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## **Long-term quality of life after breast cancer**

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Breast cancer is the most common cancer among women. Worldwide, approximately 1.4 million women are diagnosed with breast cancer each year. Due to advances in early detection, treatment, and follow-up care, most of these women will become long-term survivors (> 5 years post diagnosis). As more and more women are surviving breast cancer, quality of life (QoL) has become a major focus in research and clinical practice. Nevertheless, studies on long-term survivors - specifically population-based and longitudinal studies - are very scarce. Given the increasing number of long-term breast cancer survivors and the necessity of valid, generalizable results to tailor care to the specific needs of this growing population, this dissertation aimed to explore in detail QoL of long-term breast cancer survivors. Due to its high prevalence among and significance for long-term breast cancer survivors, fear of recurrence (FoR) was focused on in detail.

To investigate QoL among long-term breast cancer survivors, cross-sectional, as well as longitudinal analyses were performed. Analyses were based on two different population-based empirical studies (VERDI and CAESAR), as well as reference data of the German general population. The VERDI-study was conducted in Saarland, with longitudinal QoL assessments at one, three, five, and ten years post-diagnosis. The multi-regional CAESAR-study was based on several cohorts of long-term breast cancer survivors, recruited by the six participating German cancer registries.

For the cross-sectional analysis of QoL, data of participants of the CAESAR study (N=2671) and the 10-year follow-up of the VERDI-study (N=182) were utilized. In addition, QoL of survivors was compared to QoL of women of the German general population (N=968). Results showed that even though global QoL of survivors was comparable to global QoL of the general population, survivors did experience statistically significant, clinically meaningful restrictions in several QoL dimensions, such as social functioning, fatigue, insomnia, or financial difficulties. Generally, younger women were affected most by the restrictions. Number of concurrent diseases, age, as well as considering oneself as a tumor patient were

identified as the strongest potential determinants of QoL, with younger women, reporting more concurrent diseases, and considering themselves as tumor patients experiencing lower QoL than older women, suffering from fewer diseases, and not considering themselves as tumor patients. Potential differential effects of sociodemographic factors by status (survivor vs. reference) were also examined. Different magnitudes of an effect in the same direction as well as completely opposite effects of variables on QoL were found, with age and employment exhibiting the strongest interactions. For example, the effect of age on cognitive functioning, social functioning or financial difficulties was found to be opposite for references and survivors. Younger women of the German general population generally reported higher cognitive and social functioning and less financial problems as compared to women aged 75 and older, whereas younger survivors experienced poorer cognitive and social functioning and were reporting a higher financial burden than survivors aged 75 and older.

Longitudinal development of QoL over ten years was examined in 160 participants who responded in all follow-up rounds of the VERDI-study and compared to the time course of QoL in references (N=968). Even though for both, survivors and references, a decline in functioning and QoL as well as an increase in symptoms was observed over time, the magnitude of the changes differed. In general, breast cancer survivors reported a greater decline in functioning and a bigger increase in symptoms over the follow-up period. Also, over the entire time span, survivors scored worse on functioning and symptom severity than references, with some restrictions strengthening from year one to year ten.

To examine FoR in long-term breast cancer survivors, a systematic review was carried out, followed by an analyses of data of participants of the CAESAR-study (N=2671). Eight studies were included in the review. Results of the studies indicated that breast cancer survivors still experienced FoR five and more years post-diagnosis. Age and education were consistently found to be negatively associated with FoR. Results of the CAESAR study supported previous findings. Long-term breast cancer survivors were found to experience FoR, with substantial proportions of 10% and 6% of the women reporting moderate or high FoR, respectively. Among potential determinants of FoR, age and considering oneself as a tumor patient were found to exhibit the strongest associations with FoR, with younger women still considering themselves as tumor patients experiencing higher levels of FoR than older women, not feeling like tumor patients. Moreover, FoR was found to be negatively associated with QoL, as well as positively related to depression.

In conclusion, even though experiencing good global QoL, long-term breast cancer survivors reported long-lasting restrictions in specific dimensions of QoL, including FoR. Of the potential determinants, psychosocial and sociodemographic factors were found to be far more important in QoL and FoR than medical factors. Generally, younger survivors tended to be impacted most by detriments, pointing out the necessity to be particularly attentive to needs of younger survivors, while also being aware of the differential effects age might have on survivors as compared to women of the general population. As the number of long-term breast cancer survivors is expected to increase, more research and the transfer of relevant results into medical and psychosocial care is needed to guarantee the highest possible well-being and QoL for this population.