Fear of cancer recurrence across the survivorship trajectory: Results from a survey of adult long-term cancer survivors

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Abstract
Objective: Our study analysed fear of cancer recurrence (FoR) in long-term cancer survivors in relation to medical variables, depression, anxiety, and quality of life.

Methods: We present data obtained from 1,002 cancer survivors (53% male, mean age=68 years, 26% prostate cancer, 22% breast cancer) across all cancer types 5 (N=660) and 10 (N=342) years after diagnosis, who were recruited via a large Clinical Cancer Registry in Germany in a cross-sectional study. FoR, depression, and anxiety were measured using validated self-report questionnaires (12-item short version of the Fear of Progression Questionnaire [FoP-Q-SF], Patient Health Questionnaire-9 [PHQ-9], and General Anxiety Disorder-7 [GAD-7]). Hierarchical regression models were carried out with FoR as dependent variable and time since diagnosis as control variable.

Results: We found high FoR-values in 17% of the cancer survivors (FoP-Q-SF total score>33). FoR was higher in the 5-year cohort (P=.028, d=0.153). Cancer survivors were most worried about the future of the family; they report being nervous prior to doctor’s appointment and being afraid of relying on strangers help. Higher FoR was related to female gender (Beta=.149, P=.001), younger age (Beta=-.103, P<.001), low social (Beta=-.129, P<.001) and emotional functioning (Beta=-.269, P<.001), received hormone therapy (P=.025, d=0.056), and high anxiety levels (Beta=.227, P<.001).

Conclusions: Even though FoR declines slightly over time, it is still a common mental health problem for long-term survivors even 10 years after cancer diagnosis. Since FoR is associated with reduced emotional and social quality of life, patients who are at greater risk of experiencing FoR must be identified and supported. Particularly at risk are younger women who received hormone therapy.

KEYWORDS
anxiety, cancer, depression, fear of cancer recurrence, oncology, quality of life, survivorship
Increasing proportions of patients diagnosed with cancer will become long-term survivors. After active treatment, cancer survivors are faced with prognostic uncertainty about survival, physical and psychosocial late and long-term symptoms, surveillance, and consequences of treatment such as infertility or cognitive impairments. One of the most commonly reported psychological problems experienced by cancer survivors is a fear of cancer recurrence (FoR). FoR has been defined as "fear, worry, or concern relating to the possibility that cancer will come back or progress" and thus refers to fears that arise from this life-threatening or disabling disease and its treatment. FoR represents a continuum between functional and dysfunctional anxiety that can affect all areas of life. FoR can be distinguished from anxiety disorders by its relation to the reality of the severity and threat of the cancer. Most FoR models emphasise the centrality of prognostic uncertainty associated with maladaptive cognitive, emotional, and behavioural responses that are based on fear, including elevated worry, avoidance behaviour, over-vigilance for symptoms of recurrence, and an inability to plan for the future. In extreme cases, FoR has been associated with the development of anxiety disorders, posttraumatic stress symptoms, and depression. FoR can persist for a long time after active treatment ends, and even 5 or more years after diagnosis, the majority of long-term cancer survivors worried about the disease progressing or recurring accompanied by limitations in the quality of life. In a systematic review of Simard et al including quantitative studies of FoR in adult cancer survivors across different cancer sites and assessment strategies, 22 to 87% of cancer survivors reported moderate to high degree of FoR (on average 49%). Results indicate that FoR is relatively stable over time. Also, the systematic review of Koch et al including studies with long-term and short-term survivors indicated no significant change of FoR over time. Factors associated with FoR in adult cancer survivors included younger age, female gender, living with a partner, and being employed. Several other associated factors are reported in the literature, such as psychological distress, lower quality of life, sleep disturbance, and poor concentration. Several studies also describe an influence of the received cancer treatment on FoR (chemotherapy, radiation therapy, and surgery).

In summary, it can be stated that FoR can last for many years, leads to quality of life limitations, and can result in the development of mental disorders. In addition, FoR is the most frequently reported unmet need among cancer survivors. Therefore, FoR is a relevant topic in cancer survivorship research. While in recent years, psychosocial research has more focused on the study of anxiety disorders according to psychiatric diagnostic systems, real fears of the recurrence or progression of the cancer disease received little attention. Also, previous research on FoR has mostly focused on breast cancer patients and on periods of survival of up to 2 years following diagnosis. There is a clear research gap in the extant literature on FoR and the most frequent concerns in long-term cancer survivors. The concept of FoR contributes to a clarification of the diagnosis of psychological distress in cancer patients and thus to an improvement of psychosocial cancer care. Therefore, identifying patients who are at greater risk of experiencing FoR may improve patient management and update interventions to reduce FoR.

In our study, we provide data about FoR from a large sample of adult long-term cancer survivors across all cancer types. We focus on periods of survival of up to 10 years following diagnosis. Furthermore, our study aimed to identify factors associated with FoR and to depict the relationships to psychological distress (anxiety and depression) and quality of life. Our research questions are as follows:

1. What is the prevalence of FoR in long-term cancer survivors?
2. Which areas of FoR are particularly relevant in long-term cancer survivors?
3. Is FoR in long-term cancer survivors associated with demographic and cancer treatment specific characteristics? What is the relationship to psychological distress (anxiety and depression) and quality of life?

2 | PATIENTS AND METHODS

2.1 | Study design

In this cross-sectional cohort study, we recruited patients via the Clinical Cancer Registry Leipzig, Germany, who were diagnosed with cancer 5 or 10 years previously. Because the term long-term survivorship is often used at a minimum of 5-year postcancer diagnosis in the literature, we chose the first cohort at 5 years after the primary cancer diagnosis and the second cohort at 10 years postprimary cancer diagnosis to capture late- and long-term conditions after the usual follow-up periods. Thus, we are able to show the long-term path of a cancer patient in a life stage and development perspective.

2.2 | Study participants

Patients were eligible for study participation if they had a confirmed diagnosis of cancer 5 years (cohort 1) or 10 years (cohort 2) previously according to the local cancer registry, were aged between 18 and 85 years at the time of diagnosis, and were able to speak and read German. All participants provided written, informed consent according to the Declaration of Helsinki. The study received research ethics committee approval by the University of Leipzig (Az. 070-14-10032014).

2.3 | Recruitment and data collection

Access to the patients was provided by the Cancer Registry at the Cancer Center Leipzig. The Clinical Cancer Registry provided data on sex, age, ICD-10 diagnosis, time of diagnosis, and cancer treatments received. Trained personnel in the Cancer Registry extracted patients who both gave general permission to be contacted for research
projects and fulfilled our inclusion criteria. Eligible patients received a study information letter and were asked to participate in the survey. A prepaid reply card was enclosed. Patients who consented to participate received a set of questionnaires by mail or were able to complete the questionnaires online using the Lime Survey software.

2.4 Study measures

2.4.1 Fear of cancer recurrence

We used the 12-item short version of the Fear of Progression Questionnaire (FoP-Q-SF).7

The FoP-Q is a validated, reliable instrument, developed by Herschbach et al to measure FoR in chronically ill persons.5 In a systematic review of Thewes et al on all current multi-item self-report questionnaires that assess FoR in cancer patients, the FoP-Q received the highest total quality rating of all instruments.23 The questionnaire has a high internal consistency (Cronbach’s alpha=0.87). The FoP-Q-SF items are scored on a 5-point Likert Scale ranging from 1 (“never”) to 5 (“very often”), higher values indicating higher levels of anxiety. High FCR was defined as FoP-Q-SF total score of 34 or higher.24

2.4.2 Depressive (Patient Health Questionnaire-9) and general anxiety disorder (General Anxiety Disorder-7) symptomatology

The Patient Health Questionnaire (PHQ)25 is validated in German and assesses psychiatric disorders according to the DSM-IV criteria. For our study, we used the modules for depressive (PHQ-9) and general anxiety disorder (General Anxiety Disorder-7 (GAD-7)) symptomatology. The frequency of respective symptoms within the last 2 weeks is rated on a 4-point Likert scale ranging from “not at all” to “almost every day.” For the PHQ-9, a sum score of 0-27 results, with values of ≥5, ≥10, and ≥15 indicating mild, moderate, or severe depressive symptoms. The sum score of the GAD-7 ranges from 0 to 21, with values of ≥5, ≥10, and ≥15 indicating mild, moderate, or severe anxiety symptoms.

2.4.3 Quality of life

To analyse in which way FoR is associated with quality of life, we used the five function scales of the German version of EORTC QLQ-C30, a widely validated measure for evaluating health-related quality of life in cancer patients.27 All scales have a score range between 0 and 100. High scores of the function scales indicate a high quality of life. In addition, we included the scale measuring “Global quality of life.”

2.5 Statistical methods

We carried out quantitative data analysis using the Statistical Package for the Social Sciences (SPSS 24; IBM, Armonk, NY). We calculated descriptive statistics for both continuous (frequencies, mean, and standard deviation) and categorical variables (frequencies and percentages). Comparisons between subgroups of cancer survivors or between participants and nonresponder were performed in a one-way analysis of variance (ANOVA). Results were used to calculate effect size r, which we further transformed to Cohen’s d.28 Linear correlations between two variables were examined with bivariate correlations (Pearson’s r).

To analyse on which variables FoR can regress on, the FoR-associated variables identified in ANOVA and Pearson Correlation were merged into symptom blocks:

- Block 1 and 2: control variables (time since diagnosis, sex, and age)
- Block 3: cancer treatment
- Block 4: quality of life dimensions
- Block 5: psychological distress

We performed a hierarchical regression model with FoP-Q sum-score as a dependent variable. Time since diagnosis, sex, and age were included as control variables in the first step for all analyses. We calculated stepwise regressions with backward elimination for P>.20. The hierarchical regression using the symptom blocks was carried out to gain a comprehensive and differentiated understanding of the contribution of each area (cancer treatment, quality of life, and psychological distress) to the explanation of FoR. Depression and anxiety were added to the model as the last block to see how the psychological distress is associated with FoR after controlling the other variables.

3 RESULTS

3.1 Sample

Patient recruitment was carried out from 2014 October to 2015 November. Out of 2082 eligible patients (5-year cohort=1396/10-year cohort=686), 1105 (response rate=53%) participated in the study. Among those, 1002 patients (5-year cohort=660/10-year cohort=342) returned a complete questionnaire and were included in the final analysis (postal participation: n=758/online participation: n=244). The patients who completed the questionnaires online were younger (M=62.1 years; P<.001), and the percentage of male patients was higher (60.2% male; P=.008) than in the group of patients who participated by mail (M=68.2 years; 50.5% male).

3.1.1 Nonresponder analysis

Study participants were more often male (53%) than nonresponder (47%) (P=.013). The two groups also differed in terms of cancer type (P=.001). Study participants were more likely to have prostate cancer (25.5% vs. 16.5%) and more rarely skin cancer (5.8% vs. 7.8%) and
colon cancer (4.7% vs. 6.0%) than the nonresponder. We found no significant age differences between both groups (nonresponder: M=65.8 years; \( P = .054 \)).

Table 1 shows social and medical characteristics for all participants separated for the two cohorts (5 and 10 years post diagnosis). In the 10-year cohort, survivors had a higher household income (\( P = .018 \)) and were more likely diagnosed with haematological cancer and less likely diagnosed with breast cancer (\( P < .001 \)).

### 3.2 Fear of cancer recurrence

We found high FoR-values in 17.1% of the long-term cancer survivors (FoP-Q-SF total score \( \geq \) 34). In the 5-year cohort, 19% of the survivors showed high FoR-values, while the 10-year cohort had 13.4%. The mean of the sum score for the total sample was 24.6 (SD=9.3, range=12-60). The mean score in the 5-year cohort was 1.4 points higher than in the 10-year cohort (M=25.1 vs. 23.7).

### TABLE 1 Sample characteristics for both cohorts 5 and 10 years after cancer diagnosis

|                        | Total Sample n (%) | 5-Year Postcancer Diagnosis Cohort n (%) | 10-Year Postcancer Diagnosis Cohort n (%) | \( P \) |
|------------------------|--------------------|----------------------------------------|------------------------------------------|-------|
| Age, M (SD)            |                    |                                        |                                          |       |
| 18-49 years            | 66.7 (10.5)        | 66.3 (10.5)                            | 67.6 (10.4)                              | .052  |
| 50-70 years            | 69 (6.9)           | 49 (7.4)                               | 20 (5.8)                                 |       |
| 71-85 years            | 468 (46.7)         | 325 (49.2)                             | 143 (41.8)                               |       |
| 71-85 years            | 465 (46.4)         | 286 (43.3)                             | 179 (52.3)                               |       |
| Sex                    | Male               | 530 (52.9)                             | 350 (53.0)                               | .947  |
| Marital situation      | Married            | 719 (72.0)                             | 469 (71.4)                               | .893  |
|                        | Single             | 64 (6.4)                               | 45 (6.8)                                 |       |
|                        | Divorced           | 110 (11.0)                             | 75 (11.4)                                |       |
|                        | Widowed            | 105 (10.5)                             | 68 (10.9)                                |       |
| Cohabiting             | Yes                | 777 (79.8)                             | 504 (78.9)                               | .356  |
| Education              | Elementary school (8-9 y) | 284 (28.4)                         | 185 (28.1)                               | .166  |
|                        | Junior high school (10 y) | 336 (33.6)                         | 235 (35.7)                               |       |
|                        | High school (13 y)  | 61 (6.1)                               | 44 (6.7)                                 |       |
|                        | University         | 314 (31.4)                             | 191 (29.0)                               |       |
|                        | Other              | 5 (0.5)                                | 4 (0.7)                                  |       |
| Employment status      | Employed           | 204 (20.4)                             | 136 (21.0)                               | .847  |
|                        | Retirement pension | 665 (67.7)                             | 436 (67.2)                               |       |
|                        | Disability pension | 92 (9.2)                               | 63 (9.7)                                 |       |
|                        | Unemployed/housewife/househusband | 20 (2.0)                   | 13 (2.0)                                 |       |
| Household income       | <1500€             | 285 (28.5)                             | 212 (32.1)                               | .018  |
|                        | 1500-2500€         | 444 (44.4)                             | 281 (42.6)                               |       |
|                        | >2500€             | 222 (22.2)                             | 133 (20.1)                               |       |
| Cancer diagnosis       | Prostate           | 255 (25.5)                             | 175 (26.5)                               | <.001 |
|                        | Breast             | 218 (21.8)                             | 156 (23.6)                               |       |
|                        | Gynaecological     | 95 (9.5)                               | 59 (8.9)                                 |       |
|                        | Head and neck      | 78 (7.8)                               | 53 (8.0)                                 |       |
|                        | Haematological     | 75 (7.5)                               | 38 (5.8)                                 |       |
|                        | Skin               | 58 (5.8)                               | 46 (7.0)                                 |       |
|                        | Kidney             | 50 (5.0)                               | 26 (3.9)                                 |       |
|                        | Colon              | 47 (4.7)                               | 26 (3.9)                                 |       |
|                        | Other              | 125 (12.5)                             | 81 (12.3)                                |       |
| Medical data\(a\)     | Cancer recurrence  | 106 (11.1)                             | 63 (10.1)                                | .193  |
|                        | Metastases         | 104 (10.9)                             | 75 (12.0)                                | .156  |
|                        | Second cancer disease | 192 (19.6)                        | 123 (19.1)                               | .611  |
| Received treatment     | Surgery            | 874 (91.9)                             | 583 (92.7)                               | .258  |
|                        | Chemotherapy       | 363 (49.1)                             | 241 (49.1)                               | .977  |
|                        | Radiotherapy       | 577 (68.9)                             | 382 (68.5)                               | .693  |
|                        | Hormone therapy    | 190 (28.4)                             | 137 (30.1)                               | .168  |
| Number of treatments   | 0-1                | 359 (36.1)                             | 237 (36.2)                               | .214  |
|                        | 2-3                | 529 (53.2)                             | 338 (51.6)                               |       |
|                        | \( \geq 4 \)       | 106 (10.7)                             | 80 (12.2)                                |       |

\(a\) Based on the self-reports of patients.
The result was significant, but the effect was very small \((P=.028; d=0.153; \text{Table 2})\).

The single-item analysis (Figure 1) showed that the most frequent fears included being nervous prior to doctor's appointment or examinations, worrying about the family and being afraid of relying on strangers for activities of daily living. These patterns, however, did differ between age cohorts. Patients aged 18–49 years showed significant higher levels of work-related concerns \((P<.001)\) as well as fear of disease progression \((P<.001)\) and higher fear prior to doctor's examinations \((P<.001)\). In addition, they significantly more often reported having physical sensations, eg, rapid heartbeat \((P<.001)\).

3.3 Factors associated with FoR

In bivariate analyses, FoR was higher in survivors who were female, younger, and who received radiation, chemotherapy, or hormone therapy \((\text{Table 2})\). High FoR was reported by 26% of the female survivors and 10% of the males. FoR also differed between cancer diagnoses. In breast cancer survivors and gynaecological cancer survivors, 27% and 22% showed high FoR, respectively, in contrast to only 5% of prostate cancer survivors. If gender was included in the comparison of FoR by cancer type, the differences were less relevant. There were no significant differences in female survivors \((P=.566)\), and the differences in male survivors were few significant; patients with prostate cancer had lower FoR than men with other cancer diagnoses \((P=.023)\).

There were significant negative correlations between FoR and all quality of life functions scales and global quality of life \((r=-0.418 \text{ to } -0.639, P<.001)\). Moderate positive correlations were found between FoR and depression \((r=0.492, P<.001)\) as well as anxiety \((r=0.531, P<.001)\).

3.3.1 Hierarchical regression model

We performed a hierarchical regression model with FoR (FoP-Q sum-score) as a dependent variable \((\text{Table 3})\). The following associated factors for higher FoR were identified: female gender, younger age, hormone therapy in the past, low social, emotional and cognitive function, and anxiety. The highest variance explanation was found between the third and fourth model \((\text{adjusted } r^2: \text{third model}=0.143/\text{fourth model}=0.498)\). That is, social and emotional quality of life dimensions had the strongest relationship with FoR.

![FIGURE 1](image) Single-items of the Fear of Progression Questionnaire \((1=\text{never to } 5=\text{very often})\) for different age cohorts in long-term cancer survivors
### TABLE 2  Fear of cancer recurrence in long-term cancer survivors in relation to demographic and cancer specific variables

|                      | High FoR % | FoP-Q Sum Score M (SD) | Significance | Effect Size Cohen’s d |
|----------------------|------------|------------------------|--------------|----------------------|
| **Time since diagnosis** |            |                        |              |                      |
| 5 y                  | 19.0       | 25.1 (9.6)             | .028         | 0.153                |
| 10 y                 | 13.4       | 23.7 (8.7)             |              |                      |
| **Sex**              |            |                        |              |                      |
| Male                 | 9.5        | 22.1 (8.4)             | <.001        | 0.593                |
| Female               | 25.7       | 27.4 (9.5)             |              |                      |
| **Age cohorts**      |            |                        |              |                      |
| 18-49 y              | 34.3       | 28.8 (10.1)            | <.001        | 0.368                |
| 50-70 y              | 21.0       | 25.9 (10.1)            |              |                      |
| 71-85 y              | 10.3       | 22.5 (7.8)             |              |                      |
| **Cancer diagnosis** |            |                        |              |                      |
| Breast               | 26.9       | 27.9 (9.5)             | <.001        | 0.785                |
| Gynaecological       | 22.2       | 26.4 (9.6)             |              |                      |
| Kidney               | 14.9       | 25.2 (9.0)             |              |                      |
| Haematological       | 14.1       | 25.1 (8.6)             |              |                      |
| Colon                | 14.0       | 24.6 (8.4)             |              |                      |
| Skin                 | 16.7       | 23.7 (10.1)            |              |                      |
| Head and neck        | 14.1       | 23.6 (10.2)            |              |                      |
| Prostate             | 4.9        | 20.6 (7.0)             |              |                      |
| **Radiation**        |            |                        |              |                      |
| Yes                  | 20.3       | 25.6 (9.4)             | <.001        | 0.237                |
| No                   | 12.3       | 23.1 (8.8)             |              |                      |
| **Chemotherapy**     |            |                        |              |                      |
| Yes                  | 25.5       | 27.2 (9.8)             | <.001        | 0.424                |
| No                   | 12.3       | 23.1 (8.7)             |              |                      |
| **Hormone therapy**  |            |                        |              |                      |
| Yes                  | 25.8       | 27.3 (9.4)             | <.001        | 0.362                |
| No                   | 14.8       | 23.9 (9.1)             |              |                      |

Note. High FoR: FoP-Q-SF total score ≥ 34.

Abbreviation: FoR: fear of cancer recurrence.

### TABLE 3  Fear of cancer recurrence - associated factors: Hierarchic regression model

| Dependent Variable: FoP-Q sum-score | Model 1 Beta (P) | Model 2 Beta (P) | Model 3 Beta (P) | Model 4 Beta (P) | Model 5 Beta (P) |
|-------------------------------------|------------------|------------------|------------------|------------------|------------------|
| Time since diagnosis                | -.078 (.019)*    | -.062 (.048)*    | -.056 (.072)     | -.040 (.099)     | -.037 (.116)     |
| Sex                                 | .257 (.001)***   | .224 (.001)***   | .148 (.001)***   | .149 (.001)***   | .103 (.001)***   |
| Age                                 | -.198 (.001)***  | -.180 (.001)***  | -.114 (.001)***  | -.103 (.001)***  | -.093 (.001)***  |
| Surgery                             | -.022 (.478)     | .002 (.946)      | .002 (.921)      |                 |                 |
| Radiation                           | .010 (.785)      | -.036 (.194)     | -.030 (.260)     |                 |                 |
| Chemotherapy                        | .115 (.001)***   | .033 (.202)      | .029 (.258)      |                 |                 |
| Hormone therapy                     | .095 (.004)***   | .050 (.046)*     | .056 (.025)*     |                 |                 |
| Global quality of life              | -.061 (.085)     | -.065 (.061)     |                 |                 |                 |
| Social functioning                  | -.141 (.001)***  | -.129 (.001)***  |                 |                 |                 |
| Physical functioning                | -.052 (.178)     | -.070 (.067)     |                 |                 |                 |
| Emotional functioning               | -.362 (.001)***  | -.269 (.001)***  |                 |                 |                 |
| Cognitive functioning               | -.091 (.002)**   | -.079 (.009)**   |                 |                 |                 |
| Role functioning                    | -.055 (.180)     | -.055 (.167)     |                 |                 |                 |
| Depression                          | -.074 (.096)     |                 |                 |                 |                 |
| Anxiety                             | .227 (.001)***   |                 |                 |                 |                 |

Adjusted $r^2$: .005 .122 .143 .498 .516

$p =$significance.

*P<.05.

**P<.01.

***P<.001.
4 | CONCLUSIONS

The study presents data on FoR obtained from 1002 cancer survivors across all cancer types. The results demonstrate that FoR is a common response to a cancer diagnosis and the associated treatments; 17% of the long-term cancer survivors reported high FoR. We found a small but significant difference in FoR between the 5- and 10-year cohorts, with the former reporting higher levels of FoR. Research findings on the relationship between FoR and time since diagnosis have been rather inconsistent. Most studies reported no association between time since diagnosis and severity of self-reported FoR.\textsuperscript{1-11} In line with our research findings, however, Mehnert et al found a decrease in FoR within 1 year after cancer rehabilitation.\textsuperscript{79} In view of the ambiguity between research findings regarding FoR and time since diagnosis, irrespective of cancer type, Lee-Jones et al argued that FoR may be driven more by patients’ personal perception of the risk of recurrence, influenced, ie, by treatment type and cancer stage, rather than objective measures of remission.\textsuperscript{30} The theoretical model based on Leventhal’s Self-Regulation Model of Illness\textsuperscript{31} has been supported by Rabin et al showing that FoR in breast cancer patients was significantly influenced by the patients’ perceived timeline of cancer.\textsuperscript{32} For instance, patients who believed their disease to be chronic showed higher levels of FoR irrespective of the objective time course of their disease. Consistent with this theoretical framework and previous research results, which found a significant relationship between treatment type and greater FoR among breast cancer survivors,\textsuperscript{13,19} we found significantly higher FoR in patients who had received hormone therapy. Adding to these results, past research found the relationship between treatment type and FoR to be influenced by treatment satisfaction\textsuperscript{33} and symptom control.\textsuperscript{19}

Confirming previous research, we found significant positive associations between FoR and depression and anxiety (whereby the correlation with depression was significant only in the bivariate analyses), FoR has consistently been identified in the literature as being associated with anxiety and depression, although the study designs used did not allow for causality statements and the direction of this relationship.\textsuperscript{16,18} Other studies also identified an association between FoR and intrusive thoughts or increased prevalence of PTSD.\textsuperscript{11} That is why FoR is not simply an emotional factor (eg, anxiety); it is a multidimensional construct. According to Leventhal’s Self Regulation Model\textsuperscript{21} and Lee-Jones’s initial FoR formulation,\textsuperscript{30} the patient’s emotional reaction (eg, fear) can be the result of interpretations and cognitions of the threat of cancer.

In line with previous findings which reported FoR to be prevalent around cancer follow-up examinations,\textsuperscript{34} the highest concern identified in our study was the fear prior to doctor’s examinations. Routine examinations may remind the patient of the disease and increase the fear of getting sick again or receiving bad news. As a result, patients may avoid follow-up appointments,\textsuperscript{35} negatively interfering with the possible health benefits resulting from regular medical supervision. Worrying about the future of their family was another frequent concern of patients 5 and 10 years after diagnosis. Similar results have been found across different types of cancer.\textsuperscript{36-38} Only a few studies have focused on the specific concerns experienced by patients. Those studies found patients to be concerned about the sadness and worries induced in family members,\textsuperscript{26} family disruption,\textsuperscript{39} and the economic burden placed on their spouses or children who need to take care of their loved ones.\textsuperscript{37,39}

Large proportions of patients in our sample are ≥65 years and may have already retired. Thus, work-related concerns are likely to appear less prominent in our sample considering all age groups. However, those patients of working age (ie, 18–49 years) showed significant higher levels of work-related concerns compared with the older age cohorts including fear of being less productive at work or fear of not being able to work anymore.

The most consistent predictor of high FoR in previous studies was younger age,\textsuperscript{1,11} which was confirmed by our study results. We also found higher FoR in women compared with men. In the literature, most studies suggested that women experienced higher FoR than men, but there are also studies, mainly in specific cancer sites, that found no relationship.\textsuperscript{1,11} Simard et al\textsuperscript{40} reported that gender association with FoR disappeared when cancer type was controlled for.

4.1 | Study limitations

The present study has several strengths. The large dataset was accessed via a cancer registry, which ensured validated diagnostic information as well as excellent representation of the diagnoses of cancer patients in Germany. Furthermore, a wide range of patients was included regarding age (18 to 85 years) and time since diagnosis, with patients up to 10 years after diagnosis. However, there are also limitations. FoR is a construct that is subjected to strong fluctuations over time. For this reason, a longitudinal survey would provide even more accurate observation.\textsuperscript{30} Furthermore, due to the cross-sectional design of this study, it is not possible to show the causal relationships between FoR and the examined factors.

4.2 | Clinical implications

Even though FoR declines slightly over time, it is still a common mental health problem for long-term survivors even 10 years after cancer diagnosis. However, the use of different FoR measurement tools and limited available interventions have hindered the transfer of knowl-
edge into patient care. Since FoR is associated with reduced emotional and social quality of life, patients who are at greater risk of experiencing FoR must be identified and supported. Particularly at risk are younger women who received hormone therapy. Further research is necessary to examine influencing factors of FoR among cancer survivors in the long-term course.

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COMPLIANCE WITH ETHICAL STANDARDS

All procedures performed were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Prior to participation, all patients provided written informed consent. The study received research ethics committee approval by the University of Leipzig (Az. 070-14-10032014).

CONFLICT OF INTEREST STATEMENT

The funding source was not involved in any stage of the research process. The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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