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Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors

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Abstract

Objective: Psychosocial comorbidity and quality of life (QOL) and its association with knowledge, utilization, and need for psychosocial support have been studied in long-term breast cancer survivors. **Methods:** One thousand eighty-three patients were recruited through a population-based cancer registry an average of 47 months following diagnosis (66% response rate). Self-report measures (e.g., Hospital Anxiety and Depression Scale, Posttraumatic Stress Disorder Checklist—Civilian Version, and Short-Form Health Survey) were used. **Results:** Thirty-eight percent of patients had moderate to high anxiety, and 22% had moderate to high depression; posttraumatic stress disorder was observed in 12%. The overall psychological comorbidity was 43% and 26% for a possible and probable psychiatric disorder. Disease progress, detrimental interactions, less social support, a lower educational level, and younger age were predictors of psychological comorbidity (P<.004). Lower QOL (P<.01) and higher levels of anxiety (P<.001) were observed in cancer survivors compared to age-adjusted normative comparison groups. Time since diagnosis had no significant impact on psychological comorbidity as well as QOL. Forty-six percent of women felt insufficiently informed about support offers. Insufficient knowledge was associated with older age and lower education (P<.05). Since diagnosis, 57% had participated in cancer rehabilitation and 24% in other psychosocial support programs. Fifteen percent of all patients and 23% of those with a possible psychiatric disorder expressed their need for psychosocial support. Women with distress and perceived support needs who did not participate in past support programs were older, less educated, and less informed (P<.05). **Conclusion:** Findings show the long-term impact of breast cancer and indicate need for patient education, screening for psychosocial distress, and implementation of psychological interventions tailored in particular for older women.

Keywords: Anxiety; Depression; Long-term breast cancer survivors; Psychosocial distress; Psychosocial support; PTSD; Quality of life

Introduction

Breast cancer is the most common cancer among women in Germany as well as in developed countries with an estimated annual incidence of 1,152,161 new cases worldwide [1,2]. The increase of breast cancer incidence with age and the improvement in survival rates through use of enhanced treatment regimes within recent years lead to a growing number of older patients and long-term survivors [2,3]. The consequences that evoke from this development do not merely include only physical health components such as a variety of late side effects during follow-up care [4], but also a wide range of potentially persistent psychosocial problems and needs [5,6].

Over the past decades, a considerable amount of research has shown the significant emotional and social impact of breast cancer and its treatment on patients and their families [6]. Previous studies using self-report screening measures have reported distress, anxiety, and depression in, on average, one quarter to one third of breast cancer patients with levels up to 50% following diagnosis and treatment [6–12]. While

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high levels of psychosocial distress have been found within the first year postdiagnosis, there is evidence for an improvement in distress, psychosocial well being, and quality of life (QOL) in long-term survivors [13–15], even though few research has shown no improvement or even a decline in physical and/or mental health (MH), specifically in older women [6,11,16,17]. Risk factors for psychosocial distress and lower levels of QOL include fewer personal resources and maladaptive coping strategies, poorly controlled physical symptoms, lack of social support, psychiatric medical history, poor doctor–patient communication, lower educational level, as well as younger or intermediate age [6,18,19]. However, although younger women seem to have higher levels of psychosocial distress and report more unmet needs [20], they were also found to be more aware of psychosocial interventions and more likely to participate in support offers than older women [21].

Research has shown that older women [22–24] and those with lower socioeconomic status [25] are less likely to receive standard treatment and information about breast cancer care. Whether this might also be the case for psychosocial care has not been widely investigated so far. A study in breast cancer patients aged from 55 to 97 years [26] found that older women do highly value the information about breast cancer care provided by their breast cancer physician. However, while younger women did also receive more written information from other sources such as primary care physicians, family, and friends, specifically, women aged 57 years or older were found to get less written information from other sources. Furthermore, women who rated their ability to communicate with their physicians less highly were found to have lower levels of emotional health, suggesting that, in particular, patients with substantial need for support are less likely to actively seek help. However, although this study focused on oncological care information, it can be assumed that information about psychosocial care and support might also be less given to older women.

Knowledge about psychosocial support offers is an important requirement for their use. Eakin and Strycker [27] led a study in 2001 on the knowledge about and participation in psychosocial support offers among patients with breast, colon, and prostate cancer. The findings indicated that only a percentage of patients were informed of existing support offers, and that knowledge of these offers was not consequently accompanied by participation in them. The authors were able to show that, in addition to a higher degree of education, a referral by the physician played an important role for the utilization of psychosocial support offers.

While many psychosocial and QOL studies have been conducted with breast cancer patients, few studies have concentrated specifically on the association between psychological comorbidity and the awareness and utilization of psychosocial support offers in long-term survivors. Hodgkinson et al. [28] found a high percentage (86%) of reported unmet needs in breast cancer survivors and a significantly higher percentage in those patients with high levels of anxiety or depression. However, research including older women has been relatively rare so far.

The purpose of this cross-sectional cancer registry-based study is to provide information about the prevalence of anxiety, depression, and posttraumatic stress disorder (PTSD), as well as about health-related QOL in long-term breast cancer survivors. Group comparisons with population-based normative values for anxiety, depression, and QOL have been undertaken. We furthermore investigate perceived knowledge, utilization, and subjective need for psychosocial support. The study examines predictors of psychological comorbidity as well as predictors of psychosocial support needs, taking into account specifically the time since breast cancer diagnosis, age, and educational level. We hypothesize that psychological comorbidity and awareness of and need for psychosocial support are significantly associated with age, educational level, time since diagnosis, and disease stage.

Patients and methods

Study design and participants

Patients older than 18 years with a clinical diagnosis of breast cancer confirmed between 6.5 years and 18 months prior to our survey were recruited through the population-based Cancer Registry of the Federal German state of Hamburg. The period of 18 months postdiagnosis was the earliest feasible time due to the cancer registration procedure. The Hamburg Cancer Registry has a case completeness for breast cancer higher than 95% [29]; however, registration and participation in research projects are voluntary for patients. The protocol received local research ethics committee approval. Written informed consent was obtained from all patients.

For each year postdiagnosis (18–24 months, up to 36, 48, 60, and more than 60 months to less than 78 months), the data sets of 400 women were randomly selected by the cancer registry. The upper time limit of 78 months postdiagnosis was determined by the cancer registry due to the fact that several studies in breast cancer patients using self-report measures were conducted at the same time as our research. The limit was defined to avoid possible distress in patients caused through repeated requests for study participation. The data sets contained name, address by date of registration, age, month and year of cancer diagnosis of each patient, as well as complete TNM status and histopathological grading for the majority of patients (77.1%). A set of self-report questionnaires, consent forms, and a self-addressed stamped envelope were mailed to a total of 2000 patients. A reminder letter was sent after 4 weeks. Among these women, 321 (16.1%) had moved to an unknown address and did not receive our set of questionnaires, 39 (2.0%) had recently died, and 7 (0.4%) were not able to participate due to severe cognitive or physical problems