a consisted of the sociodemographic, disease-related, and work(place)-related variables; M2a integrated the number of job changes; lastly, M3a added the average involuntariness of job changes, thereby estimated according to those participants who experienced at least one job change. We additionally calculated the models M1b–M3b with nonimputed data (Table 3). The assumptions of no multicollinearity, no autocorrelation of residuals, and no perfect linearity were tested for and subsequently met.

All statistical data were analyzed using the IBM SPSS Statistics version 24.

## Results

### Descriptive results

The study enrolled 184 BCSs, with a mean age of 57 years. On average, the respondents had 1.5 children, and almost 73.0% of them were married. In general, different levels of vocational training were observed. Nearly two-thirds had lower vocational training. The mean UICC TNM stage was 1.4, and the majority (80.4%) did not have a relapse within 5–6 years after diagnosis. Table 1 shows the descriptive statistics of the sample.

In total, 105 BCSs reported 410 job changes during the 5–6-year period after diagnosis. More than half of the respondents (57.0%) experienced at least one job change. The most common changes were decreased working time (19.8%), decreased payment (10.5%), and decreased workload (10.0%). Furthermore,

16.1% of the job changes were experienced rather involuntarily or involuntarily, affecting 9.8% of the participants. Among the involuntary job changes, increased workload (15.2%) and increased scope of work (15.2%) were the most often reported changes, followed by retirement entry caused by reduced earning capacity or early retirement (12.1%) and decreased working time (12.1%). Table 2 lists the descriptive results.

### Multivariate results

Table 3 shows results of the three stepwise linear regression models. The model M1a, which included sociodemographic, disease-related, and work(place)-related variables, reached significance ( $F [9, 81] = 3.372, p < 0.01$ ) and explained 18.9% of variance in satisfaction with the occupational development 5–6 years after diagnosis (adjusted  $R^2$ ). The variables

**Table 1** Descriptive statistics of the sample

		Imputed data			Nonimputed data				
		<i>n</i> (%)	Mean	Standard deviation	Min–max	<i>n</i> (%)	Mean	Standard deviation	Min–max
Sociodemographic variables									
Age in years (T4)			56.90	6.54	36–79		56.93	6.82	36–79
	Missing	0 (0)				15 (8.2)			
Marital status (T4)	Married	134 (72.8)				134 (72.8)			
	Unmarried	50 (27.2)				50 (27.2)			
	Missing	0 (0.0)				0 (0.0)			
Number of children (T4)			1.52	0.98	0–4		1.52	0.98	0–4
	Missing	0 (0.0)				0 (0.0)			
Vocational training (T1)	Lower training	117 (63.6)				106 (57.6)			
	Higher training	67 (36.4)				67 (36.4)			
	Missing	0 (0)				11 (6.0)			
Disease-related variables									
UICC TNM stage (T1)			1.43	0.73	0–4		1.48	0.78	0–4
	Missing	1 (0.5)				34 (18.5)			
Recurrence (up to T4)	No	148 (80.4)				145 (78.8)			
	Yes	36 (19.6)				36 (19.6)			
	Missing	0 (0)				3 (1.6)			
State of health ( $\Delta T2$ – $T3$ )			0.26	0.64	–2 to 2		0.27	0.68	–2 to 2
	Missing	0 (0)				26 (14.1)			
State of health ( $\Delta T3$ – $T4$ )			0.05	0.74	–2 to 2		0.06	0.76	–2 to 2
	Missing	0 (0)				20 (10.9)			
Work (place)-related variables									
Social capital (T4)			3.00	0.68	1–4		3.00	0.68	1–4
	Missing	22 (12.0)				22 (12.0)			
Number of job changes (up to T4)			2.23	3.20	0–22		2.23	3.20	0–22
	Missing	0 (0.0)				0 (0.0)			
Involuntariness of job changes, averaged (T4)			2.00	1.17	1–5		1.98	1.19	1–5
	Missing	79 (42.9)				84 (45.7)			

**Table 2** Job changes in breast cancer survivors (BCSs) since diagnosis

	All job changes ( <i>n</i> = 105 participants)		Involuntary job changes* ( <i>n</i> = 18 participants)	
	<i>n</i>	%	<i>n</i>	%
Decreased working time	81	19.76	8	12.12
Decreased payment	43	10.49	5	7.58
Decreased workload	41	10.00	6	9.09
Increased workload	40	9.76	10	15.15
Retirement entry	40	9.76	8	12.12
Decreased scope of work	37	9.02	4	6.06
Increased scope of work	32	7.80	10	15.15
Increased payment	32	7.80	5	7.58
Increased working time	24	5.85	2	3.03
Change of employer	21	5.12	5	7.58
Change within employer	19	4.63	3	4.55
Total	410	100.00	66	100.00

Note: \*Job changes rated as “rather involuntary or involuntary” on a 5-point Likert scale

age ( $\beta = 0.038$ ,  $t = 2.365$ ,  $p < 0.05$ ), state of health  $\Delta T2-T3$  ( $\beta = 0.422$ ,  $t = 2.998$ ,  $p < 0.01$ ), state of health  $\Delta T3-T4$  ( $\beta = 0.349$ ,  $t = 2.420$ ,  $p < 0.05$ ), and social capital of the workplace where the respondents returned to ( $\beta = 0.270$ ,  $t = 2.071$ ,  $p < 0.05$ ) had a significant positive association with occupational development satisfaction 5–6 years after diagnosis in BCSs. In contrast, marital status, number of children, vocational training, UICC TNM stage, and recurrence were insignificant in M1a.

M2a, which additionally included the number of job changes, reached significance ( $F [10, 80] = 3.069$ ,  $p < 0.01$ ), with an adjusted  $R^2$  of 18.7%. The variables age ( $\beta = 0.038$ ,  $t = 2.408$ ,  $p < 0.05$ ), state of health  $\Delta T2-T3$  ( $\beta = 0.436$ ,  $t = 3.072$ ,  $p < 0.01$ ), state of health  $\Delta T3-T4$  ( $\beta = 0.353$ ,  $t = 2.446$ ,  $p < 0.05$ ), and social capital of the workplace where the respondents returned to ( $\beta = 0.297$ ,  $t = 2.219$ ,  $p < 0.05$ ) had a significant positive association with occupational development satisfaction of BCSs 5–6 years after diagnosis. In this model, marital status, number of children, vocational training, UICC TNM stage, recurrence, and number of job changes were insignificant.

M3a also integrated the averaged involuntariness of job changes and was estimated for participants with at least one job change since diagnosis. It also reached significance ( $F [11, 79] = 5.079$ ,  $p < 0.001$ ), with an adjusted  $R^2$  of 33.3%. The variables age ( $\beta = 0.032$ ,  $t = 2.229$ ,  $p < 0.05$ ), state of health  $\Delta T2-T3$  ( $\beta = 0.440$ ,  $t = 3.428$ ,  $p < 0.01$ ), state of health  $\Delta T3-T4$  ( $\beta = 0.436$ ,  $t = 3.301$ ,  $p < 0.01$ ) had a significant positive association with occupational development satisfaction of BCSs 5–6 years after diagnosis. Conversely, higher levels of involuntariness ( $\beta = -0.323$ ,  $t = -4.299$ ,  $p < 0.001$ ) had a significant negative association with occupational

development satisfaction 5–6 years after diagnosis. Moreover, marital status, number of children, vocational training, UICC TNM stage, recurrence, social capital of the workplace where the respondents returned to, and number of job changes were insignificant in this model.

In comparing the results between the imputed data (M1a–M3a) and the nonimputed data (M1b–M3b) (Table 3), the regression coefficients were similar, except for the variables marital status, number of children, vocational training, and recurrence, which were smaller in the models with imputed data.

For reliability analysis, Cronbach’s alpha was calculated for the validated instrument social capital (Cronbach’s alpha, 0.94).

## Discussion

This study aimed to (1) describe BCSs’ involuntary job changes and (2) explore the associations between such job changes, involuntariness, and occupational development satisfaction 5–6 years after breast cancer diagnosis, while controlling for sociodemographic, disease-related, and work(-place)-related variables.

In the descriptive results, more than half of the participants reported job changes 5–6 years after the diagnosis. This proportion is lower than that reported by Steiner et al. [13] in which 67% of cancer survivors in the USA experienced job changes within 2 years after diagnosis. Such variation may be explained by the fact that Germany has different employment laws and special protection for employees with disabilities (e.g., in terms of dismissal). In the multivariate results, the

**Table 3** Results of the stepwise linear regression models

	M1a imputed				M2a imputed				M3a imputed			
	Regression coefficient	Standard error	T-value	Significance	Regression coefficient	Standard error	T-value	Significance	Regression coefficient	Standard error	T-value	Significance
(Intercept)	1.072	0.979	1.094	0.277	0.834	1.015	0.821	0.414	2.076	0.964	2.153	0.034*
Sociodemographic variables												
Age in years (T4)	0.038	0.016	2.365	0.020*	0.038	0.016	2.408	0.018*	0.032	0.015	2.229	0.029*
Unmarried (T4) (reference: married)	0.135	0.224	0.600	0.550	0.103	0.227	0.455	0.651	0.207	0.207	1.001	0.320
Number of children (T4)	-0.177	0.102	-1.746	0.085	-0.176	0.102	-1.733	0.087	-0.176	0.092	-1.907	0.060
Lower vocational training (T1) (reference: higher vocational training)	0.283	0.194	1.464	0.147	0.302	0.195	1.549	0.125	0.340	0.177	1.925	0.058
Disease-related variables												
UICC TNM stage	0.002	0.128	0.015	0.988	-0.003	0.128	-0.020	0.984	-0.028	0.116	-0.243	0.808
Recurrence (up to T4) (reference: no recurrence)	-0.195	0.249	-0.786	0.434	-0.213	0.250	-0.855	0.395	-0.221	0.226	-0.978	0.331
State of health ( $\Delta T2-T3$ )	0.422	0.141	2.998	0.004**	0.436	0.142	3.072	0.003**	0.440	0.129	3.428	0.001**
State of health ( $\Delta T3-T4$ )	0.349	0.144	2.420	0.018*	0.353	0.144	2.446	0.017*	0.436	0.132	3.301	0.001**
Work(place)-related variables												
Social capital (T4)	0.270	0.130	2.071	0.042*	0.297	0.134	2.219	0.029*	0.198	0.124	1.602	0.113
Number of job changes (up to T4)					0.029	0.032	0.901	0.370	0.035	0.029	1.202	0.233
Involuntariness of job changes, averaged (T4)									-0.323	0.075	-4.299	0.000***
Adjusted R <sup>2</sup>		0.189				0.187				0.333		
	M1b nonimputed				M2b nonimputed				M3b nonimputed			
	Regression coefficient	Standard error	T-value	Significance	Regression coefficient	Standard error	T-value	Significance	Regression coefficient	Standard error	T-value	Significance
(Intercept)	0.856	1.069	0.801	0.427	0.983	1.091	0.901	0.372	2.005	1.048	1.914	0.061
Sociodemographic variables												
Age in years (T4)	0.036	0.018	2.014	0.049*	0.036	0.018	1.992	0.052	0.032	0.016	1.951	0.057
Unmarried (T4) (reference: married)	0.396	0.240	1.652	0.105	0.450	0.254	1.770	0.083	0.558	0.235	2.372	0.022*
Number of children (T4)	-0.288	0.113	-2.559	0.014*	-0.291	0.113	-2.568	0.013*	-0.267	0.104	-2.564	0.013*
Lower vocational training (T1) (reference: higher vocational training)	0.640	0.214	2.996	0.004**	0.638	0.215	2.971	0.005**	0.638	0.197	3.246	0.002**
Disease-related variables												
UICC TNM stage	-0.064	0.129	-0.496	0.622	-0.069	0.130	-0.534	0.596	-0.102	0.119	-0.856	0.396
Recurrence (up to T4) (reference: no recurrence)	-0.820	0.283	-2.897	0.006**	-0.826	0.285	-2.899	0.006**	-0.835	0.261	-3.200	0.002**
State of health ( $\Delta T2-T3$ )	0.485	0.149	3.252	0.002**	0.480	0.150	3.195	0.002**	0.515	0.138	3.735	0.000***
State of health ( $\Delta T3-T4$ )	0.364	0.161	2.254	0.029*	0.353	0.163	2.169	0.035*	0.478	0.154	3.104	0.003**
Work(place)-related variables												
Social capital (T4)	0.387	0.131	2.956	0.005**	0.382	0.132	2.896	0.006**	0.267	0.126	2.123	0.039*

**Table 3** (continued)

Number of job changes (up to T4)	-0.024	0.036	-0.667	0.508	-0.027	0.033	-0.834	0.408
Involuntariness of job changes, averaged (T4)					-0.264	0.081	-3.258	0.002*
Adjusted R <sup>2</sup>	0.423	0.417						0.511

Note: \*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$

number of job changes alone does not significantly influence the BCSs' satisfaction with their occupational development or enhance the exploratory power of the model.

According to the descriptive results, 16% of all job changes after breast cancer were involuntary or rather involuntary. The most commonly reported involuntary changes were increased scope of work, increased workload, and retirement entry. These changes suggest that meeting the (increasing) demands at work might be challenging for BCSs, forcing them to reduce their working time or retire (early retire or retire because of reduced earning capacity). Regarding the multivariate findings, involuntariness of job changes was negatively associated with BCSs' satisfaction with their occupational development 5–6 years after diagnosis. After the inclusion of involuntariness in the model, the adjusted  $R^2$  increased by approximately 15%. Therefore, involuntariness can be an important barrier for the BCSs' ability to work as desired and may be linked to other disadvantages, such as financial strain. Offering access to rehabilitation services for BCSs several years after their diagnosis might be crucial to help them meet the work demands and prevent involuntariness in the long run. These results can be discussed against the background of life-event research. Stressful work-related events, particularly involuntary job disruptions, decrease one's well-being both directly and indirectly (mediated by coping and supportive resources) [19]. The present results underline that the quality of stress-inducing events is a more important indicator than the frequency [19]. Involuntariness in the work context might not only affect mental health but also the satisfaction with occupational development.

In linear regression model analysis, the sociodemographic, disease-related, and work(place)-related factors were associated with BCSs' satisfaction with their occupational development 5–6 years after being diagnosed.

The present study showed that higher age is positively associated with BCSs' satisfaction with their occupational development [17]. Meanwhile, marital status had no significant association. Literature on the relationship between marital status and work satisfaction seems to be varied. While Clark [32] found that married people are more satisfied with work, Gazioglu and Tansel [33] reported that work satisfaction is higher among unmarried individuals. Furthermore, Mehnert and Koch [17] described that BCS' work satisfaction is associated with higher education, but the present study revealed that vocational training is not associated with higher levels of satisfaction with the occupational development. However, other studies also found that lower vocational training is associated with higher levels of work satisfaction [33]. Hence, the evidence seems ambiguous. Other indicators such as physical or mental strain of the job could be more suitable predictors of work satisfaction and satisfaction with the occupational development in BCSs, given that many suffer from long-term consequences of the disease and its treatment.



In a previous study, disease-related variables (cancer entity, stage, disease phase/remission, time since diagnosis, and treatments) were not associated with work satisfaction [17]. Consistent with these results, the UICC TNM stage and recurrence since the time of diagnosis did not show significant effects in the present analyses. In finding significant effects for subjective health status, subjective measures may be more suitable predictors for satisfaction with the occupational development than the objective measures. In the present study, an increase in the self-reported state of health from T2–T3 and T3–T4 was significantly associated with higher levels of satisfaction with the occupational development. These outcomes are in line with those of a former study that suggested an association between work satisfaction and health-related quality of life [17].

Regarding work(place)-related variables, a positive association was found between higher levels of social capital in the workplace where the participants returned to and satisfaction with the occupational development 5–6 years after diagnosis in M1a and M2a. This finding is consistent with the results of Ommen et al. [34], who found a positive association between social capital and work satisfaction among hospital-based physicians. Given that the association between social capital of the workplace and satisfaction with the occupational development is rarely studied, the discussion was extended to include findings on social support of the workplace as both concepts are distinct but similar. Pearlin et al. [19] discovered that social support, such as at the workplace, could reduce the impact of involuntary job disruptions on mental well-being. Workplaces with more trust, understanding, and common values can possibly better suit the needs of returning workers after cancer. Previous studies explored these needs as well as other factors, including vulnerability, understanding, and the need for support [35, 36]. Furthermore, a recent intervention designed to support employers after cancer established communication between employers and employees by helping them understand the survivors' situation by informing and considering different cancer "experience types" [37]. These aspects might already be more pronounced in workplaces with higher levels of social capital, increasing BCSs' satisfaction with the occupational development. The SOCAPO-E instrument was designed to measure social capital according to the evaluations of many employees and validated for healthcare organizations. In the present study, the instrument was appropriately used for single social capital evaluations per workplace, with Cronbach's alpha of 0.94.

The comparison of the results between the imputed data (M1a–M3a) and the nonimputed data (M1b–M3b) revealed similar regression coefficients, except for variables such as marital status, number of children, vocational training, and recurrence. For these variables, the coefficients were higher in the nonimputed results, possibly indicating overestimation.

## Strengths and limitations

To our knowledge, this study is the first to focus on the occurrence of involuntary job changes and explore the associations between job changes, involuntariness, and satisfaction with the occupational development 5–6 years after breast cancer diagnosis, while controlling for sociodemographic, disease-related, and work(place)-related variables.

The longitudinal design considers numerous sociodemographic as well as disease-related and work(place)-related influencing factors. The measurement time points covered different stages of the cancer journey, starting from acute therapy until the 5-year survivor phase.

The B-CARE study applied an observational approach. Hence, only associations and not causal relations could be described. The study design hinders the comparison of job patterns between BCSs and healthy women. Therefore, we could not evaluate whether BCSs' experiences differed in terms of the number of job changes and their involuntariness. Nevertheless, the results showed that involuntariness occurred and that support is needed to aid BCSs' ability to work as desired. Future research may include a healthy comparison group.

Considering the design of the PIAT and B-CARE projects, which required respondents to answer surveys at several measurement time points, a bias in the sample toward BCSs with better physical and mental health status was possible. Assuming the occurrence of this bias, variables, such as subjective health status, might have been underestimated and actually lower, while the satisfaction with the occupational development might have been overestimated. Furthermore, in the original sample and the analyzed subsample, more motivated and educated people and those with sufficient language skills were likely overrepresented. Therefore, individuals with more precarious employment situations or those with a migration background were possibly underrepresented.

Recall bias could affect the retrospective variables measured at T4 that referred to RTW (e.g., the social capital of the workplace where the BCSs returned to). Moreover, the dependent variable of satisfaction with the occupational development included a single nonvalidated item wherein participants were asked to evaluate the time span of 5–6 years prior; therefore, this could be vulnerable to a recall bias or be influenced by recent events. However, during the pretests, no problems in recalling this information were noted. Satisfaction with the occupational development was measured at T4 only; therefore, we could not rule out the existence of differences in satisfaction with the occupational development before the diagnosis because we did not compare previous satisfaction with the occupational development before and after the diagnosis. All measured job changes were included in the analyses equally. However, the bi-directionality (increase/decrease) of some changes could potentially impact the satisfaction with

the occupational development because some changes may be generally regarded as positive or negative. For instance, an increase in payment could be considered a positive change. However, the present results showed that BCSs' involuntariness ratings of job changes are complex, similar to the increase in payment, which was rated as (rather) involuntary (Table 2). Additionally, a recent qualitative study indicates that job changes, even when financially disadvantageous, are welcomed by male BCSs [38].

In addition, the sample size in this study was rather small, indicating limited statistical power.

## Conclusion

Job changes alone were not substantially associated with BCSs' satisfaction with the occupational development 5–6 years after diagnosis. However, experiencing involuntary job changes is associated with lower levels of BCSs' satisfaction with their occupational development. Thus, long-term support aiming at strengthening the work ability is essential to prevent BCSs from experiencing involuntariness and enable their ability to work as desired. The significance of workplace characteristics highlights the need for employers to encourage satisfying work participation. Involuntariness is an important measure to understand how disadvantageous work-related outcomes are and to determine the need for support. For a more distinct understanding of BCSs' long-term work-related outcomes, conducting more research on subjective work-related outcomes is necessary.

**Supplementary Information** The online version contains supplementary material available at <https://doi.org/10.1007/s11764-021-01035-5>.

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**Author contribution** NE and CK supervised the B-CARE study. HP, NE, and CK supervised the PIAT study. AE collected the PIAT data. KH and PH collected the B-CARE data, matched B-CARE with PIAT data, and performed the data analyses. The article was first drafted by KH. All authors discussed the results and critically revised the article for important intellectual content. All authors read and approved the final manuscript.

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**Data availability** According to the patient consent form, data is not available for scientific use by others, other than the project group members.

## Declarations

**Ethics approval** The approval of the ethics committees of the Medical Faculties of the University of Bonn (reference number: 316/18) and University of Cologne (reference number: 12-171) was obtained.

**Consent to participate** Written informed consent was obtained from all individual participants included in the study.

**Conflict of interest** CK and CB are employees of the German Cancer Society (DKG). All other authors declare no conflicts of interest.

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**3.5 Conflicting demands, coping, and adjustment: A grounded theory to understand rehabilitation processes in long-term breast cancer survivors**

## ORIGINAL ARTICLE

# Conflicting demands, coping, and adjustment: A grounded theory to understand rehabilitation processes in long-term breast cancer survivors

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## Abstract

**Objective:** This study explores rehabilitation processes in long-term cancer survivors (CSs) and explains the causes, contexts, and consequences under which decisions related to rehabilitation are made.

**Methods:** Within the mixed-methods Breast Cancer Patients' Return to Work (B-CARE) project, conducted from 2018–2020, data were collected through a written survey and semi-structured interviews with CSs 5–6 years after their diagnosis. In total, 184 female CSs participated in the survey, and 26 were interviewed. A qualitative grounded theory approach was applied.

**Results:** The 26 interviewees were 57 years old on average, 70% were married, and 65% had children. The participants experienced incompatibilities caused by the cancer disease in their areas of life and the demands that arose from it. To reconcile demands from the areas family, work, leisure time, household, and disease, the interviewed CSs used different coping mechanisms and adjusted their lives by prioritizing certain areas as a consequence. This prioritizing was often to the detriment of work and rehabilitation. Furthermore, it worked as a barrier for participation in rehabilitation programs and explains why CSs experienced job changes after their return to work.

**Conclusions:** Physical and mental long-term effects were observed in the interviewees' lives 5–6 years into survival. The study results stress the importance of individualized and needs-oriented survivorship care.

## KEYWORDS

cancer, cancer survivorship, coping, grounded theory, oncology, psycho-oncology, qualitative, rehabilitation, return to work

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## 1 | BACKGROUND

Understanding how cancer survivors (CSs) make their decision regarding participation in rehabilitation measures offered by European welfare states can help to identify and reduce barriers. In terms of rehabilitation, CSs in Germany are entitled to participate in 3 weeks of mainly in-patient rehabilitation covered by the German Federal Pension Insurance (eligibility criteria defined in Social Security Code VI §9-12). This multidisciplinary program targets physical, psychological, social, and occupational outcomes of the disease in a full-day setting. Depending on CSs' health-related consequences on work participation, this program can be granted several times throughout the survival phase. While rehabilitation measures can be recommended by physicians, patients themselves decide to apply in Germany. Psycho-oncological support is offered to patients free of charge during acute care in cancer centers and after hospitalization through office-based practitioners. In recent years, a decline in the participation rates of oncological rehabilitation programs has been observed.<sup>1</sup>

As more than half of the diagnosed breast cancer cases in Europe in 2020 affected people of working age (15–64 years),<sup>2</sup> work participation is an important aim of the recovery process. While 70% of breast CSs who were employed at the time of diagnosis returned to work on average 8.3 years into survival,<sup>3</sup> problems meeting demands at work in the long run apparently exist. This aspect leads some researchers to understand return to work (RTW) as a process rather than a single event.<sup>4,5</sup>

Understanding how CSs make decisions related to rehabilitation may contribute to explaining declining participation rates or work-related problems in the aftermath of RTW and help tailor better patient-center support measures.

While research on barriers to participation in rehabilitation is scarce, initial studies discovered personal, family-related, work-related, and practical motives and barriers for utilization.<sup>6–8</sup> Regarding work participation of CSs, extensive quantitative research studied sociodemographic, psychosocial, disease-related, and work-related determinants of RTW.<sup>9–11</sup> Moreover, qualitative findings identified personal, environmental, and occupational aspects as key factors for RTW.<sup>5</sup> Multidisciplinary rehabilitation was observed to benefit RTW in CSs.<sup>12</sup> Additionally, the phase after the initial RTW has been subjected to research. Approximately 56% of CSs reported a change in their occupational role, and 57% reduced their working hours 2 years following their diagnosis in the United States.<sup>13</sup> In all, 81% attributed this reduction to the cancer disease.<sup>13</sup> Among CSs who made work changes significantly more were among others female, more comorbid, worked fewer hours, and showed poorer work ability and quality of life compared with those without changes.<sup>14</sup> To combine present knowledge, models on work-related outcomes of CSs were developed.<sup>15–18</sup> While quantitative models mostly focused on determinants of work-related outcomes, qualitative models were able to include CSs' perspectives and the processual character of RTW. However, these models were limited to work-

related outcomes and did not examine how different areas of life shape CSs' rehabilitation processes.

To understand interrelations of areas of life and how they influence decision-making during the rehabilitation process, a more holistic approach incorporating individual life circumstances is needed. Hence, the present study aims to capture long-term CSs' reality of life to conclude how the cancer disease and its treatment still affect CSs' lives 5–6 years after their diagnosis and explore their rehabilitation processes. In particular, the causes, contexts, and consequences under which decisions related to rehabilitation utilization are made are investigated.

## 2 | METHODS

### 2.1 | Study design

This study uses data from the mixed-methods Breast Cancer Patients' Return to Work (B-CARE) project, conducted in Germany from 2018–2020.<sup>19</sup> Survey and interview data were collected to study breast CSs' rehabilitation 5–6 years after diagnosis. The present study focuses on the interview data, which were collected and analyzed using grounded theory methodology.<sup>20</sup>

A positive vote of the ethics committee of the Medical Faculty of the University of Bonn was obtained (reference number: 316/18). The study was registered in the German Clinical Trials Registry (DRKS00016982).

### 2.2 | Recruiting and sampling

Breast cancer patients with initial diagnosis and surgery were recruited in German cancer centers in 2013 during the preceding PIAT project (“Strengthening patient competence: Breast cancer patients' information and training needs”).<sup>30</sup> PIAT participants with consent for recontacting were invited to participate in the follow-up B-CARE project 5–6 years later. From 184 women who answered the B-CARE survey and gave consent to be recontacted, 26 were interviewed. Potential interviewees were invited via telephone or email and informed about the procedure. Informed consent was obtained. Phases of sampling, interviewing, and analyzing alternated.<sup>20</sup> The sampling started with heterogeneous cases, as variation in experiences helped explore the diversity of the phenomenon under study. With the insights from analyzing the first interviews, sampling could be driven by theoretical considerations aiming to refine the developing theory (theoretical sampling).<sup>20</sup> Thus, participants with specific characteristics considered to have the potential to complement the theory were sampled using previously collected survey data (e.g., rehabilitation participation, occupational situation, and socio-demographics). Sampling continued until no new information for the grounded theory emerged (theoretical saturation).<sup>20</sup> Table 1 shows the sample characteristics.

TABLE 1 Sample characteristics ( $n = 26$  interviewees)

		<i>n</i>	Mean
Age in years			56.73
	Missing	0	
Marital status	Married	18	
	Single	4	
	Divorced	3	
	Widowed	1	
	Missing	0	
Children	Yes	17	
	No	7	
	Missing	2	
Vocational training	No vocational training	1	
	Vocational training	9	
	Specialized/master craftsman training	4	
	University	11	
	Missing	1	
Employment status	Full-time	8	
	Part-time	13	
	Retired <sup>a</sup>	5	
	Missing	0	
UICC TNM stage	0	2	
	1	11	
	2	8	
	3	1	
	Missing	4	
Recurrence	No	21	
	Yes	5	
	Missing	0	

<sup>a</sup>Includes early retirement and reduced earning capacity retirement.

### 2.3 | Data collection

Data were collected through semi-structured telephone or face-to-face interviews (in the interviewees' preferred location, mainly their home) and lasted 53 min on average. An interview guide with open-ended questions<sup>21</sup> was used after two cognitive pretests. Two female research assistants (KH, PH; PhD candidates) conducted the interviews. Using different interviewers and an interview guide reduced potential biases attributed to the interviewer. As sensitive topics (e.g., body image) and emotional reactions occurred, interviews were conducted by interviewers of the same sex.

### 2.4 | Data analysis

The audiotaped interview material was transcribed verbatim. The interview transcripts were read for note-making and pre-structuring. Then, codes were generated and assigned to interview segments during open coding, to describe and conceptualize data.<sup>20</sup> To develop a theory reflecting a variety of CSs' experiences, constant comparisons of analyzed and new transcripts were used to develop codes into more general concepts over time.<sup>20</sup> Concepts were subsumed into categories and subsequently, axial and selective coding was applied to analyze relations among concepts and categories.<sup>20</sup> Memos were written to support analysis. The analysis was conducted with ATLAS.ti v8.4.25 guided by Friese's instructions.<sup>22</sup> Data were coded by two researchers and in two research workshops. The findings were interpreted and discussed by the project team. Member checks using interpreted and summarized data were performed with five interviewees.

Quotes were selected to illustrate the results. Filling words and duplications were omitted to increase readability.

## 3 | RESULTS

### 3.1 | Cancer survivors' experiences

The interviewees experienced incompatibilities in their areas of life (family, work, leisure time, housekeeping, and managing cancer disease) even 5–6 years after their diagnosis because of the disease and pre-existing incompatibilities. The incompatibilities varied in duration, extent, and intensity. To reduce incompatibilities, CSs' used different coping strategies. The strategies could help to reduce incompatibilities directly or indirectly through adjustments of life that occurred as a consequence. Strategies depended on intervening conditions such as the availability of support measures. Figure 1 shows the findings that will be explained in detail in the following.

### 3.2 | Cancer and incompatibilities of areas of life

The analysis showed that the areas family, work, leisure time, housekeeping, and managing cancer disease were relevant in the interviewees' lives. As the disease-related area of life ties resources (e.g., time and energy), it is accompanied by greater conflict potential between areas. Furthermore, it could amplify pre-existing incompatibilities in women who struggled to reconcile their resources before diagnosis. The disease management is still present 5–6 years after diagnosis, and experiencing long-term effects could foster incompatibilities. As many interviewees reported situations requiring reconciling demands of areas, *incompatibilities of areas of life* emerged as the core category.

Experienced incompatibilities are individualistic and differ in intensity, extent, and duration. Incompatibilities were observed between all areas of life with the disease. Several incompatibilities

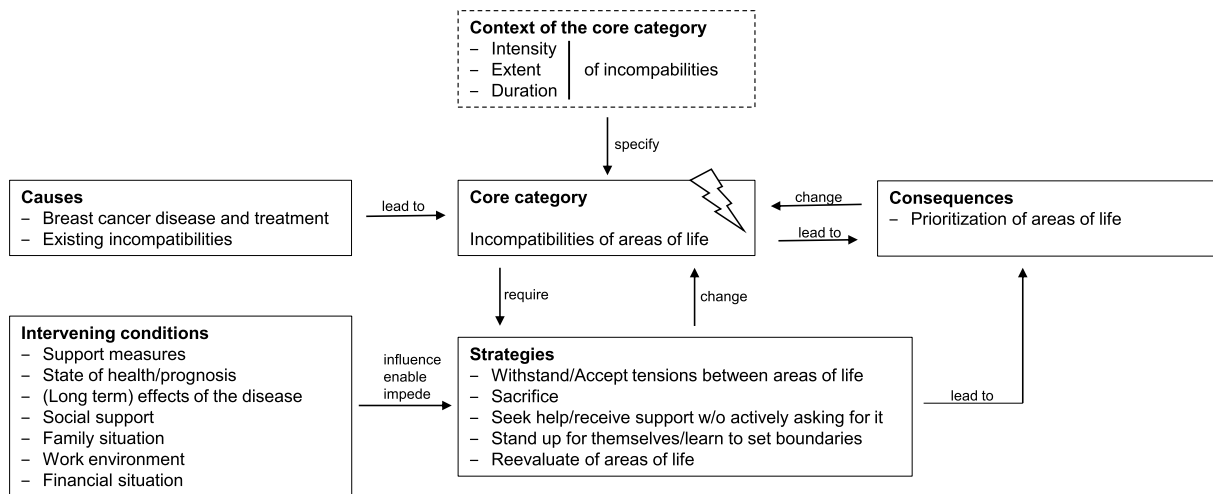


FIGURE 1 Theory of incompatibilities in the areas of life<sup>20,23</sup>

could occur simultaneously. In the following quotes, P5 expresses tensions between the areas such as family and disease as well as work and disease.

“The same applies to these self-help groups which I actually thought about once in a while, about going there possibly or maybe being able to contribute something to them. But I had so much going on in my private life, including with my younger son, with the disability, that I said, adding that is just too much for me.” P5

“At the rehabilitation facility, I was told not to take on too many [working] hours too quickly, if possible, to make sure that I would have enough time for all my (laughs) other appointments, that is, the exercise and doctor's appointments because that just remains really time-intensive for the first few years. [...] Afterward, you continue to have mammography and gynecologist appointments. I had to keep going to radiotherapy. Then there are other minor ailments that resulted from this chemotherapy, organs that might have caused some problems, teeth, and eyes. (Laughs) Everything suffered a little under it. So, I had a lot of appointments in the first few years after acute therapy. And so, I simply had to make sure that I kept two days a week open. One day for rest and housework. And one, on average, for doctor's appointments. Actually, I have stuck to that to this day.” P5

Incompatibilities between the areas could pertain over a varying time stretch. An increased demand of resources in the family area could contribute to short-term, for example, elderly relatives needing

support until recovery, or long-term incompatibilities, for example, taking care of a disabled child.

### 3.3 | Strategies

The interviewees used different coping strategies to buffer or solve incompatibilities. One of these coping strategies was withstanding or accepting. In the following excerpt, P1 tells about her joint pains as a late effect of treatment and how they affect her work as a kindergarten teacher to this day.

“Well, it does take a lot of effort for me to get up from the carpet (laughs) after we look at a picture book or do a puzzle [...]. But I still choose to do it because I think that I have to exercise anyway and it's just the way it is. And I have already made peace with that.” P1

Besides acceptance, the above-mentioned excerpt further shows that the interviewee consciously confronts herself with her limitation instead of avoiding activities that trigger the joint pains. This behavior is an example for the coping strategy wanting to be strong. Some participants avoided appearing “weak” to prevent burdening their social environment by causing worries. Besides, being in need did not seem compatible with the self-perception of some participants because they avoided being regarded with pity.

Making sacrifices in some areas was another coping strategy. For example, interviewees reduced their working hours in favor of rehabilitation. P5's aforementioned statement, “At the rehabilitation facility, I was told not to take on too many [working] hours too quickly, if possible, to make sure that I would have enough time for all my other appointments [...],” demonstrates how she made sacrifices in the work area to have sufficient time for her recovery.



Social support helped prevent and buffer incompatibilities and functioned as a coping strategy, either in an active help-seeking manner or more passively by accepting offered support. Partners and family, friends, other CSs, physicians, and psychotherapists represented sources of social support. Colleagues and supervisors could assist with incompatibilities between work and the disease by helping out with physically demanding tasks or offering a flexible working schedule, as explained by P11:

"Now I also have a female boss [...] who reacted really well and kept saying: "If you feel like you want to go home earlier, you somehow need an hour or so to get away from everything, feel free to do just that. And that naturally also made me feel very, very good to know that I was somehow not under constant observation." P11

The cancer experience led to change in attitudes toward life for some participants. This aspect included focusing on personal well-being and decreased willingness to accept stress. The changed attitude helped interviewees reduce tensions among areas of life because they could better protect their personal boundaries, as shared by P22:

"In the past, the word ["no"] was missing from my vocabulary, but today, I do say it sometimes. And sometimes, I am just more selfish and say: "No, I have an appointment now or I am going walking or you just have to wait for an hour before you can eat." [...] Well, I think it was important for me to understand that I need to not always just look out for others, but a little more for myself." P22

Some women were able to maintain changes in their attitudes, whereas others could not preserve these changes on a daily life basis.

Changed attitudes toward life were also accompanied with a reevaluation of areas of life. This reevaluation aided in coping with incompatibilities. Life in general and some areas were more appreciated, whereas others areas were less appreciated, as P16 underlines:

"A lot of things were simply a matter of course. But that's no longer the case since then, I see a lot of things differently, I am grateful for every good word, for every kind word, for any sign of care and attention. I don't see a lot of materialistic things as important at all any more." P16

### 3.4 | Intervening conditions

Several intervening conditions that influenced the availability of coping strategies for the interviewees were identified. Individual

traits such as optimism, self-efficacy, or coping styles influenced how interviewees coped. Moreover, aspects related to the state of health influenced how the interviewed CSs dealt with incompatibilities. A poorer prognosis, relapses, or manifold mental and physical late effects could, for instance, foster the strategy devaluation of work. The existence of social contacts is a prerequisite for using them as a coping resource for social support. Family structure was another influential factor in coping strategies. Interviewees with children, especially younger ones, seemed to be more prone to the strategy of wanting to be strong to avoid intimidating family members and protect them from harm, as P25 explains:

"When I was doing so poorly in August, I got up every morning and got dressed, and just sat down, on the chair or the sofa. [...] I didn't want them [my children] to be worried just because I might be lolling about a little right then." P25

Work environment could also influence coping mechanisms. For example, an understanding atmosphere allowed interviewees to open themselves up when in need of support or to set boundaries according to their more limited productivity after RTW. Additionally, the awareness of support measures influences how the interviewees coped with incompatibilities because it is a precondition for considering using them. Support measures include in- and outpatient rehabilitation interventions, progressive reintegration, or adjustments of the workspace. Next, the availability (e.g., proximity to place of residence) and access (e.g., application and allowance) impact whether these measures can become a strategy to cope with incompatibilities. Financial aspects played a role in the coping process because the disease is accompanied with additional expenses in contrast to reduced income (e.g., expiring pay continuation or sickness benefits).

### 3.5 | Consequences

As a consequence of tensions among areas of life, many interviewees' set priorities to balance demands of all areas. Adjustments became visible in terms of family, for example, shifting responsibilities to family members; household, for example, hiring domestic helpers; occupation, for example, reducing working time or early retirement; health, for example, neglecting rehabilitation needs; or leisure time, for example, reducing social activities and hobbies. P8 reduced her working hours as a consequence of devaluation of work, which she expresses in the following:

"That you don't always sacrifice or wear yourself out; you get no gratitude for that anyway, not even at work, right? Whatever you do, sacrificing yourself too much is ultimately unhealthy and takes away from your own time and well-being. And, I am not, well, at my age, on any career ladder. I don't have to prove myself any

longer. And so I said, I can take things a little slower now. And really focus on my, my private life and on what is good for me." P8

Preferences seem to be situational because some interviewees decided for or against areas depending on specific incompatibilities. Overall, the interviewed CSs set their priorities to the detriment of work and health; however, younger, childless participants focused on their career.

## 4 | DISCUSSION

The present study aimed to capture long-term CSs' reality of life to conclude how the cancer disease and its treatment still affect CSs' lives 5–6 after diagnosis and explore their rehabilitation processes.

According to our findings, the rehabilitation processes of interviewed breast CSs were influenced by conflicting demands of areas of life, coping, and adjusting to such incompatibilities. The core category *incompatibilities among areas of life* is in line with earlier findings. Wilmoth<sup>24</sup> describes that women enlisted for the military affected with breast cancer had to balance demands and expectations from three systems, that is, the military career, medical and social support system. Other studies also reported on CSs' problems to balance work and treatment demands.<sup>15</sup> Furthermore, member checks conducted with five interviewees validated our findings because all reinterviewed participants were able to identify with the core category. Setting priorities was strenuous for most interviewees and could affect their satisfaction with certain areas or life in general. Experiencing not being able to meet demands due to limited productivity was burdensome for some participants. Previous research demonstrated that emotional functioning predicted the need for psycho-oncological support.<sup>25</sup> Thus, breast CSs could be in need of psycho-oncological support that targets solving incompatibilities.

The present findings contribute to the limited state of research on drivers and barriers for participation in rehabilitation measures. Perceived incompatibilities between areas of life led some interviewees to waive rehabilitation offers. The awareness and availability of more individualized and flexible support measures should be increased. Outpatient rehabilitation programs or programs integrating CSs' children could counter the barrier of incompatibilities.

Our findings suggest that job changes can result from incompatibilities among areas. To reconcile incompatibilities, some of the interviewed women tried to adjust work demands by working less hours or entering retirement. Additionally, women devaluated work to shift their resources to family and leisure time. Pearlin et al.<sup>26</sup> describe that devaluation of work is most likely because "[o]ne cannot as easily demean the importance of a spouse or of a child as he can devalue his work or an unattainable life-style." They further explain that people attach varying importance to different areas of their lives to be able to mitigate stress.<sup>26</sup> Strains

from areas of secondary importance have less power to cause stress and threaten one's self.<sup>26</sup> Although the interviewed CSs managed to adjust to new life circumstances, support throughout the survival phase could prevent the need to prioritize certain areas. Prioritization can be accompanied by financial losses and hinder a sustainable RTW. In accordance with the explanation given by Pearlin et al.<sup>26</sup>, we observed that younger, childless interviewees focused on their careers, as did those who were single and had financial pressure to work.

### 4.1 | Study limitations

This study allowed for an exploration of CSs' perspective on their recovery process and an understanding of how decisions related to rehabilitation are made. The qualitative nature of the study limits the generalizability of the results.

The sample consisted of female breast CSs and did not include other cancer types. While the participants varied regarding participation in rehabilitation, the study included predominantly CSs who returned to paid work. The interviewees were all located in Germany and exposed to the present system when recovering. CSs' experiences may be influenced by particularities of the social system (e.g., focus on in-patient rehabilitation, dual system of health and pension insurance in Germany). However, the main findings are in line with earlier results suggesting that incompatibilities might be a more general phenomenon among CSs. Future research should investigate the experiences of CSs affected by other cancer types, those who were not able to RTW, and those who recovered in different health care systems.

The initial interviews were face-to-face to monitor participants' reactions to the interview situation. After positive experiences, we conducted telephone interviews because they allowed more flexible timings and continuation of data collection during the COVID-19 pandemic. Interviewees already participated in the preceding study so that familiarity was established. The interview structure remained the same due to the use of a guide irrespective of the interview method. The interview length did not differ between methods. Therefore, a bias seems unlikely. No differences between telephone and face-to-face interviews were detected in other studies.<sup>27,28</sup>

### 4.2 | Clinical implications

Mental and physical recovery after breast cancer is a process with an individualistic timing, eventually continuing 5–6 years into survival. Coping with incompatibilities of areas of life and related adjustments can be strenuous for CSs, can decrease their satisfaction, and can be barriers for participation in rehabilitation. Hence, psycho-oncological support should target these incompatibilities. Proactive interventions could help to reach CSs with limited timely resources. Measures that

target the CSs' family<sup>29</sup> or employer could facilitate reconciling demands.

## 5 | CONCLUSION

CSs' lives are affected by long-term effects of the disease and treatment 5–6 years into survival. Exploring how these late effects influence CSs' lives and decisions throughout the phase of rehabilitation is crucial. It emphasizes the significance of individualized and needs-based long-term survivorship care.

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## CONFLICT OF INTEREST

Clara Breidenbach and Christoph Kowalski are employees of the German Cancer Society. Marco Streibelt is an employee of the German Federal Pension Insurance (Deutsche Rentenversicherung Bund), which instructs rehabilitation measures and funded the B-CARE project.

## AUTHOR CONTRIBUTIONS

Nicole Ernstmann and Christoph Kowalski supervised the B-CARE study. Kati Hiltrop and Paula Heidkamp collected the B-CARE data and performed the data analyses. The article was first drafted by Kati Hiltrop. All authors discussed the results and critically revised the article for important intellectual content. All authors read and approved the final manuscript.

## DATA AVAILABILITY STATEMENT

Research data are not shared.

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#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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## 4. Discussion

The first objective of this doctoral thesis was the expansion of knowledge on the sustainability of RTW by making a contribution to closing the research gap on the breast cancer survivors' perspective on job changes in the aftermath of their RTW. The second was to explore whether recovery processes resemble a transition from sick to healthy or whether an interplay of roles occurs based on the theoretical concepts of the sick role and the conceptual model of the experience of cancer and work. For these purposes, the following research questions were addressed:

- (1) How do breast cancer survivors experience their RTW and the phase afterward?
- (2) How do breast cancer survivors experience and evaluate job changes after their RTW?
- (3) How and why do job changes occur in breast cancer survivors after their RTW?

Overall, the results of this dissertation demonstrated that, in line with earlier findings (Main et al. 2005; Kennedy et al. 2007; Rasmussen and Elverdam 2008), breast cancer survivors felt naturally motivated to return to work (Section 3.1). Their experiences throughout the RTW process were primarily positive and supportive (Section 3.1). A small number of stigmatizing experiences in the work context were reported by male breast cancer patients (Section 3.1). Despite the survivors' natural motivation to work, negative mental and physical long-term effects of the cancer disease and its treatment on productivity were found (Section 3.1, Section 3.5). This dissertation extended previous research by determining that financially disadvantageous job changes following RTW were wanted and welcomed by the interviewed male breast cancer survivors (Section 3.1). These job changes could be viewed as adaptations to ongoing limitations and therefore indicate an "incapacity" to fully perform the healthy role in the work area (Parsons 1972). After describing the mixed methods approach of the B-CARE project in the study protocol (Section 3.3), job changes from the survivors' perspective and the hypothesis that the involuntariness might be a decisive factor were further investigated (Section 3.4). It was shown that job changes varied in terms of voluntariness and that higher levels of involuntariness of job changes were significantly associated with lower occupational development satisfaction since diagnosis (Section 3.4). However, no association with the mere amount of job changes was found. The most common

involuntary changes, such as scope of work, increased workload, and entry into retirement, indicate that breast cancer survivors may have problems meeting their work demands in the long term. These findings once more indicate that 5–6 years after their diagnosis, breast cancer survivors have not yet reached the full capacity to perform their worker role (Parsons 1972). To the best of the author's knowledge, the present work is the first to investigate the role of the involuntariness of job changes. Although job changes were investigated in terms of quantity, this dissertation's results demonstrate the relevance of focusing on quality as well (Section 3.4). The newly developed *theory of incompatibilities in the areas of life* in this dissertation (Section 3.5) explains why (involuntary) job changes may exist. Exploring long-term breast cancer survivors' reality of life revealed that the interviewees struggled to balance demands of different areas of life (family, work, household, leisure time, and disease). As a consequence, prioritization of single areas was a means to cope with incompatibilities. Often, the interviewed breast cancer survivors tended to prioritize areas other than work, which is why job changes such as a reduction of working hours or entry into retirement were observed. The problems encountered in balancing demands can be interpreted as role conflicts and linked to the theoretical framework of this doctoral thesis (Section 2.1). Overall, the results of this dissertation indicate that cancer survivors do not fully regain the "optimum capacity" to perform their daily roles as Parsons' (1972) concept of health would predict. Therefore, Parsons' view on the sick role might be ideal-typical (Segall 1976), as in this dissertation, the transition from sick back to healthy roles was identified as a continuous, non-linear, overlapping process that can still be ongoing 5–6 years after diagnosis, as opposed to a switch that can be flipped. Thereby, the present findings support the conceptual model of the experience of cancer and work (Wells et al. 2013).

#### **4.1 Strengths and limitations**

This doctoral thesis comprises various article types—original articles, a letter to the editor, and a study protocol—to study the sustainability of RTW in breast cancer survivors based on job changes.

One strength of this dissertation lies in its application of both qualitative and quantitative research methods. Drawing on data that were both qualitative and quantitative in nature from the mixed-methods N–MALE and B–CARE projects allowed for maximization of the strengths and reduction of the weaknesses of each type of data (Klassen et al. 2012). Diverse methods were applied in analyzing these data, including quantitative descriptive measures and regression analyses as well as qualitative content analysis and grounded theory. In doing so, this dissertation was able to provide more comprehensive insight into breast cancer survivors' perspectives on job changes than studies that took either a quantitative or qualitative approach.

Another strength is the inclusion of diverse stakeholder perspectives at various stages of data collection and analysis. The N–MALE and B–CARE projects were conducted by multi-disciplinary teams with the help of relevant project partners. As a corollary, a comprehensive understanding of occupational rehabilitation processes, including job changes, was established.

Patient-centeredness is another strength of the dissertation and was achieved through the application of a participatory research approach, a mixed-methods design, and the use of patient experience measures, respectively, patient-reported outcome measures. The patient-centered nature of the research process helps to detect relevant aspects of the phenomenon under study from the patient perspective and complements the researchers' view.

Further, the perspectives of both male and female breast cancer survivors were taken into account. Due to its rarity—only 1% of breast cancer diagnoses affect males (Giordano 2018)—male breast cancer is understudied (da Silva 2016). This dissertation makes a unique contribution to the literature by describing the RTW experiences of male breast cancer survivors.

Another strength of this dissertation is its empirical and theoretical contribution. The theory of incompatibilities in the areas of life was developed as part of this dissertation (Section 3.5). In consideration of breast cancer survivors' reality of life, the theory explains how role incompatibilities can hinder the use of rehabilitation measures and foster job changes. These



findings add new aspects to the conceptual model of the experience of cancer and work (Wells et al. 2013). For instance, causes of incompatibilities among areas of life were investigated, incompatibilities were described in detail (extent, intensity, and duration), additional, more general coping strategies were identified, and intervening conditions that influence these strategies were analyzed.

Despite its strengths, the limitations of this dissertation must be acknowledged. When interpreting the results of this doctoral thesis, it should be noted that the quantitative analyses do not allow for interpretation of causal relationships due to the non-experimental study design. The small sample sizes limit the statistical power of the regression analyses. Regarding the qualitative analyses, the results cannot be generalized. A sample bias toward more motivated and healthier breast cancer survivors is likely and should be considered when interpreting the results. Finally, this dissertation focused on breast cancer survivors from Germany. Given differences in health care provision among countries that may impact the success of breast cancer patients' rehabilitation processes, it is unclear how the findings of this dissertation apply to survivors in other countries. Furthermore, this dissertation focused on breast cancer patients, and the findings may not necessarily be generalizable to other cancer types, as experiences may differ. For example, Kiasuwa Mbengi et al. (2016) report differences in work-related outcomes by cancer type in their review.

## **4.2 Implications**

This dissertation contributed to the understanding of the sustainability of RTW in breast cancer survivors by investigating the role of job changes. Several implications arise from the presented results, which demonstrated that an initial RTW does not guarantee satisfactory work participation in the long term.

### *Practical implications*

This dissertation's results emphasize the importance of raising awareness of potential long-term hardship among stakeholders of breast cancer survivorship care (e.g., gynecologists or office-based oncologists). Male breast cancer patients and their needs should receive particular attention to reduce inequalities in care. It can be concluded that existing mental and physical long-term effects and their respective influence on survivors' job changes in relation to the sustainability of RTW should be factored into survivorship care. Existing screening tools can detect support needs during aftercare before dissatisfactory or financially onerous work outcomes occur. For example, the quality of working life questionnaire for cancer survivors can be used to screen persons who have returned to work but may be at risk in regard to job changes (Jong et al. 2016).

In terms of RTW and work-related counseling, barriers such as perceived knowledge gaps of breast cancer specialists (Lamort-Bouché et al. 2020) and problems receiving compensation from the healthcare or pension insurance for work-related counseling could be reduced. In doing so, existing interface problems during the transition from rehabilitation to RTW can possibly be reduced. A recent study found that more than 20 % of oncological patients in a study from Germany express support needs related to work after participating in a rehabilitation program (Kähner and Leibbrand 2020).

This doctoral thesis has shown that workplace characteristics were significantly associated with the occupational development satisfaction of breast cancer survivors. This means that employers can contribute to a sustainable RTW by providing assistance during different stages, from disclosure to the actual RTW and follow-up (Greidanus et al. 2020). Therefore, informing employers of survivors' needs and adjustments to working conditions and stressing the relevance of communication may be useful. First interventions for employers are currently being developed (Greidanus et al. 2020), but their effectiveness still needs to be validated. According to the present findings, the various coping styles and communication needs of survivors should be considered when developing such interventions.

Also support offers for survivors will likely contribute to a sustainable RTW and should, therefore, be implemented in practice. For instance, multidisciplinary rehabilitation was reported to be beneficial for RTW rates compared to usual care (Boer et al. 2015). Outseeking interventions can help address cancer survivors with repressive coping mechanism such as accepting, staying strong, and sacrificing.

### *Implications for research*

The aim to better understand survivors' perspective was realized through (1) the use of patient experience measures, respectively, patient-reported outcome measures, (2) the application of a participatory research approach, and (3) the use of mixed methods. First, the findings emphasize the relevance of patient experience and patient-reported outcome measures for research on medical-sociological health services when investigating work-related outcomes in breast cancer survivors. In the present analyses, objective disease-related measures such as cancer staging failed to significantly predict occupational development satisfaction, while a subjective self-reported quality-of-life measure performed well. Moreover, the mere number of job changes was not significantly related to occupational development satisfaction. In contrast, involuntariness of the job changes was associated with this outcome. Therefore, future qualitative and quantitative research should incorporate patient experience measures and patient-reported outcome measures to reflect breast cancer survivors' subjective perspective. Second, the application of a participatory research approach proved to be beneficial in studying the perspective of survivors. By including representatives of self-help, the N–MALE and B–CARE projects benefitted from their patient-centered view from data collection to interpretation. Scholars should follow this approach in future work as the patient perspective enriches and helps patient-center health services research. Third, this dissertation showed the benefits of a mixed-methods approach, which allowed grounding of the findings in the participants' experiences (Wisdom and Creswell 2013). While the quantitative analyses helped to detect associations (e.g., Section 3.4), the qualitative analyses created a better understanding of the survivors' perspective (e.g.,

Section 3.5). Therefore, the combination of different methods and types of data seems to be a promising approach to create a more comprehensive picture of the investigated phenomena.

Inequalities and special needs may arise from being exposed to a care system that is tailored to female patients and societies that perceive breast cancer as a “women’s disease” (Halbach et al. 2020; Midding et al. 2018; Nguyen et al. 2020; Bootsma et al. 2020). These circumstances stress the need to further study male breast cancer patients’ experiences to reduce health inequalities and detect healthcare gaps. Due to the rarity of male breast cancer, international collaborations may be useful to obtain larger sample sizes.

Due to aforementioned differences in healthcare provision among countries and the focus on breast cancer survivors in this dissertation, the results may not be valid in other contexts. Thus, future research on the sustainability of RTW and the indicator job changes may include the experiences of survivors from other countries or cultural contexts and those affected by other cancer types.

Overall, descriptive studies are used in medical-sociological health services research to detect gaps between achievable and delivered quality of care, particularly in regard to patient-centeredness. After descriptive studies, interventional studies may follow aiming to close existing gaps in care and patient-centeredness. Accordingly, the results of this dissertation and the B-CARE project will provide the foundation for the next phase in the research process. According to the Medical Research Council framework (Craig et al. 2008), the interventional research phase will commence with a feasibility study aiming at developing an intervention to better support cancer survivors with their return to and retention of work.

### *Theoretical implications*

The findings of this dissertation demonstrated that the breast cancer survivors’ experiences were not in accordance with the more general concept of the sick role. The more specific conceptual model of the experience of cancer and work (Wells et al. 2013) was proven to be more applicable for the investigation of the survivors’ perspective on the sustainability of

RTW. This doctoral thesis further developed Wells and colleagues' (2013) model and can be applied in future research on the subjective survivors' perspective. In particular, the developed grounded theory of incompatibilities in the areas of life has the potential to explain the rehabilitation processes and decision-making of breast cancer survivors throughout these processes. During the development of the grounded theory, no specific focus on work-related outcomes was set. Rather, this approach involved an attempt to understand these outcomes by putting them in context in regard to breast cancer survivors' lives. The findings suggest that work-related outcomes such as job changes cannot be understood in isolation from the life circumstances in which they arise. Thus, theories and empirical models on breast cancer survivors' work outcomes should adopt a wider perspective that takes into account other roles and areas of life. Future research on cancer survivors' work outcomes should continue theory development, for instance, with the objective to explore the validity of theories in different contexts (e.g., countries, cancer types).

#### *Implications for medical-sociological health services research*

According to a recent memorandum (Baumann et al. 2016), the theoretical foundation of health services research needs more emphasis to increase the quality of research through critical theoretical reflection, among other reasons. The present doctoral thesis addressed this issue through the application of role theories to breast cancer as a common cancer disease, the advancement of a medical-sociological model, the creation of a grounded theory, and the discussion of further steps to be taken to continue advancing theory in regard to this topic.

Health inequalities are a central interest of medical-sociological research. The present analyses contributed to a better understanding of the link between the sustainability of RTW and inequalities in breast cancer survivors. Because certain groups of cancer survivors (e.g., being female, older age, more comorbid, etc.) are particularly affected by job changes following their RTW (Gudbergsson et al. 2008; Mols et al. 2009), job changes can represent a work outcome that hinders sustainable RTW. In fact, as this dissertation has explained, job

changes may cause and augment social inequalities if they are accompanied with financial losses. Further investigation of job changes is necessary to assess their financial toxicity.

To conclude, this doctoral thesis highlights that investigating the sustainability of RTW from cancer survivors' perspective is a promising way forward to reveal support needs throughout the survivorship phase with the goal of eventually enabling work and social participation as desired.

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