Psychological adjustment in cancer survivorship – trajectories of fear of recurrence, depression, anxiety, and coping in breast cancer survivors

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Table of contents

List of abbreviations

BC	Breast cancer
CS	Cancer survivorship
CSs	Cancer survivors
BCSs	Breast cancer survivors
CPs	Cancer patients
FoR	Fear of cancer recurrence
PCC	Patient centered care
HSR	Health services research

1. Abstract

Breast cancer (BC) is the most common cancer among women in Germany. Screening programs and treatment advances have increased these patients' chance of early diagnosis and survival rates. Therefore, the topic of cancer survivorship (CS) has gained importance. While high levels of psychological distress are well documented for patients with cancer during diagnosis and treatment, there is a lack of research on psychological outcomes in long-term cancer survivors. This study aimed to gain a better understanding of psychological adjustment over the course of BC survivorship and to discuss patient-centeredness in the provision of psycho-oncological healthcare for CSs. To achieve this, the following research questions were addressed: (1) How do BC survivors (BCSs) experience fear of cancer recurrence (FoR), depression and anxiety over the course of CS? (2) How do BCSs cope with challenges in the context of CS? (3) Which factors are associated with FoR, depression, anxiety and coping in BC survivorship? To answer these questions, quantitative and qualitative data for three publications were obtained from female BC survivors within the mixed-methods B-CARE project ("breast cancer patients' return to work"). Quantitative data consisted of longitudinal survey data from four measurement time points, namely, during hospitalization (T1) and 10 weeks (T2), 40 weeks (T3), and 5–6 years after hospital discharge (T4), and were analyzed using descriptive statistics and regression models. Qualitative data were obtained through semi-structured interviews conducted 5–6 years after hospital discharge and were analyzed trough qualitative content analysis. The results indicated that (1) BCSs experienced significant levels of FoR, depression and anxiety even 5–6 years after hospital discharge, with FoR decreasing and depression and anxiety increasing over time; (2) BCSs employed approach- and avoidance-orientated coping strategies during medical and occupational rehabilitation to deal with the consequences of cancer; and (3) psychological distress and coping in BCSs were associated in sociodemographic, personal, treatment, and health-related variables. The results show the long-term adverse mental effects of cancer and its treatment and highlight the individual adaptation requirements of CSs. The findings indicate the need for more patient-centeredness in the provision of psycho-oncological healthcare for long-term CSs.

2. Introduction and aims with references

Breast cancer (BC) is the most common cancer among women in Germany, with almost 70,500 newly diagnosed cases annually (Robert Koch-Institut 2023). Screening programs and treatment advances have increased these patients' chance of early diagnosis and survival rate: the relative 5-year survival rate is 88 %, and the 10-year survival rate is 83 % (Robert Koch-Institut 2023). Cancer survivorship (CS) centers on the well-being and health of individuals with cancer from diagnosis throughout their lifespan, encompassing the physical, mental, emotional, social, and financial consequences of cancer and its treatment (National Cancer Institute 2024). The physical and mental consequences of cancer can encompass a variety of long-term and late effects such as pain, fatigue, and sleeping difficulties (Götze et al. 2018), which may persist for more than 10 years after treatment (Harrington et al. 2010). After the completion of acute treatment, cancer survivors (CSs) still report a significant impact on their quality of life and increased severity of physical symptom than the population (Firkins et al. 2020; Götze et al. 2018). As regards the working life, CS can be associated with an increased risk of unemployment, early retirement (Mehnert 2011), and involuntary job changes (Hiltrop et al. 2022). Failure to return to work after cancer is, in turn, associated with mental health disadvantages (Lieb et al. 2022). On a social level, CSs experience changes in their social roles and social system (King et al. 2024). The existential experience of (breast) cancer and its consequences on all levels during survivorship can emotionally lead to individually varied reactions, triggering feelings such as fear, sadness, insecurity, anger, and guilt (King et al. 2024). In BC survivors (BCSs), an increased risk for adverse mental health outcomes, such as anxiety and depression, exists even years after diagnosis (Carreira et al. 2018; Harrington et al. 2010). To address the psychological needs of cancer patients (CPs), the German National Cancer Plan set the goal of ensuring appropriate psycho-oncological care. According to the S3 guideline for psycho-oncological diagnostics, counseling, and treatment of adult CPs (Leitlinienprogramm Onkologie 2023), psycho-oncological interventions aim to address psychological and social issues as well as functional impairments in the context of cancer diagnosis and treatment. They also aim to support coping with the illness, improve mental well-being, alleviate the accompanying and subsequent problems of medical diagnosis or therapy, strengthen social resources, enable participation, and maintain or enhance the quality of life of patients and their families. In Germany, psycho-oncological care takes place in inpatient care (e.g., cancer centers, oncological rehabilitation) and outpatient (e.g., psychological psychotherapists, psychosocial cancer counseling centers) care settings. These services are mainly aimed at CPs but can also be partially provided to CSs. Nevertheless, a strong consensus exists among experts that the German care system for long-term CSs currently lacks systematically structured and holistic care services (AG LONKO („Langzeitüberleben nach Krebs“) im Nationalen Krebsplan 2021 a). To ensure access to survivorship programs for CSs, research on long-term data regarding psycho-oncological outcomes after a cancer diagnosis is warranted (AG LONKO („Langzeitüberleben nach Krebs“) im Nationalen Krebsplan 2021 b).

2.1 Theoretical Framework

Health services research (HSR) examines health-care structures and processes from the perspective of patients and populations considering complex contextual conditions, describes outcomes at the healthcare level under everyday conditions, and evaluates complex interventions to improve care (Pfaff and Schrappe 2011). The throughput model (Pfaff and Schrappe 2011) is often used to describe and examine health-care service in terms of (1) patient characteristics (e.g., socio-demographic), resources for providing health services (material, immaterial), and the characteristics of providers (e.g., qualifications) (input); (2) healthcare service (e.g., chemo–therapy) and their context (e.g., provider–patient interaction) (throughput); (3) the provided healthcare service (output); and (4) the resulting outcomes, such as the patients’ physical, psychological, behavioral, or social outcomes (outcome). In the present study, the throughput model is used as a theoretical framework to describe the long-term psychological effects of BC diagnosis and treatment on BCSs (outcome). The model also enables examination of the associations with the outcome on various levels: individual level (e.g., associations with the sociodemographic factors of BCSs) (input); treatment level (e.g., such as associations with chemotherapy) (output); and health-related level (e.g., associations with fatigue) (outcome). Considering the needs of BCSs within the healthcare system, the present study also adopts the concept of patient-centered care (PCC) as a second theoretical framework. PCC is characterized by adequate access to continuous and coordinated care and by competent, empathetic, and respectful providers who, among others, integrate medical and nonmedical care, adopt a biopsychosocial perspective, tailor care to individual needs, and establish partnership to support both physical and mental well-being (Ernstmann and Scholl). There are many PCC models. One central model, based on a systematic review, is the integrative model of patient-centeredness (Scholl et al. 2014). This model identifies 15 dimensions relevant to PCC, which can be differentiated into principles, enablers and activities. Principles include the essential characteristics of the clinician (e.g., empathy), the clinician–patient relationship (e.g., trust), consideration of the patient as a unique person, and alignment of care within a biopsychosocial perspective. Enablers include the clinician–patient communication; integration of medical and non-medical care, teamwork and teambuilding; as well as access to and coordination and continuity of care. Activities include patient information; patient involvement in care, as well as involvement of family and friends; patient empowerment; as well as physical and emotional support of patients. In this study, the integrative model of patient-centeredness and the throughput model are merged (Figure 1) to examine the psychological outcomes of BCSs and to discuss patient-centeredness in the provision of healthcare for CSs.

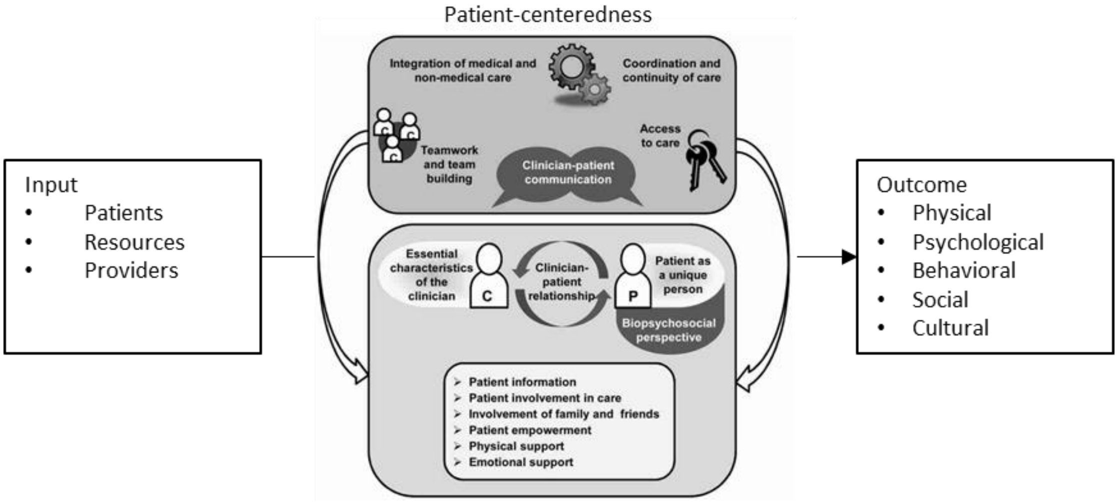

Figure 1: Theoretical framework based on the throughput model (Pfaff and Schrappe 2011) and the integrative model of patient-centeredness (Scholl et al. 2014)

2.2 Empirical Background

A large portion of research has focused on the psychological adjustment of CPs, indicating that cancer diagnosis and treatment is associated with emotional distress. A study involving 3724 CPs across Germany found that approximately half of the CPs perceived clinically significant levels of psychosocial distress (Mehnert et al. 2018). A higher risk for psychological distress was significantly associated with female sex, higher age, unemployment, gynecological and pancreatic cancer, and advanced stages of the disease. A study by Goerling et al. (2023) reported significantly higher levels of anxiety in CPs than in the general population, with a greater risk observed among CPs who were female, younger, single, and unemployed. Furthermore, Hinz et al. (2010) demonstrated that CPs exhibited twice the risk for anxiety and depression than the general population, with a higher risk observed among younger CPs. In terms of the prevalence of mental disorders among CPs, a study involving 2141 CPs across Germany reported a 4-week prevalence of 32 % for all CPs, with the highest prevalence observed among BC patients at 42 % (Mehnert et al. 2014). The most prevalent mental disorders were anxiety and mood disorders. By comparing these findings with the 4-week prevalence of mental disorders in the general population in Germany (20 %), the authors highlighted an overall higher prevalence among CPs. In a subsequent study, Vehling et al. (2022) investigated the same study population regarding the 12-month prevalence of mental disorders and compared the findings with gender-matched controls from the general population. The results indicated that the 12-month prevalence rate of mental disorders was significantly higher among the CPs. Consistent with these findings, Springer et al. (2024) reported that psychological need is one of the most commonly cited unmet supportive care needs among CPs in general, particularly BC patients. To examine the quality of life and psychological adjustment among long-term CSs, Götze et al. (2018) analyzed cross-sectional data from CSs in Germany diagnosed 5 or 10 years ago and compared it with the data from the general population. Although no significant differences were observed in quality of life based on the timing of diagnosis, long-term CSs exhibited lower overall quality of life than the general population, particularly in areas such as psychological well-being, role function, and social life. In the same study cohort, moderate-to-severe levels of depression and anxiety were observed in 17 % and 9 % of the participants, respectively (Götze et al. 2020). BCSs exhibited the highest levels of depression and anxiety descriptively, and the risk was significantly higher for female, younger CSs. A systematic review focusing on the adverse mental health outcomes of BCSs (Carreira et al. 2018) also demonstrated a significantly higher risk among BCSs for depression, anxiety, and other outcomes, such as sexual dysfunction, stress-related disorders, suicide, and somatization. A significant source of anxiety for CSs is the fear that the cancer could progress or recur. Fear of cancer recurrence (FoR) is frequently reported to be the major concern or one of the biggest worries of CSs even years after diagnosis (Simard et al. 2013). These findings indicate the long-term consequences of (breast) cancer and its treatment on emotional levels, even many years after diagnosis.

2.3 Aims

While research on the psychological adjustment of CPs during diagnosis and acute treatment has already been conducted, studies focusing on long-term psychological outcomes, such as depression and FoR, as well as risk factors for psychological distress, are still warranted. Therefore, the present study aimed to gain a better understanding of psychological adjustment over the course of BC survivorship to contribute to patient-centeredness in psycho-oncological care. Considering the throughput model (Pfaff and Schrappe 2011), the study also aimed to obtain cross-sectional and longitudinal data on the patient-reported outcomes of BCSs and explore associations with characteristics at various levels of the model. To achieve these goals, the following research questions were addressed:

1. How do BCSs experience FoR, depression, and anxiety over the course of cancer survivorship? 2. How do BCSs cope with challenges in the context of CS? 3. Which factors are associated with FoR, depression, anxiety, and coping in BC survivorship?

2.4 References

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3. Publications

The three publications were based on data from the B-CARE project, which was funded by the German Statutory Pension Insurance.

The first original article aimed to investigate the prevalence, individual courses, and determinants of FoR in long-term BCSs with and without recurrence. The second original article aimed to describe the prevalence, development, and determinants of depression and anxiety in long-term BCSs and identify the predictors of increase anxiety and depression levels over time. The third original article aimed to gain a deeper understanding of the coping processes of BCSs during medical and occupational rehabilitation and analyze the contextual factors of coping.

1) Quantitative data from 184 BCSs were obtained at four measurement time points: during hospitalization (T1) and 10 weeks (T2), 40 weeks (T3), and 5–6 years (T4) after hospital discharge. Descriptive statistics and chi-squared tests were conducted to describe the prevalence and individual courses of FoR. Logistic regression was performed to investigate the determinants of dysfunctional FoR 5–6 years after hospital discharge.

2) Quantitative data from 164 BCSs were obtained at four measurement time points: during hospitalization (T1) and 10 weeks (T2), 40 weeks (T3), and 5–6 years (T4) after hospital discharge. Anxiety and depression were measured using the Hospital Anxiety and Depression Scale. Furthermore, Sankey diagrams were created for the visual presentation of prevalence over time. Logistic and linear regression models were calculated to identify the determinants of anxiety and depression.

3) Qualitative data from 26 BCSs were collected through semi structured interviews 5–6 years after their diagnosis. A qualitative content analysis was conducted to investigate the coping strategies and contextual factors of coping among BCSs.

3.1 Publication 1: Individual courses and determinants of fear of cancer recurrence in long-term breast cancer survivors with and without recurrence

Heidkamp P, Breidenbach C, Hiltrop K, Kowalski C, Enders A, Pfaff H, Weltermann B, Geiser F, Ernstmann N. Individual courses and determinants of fear of cancer recurrence in long-term breast cancer survivors with and without recurrence. Support Care Cancer 2021;29: 7647–7657. https://doi.org/10.1007/s00520-021-06329-z

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https://doi.org/10.1007/s00520-021-06329-z

ORIGINAL ARTICLE

Individual courses and determinants of fear of cancer recurrence in long-term breast cancer survivors with and without recurrence

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Abstract

Objective This study investigated the prevalence, individual courses, and determinants of fear of cancer recurrence (FoR) in long-term breast cancer survivors (BCSs) with and without recurrence.

Methods A total of 184 breast cancer survivors were surveyed at four measurement time points: during hospitalization (T1), 10 weeks (T2), 40 weeks (T3), and 5–6 years (T4) after hospital discharge. Descriptive statistics, chi-square tests, and logistic regression were performed.

Results Respondents were females and 57 years old, on average. At T1, T3, and T4, 54.8%, 31.6%, and 29.7% of BCSs, respectively, were classified as having dysfunctional levels of FoR. Dysfunctional FoR decreased from T1 to T3 ($\chi^2(1) = 17.11$, $p = 0.000$; $N = 163$) and remained stable afterwards. Eight subgroups of individual courses of FoR over time could be described: (1) constant functional FoR; (2) constant dysfunctional FoR; (3) improving from dysfunctional to functional FoR from T1 to T3; (4) improving from dysfunctional to functional FoR from T3 to T4; (5) worsening from functional to dysfunctional FoR from T1 to T3; (6) worsening from functional to dysfunctional FoR from T3 to T4; (7) dysfunctional FoR at T1 and T4, and functional FoR in between; and (8) functional FoR at T1 and T4, and dysfunctional FoR in between. Logistic regression analysis revealed that being divorced/widowed, showing high levels of fatigue, being treated by chemotherapy, and having low confidence in treatment were associated with dysfunctional FoR 5 to 6 years after diagnosis (Nagelkerkes' Pseudo-R2 = 0.648).

Conclusions The findings reveal that FoR is a significant issue in long-term BCSs and has the potential to become a persistent psychological strain. We emphasize the need for increased awareness of FoR among BCSs and the need for support programs.

Keywords Anxiety · Breast cancer · Fear of cancer recurrence · Oncology · Relapse · Survivorship

Background

Even years after diagnosis and active treatment, cancer survivors suffer from their disease in multiple ways and report lower levels of quality of life compared to the non-affected population [1, 2]. A widespread source of psychological distress, which is not only one of the most important strains in cancer patients in acute treatment [3], but also affects long-term cancer survivors, is the fear of cancer recurrence (FoR) [4, 5]. FoR is defined as "Fear, worry, or concern relating to the possibility that cancer will come back or progress." [6] FoR is basically described as an appropriate reaction to cancer and its life-threatening potential and can enhance motivation, for example, to keep appointments for follow-up care or to engage in a healthy lifestyle [7]. However, FoR can also become dysfunctional

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when clinically significant severity is reached [6–8] and can be associated with lower quality of life, depression, and anxiety, even years after diagnosis [9, 10]. There is an expert consensus that dysfunctional FoR comprises certain characteristics, such as high levels of preoccupation and worry, which are persistent, as well as hypervigilance to bodily symptoms [6, 8]. In addition, high levels of FoR are associated with a higher risk of diagnosis with a psychiatric disorder compared to non-clinical levels [11]. Even years after diagnosis, a substantial number of cancer survivors suffer from FoR, which can be classified as dysfunctional [9–11]. However, studies that use predefined cutoff values for the clinical significance of FoR are rare; therefore, interpretations in terms of functional or dysfunctional levels of FoR in cancer survivors are limited [4, 5]. Regarding the course of FoR in cancer survivors over time, most studies found FoR to be stable [4, 5]. However, for a better understanding of FoR in long-term cancer survivors, not only mean values but also more individual courses of FoR need to be considered. The first studies that investigated group-based trajectories of FoR in cancer patients identified three patterns: constant low FoR over time, constant high FoR over time, and decreasing FoR over time [12, 13]. As these studies focused on the first year of the cancer, generalization to long-term cancer survivors is limited. Furthermore, for a better understanding of individual experiences of FoR in the long term, it should be considered whether breast cancer survivors (BCSs) actually have a recurrence over the course of the disease or not. Previous studies found both positive associations between having a recurrence and FoR and no significant relationship between these variables [5, 9].

Therefore, the present study aims to (1) investigate the prevalence of functional and dysfunctional FoR in long-term BCSs over a period of 5 to 6 years after diagnosis, (2) describe individual courses of functional and dysfunctional levels of FoR of BCSs with and without recurrence from hospitalization to 5–6 years after diagnosis, and (3) analyze the association of dysfunctional FoR in long-term BCSs 5–6 years after diagnosis with sociodemographic and health- and treatment-related variables.

Methods

Study design and participants

The B-CARE project ("breast cancer patients' return to work") was initiated in 2018 to study sociodemographic and psychosocial determinants of breast cancer patients' use of medical rehabilitation and return to work. B-CARE is a longitudinal study that uses survey data of breast cancer patients from four measurement time points: during hospitalization (T1), 10 weeks after hospital discharge (T2), 40 weeks after hospital discharge (T3), and 5–6 years after hospital discharge (T4) (T1: n = 1359; T2: n = 1248; T3: n = 1202; T4: n = 184). The flow of participants is shown in Fig. 1. Data from the first three measurement time points were collected during the preceding PIAT project ("Strengthening patient competence: Breast cancer patients' information and training

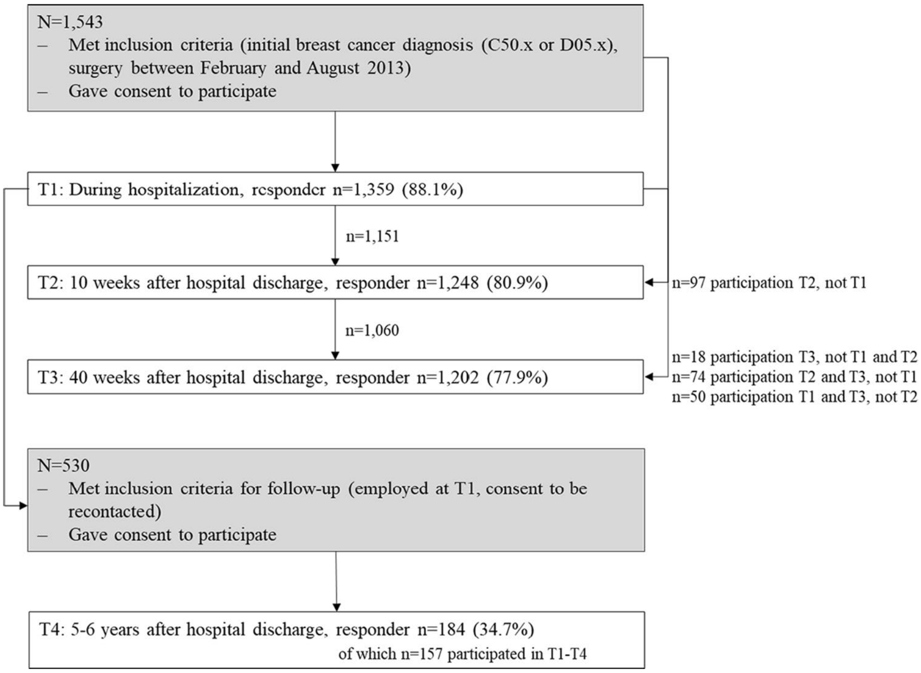


Fig. 1 Flow of participants. Note: The number of respondents composes of participants who consecutively participated in every survey wave and those who participated at least once. Dropouts occurred due to non-response, death, or unverifiable addresses

needs"). The PIAT study was initiated in 2013 and patients with an initial diagnosis of breast cancer (n = 1359; C50.x or D05.x) from n = 60 breast cancer centers throughout Germany were recruited for the study [14, 15]. Patients were surveyed during hospitalization. They received a questionnaire via mail 10 weeks and 40 weeks after hospital discharge. In 2019, B-CARE carried out a follow-up survey of a subsample of 530 patients who gave their consent to be re-contacted and who were working at the time of their diagnosis. Hundred and eighty-four patients participated in the survey 5 to 6 years after hospital discharge (response rate = 35%). Responder and non-responder at T4 did not differ significantly regarding FoR, medical, psychosocial, and sociodemographic characteristics (e.g., UICC TNM stage, number of comorbidities, age) (analyses not shown). Detailed information on the study design and sampling process can be found elsewhere [16].

Table 2 Variables measured at T1, T2, T3, and T4

Variables	T1	T2	T3	T4
Fear of cancer recurrence (FoP-Q-SF)	x		x	**x**
Sociodemographic variables				
Age				**x**
Family status	x	x	x	**x**
Number of children				**x**
Employment status	x	x	x	**x**
Vocational education level	**x**			
Health-related variables				
Cancer classification (UICC)	**x**			
Number of comorbidities	x			**x**
Recurrence status				**x**
Fatigue (Fatigue Assessment Questionnaire)				**x**
Treatment-related variables				
Chemotherapy	**x**	**x**	**x**	
Radiation therapy	**x**	**x**	**x**	
Hormonotherapy	**x**	**x**	**x**	
Confidence in treatment	**x**			

Note: Variables examined in the logistic regression analysis in bold

Measurements

Fear of cancer recurrence

The short form of the *Fear of Progression Questionnaire* (FoP-Q-SF) [17] was used to collect data at T1, T3, and T4. The FoP-Q-SF consists of 12 items and includes four subscales (affective reactions, partnership/family, occupation, and loss of autonomy) of the original version [18]. Table 1 gives an overview of the items of the FoP-Q-SF [19]. The 12 items were assessed using a 5-point Likert scale (1 = "never" to 5 = "very often"), leading to total scores ranging from 12 to 60, where higher values indicate higher levels of FoR. A cutoff score of 34 or above was used to identify dysfunctional levels of FoR [20]. At T3, item 12 of the FoP-Q-SF was missing in the survey, leading to a total of 11 items. In order to ensure that the results (possible range: 11–54) were still comparable to the results of the original 12-item version, the total scores were standardized to the original metric (possible range: 12–60). Therefore, total scores of the 11 items were divided by their possible maximum values based on the respective number of missing values for each participant. Values were then multiplied by the maximum possible value of the original instrument.

Determinants of FoR

To identify the determinants of functional and dysfunctional FoR at T4, data on sociodemographic and health- and treatment-related variables were collected. Table 2 gives an overview of the variables measured at T1, T2, T3, and T4. Sociodemographic data, such as age and number of children, were assessed in the questionnaire at T4. The variables family status and employment status were assessed at T1, T2, T3, and T4. In order to analyze the most current data on family

Table 1 Items of the short form of the Fear of Progression Questionnaire (FoP-Q-SF)

(1) Being afraid of disease progression
(2) Being nervous prior to doctor's appointment or periodic examinations
(3) Being afraid of pain
(4) Being afraid of becoming less productive at work
(5) Having physical sensations, e.g., rapid heartbeat, stomach ache, nervousness
(6) Being afraid of the possibility that the children could contract cancer
(7) Being afraid of relying on strangers for activities of daily living
(8) Being afraid of no longer be able to pursue hobbies
(9) Being afraid of severe medical treatments in the course of the illness
(10) Worrying that medication could damage the body
(11) Worrying about what will become of the family
12) Being afraid of not being able to work anymore

status and employment status, these variables were only examined at T4. The variable "highest vocational education level achieved" was assessed at T1. Data on cancer classification were added by the clinical personnel at T1, according to the categories of the Union Internationale Contre le Cancer (UICC) [21]. The number of comorbidities was assessed at T1 and T4. In order to use the most current data on comorbidities, the variable was only examined at T4. Recurrence status was assessed using the questionnaires at T4. To collect data on fatigue, the *Fatigue Assessment Questionnaire* [22] was used at T4. The FAQ consists of 20 items and three subscales (physical, affective, and cognitive fatigue). Treatment-related characteristics, such as being treated by chemotherapy, radiation therapy, or hormonotherapy, were assessed in the questionnaire at T1, T2, and T3. If a treatment type was provided at least once over the three measurement time points, it was considered given. The single item variable "confidence in treatment," which measures a positive belief in the outcome of the treatment, was assessed in the questionnaire at T1 using a 10-point Likert scale (0 = "not confident", 10 = "confident"). The 20 items were assessed using a four-point Likert scale (0 = "not at all" to 3 = "very much"), leading to the highest possible sum score of 60, where higher values indicate higher levels of fatigue.

Statistical methods

Statistical analyses were conducted using IBM SPSS Statistics version 24. Missing values were deleted list wise. To describe the prevalence of functional and dysfunctional levels of FoR over time, descriptive statistics and chi-square tests were conducted.

Individual courses of FoR were described for each participant with data on FoR available at T1, T3, and T4. Furthermore, individual courses of FoR were illustrated separately for participants with and without recurrence. By using the cutoff of 34, the participants were classified as having either functional or dysfunctional levels of FoR at T1, T3, and T4. Based on theoretical assumptions regarding the number of possible courses (3 time points, 2 values), eight different groups of courses were expected: (1) functional FoR at T1, T3, and T4; (2) dysfunctional FoR at T1, T3, and T4; (3) functional FoR at T1 and T3, and dysfunctional FoR at T4; (4) functional FoR at T1 and dysfunctional FoR at T3, and T4; (5) dysfunctional FoR at T1 and T3, and functional FoR at T4; (6) dysfunctional FoR at T1 and functional FoR at T3, and T4; (7) functional FoR at T1 and T4, and dysfunctional FoR at T3; (8) dysfunctional FoR at T1 and T4, and functional FoR at T3. Depending on the level of FoR at each time point, participants were assigned to a subgroup.

To investigate the determinants of functional or dysfunctional FoR at T4, logistic regression modeling, which facilitated the estimation of the sociodemographic and health- and treatment-related characteristics as predictors of FoR with the help of the maximum likelihood method, was applied. The variables were included in a block-wise manner. The first model (M1) contains sociodemographic, health-related, and treatment-related variables. In the second model, the variables fatigue and confidence in treatment were added.

Results

Descriptive results

The sample consisted of 184 female breast cancer survivors. N = 145 reported no cancer recurrence and n = 36 reported to have had a recurrence. The sample characteristics are reported in Table 3. Data on FoR at T1, T3, and T4 was available for n = 155 participants. Of those, n = 122 reported no cancer recurrence and n = 32 reported to have had a recurrence. For n = 1, there was no data on recurrence status available.

Figure 2 shows the proportions of functional and dysfunctional FoRs over time. The results revealed a decline in dysfunctional levels of FoR from T1 to T3 and a stable course afterwards.

Regarding individual courses of FoR over time, eight subgroups could be identified (Fig. 3a): (1) 38.1% of BCSs reported constant functional levels of FoR at all measurement time points; (2) 17.4% of BCSs showed constant dysfunctional levels of FoR at all measurement time points; (3) 19.4% of BCSs improved from a dysfunctional to a functional level of FoR from T1 to T3 and remained functional afterwards; (4) 10.3% of BCSs reported dysfunctional levels of FoR at T1 and T3 and improved to a functional level at T4; (5) 1.3% had dysfunctional levels of FoR from T1 to T3 and remained dysfunctional afterwards; (6) 3.2% showed functional levels of FoR at T1 and T3 and dysfunctional FoR at T4; (7) 7.7% of BCSs showed dysfunctional levels of FoR at T1 and T4, but reported functional FoR at T3; and (8) 2.6% of BCSs showed functional levels of FoR at T1 and T4, but reported dysfunctional FoR at T3.

With regard to BCSs without recurrence (Fig. 3b), (1) 44.3% of BCSs reported constant functional levels of FoR; (2) 13.1% of BCSs showed constant dysfunctional levels of FoR; (3) 18% of BCSs improved from a dysfunctional to a functional level of FoR from T1 to T3 and remained functional afterwards; (4) 9.8% of BCSs reported dysfunctional levels of FoR at T1 and T3 and improved to a functional level at T4; (5) 1.6% had dysfunctional levels of FoR from T1 to T3 and remained dysfunctional afterwards; (6) 2.5% showed functional levels of FoR at T1 and T3 and dysfunctional FoR at T4; (7) 9.0% of BCSs showed dysfunctional levels of FoR at T1 and T4, but reported functional FoR at

Table 3 Characteristics of study participants (n = 184)

		Abs (%)	Mean	Standard deviation	Min–max
Dependent variable: fear of recurrence (FoR)					
T1			35.10	8.61	18–60
	Missing	13 (7.1)			
T3			31.23	8.46	16.36–54.55
	Missing	20 (10.9)			
T4			29.14	9.06	12–54
	Missing	8 (4.3)			
Independent variables: sociodemographic variables					
Age in years (T4)			56.93	6.82	36–79
	Missing	15 (8.2)			
Marital status (T4)	Married	134 (72.8)			
	Single	17 (9.2)			
	Divorced/widowed	33 (17.9)			
	Missing	0 (0.0)			
Number of children (T4)			1.52	0.98	0–4
	Missing	0 (0.0)			
Vocational training (T1)	Low	106 (57.6)			
	Intermediate	34 (18.5)			
	High	33 (17.9)			
	Missing	11 (6.0)			
Employment status (T4)	Full time	51 (27.7)			
	Part time/occupational rehabilitation	85 (46.2)			
	Non-working	42 (22.8)			
	Missing	6 (3.3)			
Independent variables: health-related variables					
UICC TNM stage (T1)	UICC 0/1	79 (42.9)			
	UICC 2/3/4	71 (38.6)			
	Missing	34 (18.5)			
Number of comorbidities (T4)			1.01	1.10	0–5
	Missing	17 (9.2)			
Recurrence (T4)	No	145 (78.8)			
	Yes	36 (19.6)			
	Missing	3 (1.6)			
Fatigue (T4)			20.75	15.62	0–59
	Missing	1 (0.5)			
Independent variables: treatment-related variables					
Chemotherapy (T1, T2, and T3)	No	95 (51.6)			
	Yes	80 (43.5)			
	Missing	9 (4.9)			
Radiation therapy (T1, T2, and T3)	No	113 (61.4)			
	Yes	62 (33.7)			
	Missing	9 (4.9)			
Hormonotherapy (T1, T2, and T3)	No	54 (29.3)			
	Yes	121 (65.8)			
	Missing	9 (4.9)			
Confidence in treatment (T1)			8.99	1.29	2–10
	Missing	11 (6.0)			

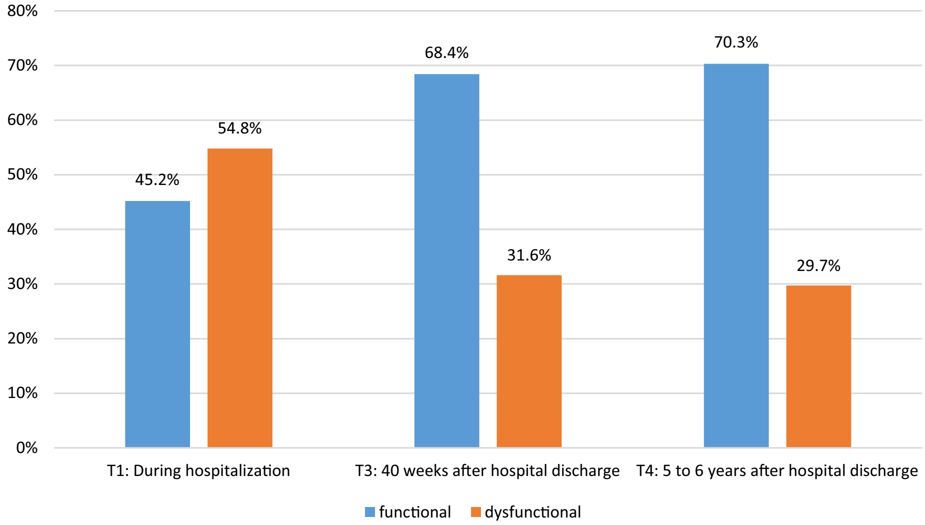


Fig. 2 Levels of fear of recurrence at T1, T3, and T4. N = 155

T3; and (8) 1.6% of BCSs showed functional levels of FoR at T1 and T4, but reported dysfunctional FoR at T3.

Regarding BCSs with recurrence (Fig. 3c), seven subgroups could be identified: (1) 15.6% of BCSs reported constant functional levels of FoR; (2) 34.4% of BCSs showed constant dysfunctional levels of FoR; (3) 21.9% of BCSs improved from a dysfunctional to a functional level of FoR from T1 to T3 and remained functional afterwards; (4) 12.5% of BCSs reported dysfunctional levels of FoR at T1 and T3 and improved to a functional level at T4; (5) 6.3% of BCSs showed functional levels of FoR at T1 and T3 and dysfunctional FoR at T4; (6) 3.1% of BCSs showed dysfunctional levels of FoR at T1 and T4, but reported functional FoR at T3; and (7) 6.3% of BCSs showed functional levels of FoR at T1 and T4, but reported dysfunctional FoR at T3.

Multivariate results

Chi-square tests of independence were performed to examine the relationship between functional and dysfunctional FoR and time. There was a significant relationship between the levels of FoR and time for T1 and T3 ($\chi^2(1) = 17.11$, $p = 0.000$; N = 163). Dysfunctional levels of FoR were more likely at T1 than at T3, indicating a decrease in dysfunction and an increase in functional FoR over time. There was no significant association between functional or dysfunctional levels of FoR and time at T3 and T4 ($\chi^2(1) = 0.14$, $p = 0.71$; N = 156).

To analyze the determinants of dysfunctional FoR 5 to 6 years after initial diagnosis, a logistic regression model was estimated. Table 4 shows the results of the logistic regression for FoR at T4.

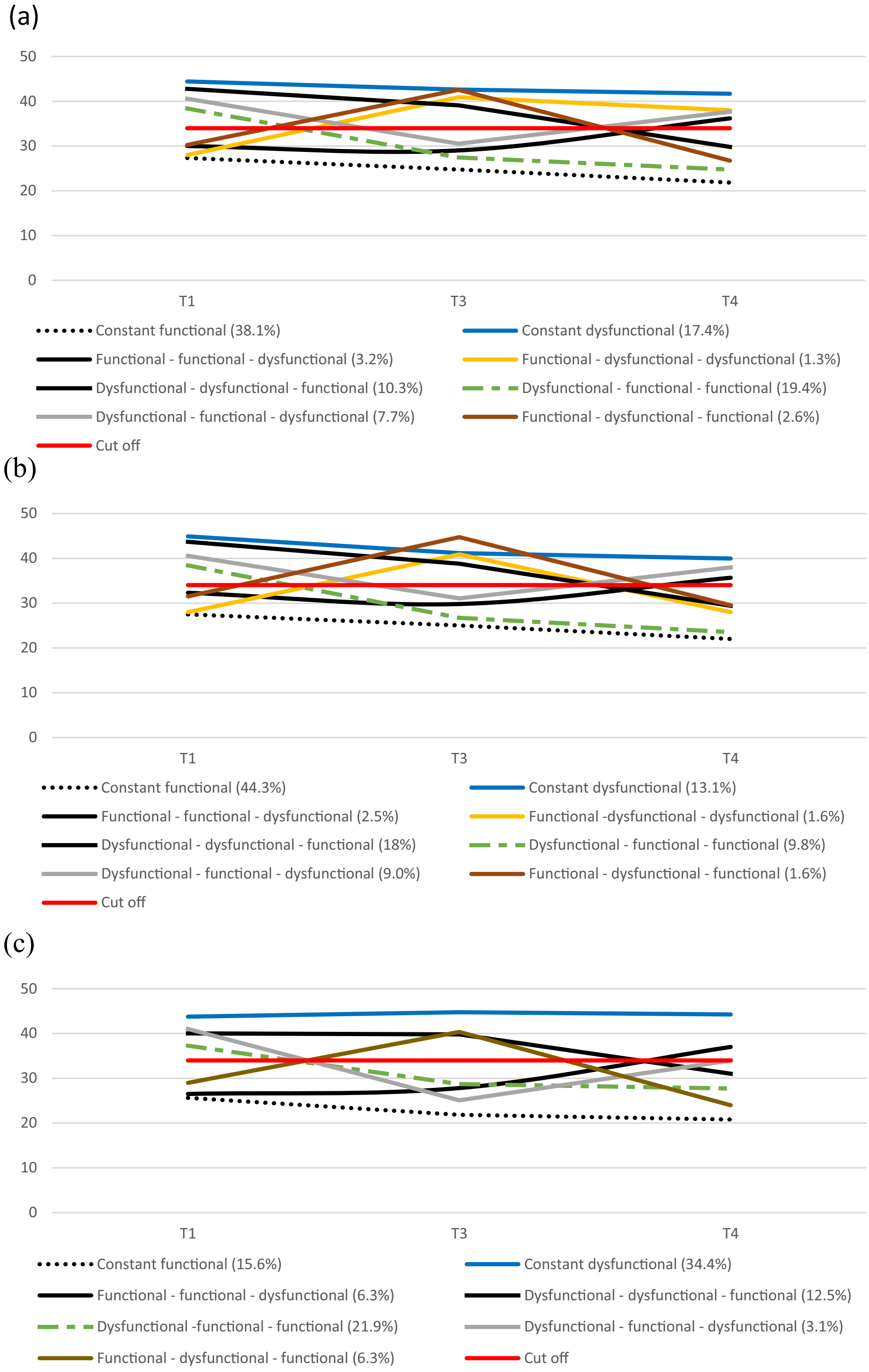
Model 1 shows that older adults (OR = 0.90; 95% CI = 0.82–1.00) and those who reported more comorbidities (OR = 2.46; 95% CI = 1.49–4.04) were more likely to report dysfunctional FoR at T4. BCSs who were married were less likely to report dysfunctional FoR (OR = 0.12; 95% CI = 0.03–0.53) than those who were divorced or widowed. Being treated with chemotherapy (OR = 10.48; 95% CI = 2.71–40.53) was associated with a higher risk for dysfunctional FoR at T4.

After inclusion of the variables fatigue and confidence in treatment (model 2), the association between age and FoR (OR = 0.98; 95% CI = 0.87–1.10) and that between comorbidities and FoR (OR = 1.37; 95% CI = 0.75–2.52) was no longer significant. Like Model 1, Model 2 shows that married BCSs were less likely to report dysfunctional FoR 5 to 6 years after hospital discharge (OR = 0.14; 95% CI = 0.02–0.83) than those who were divorced or widowed. Being treated with chemotherapy (OR = 5.53; 95% CI = 1.22–25.15) was associated with a higher risk for dysfunctional FoR at T4. BCSs who reported lower confidence in treatment at T1 (OR = 0.63; 95% CI = 0.41–0.97) and higher levels of fatigue (OR = 1.11; 95% CI = 1.05–1.12) were more likely to show dysfunctional levels of FoR at T4.

Discussion

Regarding the prevalence of FoR among BCSs, the results show that 5 to 6 years after hospitalization, most BCSs (70%) experienced functional levels of FoR. However, almost one-third of the BCSs reported dysfunctional levels of FoR. This number is higher compared to that reported in other studies [9, 10]. These differences may be explained by the younger age and employment status of the participants in the study

Fig. 3 (**a**) Individual courses of fear of cancer recurrence from T1 to T4 (n = 155); (**b**) individual courses of fear of cancer recurrence from T1 to T4 of BCSs without recurrence (n = 122); (**c**) individual courses of fear of cancer recurrence from T1 to T4 of BCSs with recurrence (n = 32)



sample. There is strong evidence that younger age is associated with higher FoR [5, 23]. With regard to employment status, it must be noted that the FoP-Q-SF includes two items that evaluate occupational worries, leading to a higher FoR score if working life is still an issue.

Regarding the average course of FoR over time, the results show a decrease in dysfunctional and an increase in functional levels of FoR during the first 40 weeks after hospital discharge and a stable course 5 to 6 years after hospital discharge. These results are comparable to those of

Table 4 Logistic regression model with fear of recurrence as the dependent variable (n = 140)

		Model 1		Model 2	
Variables	Response trait	OR	95% CI	OR	95% CI
Age in years	Metric	0.90*	0.82–1.00	0.98	0.87–1.10
Marital status	Married	0.12**	0.03–0.53	0.14*	0.02–0.83
	Single	0.17	0.20–1.43	0.57	0.04–9.04
	Divorced/widowed	1.0		1.0	
Number of children	Metric	1.17	0.70–1.96	1.01	0.56–1.81
Vocational training	Low	2.02	0.59–6.99	1.77	0.39–8.08
	Intermediate	0.76	0.16–3.72	0.59	0.90–3.86
	High	1.0		1.0	
Employment status	Full time	0.78	0.16–3.99	2.06	0.24–17.43
	Part time/occupational rehabilitation	0.85	0.21–3.56	2.26	0.40–12.69
	Non-working	1.0		1.0	
UICC TNM stage	Stage 0/I	0.75	0.23–2.38	0.76	0.19–3.12
	Stage II/III/IV	1.0		1.0	
Number of comorbidities	Metric	2.46**	1.49–4.04	1.37	0.75–2.52
Recurrence	No	2.23	0.71–6.94	1.50	0.38–5.98
	Yes	1.0			
Chemotherapy	Yes	10.48*	2.71–40.53	5.53*	1.22–25.15
	No	1.0		1.0	
Radiation therapy	Yes	2.63	0.81–8.59	2.99	0.74–12.12
	No	1.0		1.0	
Hormonotherapy	Yes	2.95	0.92–9.46	2.55	0.67–9.72
	No	1.0		1.0	
Fatigue	Metric			1.11**	1.05–1.17
Confidence in treatment	Metric			0.63*	0.41–0.97
Nagelkerkes-R^2		0.461		0.632	

*p < 0.05; **p < 0.01. Functional FoR = 0, dysfunctional FoR = 1

other studies that show a decrease in FoR during the first year after diagnosis but no long-term effect of time after diagnosis [9, 24–26].

Considering the overall sample, most BCSs showed constant functional levels of FoR (38.1%), followed by BCSs who improved from a dysfunctional to a functional level over time (29.7%) and BCSs who reported constant dysfunctional FoR (17.4%). Only a small number of BCSs showed a functional level of FoR at T1 and a dysfunctional level of FoR at T4 (4.5%). As the majority of BCSs in the present study showed steady FoR in terms of functional or dysfunctional levels, our findings partly support those of studies that found FoR in cancer survivors to be stable over time [4, 5]. On the other hand, in almost 45% of the participants, the intensity of FoR changed over the course of 5 to 6 years, indicating that time has the potential to affect FoR.

When comparing the individual courses of FoR of BCSs with and without recurrence, it appears that BCSs with recurrence descriptively show more often constant dysfunctional FoR (34.4%) and less often constant functional levels of FoR (15.6%) over the course of 5–6 years after diagnosis than BCSs without recurrence. These results suggest a positive association between having had a recurrence and dysfunctional FoR and are in accordance with previous research [9]. Furthermore, the results suggest that BCSs with recurrence show more dysfunctional FoR right from the start, even before having the actual recurrence.

The results of the logistic regression revealed a significant association between the marital status and the intensity of FoR in long-term BCSs. Women who were married were less likely to report dysfunctional FoR 5 to 6 years after diagnosis than women who were divorced or widowed. However, the effect was small (OR = 0.14). This association could be explained in terms of social support, which is probably more available for married than for divorced or widowed BCSs. Social support acts as a protective factor to lower the impact of stressors [27] and is negatively associated with higher FoR in long-term cancer survivors [28].

Furthermore, BCSs who were suffering from higher levels of fatigue were more likely to show dysfunctional FoR 5 to 6 years after diagnosis than BCSs who experience low levels of fatigue. These results are in accordance with previous research, which found strong evidence for the association between fatigue and other physical symptoms related to higher FoR [5]. This relationship might be explained by the ability of bodily sensations to trigger thoughts about cancer recurrence and the corresponding emotions and the fact that hypervigilance to bodily symptoms is a key characteristic of dysfunctional FoR [8].

BCSs who were treated with chemotherapy were at a higher risk for dysfunctional FoR at T4. These results are comparable to those of other studies [10, 29]. Adjuvant therapy is performed in order to reduce the risk of cancer recurrence and to draw the patients' attention to this risk, leading to higher levels of FoR. Another explanation for this association might be the long-term side effects of the therapy, which still cause physical symptoms years after treatment. Furthermore, treatment with chemotherapy could be an indicator of the severity of the cancer, leading to higher levels of FoR. However, cancer staging was not a significant predictor of FoR in the present study. In addition, chemotherapy often is recommended to younger cancer patients, who tend to show higher levels of FoR [5, 23].

Moreover, BCSs who reported lower confidence in treatment during hospitalization were more likely to show dysfunctional levels of FoR at T4 compared to BCSs who were more optimistic about their therapy. These results confirm those of previous studies that identified pessimism as a risk factor for cancer-related health concerns, anxiety, and depression in cancer survivors [30, 31].

The first model revealed significant associations between age and FoR at T4 as well as comorbidities and FoR at T4. After including the variables fatigue and confidence in treatment, the associations were no longer significant. This effect might be explained by the correlations between the variables, leading to the disappearance of the associations in the second model.

Study limitations

There are some study limitations which should be considered when interpreting the presented results.

The B-CARE study is an observational, and not an experimental, study. Therefore, only associations, but not causality, can be drawn from the results. The present study used a longitudinal study design with data collection at several measurement time points over a time span of 5 to 6 years. It is possible that study participants differ from non-participants in terms of health condition and emotional strain, which could have affected their motivation or ability to participate in the study. This bias could have led to an underestimation of the FoR of the BCSs. However, responder and non-responder at T4 did not differ significantly regarding FoR, medical, psychosocial, and sociodemographic characteristics.

Moreover, the use of a written survey could have resulted in the exclusion of patients who do not have sufficient reading, writing, or language skills. In terms of generalizability, it should be noted that only BCSs who worked prior to their diagnosis were considered in the present study. Therefore, a bias toward a younger and more educated sample is possible.

By interpreting the individual courses of FoR, it is important to consider that the courses were illustrated descriptively and that some of the subgroups have low sample sizes.

Clinical implications

The presented findings emphasize the relevance of FoR in BCSs and indicate that a significant number of BCSs suffer from dysfunctional fear and worries even years after diagnosis. As different courses of FoR have been illustrated, continuous screening for FoR over the course of the disease and survivorship is required. Therefore, health personnel in inpatient and outpatient settings should be aware of FoR and its characteristics, which indicate dysfunctional levels of FoR (e.g., hypervigilance to bodily symptoms). The presented findings on the determinants of dysfunctional FoR in long-term BCSs could be helpful in identifying high-risk groups, such as those who are divorced or widowed, those who have been treated using chemotherapy, those who report low confidence in treatment right from the start, and those who report high levels of fatigue as a long-term consequence of the cancer. In addition, therapeutic interventions could be derived from the reported risk factors, for example, activation of social networks or cognitive restructuring regarding the meaning of bodily symptoms. At the same time, it should be acknowledged that there are many proven interventions for FoR (e.g., ConquerFear [32]). The study results reveal that a substantial number of BCSs have constant dysfunctional levels of FoR over a period of 5 to 6 years, indicating that for many BCSs, time, per se, does not have a curative effect. Therefore, more support options accessible for both cancer patients and long-term cancer survivors in the health care system are required.

Conclusion

Overall, the findings from this study suggest that FoR is a significant issue among long-term BCSs. Almost one-third of the BCSs reported dysfunctional levels of FoR 5 to 6 years after diagnosis, indicating the potential of FoR to be a serious and persistent psychological strain following cancer. The findings support the need for increased awareness of the presence of FoR during and years after treatment and the need for support programs. Attention should be given to those who are divorced or widowed, who have undergone chemotherapy, who show low confidence in treatment, and who report high levels of fatigue. To gain a deeper understanding of FoR in cancer survivors, further studies involving both quantitative and qualitative data are needed.

Author contribution Nicole Ernstmann, Christoph Kowalski, and Holger Pfaff designed and supervised the PIAT study. Anna Enders collected PIAT data. Paula Heidkamp and Kati Hiltrop collected B-CARE data and matched B-CARE to PIAT data. Paula Heidkamp performed data analysis. Paula Heidkamp wrote the first draft of the manuscript. Clara Breidenbach, Kati Hiltrop, Nicole Ernstmann, Christoph Kowalski, Birgitta Weltermann, Franziska Geiser, Anna Enders, and Holger Pfaff discussed the results and commented on the manuscript.

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Data availability Research data are not shared.

Code availability Not applicable.

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.

Consent for publication All participants gave written informed consent for data analysis and publication.

Conflict of interest Clara Breidenbach and Christoph Kowalski are employees of the German Cancer Society.

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3.2 Publication 2: Prevalence and determinants of anxiety and depression in long-term breast cancer survivors

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RESEARCH ARTICLE

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Prevalence and determinants of anxiety and depression in long-term breast cancer survivors

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Abstract

Background: There is a significant number of long-term breast cancer survivors in Germany. However, research on the psychological challenges of cancer survivors is limited. This analysis describes prevalence, development and determinants of depression and anxiety 5 to 6 years after diagnosis and identifies predictors for an increase of anxiety and depression over time.

Methods: Data from 164 women was collected by survey and tumour documentation during post-operative hospital stay, 40 weeks and 5 to 6 years after diagnosis. Anxiety and depression were measured by the Hospital Anxiety and Depression Scale. Sankey-diagrams were created for visual presentation of prevalence over time. Logistic and linear regression models were calculated to identify determinants of anxiety and depression.

Results: Respondents had higher levels of depression and anxiety 5 to 6 years than 40 weeks after the diagnosis. Lower vocational status and having children were associated with depression, surgery type was correlated with anxiety, and age, as well as comorbidities, were predictors for both anxiety and depression 5 to 6 years after diagnosis. An increase of depression over time was more likely when having children and comorbidities. An increase in anxiety was less likely after cancer recurrence.

Conclusions: Findings highlight that anxiety and depression are relevant burdens for breast cancer survivors in Germany. Several sociodemographic and clinical predictors are identified. There is need for psychosocial support after acute treatment and in the long-term. Research on psychological burdens of long-term breast cancer survivors in the identified vulnerable groups is needed.

Keywords: Anxiety, Depression, Breast cancer, Cancer survivorship, Hospital anxiety and depression scale

Background

In Germany, the 10-year breast cancer survival rate ranges from about 50% for men to about 70% for women [1]. As about 70,000 women and 700 men are diagnosed with breast cancer annually [1], there is a significant number of long-term breast cancer survivors in the German population. Hence, many of those affected need to cope with the long-term effects of breast cancer. There are a variety of difficulties breast cancer survivors have to face: employment and work-related issues [2], restrictions in quality of life as they often experience impaired physical, role, mental or cognitive functioning [3, 4], as well as fear of recurrence [5, 6]. Overall, the prevalence of psychological complaints is higher in former cancer patients than in non-affected reference populations [3,

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7–11]. It has been shown that depressive symptoms and anxiety often remain beyond the treatment phase and are found in long-term survivors [7, 12–15].

The concept of cancer survivorship is gaining more attention, however, research on mental health problems and challenges in long-term survivors is still limited compared to the phases of diagnosis and acute treatment [3, 16, 17]. Several reviews state a need for research regarding cancer survivorship and psychological challenges, especially the later years (from 5 years after a cancer diagnosis) including the identification of risk factors [3, 8, 17]. It has been indicated that depression and anxiety may be a factor in predicting breast cancer recurrence and survival [18]. Depression and anxiety in breast cancer patients in an acute treatment phase have been related to several factors [16]. For example, low emotional and social support have been associated with higher risk for depression or anxiety [19]. Physical symptoms and impairments have been related to depression and anxiety in metastazised breast cancer patients [20]. For breast cancer patients undergoing chemotherapy demographic factors such as education, age and gender as well as economic factors such as unemployment as well as psycosocial factors such as self-efficacy or perceived stress may be linked to depression [21].

This analysis aims to examine the prevalence and development of depression and anxiety 5 to 6 years after diagnosis compared to 40 weeks after diagnosis. Further, it aims to investigate a) predictors for an increase of depressive and anxiety symptoms over time and b) determinants of depression and anxiety in long-term breast cancer survivors 5 to 6 years after the diagnosis. Findings may contribute to a more tailored psycho-oncological care for long-term survivors by identifying risk groups at an early stage and designing preventive measures.

Methods

Data collection

The present analysis was carried out as part of the research project B-CARE (Breast Cancer Patients' Return to Work) funded by the Deutsche Rentenversicherung Bund (German Federal Pension Insurance). B-CARE is a mixed-methods study that was initiated to examine socio-demographic and psychosocial determinants of the use of rehabilitation services as well as determinants of occupational reintegration after breast cancer [22]**.** In order to recruit study participants, 530 patients who had participated in the PIAT study (Strengthening patient competence: Breast cancer patients' information and training needs, funded by the German Federal Ministry of Health) in 2013 and who were employed at the time of their breast cancer diagnosis in 2013/14, were asked per mail to complete a follow-up questionnaire 5 to 6 years after diagnosis in 2019. Inclusion criteria for the PIAT study were an initial breast cancer diagnosis and surgery in a German Cancer Society-certified breast cancer centre between 1 February and 31 August, 2013. For further information on the PIAT study see for example Halbach et al. [23, 24]. Participant recruiting and data collection for B-CARE was conducted by the study director and team (NE, PH, KH). A subsample of the PIAT sample that filled in written consent and the B-CARE questionnaire was included in the B-CARE study. A subset of participants that filled in the questionnaire for B-CARE was also invited for semi-structured interviews. Data from the B-CARE survey 5 to 6 years after diagnosis (T4) were then linked with data from the PIAT study from 2013 to allow for a consideration of four measurement points over 5 years (T1: during post-operative hospital stay; T2: 10 weeks after diagnosis; T3: 40 weeks after diagnosis). In the PIAT study, survey data were linked with clinical and treatment data documented by the hospital (see section "Variables"). B-CARE has been approved by the ethical committee of the University Hospital Bonn (316/18).

Variables

The following data were used for the current analyses:

There are two dependent variables in this study, anxiety as well as depression, which were operationalised according to the Hospital Anxiety and Depression Scale (HADS), measured 5 to 6 years (T4) and 40 weeks (T3) after diagnosis. The HADS measures anxiety and depression, with seven items for each construct. According to Herrmann et al. [25], the seven items were summarised as scores for each construct. In this study, scores between zero and under eight are assessed as "no anxiety" or "no depression", scores between eight and under 11 as a "mild anxiety" or "mild depression", scores between 11 and under 15 as a "moderate anxiety" or "moderate depression" and scores from 15 as "severe anxiety" or "severe depression" [25]. The HADS has been applied widely and tested for validity and accuracy [26, 27] and is recommended in the German clinical psycho-oncology guideline as one of two instruments for the assessment of psychosocial burden ([28], p. 49). It is thus widely used by psycho-oncologists not only for research but also in routine practice.

Independent variables from survey data were age as a categorical variable (under 50 years, 60 to 69 years, 70 to 79 years), vocational training (no vocational qualification, general vocational training, specialised training or training for master craftsmanship, university (of applied sciences) degree), living together with a partner (yes/no), children (yes/no), number of comorbidities (0, 1, 2 and more) and cancer recurrence (yes/no). Independent variables from tumour documentation systems in the breast cancer centres were UICC TNM stage (0, 1, 2, 3 and 4) and type of surgery (breast-conserving surgery, mastectomy).

Data analysis

First of all, descriptive statistics were calculated in order to describe the sample characteristics. Secondly, paired sample t-tests were performed that tested to what extent mean scores of depression and anxiety vary between T3 and T4. Effect size Cohen's d was calculated for the t-tests. Above, Sankey diagrams were created using the R program ("networkD3" package), in order to display how respondents' depression/anxiety levels changed over time. Subsequently, regression analyses were performed in order to identify predictors for anxiety/depression. Firstly, binominal logistic regression models were calculated in order to identify respondents' characteristics associated with shifting to a higher level of depression or anxiety according to the classification provided by Hermann et al. [25] from T3 measurement to T4 measurement. Therefore, dummy variables were created as dependent variables, coding 0 for respondents that improved or stayed at the same levels of anxiety or depression, respectively, and coding 1 for respondents that shifted to a higher level. Secondly, linear regression models were calculated in order to identify determinants for depression and anxiety at measurement T4. Only cases with valid anxiety/depression scores at T3 and T4 were included in the analyses. Missing values for the independent variables were included as separate categories in order to prevent case exclusion as well as to control for potential effects. Missing categories were excluded from the logistic regression analysis when cases in one category did not vary in the dependent variable. Independent variables for the models were chosen by theoretical considerations. Then, univariate linear (dependant variables: anxiety or depression 5 to 6 years after diagnosis) and logistic (dependant variables: increase in anxiety or depression) regressions were calculated for each independent variable. Afterwards, the variables were added stepwise to the models while monitoring the variables' coefficients/odds ratios, *p*-values and confidence intervals as well as the models R^2/Nagelkerke's-R^2 and McFadden's R^2 and Aikaike Information Criterion in order to check confounding effects and model accuracy. For all statistical analyses, except for the Sankey diagrams, STATA/IC 15.1 was used.

Results

Sample

Table 1 summarises the describtive sample characteristics. The 164 women that submitted a questionnaire were 57 years old on average at T4 (Standard Deviation (SD): 6.8; min.-max.: 36–79). The majority of the respondents (56.1%) stated that their highest level of vocational qualification was general vocational training. Most respondents lived with a partner (80.5%) and stated that they had children (79.9%). The majority was assigned to the first (39.6%) or second UICC stage (32.9%) during their postoperative hospital stay (T1). Most participants (73.2%) received breast-conserving surgery. Of the 164 respondents, 74 (45.1%) stated that they had no other disease besides cancer, 50 persons (30.5%) named one comorbidity and 40 persons (24.4%) named two or more diseases besides cancer. Thirty-four respondents (20.7%) indicated cancer recurrence after their initial breast cancer diagnosis.

Prevalence of depression and anxiety

Five to six years after the diagnosis (T4), the respondents had an average anxiety score of 8.4 (SD: 2.0), which is on the mild anxiety level. Forty weeks after the diagnosis (T3), the average score was significantly lower at 6.0 (SD: 3.8) ($t = 8.4961$, $p < .001$, $d = 0.66$, $n = 164$) indicating no anxiety. About 34% ($n = 56$) of the respondents shifted to a higher level of anxiety over time (Fig. 1, Table 1).

For depression, respondents had a significantly higher average score of 7.5 (SD: 1.9) 5 to 6 years after diagnosis (T4) than 40 weeks after diagnosis (Mean: 3.1, SD: 3.1; $t = 19.1236$, $p < .001$, $d = 1.49$, $n = 164$). At T3 measurement, 149 (90.9%) respondents had no depressive symptoms. Of these, 34.9% showed mild to severe depressive symptoms at measurement time T4. Forty-two per cent of the respondents ($n = 69$) shifted to a higher level of anxiety over time (Fig. 2, Table 1).

Multivariable analyses

Binominal logistic regression models were used to identify respondents' characteristics associated with shifting to a higher level of depression or anxiety in measurement T4 compared to T3 measurement. Model 1.1 (see Table 2) shows that respondents with children (Odds Ratio (OR) = 9.5 (1.87, 48.40), $p = .007$) and with two or more comorbidities (OR = 3.75, (1.38, 10.18), $p = .01$) were more likely to have increased levels of depression over time. When not controlling for having children and comorbidities, UICC TNM stage 0 (OR = 4.27, (1.09, 17.15), $p = .04$) as well as 3 and 4 (OR = 4.66, (1.06, 19.09), $p = .04$) are significantly associated with an increase of depression over time. The overall logistic regression model 1.1 was statistically significant, $\chi 2(17) = 32.78$, $p = .01$, with Nagelkerke's Pseudo-$R^2 = 0.27$, McFadden's $R^2 = 0.17$ and $n = 153$.

Regarding anxiety, cancer recurrence is associated with a decrease in anxiety over time (OR = 0.39 (0.16,

Table 1 Descriptive sample characteristics

Variable	Time of measurement[a], source	Options	n (%)
Anxiety	T4, survey	n (%)	164 (100)
		Mean (standard deviation)	8.4 (2.0)
		Range	3.5–14
	T3, survey	n (%)	164 (89.1)
		Mean (standard deviation)	6.0 (3.8)
		Range	0–18
Depression	T4, survey	n (%)	164 (100)
		Mean (standard deviation)	7.5 (1.9)
		Range	4–15
	T3, survey	n (%)	164 (89.1)
		Mean (standard deviation)	3.1 (3.1)
		Range	0–15
Age	T4, survey	Under 50 years	17 (10.4)
		50 to 59 years	91 (55.5)
		60 to 69 years	49 (29.9)
		70 to 79 years	5 (3.1)
		Missing	2 (1.2)
Vocational training	T1, survey	No vocational training	6 (3.7)
		General vocational training	92 (56.1)
		Specialised training or training for master craftsmanship	18 (11.0)
		University (of applied sciences) degree	46 (28.1)
		Missing	2 (1.2)
Living together with a partner	T4, survey	No	31 (18.9)
		Yes	132 (80.5)
		Missing	1 (0.6)
Children	T4, survey	No	27 (16.5)
		Yes	131 (79.9)
		Missing	6 (3.7)
UICC TNM stage	T1, clinical tumor documentation	0	11 (6.7)
		1	65 (39.6)
		2	54 (32.9)
		3 and 4	11 (6.7)
		Missing	23 (14.0)
Type of surgery	T1, clinical tumor documentation	Breast-conserving surgery	120 (73.2)
		Mastectomy	32 (19.5)
		MIssing	12 (7.3)
Number of comorbidities	T4, survey	0	74 (45.1)
		1	50 (30.5)
		2 and more	40 (24.4)
Cancer recurrence	T4, survey	No	129 (78.7)
		Yes	34 (20.7)
		Missing	1 (0.6)

[a] Time of measurement: T1 = during post-operative hospital stay; T2 = ten weeks after diagnosis; T3 = 40 weeks after diagnosis; T4 = five to six years after diagnosis

0.97), $p = .04$). However, this association is only significant when controlling for having children and type of surgery. Model 2.1 could not reach significance in total, $\chi2(19) = 18.23$, $p = .51$.

Linear regression models were used to identify determinants for depression and anxiety at measurement T4. Model 2.1 (Table 3) with depression as dependent variable indicates that respondents under 50 years showed

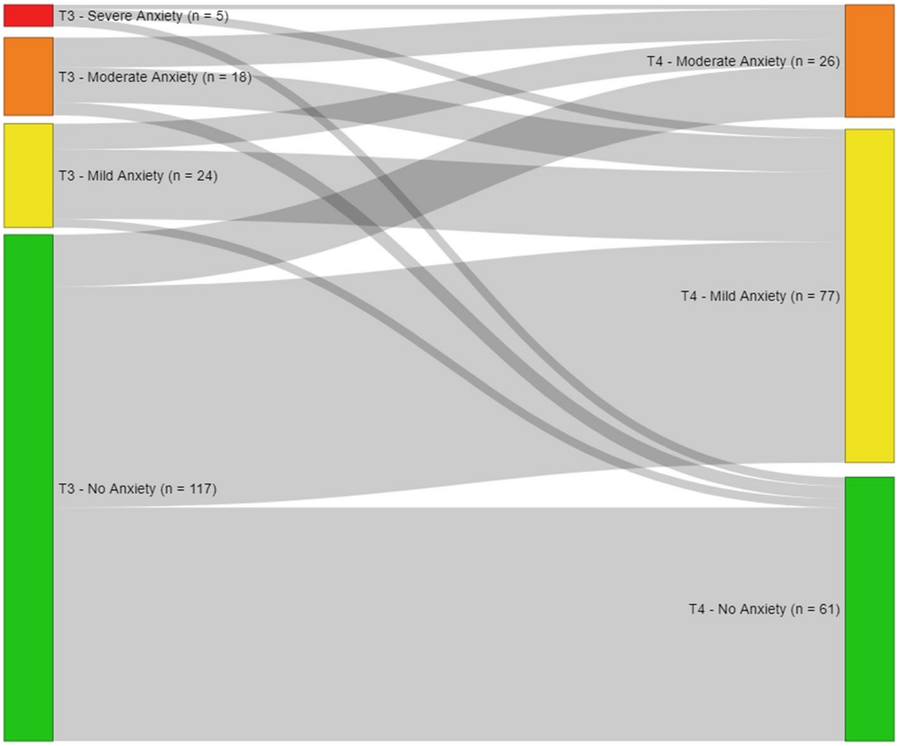

Fig. 1 Sankey-diagram showing the respondents' transfers between anxiety levels at T3 and T4 ($n = 164$); the thicker the grey line, the more patients

significantly higher values for depression than respondents in the reference group of 50 to 59 years (Coef. = 1.17 (0.21, 2.12), $p = .02$). Moreover, lower depression values were found in respondents with a university (of applied sciences) degree than respondents with a general vocational training (Coef. = −1.15 (−1.83, −0.47), $p = .001$). Having children was associated with higher depression (Coef. = 1.17 (0.35 1.98), $p = .01$). Respondents with two or more comorbidities showed higher levels of depression than survivors without comorbidities (Coef. = 1.31 (0.58, 2.03), $p < .001$). Model 2.1 explains about 32% of the variance in depression ($n = 164$) and is statistically significant (F(22, 141) = 3.05, $p < .001$).

The linear regression model regarding anxiety, model 2.2, showed that respondents under 50 years old show higher levels of anxiety than the reference group (Coef. = 1.08 (0.03, 2.12), $p = .04$) as well as those with comorbidities (two or more vs. no comorbidities; Coef. = 0.94 (0.15, 1.73), $p = .02$). However, the significant correlation with comorbidities only applies when controlling for age. Receiving a mastectomy was associated with higher anxiety scores than receiving breast-conserving surgery (Coef. = 0.91 (0.14, 1.71), $p = .03$) Model 2.2 is significant (F(22, 141) = 1.65, $p = .04$) and explains about 20% of the variance of anxiety at T4 ($n = 164$).

Discussion

The objective of this analysis was to describe the prevalence, development and determinants of depression and anxiety in long-term breast cancer survivors in Germany. The findings reveal that survivors show significantly higher depression and anxiety scores 5 to 6 years after diagnosis than 40 weeks after diagnosis. According to Cohen [29], the effect sizes of these findings are medium to large. As the Sankey-diagrams demonstrate, about one-third of the respondents recorded a change to a higher level of depression over time, and more than one third shifted to a higher level of anxiety. In total, the sample showed higher values for depression and anxiety 5 to 6 years after diagnosis than women in the German general population ([30]: anxiety 5.0, depression 4.7). An explanation for these detected trajectories might be that 40 weeks after the diagnosis, positive emotions, like relief and appreciation of life prevail, because of the illness that had just been conquered [31]. In comparison, 5 to 6 years after the diagnosis, women have to deal with the emotional, social, financial and physical long-term effects of their breast cancer diagnosis, which might lead to more anxiety and depression. The literature on the topic is sparse, however, it is acknowledged that depression and anxiety are serious issues for breast cancer survivors and should be addressed [7, 12, 32, 33].

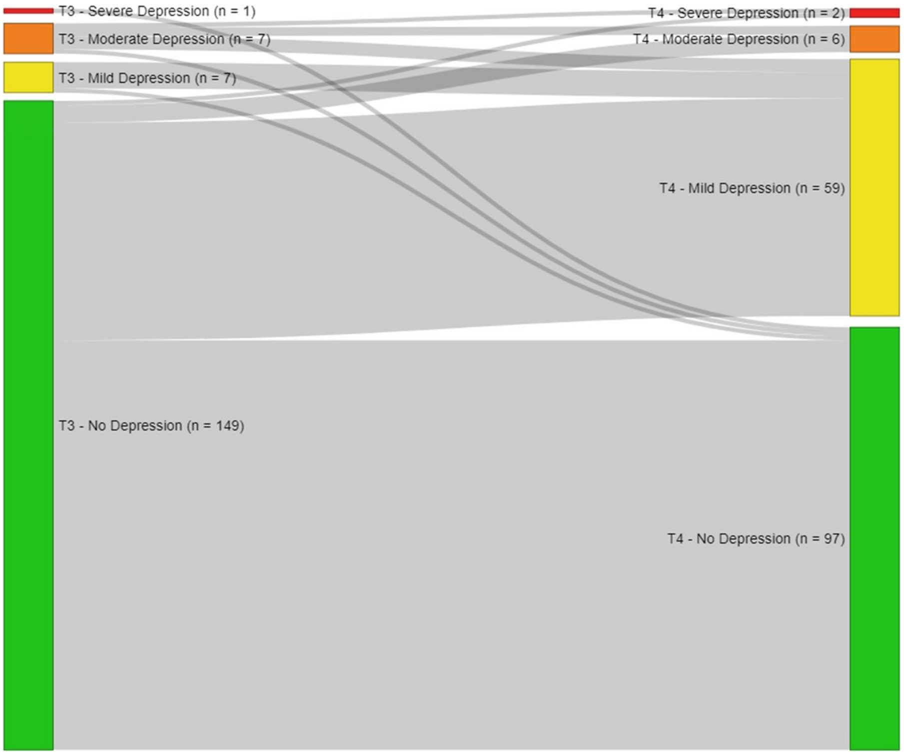

Fig. 2 Sankey-diagram showing the respondents' transfers between depression levels at T3 and T4 ($n = 164$); the thicker the grey line, the more patients

Multivariable analyses revealed patient characteristics that were significantly associated with higher levels of psychological burden 5 to 6 years after diagnosis. Age was reported to be associated with depression and anxiety: Respondents younger than 50 years were more distressed than survivors in their fifties. Research has shown that the variation of the psychologic impact of cancer is related to age, in that older persons are often less affected [7, 32, 33]. Receiving a cancer diagnosis at a younger age often relates to a better prognosis, however, it might also question feelings of security and controllability, e.g., regarding reproductive concerns [34]. Consistent with the literature [7], we found vocational training level to be a significant predictor for depression 5 to 6 years after diagnosis.

Furthermore, having two or more comorbidities was found to be associated with the level of depression and anxiety 5 to 6 years after the diagnosis, as well as an increase of depression over time. This finding is consistent with previous findings [12, 17] and might be explained by the fact that better physical health may help to manage daily requirements as well as to rebuild structure and normalcy to daily life after the active treatment phase.

Our analysis indicates that having children correlates with an increase of depression over time, which has been reported before [35, 36]. A review by Semple and McCane [37] highlights that parents with cancer might struggle to talk to their children about cancer, experience feelings of failure as a parent or perceive an increased effort in order to maintain routines at home for their children.

Mastectomy in our analysis is related to higher anxiety scores 5 to 6 years after the diagnosis compared to survivors with breast-conserving surgery which is in line with previous research [38] and might be related to body image issues [39] and pain [40]. Cancer recurrence, in turn, is associated with a decrease in anxiety over time. This finding might be explained by illness trajectories in chronic illnesses [41, 42]: If cancer recurs or progresses, coping phases might start over such as shock, defence mechanisms, anger and acceptance. However, the HADS only measures anxiety that someone would admit to oneself. Thus, if women are in a phase of defence due to a recurrence of their disease, they might not admit anxiety to themselves, and it might not be detected. Moreover, the model investigating determinants for an increase of anxiety could not reach significance, which indicates that

Table 2 Results of logistic regression analyses for the increase of depression (Model 1.1) and an increase of anxiety (Model 1.2)

Variable	Options	Model 1.1. Increase Depression			Model 1.2. Increase Anxiety		
		Odds ratio	*p*-value	95% CI	Odds ratio	*p*-value	95% CI
Intercept		0.05	.002	0.01	0.53	.32	0.15 1.89
Age	Under 50 years	1.40	.62	0.37 5.28	0.30	.08	0.08 1.13
	50 to 59 years	Reference					
	60 to 69 years	0.59	.27	0.23 1.50	0.55	.17	0.24 1.28
	70 to 79 years	0.38	.50	0.02 6.25	0.27	.31	0.02 3.36
	Missing				1.20	.91	0.06 24.12
Vocational training	No vocational training	2.76	.30	0.40 19.16	0.70	.71	0.11 4.57
	General vocational training	Reference					
	Specialised training or training for master craftsmanship	0.83	.77	0.23 2.94	0.63	.44	0.20 2.04
	University (of applied sciences) degree	0.48	.15	0.18 1.31	0.68	.37	0.29 1.58
	Missing						
Living together with a partner	No	Reference					
	Yes	1.03	.96	0.36 2.96	1.17	.74	0.45 3.02
	Missing						
Children	No	Reference					
	Yes	9.53	.007	1.87 48.40	2.38	.11	0.86 6.81
	Missing	Reference			1.93	.56	0.21 17.92
UICC TNM stage	0	2.33	.27	0.51 10.57	1.05	.95	0.25 4.29
	1	Reference					
	2	0.88	.79	0.36 2.19	1.00	1.00	0.44 2.29
	3 und 4	2.45	.25	0.56 11.18	0.58	.47	0.13 2.53
	Missing	0.83	.84	0.15 4.72	0.45	.29	0.10 2.01
Type of surgery	Breast-conserving surgery	Reference					
	Mastectomy	1.25	.66	0.46 3.44	1.71	.25	0.69 4.25
	Missing	0.61	.64	0.08 3.77	5.70	.06	0.91 35.87
Number of comorbidities	0	Reference					
	1	1.05	.92	0.41 2.71	0.90	.80	0.39 2.06
	2 and more	3.75	.01	1.38 10.18	1.15	.76	0.47 2.81
Cancer recurrence	No	Reference					
	Yes	1.57	.33	0.64 3.86	0.39	.04	0.16 0.97
	Missing						
n		153			160		
Nagelkerke's-R^2		0.27			0.15		
McFadden's R^2		0.17			0.08		

Predictors of higher depression/anxiety scores, 5 to 6 years after diagnosis

the major predictor for an increase of anxiety of time is not included in this analysis and results should be interpreted carefully.

Regarding the limitations of the study, these analyses are based on an observational study design that does not allow any causal interpretations. Moreover, the sample of this analysis has a slightly higher proportion of females with a university (of applied science) degree and a lower proportion of females without vocational training than in the general German population [43]. Moreover, there might be a bias in the sample regarding healthier and more motivated cancer survivors or regarding less survivors with a migration background/lack of German language skills. Future studies should recruit more groups of long-term survivors with a lower level of education or migration background in order to obtain a more distinct picture of mental health problems in these risk groups, e.g., with qualitative approaches for survivors that may experience troubles with paper-based surveys [3, 8, 17]. On top of that,

Table 3 Results of linear regression analyses for depression (Model 2.1) and anxiety (Model 2.2) 5 to 6 years after diagnosis

Variable	Options	Model 2.1. Depression			Model 2.2. Anxiety		
		Coefficient	*p*-value	95% CI	Coefficient	*p*-value	95% CI
Intercept		6.43	.001	5.45 7.42	7.57	.001	6.49 8.65
Age	Under 50 years	1.17	.02	0.21 2.12	1.08	.04	0.03 2.12
	50 to 59 years	Reference					
	60 to 69 years	0.41	.23	−0.27 1.09	−0.74	.05	−1.48 0.00
	70 to 79 years	−0.33	.72	−2.18 1.51	−1.89	.07	−3.90 0.13
	Missing	−0.97	.44	−3.47 1.53	−1.04	.45	−3.76 1.69
Vocational training	No vocational training	1.01	.18	−0.48 2.50	0.31	.70	−1.31 1.94
	General vocational training	Reference					
	Specialised training or training for master craftsmanship	0.02	.97	−0.90 0.93	0.81	.11	−0.20 1.81
	University (of applied sciences) degree	−1.15	.001	−1.83 -0.47	−0.27	.47	−1.01 0.47
	Missing	0.47	.72	−2.13 3.06	1.21	.40	−1.62 4.04
Living together with a partner	No	Reference					
	Yes	−0.67	.08	−1.43 0.91	−0.34	.42	−1.17 0.49
	Missing	1.95	.36	−2.20 6.09	−1.46	.52	−6.00 3.06
Children	No	Reference					
	Yes	1.17	.01	0.35 1.98	0.84	.06	−0.04 1.73
	Missing	1.53	.09	−0.25 3.30	0.63	.52	−1.31 2.56
UICC TNM stage	0	0.06	.92	−1.11 1.24	−0.23	.72	−1.52 1.05
	1	Reference					
	2	0.06	.86	−0.62 0.74	0.14	.71	−0.60 0.88
	3 und 4	0.20	.74	−1.00 1.39	−0.59	.38	−1.89 0.72
	Missing	0.57	.30	−0.52 1.67	0.12	.84	−1.08 1.32
Type of surgery	Breast-conserving surgery	Reference					
	Mastectomy	0.52	.16	−0.21 1.26	0.91	.03	0.10 1.71
	Missing	−1.21	.09	−2.62 0.20	0.46	.55	−1.08 2.00
Number of comorbidities	0	Reference					
	1	0.57	.09	−0.09 1.24	0.43	.25	−0.30 1.15
	2 and more	1.31	.001	0.58 2.03	0.94	.02	0.15 1.73
Cancer recurrence	No	Reference					
	Yes	0.13	.71	−0.56 0.82	−0.29	.44	−1.05 0.46
	Missing	−1.35	.45	−4.88 0.82	−0.23	.91	−4.08 3.62
n		164			164		
R^2		0.32			0.20		

data for this analysis did not provide information about change in socioeconomic status over time, which could be of interest for future research. Furthermore, no men were included in the current analysis. Only about 1 % of all breast cancer diagnoses are made in men [1]. Due to a lack of care structures, there are many uncertainties in male breast cancer patients [44], which is why future research projects should include long-term male survivors of breast cancer. Moreover, depression and anxiety were measured with only one instrument (HADS) in this study. The HADS has been widely applied and validated in many languages, however, it has also been subject of discussion, especially in terms of its current thresholds [45]. While testing the prerequisites for the linear regression model, scatter plots revealed a light violation of the assumption of homoscedasticity, suggesting that the model is suited better for predicting lower depression levels.

Conclusion

Overall, the results suggest that anxiety and depression are a serious psychological burden for long-term breast cancer survivors in Germany. Findings emphasise the need for psychological and social support services after acute treatment and in the long-term. Particular attention should be given to younger survivors, to those with children, to those with comorbidities, those with a lower level of professional training as well as to those undergoing mastectomy. Further research on the psychological burdens of long-term breast cancer survivors in the identified vulnerable groups is urgently needed in order to tailor support services and target risk groups. Moreover, future research should investigate whether survivors in need utilise counselling services and identify inhibiting and facilitating factors for the utilisation.

Abbrevations

B-CARE: Breast Cancer Patients' Return to Work; HADS: Hospital Anxiety and Depression Scale; PIAT: Strengthening patient competence: Breast cancer patients' information and training needs; SD: Standard Deviation; OR: Odds Ratio.

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Authors' contributions

NE and CK designed and supervised the B-CARE study. NE, CK and HP designed and supervised the PIAT study. AE collected PIAT data. PH and KH collected B-CARE data and matched B-CARE to PIAT data. CB performed data analysis. CB wrote the first draft of the manuscript. NE, PH, KH, AE, HP and CK discussed the results and commented on the manuscript. The author(s) read and approved the final manuscript.

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Availability of data and materials

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

Declarations

Consent for publictaion

All participants gave written informed consent for data analysis and publication.

Ethics approval and consent to participate

Ethical approval was obtained by the Ethics Committees of the Medical Faculties of Cologne (12–171) and Bonn (316/18). All participants gave written informed consent to participate in the study.

Competing interests

Christoph Kowalski and Clara Breidenbach are employees of the German Cancer Society.

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3.3 Publication 3: Coping with breast cancer during medical and occupational rehabilitation: a qualitative study of strategies and contextual factors

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RESEARCH **Open Access**

Coping with breast cancer during medical and occupational rehabilitation: a qualitative study of strategies and contextual factors

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Abstract

Purpose This study aimed to gain a deeper understanding of the coping processes of breast cancer survivors (BCSs) during medical and occupational rehabilitation after acute treatment.

Methods This study is part of the mixed-methods Breast Cancer Patients' Return to Work study conducted in Germany. Data were collected through semistructured interviews with 26 female BCSs 5–6 years after their diagnosis. A qualitative content analysis was conducted to investigate the coping strategies and contextual factors of coping of BCSs.

Results The participants used different strategies for coping with their breast cancer, namely, *approach- versus avoidance-oriented coping* and *emotion- versus problem-focused coping*. During the medical rehabilitation process, coping behavior was used mainly to address disease management and its consequences. During the occupational rehabilitation process, most coping strategies were used to overcome discrepancies between the patient's current work capacity and the job requirements. The contextual factors of coping were in the health, healthcare, work-related, and personal domains.

Conclusion The study findings provide in-depth insights into the coping processes for BCSs during the rehabilitation phase and highlight the importance of survivorship care after acute cancer treatment.

Implications for Cancer survivors The results indicate that BCSs employ approach- and avoidance-oriented strategies to cope with their cancer during rehabilitation. As both attempts are helpful in the short term to cope with physical and emotional consequences of the cancer, healthcare and psychosocial personnel should respect the coping strategies of BCSs while also being aware of the potential long-term negative impact of avoidance-oriented coping on the rehabilitation process.

Keywords Cancer, Cancer survivorship, Coping, Oncology, Qualitative, Rehabilitation, Return to work

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Introduction

Breast cancer (BC) is the most common cancer among women in Germany, with almost 70,500 newly diagnosed cases annually [1]. Screening programs and treatment advances have increased these patients' chance of early diagnosis and survival rate [1]. About 30% of these patients are 59 years old or younger [1] and thus in the working-age group. Thus, it is imperative to not only restore physical and mental abilities but also reinstate the ability to work for BC survivors (BCSs) after acute treatment. The rehabilitation phase after acute cancer treatment is characterized by the reintegration into social roles while presenting various challenges for patients, such as feeling alone with treatment-related symptoms, struggling with a different self-perception and changes in personal relationships, and returning to work, along with associated worries, such as concerns regarding one's performance limits [2, 3]. Furthermore, after completing acute treatment, cancer survivors (CSs) still report lower quality of life than the general population [4, 5] and considerable psychological distress [6]. To cope with their illness after acute treatment, BCSs employ different strategies [7, 8].

According to the transactional model of stress, *coping* is defined as "ongoing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (R. S. Lazarus, [9], p. 237). Roesch et al. [10] suggested a literature-based taxonomy to classify the coping strategies of patients with prostate cancer around two dimensions: *approach- versus avoidance-oriented coping* and *emotion- versus problem-focused coping*. *Approach-oriented coping* refers to coping activity oriented toward a threat, such as seeking information, whereas *avoidance coping* refers to an attempt to direct attention away from a threat, such as by denial [10]. *Emotion-focused coping* aims to regulate the emotional consequences of a stressful situation, such as by positive reinterpretation [11], whereas *problem-focused coping* is the active attempt to influence the source of stress, such as by seeking instrumental support.

Coping style is relevant among BCSs as different patterns predict psychological symptoms and quality of life outcomes, even years after the diagnosis [12, 13]. Compared with approach-oriented coping, avoidance-oriented coping exerts an adverse effect and is associated with lower quality of life and worse physical and psychological health [10, 12, 14–16]. To support patients with cancer who employ coping strategies with a potential negative impact on long-term quality of life, an understanding of contextual factors that influence coping style is critical. Quantitative studies on the predictors of coping in cancer patients and survivors found significant effects of education, age, sex, therapy, social support, and marital status [17–19]. However, specific knowledge of coping strategies and contextual factors is scarce for BCSs during rehabilitation. There is some evidence that patients with cancer who participate in an inpatient oncological rehabilitation program are more active in managing their illness than nonparticipants and that rehabilitation exerts positive effects on emotional stabilization, anxiety reduction, and resource strengthening for cancer patients [20]. Therefore, participation in a rehabilitation measure is assumed to exert a positive effect on how patients deal with their illness. However, to date, coping among CSs has not been a focal point of qualitative research [21]. Thus, this study aimed to gain a deeper understanding of coping processes among BCSs in Germany after acute cancer treatment during medical and occupational rehabilitation by analyzing coping strategies and contextual factors using qualitative interview data from BCSs 5–6 years after diagnosis.

Materials and methods

Study design

This study is part of the mixed-methods BC Patients' Return to Work (B-CARE) study conducted in Germany [22]. Interview and survey data were collected 5–6 years after diagnosis to explore the rehabilitation of BCSs; however, this study focused solely on the interview data, particularly on medical and occupational rehabilitation. The definition of these phases is based on the interviewees' subjective understanding of medical and occupational rehabilitation. Regarding *medical rehabilitation*, the experiences reported by patients relate to the period after acute treatment, mainly associated with the completion of chemotherapy and radiotherapy at the cancer center. During this period, interviewees either participated in an oncological rehabilitation measure or did not participate and instead pursued other activities to restore health. The *occupational rehabilitation* phase involves the process of resuming work after the diagnosis. The University of Bonn Ethics Committee of the Medical Faculty approved this study (approval number: 316/18; German Clinical Trials Registry number: DRKS00016982).

Recruitment and sampling

The B-CARE study is a follow-up to the PIAT study (Strengthening Patient Competence: Breast Cancer Patients' Information and Training Needs) and represents a subsequent survey of the PIAT sample. The preceding PIAT study aimed to explore the information needs of BC patients. A total of 1359 patients initially diagnosed with BC were recruited from 60 BC centers throughout Germany [23] and were surveyed at three measurement time points: during hospitalization (T1), 10 weeks after hospital discharge (T2), and 40 weeks after hospital discharge (T3). The follow-up B-CARE study aimed to investigate the long-term rehabilitation process of BCSs. To this end, the existing longitudinal PIAT data was utilized, and an additional measurement time point for a survey and qualitative interviews, 5–6 years after diagnosis (T4), was added. The PIAT participants who consented to be recontacted and were working at the time of diagnosis were invited to participate in the follow-up B-CARE study 5–6 years later. A total of 184 BCSs participated in the B-CARE survey. Those who had provided written consent for an additional interview were invited via telephone or email and were informed about the procedure (audio recording, data use) and subsequently provided informed consent. Regarding the selection of interviewees, purposive sampling was employed [24]. The sampling strategy aimed to include contrasting cases with characteristics considered to be relevant to the research focus. Quantitative survey data were utilized to select interviewees with differences in sociodemographic characteristics (e.g., age, family status), rehabilitation experiences (e.g., participation/nonparticipation in an inpatient oncological rehabilitation program after acute treatment), and occupational variations (e.g., return to work after treatment, job changes that occurred). The sampling process continued until data saturation was reached [25].

Data collection

Data were collected through semistructured interviews via telephone or in person between August 2019 and August 2020 in the participant's preferred location, mainly at home. The interviews were audiotaped and lasted 53 min on average. The interview guide included 12 guiding open-ended questions and discussion of medical and occupational rehabilitation topics, coping strategies, and fear of cancer recurrence. In addition to the guiding open-ended questions, the interview guide included follow-up questions that could be asked if necessary. Examples of leading open-ended and follow-up questions are as follows: (1) Leading open-ended question: "Why don't you tell us how it came about that you did not take advantage of rehabilitation measures?" Follow-up question: "What concerns did you have?" (2) Leading open-ended question: "What helped you cope with your illness?" Follow-up question: "Did you seek help? In what form?" To improve the understandability and suitability of the interview guide, two cognitive pretests were conducted. The interviews were conducted by two research assistants (KH, PH).

Data analysis

The interview materials were transcribed verbatim. For data management, transcripts were entered into the software program ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) and analyzed after a qualitative content analysis according to the method described by Kuckartz [26]. All 26 transcripts were read, and the relevant text passages were marked. A deductive coding scheme was established according to the method described by Roesch et al. [10] with two coping categories: approach-/avoidance-oriented and emotion-/problem-focused. The transcribed interviews were reviewed from beginning to end, and relevant sections of the text were assigned to the main categories. The units of meaning were coded, which could also comprise several sentences or paragraphs. The text sections with the same main categories were compiled. Then, the main categories were differentiated by assigning them subcategories. Subcategories (coping strategies) were coded deductively inspired by the work of Roesch et al. [10, 27], the COPE [28], the Coping Responses Inventory [29], and the Ways of Coping Questionnaire [11] and were complemented by inductively derived codes. All materials were coded using the resulting coding system. If necessary, text passages could also be assigned to multiple coping strategies. Furthermore, the data were coded regarding secondary information that were relevant in the context of coping behavior (e.g., health- and work-related characteristics). The main categories (e.g., health-related contextual factors) and subcategories (e.g., participation in a rehabilitation program) were inductively coded. Subsequently, the contextual factors of coping strategies were analyzed by investigating the associations between the subcategories that emerged (coping strategies) and secondary information. To ensure reliability, the data were coded by two scientists (PH, KH). Any coding differences were discussed until consent was reached. Typical quotes were selected to illustrate the results. Filling words and duplications were omitted to increase readability.

Results

Sample

A total of 26 interviewees were selected using purposeful sampling. Their average age was 57 years, and most of them were married and had a part-time employment during the time of the interview. They were first diagnosed with BC in 2013, primarily stage 1 or 2. Table 1 presents the sample characteristics at the time of the interview.

Coding trees

During medical and occupational rehabilitation, BCSs employed different coping strategies, classified as either approach- or avoidance-oriented coping. Approach-oriented coping involved problem-focused coping strategies of *seeking information*, *active coping*, *seeking instrumental support*, and *suppression of competing activities* and emotion-focused strategies of *self-control*, *seeking emotional support*, and *comparing.* In avoidance-oriented coping, BCSs employed the strategies of *distancing*, *denial*, and *seeking alternative rewards.* We also analyzed

Table 1 Sample characteristics of the 26 interviewees

Characteristics		**Interviewees (*n* = 26)**	**Mean**	**Min–max**
Age in years	Missing	0	56.73	44–72
Marital status	Married	18		
	Single	4		
	Divorced	3		
	Widowed	1		
	Missing	0		
Children	Yes	17		
	No	7		
	Missing	2		
Vocational training	No training	1		
	Vocational training	9		
	Specialized/master Craftsman training	4		
	University	11		
	Missing	1		
Employment status	Full-time	8		
	Part-time	13		
	Retired†	5		
	Missing	0		
Rehabilitation program participation after acute treatment of initial breast cancer	Yes	19		
	No	7		
UICC TNM stage of initial breast cancer ‡	0	2		
	1	11		
	2	8		
	3	1		
	Missing	4		
Recurrence	No	21		
	Yes	5		
	Missing	0		

† Includes early retirement and reduced earning capacity retirement.

‡UICC TNM = Union for International Cancer Control TNM staging [30]

the contextual factors of coping strategies to gain a better understanding of coping behavior and associated factors. The theoretical foundation for the investigation of contextual factors is based on the work of Mehnert et al. [31] in which contextual factors associated with return to work of CSs were studied. We identified contextual factors in the health, healthcare, work-related, and personal domains. Figure 1 presents the approach- and avoidance-oriented strategies and associated contextual factors.

Approach-oriented coping

Problem-focused coping

Seeking information was identified as a problem-focused strategy employed by BCSs to cope with their illness during rehabilitation. The use of this strategy is motivated by existing information needs and promoted by participating in an oncological rehabilitation program. BCSs sought information regarding long-term adverse effects, future perspectives toward the cancer, and means to have a positive impact on the prognosis. Interviewees found it helpful to receive information from other BCSs who had more time since their diagnosis or had a cancer relapse, for example, participant 3 (P3) in an inpatient rehabilitation program:

> *"There were also a lot of people there who had fallen sick again. And that's something EVERYONE is afraid of, right? And then you got to hear, how it was developing now, what are their chances? You didn't know how the disease was progressing, right? I thought it was good." —P3*

Seeking information helped normalize the interviewees' experiences, gain a clearer picture of the future disease course, cope with worries, and create a sense of control and self-efficacy.

Active coping is an attempt for active rehabilitation posttreatment, including exercise, healthy eating, participation in therapies (e.g., lymph drainage, physiotherapy), informative meetings, psychological counseling, and willingness to "do whatever it takes" to rehabilitate. It often manifests as participation in organized inpatient rehabilitation programs and was reported by interviewees who were informed about the possibility of active rehabilitation (e.g., in a rehabilitation program), who were motivated by a supportive social environment, and who experienced poor health posttreatment. Women who had physical impairments considered it more necessary to actively engage in rehabilitation than those with subjective good health status, as explained by P12 speaking about her motivation to participate in a rehabilitation program:

> *"actually the physical condition. Rather than the mental or psychological state because I had so many side effects from the chemo, I was not mobile at all and always felt tired. That was really the aspiration [sic]." —P12*

Active coping is also employed for occupational rehabilitation to cope with discrepancies between job requirements and an impaired capacity to work because of adverse treatment effects. It involves making adjustments actively, such as incorporating recovery time in the

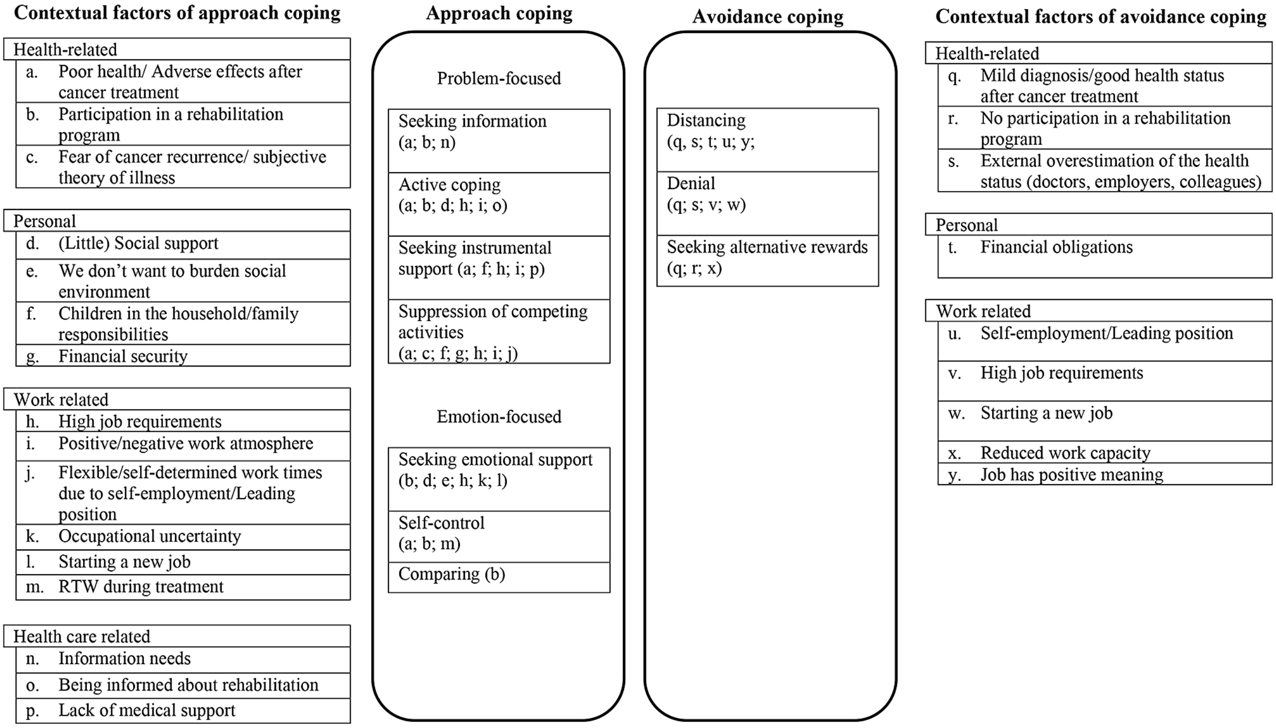

Fig. 1 Coping strategies used by breast cancer survivors and associated contextual factors during medical and occupational rehabilitation. *Note*. The associated contextual factors are shown in brackets after the coping strategies

work routine or openly communicating about the illness to workers and employers. Interviewees with high job requirements as well as social support and understanding from colleagues/employers reported using active coping. This strategy also includes seeking a new job when the current position becomes incompatible with rehabilitation and was reported in connection with performance pressure as well as the lack of support and understanding at the workplace.

Seeking instrumental support is defined as seeking of support from family and friends who care for the household or interviewees' children to enable active rehabilitation. Many interviewees sought instrumental support for continuing health problems and "inexplicable" treatment-related symptoms. They consulted rehabilitation clinic physicians and other healthcare providers (e.g., osteopaths, acupuncturists) as well as self-help groups for instrumental support. Interviewees who perceived a lack of medical support and felt devalued and neglected by physicians during treatment used this coping strategy, as reported by P6 about healthcare deficits that motivated her to seek instrumental support in a rehabilitation clinic:

> *"I already noticed that I was in pain, that it was indefinable and all a mystery and my doctors actually always told me that it doesn't exist, that the pain will go AWAY again. So they were actually negating everything or talk me into it. And I was really hoping to find someone there in the treatment center who would help me in a really HONEST way." —P6*

Seeking instrumental support also affected occupational rehabilitation and helped overcome discrepancies between job demands and impaired work capacity. Therefore, during return to work, interviewees sought support from colleagues/employers who undertook certain tasks to relieve them. Another manifestation of instrumental support is progressive reintegration, which enables employees to gradually increase their working hours after sick leave. Interviewees reported seeking instrumental support in connection with poor health posttreatment, high job requirements, as well as understanding and support from supervisors and colleagues.

Suppression of competing activities is defined as suppression of activities competing with self-care to focus on rehabilitation and recovery time. During medical rehabilitation, this strategy especially manifests as suppression of family duties and was reported by interviewees with children in the household and family responsibilities, as described by P19, an inpatient rehabilitation participant:

> *"I was really focused on myself there. I did [n't] miss my family either. That was good, I can say now that I was happy to get rid of them (laughs). And because*

> *I also had the freedom to think about things myself.” — P19*

Suppression of competing activities also occurs in the context of occupational rehabilitation, during which work obligations are adapted for impaired work capacity and health conditions posttreatment. This work subordination manifests as reduced work time, changes in work scope, stronger focus on work/life balance, and job changes. Suppression of work in favor of health activities was reported in connection with the long-term adverse effects of treatment (e.g., fatigue, joint pain), high job requirements, and support and understanding in the workplace, as reported by P19 about making adjustments due to reduced work capacity posttreatment:

> *“I'm also really grateful to my boss at the time, we agreed that I'd be working successfully again after my reintegration, but basically for a period of two years I'd be doing a job in which I was no longer exposed to maximum stress. And I wouldn't have been able to do the job anyway anymore because with a job like that, you don't know when you go to work in the morning, how long the day will be and what the day will bring. That means I wouldn't have been able to do the job under those conditions any more—i.e., with the background and in the physical condition I was in when returning to work.” — P19.*

Furthermore, financial security, particularly with married status, and having flexible/self-determined work times due to self-employment or leading positions were associated with need-oriented adaptation of work obligations in favor of health aspects. Other factors in this coping strategy are fear of cancer recurrence and a subjective theory of illness in which work stress is perceived as the cause of the cancer.

Emotion-focused coping

Seeking emotional support—particularly from fellow patients in the context of rehabilitation programs or self-help groups—is a strategy employed by many of the interviewees. Being with patients who had similar experiences made the interviewees feel understood, normalized their own feelings and perceptions, and provided them with an opportunity to express their feelings. Interviewees reported seeking emotional support from fellow patients as they did not want to burden their personal social environment or they had little social support at home. During medical rehabilitation, the interviewees sought emotional support from professionals (e.g., psychooncologists, psychotherapists, and physicians) to cope with the emotional impact of their diagnosis and its consequences. Emotional support is also sought for the psychological burden of occupational rehabilitation, particularly for emotional distress when work return is impossible due to impaired capacity or another reason, specifically to cope with uncertainty regarding the occupational future and challenges of a new job. This context especially includes feeling unable to transparently communicate about the cancer at the new workplace and dissimulation, leading to external expectations for high performance and resulting in overexertion and work overload. This association is described by P8 who started a new job posttreatment and sought emotional support:

> *“after I went back to WORK, I felt like I was having like a panic attack. I couldn't really explain it. It was also like that while I was working. And nobody at the new job knew what was wrong with me. There were two or three situations, I can remember, where I had to struggle with myself. And then I discussed it with my gynecologist. And we thought about how to deal with it. Whether it might make sense to seek psychotherapeutic support in some way.” — P8*

Self-control is an attempt to regulate one's emotion, be strong, and not let negative feelings affect one's behavior. This strategy positively affects rehabilitation because it helps overcome reluctance, such as participation in oncological rehabilitation while wishing to stay at home with the family. Self-control is used during occupational rehabilitation to support return to work and regain normalcy despite not feeling emotionally or physically prepared. Interviewees who used self-control were those who reported more serious health issues posttreatment and those who returned to work during treatment.

Comparing is a strategy based on downward comparisons with fellow patients, particularly in the context of inpatient rehabilitation. This strategy helped the interviewees accept their health condition and led to feelings of thankfulness and luck compared with others, as described by P12:

> *“There were, of course, other patients there who were going through something similar. And then you were able to see that things could always be WORSE, right? That's always a consolation or motivation somehow.” — P12*

Avoidance-oriented coping

Distancing is an attempt to draw attention away from being ill, to remove oneself from the “sick” role, and to separate from emotions related to cancer. This strategy is motivated by a desire for normalcy and wish to move beyond cancer.

Regarding medical rehabilitation, distancing includes avoidance of rehabilitation programs and of fellow patients. Distancing was reported in connection with a milder diagnosis by interviewees concerned about being burdened rather than supported by fellow patients. Thus, subjective good health facilitated this strategy.

Distancing also plays a pivotal role in occupational rehabilitation. Returning to work helps draw attention away from cancer and creates normalcy, especially if the job is positively connoted as a source of joy and self-worth. Distancing manifests as a work return during treatment, work return without progressive reintegration, and workplace avoidance of the issue of illness. Distancing is promoted if the BCS is externally perceived as recovered or healthy (e.g., new job colleagues are unaware of the cancer, workplace members do not discuss illness). This association is illustrated by P2 who returned to work during treatment and spoke about her colleagues' support:

> *"And because I then took on some OTHER tasks, the two colleagues I joined in the office turned out to be two young men, and men take things differently to women anyway, right? They don't talk about it [the illness] much at all, which made it EASIER for me because I didn't come to work to explain all sorts of details about chemotherapy; rather, when you're there, you're there and men deal with this more objectively. And they really made the beginning easy for me." — P2*

Distancing from the sick role at the workplace was reported to be associated with self-employment, having a leading position, and having financial obligations (e.g., paying off debt).

Denial refers to disclaiming physical impairments and symptoms and overestimating one's fitness and work ability to regain normalcy and move beyond cancer. Thus, it leads to refusal of organized medical or occupational rehabilitation programs and return to work with the same prediagnosis workload, resulting in physical and occupational overload. In retrospect, interviewees were able to reflect on denial, as noted by P3:

> *"So looking back, I think I wasn't yet 100% ready for work. I pretended I was, right? I have quite got my head around it, right? There were still things that needed to be done somehow. So it's hard to explain now, in retrospect. If you'd have asked me back then: 'Yes, I'm back again in top form,' right?" — P3*

This strategy was reported in connection with a milder diagnosis, external overestimation of health status, high job requirements, and starting a new job posttreatment, leading to perceived incompatibility with the sick role. External assessment by physicians or family may promote denial, as noted by P17:

> *"Of course, I'd also ask the doctor if it was okay [to go to the football match]. And then they said "Yes, if you feel OK, why shouldn't you go, right?" Yes. And then I went with the others. … and that then set everything off, of course. It was all too much, of course. But I didn't see it like that at all myself. So I didn't realize at all at myself, how sick I actually was. And how weak I actually am. …I didn't even notice that I was doing so much above and beyond the strength I had. And that was the reason why I didn't do any rehab either. Because I thought No, you're not that sick. Then, at the hospital, a doctor said "Yes, sometimes it's not good either, because there are a lot of people there who really are in a poor shape. And then you let yourself get dragged down even more, psychologically."… And I didn't realize that at all, that something actually could have been done." — P17*

Seeking alternative rewards is an attempt to direct one's attention away from the cancer and toward a source of positive feelings, such as joy and appreciation. Alternative rewards include vacation and positive activities such as enjoying culture and nature. This strategy helps recovery from disease and treatment. Interviewees who reported using this approach were those who refused inpatient rehabilitation and who had a milder diagnosis, resulting in subjective good health posttreatment. Seeking alternative rewards also comprises engagement in voluntary work, associated with reduced work capacity posttreatment. Voluntary work provides an opportunity to "give back" within the BCS's capacity and to make them feel useful and appreciated.

Discussion

This study investigated the coping processes of BCSs during rehabilitation and analyzed contextual factors. It was found that the interviewees used different coping strategies, classified as approach- or avoidance-oriented coping. The classification of coping strategies was based on the taxonomy by Roesch et al. developed for patients with prostate cancer. To the best of our knowledge, we only found one taxonomy in literature for categorizing coping strategies, specifically for patients with BC and BCSs [15]. Kvillemo et al. suggested a taxonomy that categorizes coping strategies at a higher level into engagement coping, comparable to approach coping, disengagement coping, comparable to avoidance coping, and miscellaneous coping strategies. Engagement coping is further divided into primary control coping, which includes strategies to change the stressor or related emotions, and secondary control coping, which pertains to strategies that facilitate adaptation to stress. Both taxonomies are very similar at a higher level; however, Roesch's model was preferred over Kvillemo et al.'s model for the categorization of coping strategies owing to its simplicity.

During medical rehabilitation, coping behavior mainly targets cancer management and its physical and emotional consequences, whereas coping strategies in occupational rehabilitation focus on overcoming discrepancies between job requirements and current work capacity, either by problem-focused coping with suppression of competing activities or avoidance such as denial.

The challenge for BCSs in balancing their disease and job demands posttreatment has also been described by Hiltrop et al. [32]. These authors found that BCSs perceive conflicts between cancer management and other life demands, including work. To cope with conflicting demands, BCSs tend to make sacrifices to the detriment of work [32]. These findings are consistent with our results regarding the coping strategy of suppression of competing activities.

Coping strategies encompass both dispositional and situational aspects, and dispositional tendencies can influence situational coping behavior [33, 34]. Thus, both aspects likely play a role in the coping processes investigated in this study. As we sought to understand how BCSs cope with consequences of the cancer during a specific phase of the cancer journey, we focused more on the situational aspects of coping. It is likely that coping strategies vary across the different phases of the cancer journey, each presenting unique challenges [35–37]. The results provide knowledge about a specific coping during the rehabilitation phase, which is characterized by the challenge for BCSs in processing the preceding phases (diagnosis, acute treatment) while simultaneously reintegrating into social roles and normalcy.

We also analyzed the contextual factors of coping in the health, healthcare, work-related, and personal domains. Regarding health-related factors, our results indicate that poor health and long-term adverse effects (e.g., fatigue) posttreatment promote approach-oriented coping. Contrarily, avoidance-oriented coping is associated with a milder diagnosis, resulting in subjective good health posttreatment. The results indicate that during rehabilitation, physical and mental impairments necessitate active and problem-focused coping; conversely, the absence of major health issues enables BCSs to distance from the sick role and promote avoidance-oriented coping. As avoidance can reduce chances for adequate rehabilitation, a long-term negative impact on the quality of life or work may be expected, as reported in previous studies in which avoidance- versus approach-oriented coping in cancer patients was associated with lower quality of life as well as worse physical and psychological health [10, 12, 14]. However, it should also be noted that in some cases, the decision to not participate in rehab or engage in other forms of active coping may be based on a realistic assessment of one's own state of health and performance and does not always represent an avoidance-oriented coping strategy.

In addition to the interviewees' self-perception regarding their health status posttreatment, external perceptions of others played a role in coping behavior. Avoidance-oriented coping was associated with relativizing medical opinion and being perceived as recovered or healthy by colleagues/employers. Thus, external assessment overestimating the health of BCSs may promote avoidance-oriented coping (e.g., an employer offering promotion during treatment) and may be the result of avoidance-oriented coping (e.g., a BCS's self-distancing from cancer).

Our findings indicate an association between coping style and participation in an oncological rehabilitation program. Interviewees who employed approach-oriented coping strategies were more likely to participate in a rehabilitation program. In addition, the context of a rehabilitation program enabled the use of certain approach-oriented coping strategies, such as comparing. Therefore, participating in oncological rehabilitation may represent active coping with physical and emotional consequences of the cancer and be a contextual factor that facilitates approach-oriented coping. Notably, BCSs in Germany who wish to apply for early retirement due to cancer must first undergo rehabilitation. Furthermore, in this case, participation in rehabilitation represents an active coping behavior to deal with the illness. Simultaneously, avoidance-oriented coping seems to be a barrier to rehabilitation program participation. This finding is consistent with the results of other studies [38, 39]. Deck et al. [40] analyzed the reasons for the nonuse of oncological rehabilitation of CSs, the most frequent being desire for normalcy, distance from the cancer, and avoiding fellow patients.

Healthcare deficits, such as existing information needs and perceived lack of medical support, were associated with approach-oriented coping strategies such as seeking information and instrumental support. Our findings indicate that approach-oriented coping may mitigate the impact of healthcare deficits, which is supported by Ahadzadeh and Sharif [41] who observed a moderating effect of approach-oriented coping on the negative association between information needs and quality of life in patients with BC.

Regarding work-related contextual factors, our findings suggest that support and understanding in the workplace promote problem-focused coping (e.g., seeking support from colleagues) to overcome discrepancies between job demands and work capacity. Thus, a supportive work atmosphere may be a facilitating factor in work return and contribute to successful occupational reintegration. Jin and Lee [42] supported this assumption as they found a positive effect of workplace social support on the quality of work life among CSs who returned to work. Hiltrop et al. [43] reported a positive association between the *social capital of the workplace*, which describes workplace-related aspects such as trust or common values [44], and BCSs' satisfaction with their occupational development 5–6 years after the diagnosis.

Other contextual factors associated with coping behavior are self-employment or a leading position in the workplace. Both facilitates suppression of competing activities to adapt work life to health-related needs, such as making time for rehabilitation sports during the work day or reducing work hours. This association may be explained by the possibility of scheduling working times more flexibly and autonomously. Simultaneously, avoidance-oriented coping such as distancing was reported in connection with self-employment or having a leading position. These findings are consistent with those of other studies that demonstrated an association between self-employment and the opportunity to flexibly work with an earlier return to work for CSs [45, 46]. In addition to flexible working hours, this association may be explained by financial necessity and a perceived responsibility for clients and employees, making it more necessary to distance from the sick role.

Regarding personal factors, our findings suggest an association between approach-oriented coping and social support. The presence of a supportive social environment may promote an active coping style (e.g., by motivating the BCS to participate in rehabilitation). At the same time, approach-oriented coping is employed to cope with a perceived lack of social support, such as seeking emotional support from fellow patients. Another contextual factor is financial status. Financial security, often associated with being married, allowed interviewees to suppress work activities in favor of health aspects, such as by reducing work time. Contrarily, financial obligations (e.g., debt) promoted avoidance-oriented coping strategies, such as distancing. Financial security may thus be a facilitating factor for rehabilitation, whereas financial obligations may be a barrier to the rehabilitation process.

Study limitations

Our study results provide a better understanding of the challenges, coping behaviors, and contextual factors of rehabilitation after BC. Several study limitations must be considered when interpreting these results. Because of the qualitative approach, the generalizability of the results is limited. This especially applies to the associations observed between the contextual factors and coping behavior of BCS. The study samples consisted of female BCSs who were employed before diagnosis and did not include male CSs or other tumors. Because all interviews were conducted in Germany and in the context of the specific German system of rehabilitation, the experiences of BCSs may differ from those in other healthcare systems. The interviews were conducted 5–6 years after diagnosis; thus, effects of recall bias are possible. However, the rehabilitation phase after cancer may be a salient life experience that reduces the memory effects.

Clinical implications

This study provides in-depth insights into the coping process of BCSs during rehabilitation. The results indicate that BCSs employ approach- and avoidance-oriented strategies to cope with their cancer during rehabilitation. As both strategies are helpful in the short term to cope with the physical and emotional consequences of the cancer, healthcare and psychosocial personnel should respect BCSs' coping strategies while also being aware of the potential long-term negative impact of avoidance-oriented coping on the rehabilitation process. Health and psychosocial personnel in inpatient and outpatient settings (e.g., cancer counseling centers) should speak openly to BCSs about their coping behavior and inform them about the possible long-term risks of avoidance-oriented coping. To support BCSs in coping with their illness more flexibly, information needs (e.g., regarding rehabilitation programs) should be reduced and fears (e.g., being burdened by fellow patients during rehabilitation) should be addressed. The findings regarding contextual factors for coping may help screen BCSs in inpatient and outpatient settings for disadvantageous circumstances (e.g., financial obligations, starting a new job posttreatment) and to support those engaged in a rehabilitation process. Furthermore, increasing employers' awareness of the challenges of returning to work after cancer may positively impact the occupational rehabilitation of BCSs. The literature shows that there is a lack of interventions aimed at sensitizing employers and coworkers to the needs of CSs and improving communication, thereby supporting the professional reintegration of CSs [47, 48].

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Author contributions

Nicole Ernstmann and Christoph Kowalski supervised the B-CARE study. Paula Heidkamp and Kati Hiltrop collected B-CARE data. Paula Heidkamp performed data analysis. Paula Heidkamp wrote the first draft of the manuscript. Kati Hiltrop, Clara Breidenbach, Nicole Ernstmann, Christoph Kowalski, Franziska Geiser, and Holger Pfaff discussed the results and commented on the manuscript.

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Data availability

The datasets generated and/or analyzed during the current study are not publicly available due to the patient consent form but are available from the corresponding author on reasonable request.

Declarations

Ethical approval

The University of Bonn Ethics Committee of the Medical Faculty approved this study (number: 316/18). All methods were carried out in accordance with relevant guidelines and regulations.

Consent to participate

Written informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable.

Competing interests

Clara Breidenbach and Christoph Kowalski are employees of the German Cancer Society (DKG). All other authors declare no conflicts of interest.

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Publisher's Note

4. Discussion with references

This study aimed to gain a better understanding of psychological adjustment over the course of BC survivorship by collecting psychological patient-reported data, thereby contributing to patient-centeredness in psycho-oncological care. The results of this dissertation suggest that BCSs can experience severe psychological burdens that persist for years after diagnosis: BCSs exhibited showed significant levels of FoR (publication 1) and anxiety and depression (publication 2) 5–6 years after diagnosis. As regards the average time course, the FoR level decreased during the first year after diagnosis and remained stable afterwards, whereas the depression and anxiety levels increased. However, the results also indicate the individuality of trajectories of psychological distress of BCSs, which need to be considered. As regards the examination of relevant input variables, associations of psychological distress in long-term BCSs were observed in sociodemographic, treatment, and health-related variables (publication 1 and 2). Publication 3 provided a deeper understanding of the coping behavior of BCSs and its contextual factors using the example of a specific phase in the course of CS, i.e., the rehabilitation phase. Overall, the results of this dissertation indicate the potential long-term effects of cancer and its treatment on mental health, suggesting that each phase of the survivorship experience is associated with specific challenges and adaptation requirements for the affected individuals. In light of the integrative model of patient-centeredness (Scholl et al. 2014), the results indicate the importance of discussing to what extent PCC regarding psychosocial needs is provided for CSs. A central focus of the integrative model of patient-centeredness lies in the clinician–patient relationship, which is closely associated with clinician–patient communication and clinicians adopting a biopsychosocial perspective. As regards to CSs, this relationship takes place in inpatient and outpatient setting starting from diagnosis to acute treatment, rehabilitation, follow-up care, and return to primary care. Clinicians in all areas of care should consider the psychosocial aspects of CS, approach them and give support options, instead of solely focusing on their specific field of expertise. The ongoing psychological distress highlighted in the results suggest that the psychosocial needs of BCSs are not sufficiently recognized by healthcare providers. This care gap has also been demonstrated in previous research findings, which suggest that one-third to one-half of CSs report insufficient levels of patient-centered communication, particularly regarding the clinicians' responses to emotions and helping manage uncertainty (Austin et al. 2019; Blanch-Hartigan et al. 2014; Blanch-Hartigan et al. 2016). This is particularly noteworthy as patient-centered communication has the potential to positively impact the emotional well-being of CSs, as reported in the study by Hong et al. (2021), where positive associations were observed between patient-provider discussions about emotional and social needs related to cancer, its treatment, or long-term effects, and positive mental health outcomes and benefit-finding experiences in CSs. In addition to addressing psychosocial needs as soon as they arise, CSs cite a primary concern of wanting healthcare providers to inform them of the chronic nature of cancer at an early stage, enabling them to better prepare for the physical and psychological consequences of the illness (Mead et al. 2020). Thus, the potential psychological impacts of cancer and its treatment should be considered and communicated by healthcare providers from the very beginning. The results of the dissertation indicate the need of continuing psychosocial long-term support options for CSs. This is consistent with the results of the study by Mead et al. (2020), which reported that one of the most important concerns of CSs is the need for continuous care that does not abruptly end after treatment but instead supports them on an ongoing basis with a biopsychosocial focus. Continuity of care is crucial to enable PCC (Scholl et al. 2014) and should thus be ensured to address the psycho-social needs of CSs. In Germany, continuity of psychosocial care for CSs, can be provided as part of basic psychosomatic care by general practitioners (GPs). From both the patient and the provider's perspectives, GPs play a pivotal role in addressing those needs (Deckx et al. 2021; Meiklejohn et al. 2016). Nonetheless, many GPs lack a systematic approach to addressing CSs' psychosocial needs (Deckx et al. 2021), and patients report barriers to survivorship care in primary care, such as a lack of effective communication between GPs and cancer specialists, a lack of an established or strong relationship with a GP, poor communication and coordination of care, and GPs' time constraints that hinder the provision of comprehensive survivorship care (Hayes et al. 2024; Meiklejohn et al. 2016). As CSs wish for more consistent and ongoing involvement from their GP (Meiklejohn et al. 2016), patient-centeredness should be expanded to ensure continuity of care over the course of CS.

4.1 Strengths and Limitations

The major strength of this study is use of mixed-methods approach that allows for a more comprehensive understanding of the experiences of BCSs. Within the quantitative data analysis, descriptive statistics and regression analyses were conducted, facilitating the description and comparison of depression, anxiety, and FoR between different time points as well as the exploration of associated factors. Furthermore, individual experiences were also emphasized within the quantitative original articles, detailing the individual trajectories of psychological outcomes. The qualitative data complement the quantitative results and contribute to a deeper understanding of the psychological adjustment of BCSs. The mixed-methods approach, the use of patient-reported outcome measures, and the focus on the individual experiences of BCSs support patient-centeredness, which represents a central characteristic of HSR (Pfaff and Schrappe 2011) and constitutes another strength of the dissertation. The study also has several limitations. First, all data were derived from the B-CARE study, which investigated the rehabilitation and return to work experiences of female BCSs who were employed at the time of their cancer diagnosis, thereby constraining the generalizability of the results in terms of cancer type, gender, and employment status. The B-CARE study is observational. Hence, the results can only establish associations, not causality. In addition, the rather small sample sizes should be considered when interpreting the results of regression analyses. The use of written surveys could have resulted in the exclusion of individuals who do not have sufficient reading, writing, or language skills, and it is possible that the sample is biased toward more motivated and healthier BCSs. The qualitative research approach aimed to investigate the subjective experiences of the BCSs; therefore, the generalizability of the qualitative results is not claimed.

4.2 Implications

Implications for research: In this dissertation, patient-reported psychological outcomes in BCSs were examined within a timeframe of 5–6 years post-diagnosis. More data regarding the psychological distress and psycho-oncological support needs of long-term CSs across all cancer entities and disease stages are warranted. This data collection could be part of future studies, and it could be considered to expand cancer registry documentation or introduce routine surveys of patient-reported outcomes over the long term by cancer centers. The latter could become a certification criterion, as is already the case for distress screening. Furthermore, more qualitative data should be collected to gain a deeper understanding of the complexity of phase specific challenges faced by CSs. Also, HSR should continue to develop, implement, and evaluate new care structures, such as survivorship programs with a biopsychosocial focus. At present, there are only a few such studies, such as the projects funded by the Innovation Fund, such as “Survivorship,” in which a consultation hour for long-term survivors of gynecological cancer is being implemented and evaluated at Charité Berlin (Innovationsausschuss beim Gemeinsamen Bundesausschuss 2024), and “CARE for CAYA,” a survivorship program for child, adolescent, or young adult cancer survivors conducted at 14 German sites (Salchow et al. 2020). Additionally, non-medical support interventions should be developed and implemented, as exemplified by the CARES study, which evaluates an intensified, need oriented counseling intervention on the return to work of CSs in outpatient psychosocial counseling centers (Hiltrop et al. 2023).

Practical implications: The clinician-patient relationship represents a key factor in PCC (Scholl et al. 2014) and is an essential component of health care for CSs, as demonstrated by the European Society for Medical Oncology (Stiefel et al. 2024). Therefore, raising awareness on the potential psychosocial consequences of cancer among healthcare providers who have contact with cancer patients and survivors at any time point of the CS experience is imperative. To open the conversation to sensitive psychosocial topics, an empathetic communication style is needed and healthcare providers should possess adequate communication skills, which should be continually enhanced. Suitable starting points would be more mandatory (interprofessional) communication training in medical school (Heier et al. 2024), during specialist training, and within the multidisciplinary teams in cancer centers (Karger et al. 2022). In addition, healthcare providers should actively address psychosocial support needs and not wait for CSs to raise these issues. Furthermore, communication between healthcare providers in different settings should be improved. Electronic patient records that can be accessed by all the involved healthcare providers as well as interprofessional exchange within the framework of quality circles could be helpful here. CSs should be continuously screened for psychological distress, even years after diagnosis, using existing screening instruments (e.g., distress thermometer). Particular attention should be given to vulnerable groups, such as BCSs who are single and have multiple comorbidities. CSs should be informed by healthcare providers about where they can turn to for psychological distress after completion of aftercare and low-threshold support options must be created. Conceivable options would include group therapy services, for example, at cancer centers, or encouraging the patient services of the Associations of Statutory Health Insurance Physicians to provide targeted referrals to psycho-oncologists when arranging psychotherapeutic consultations. Aside from the need for structured survivorship programs, as mentioned in the theoretical implications, resources for outpatient psycho-oncological care, for example, by resident psychological psychotherapists or cancer counselling centers, should be expanded.

4.3 References

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