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Institutionen för Neurobiologi, Vårdvetenskap och Samhälle

QUALITY OF LIFE IN FAMILY CAREGIVERS TO PERSONS WITH BREAST CANCER IN IRAN- METHODOLOGICAL AND CLINICAL ASPECTS

AKADEMISK AVHANDLING

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ABSTRACT

Background: In Iran, cancer is the third cause of death and breast cancer is the most common cancer among women. Nursing care should focus on the entire family (and not only the patient) as one unit of care. The overall aim of this thesis was to investigate quality of life (QoL) and coping capacity of caregivers of family members with breast cancer in Iran.

Method: This thesis is based on four studies, two methodological studies and two longitudinal studies that included six standardized instruments. Study I & II focused on translation into the Persian language and tested the psychometric properties of the Health Index (HI), Sense of Coherence (SOC) scale, Brief Religious Coping (RCOPE) scale, Spirituality Perspective Scale (SPS) in a healthy sample (n=333) and Caregiver Quality of Life Index-Cancer (CQOLC) scale in a sample of family caregivers (n=150). In Study III the five questionnaires (CQOLC, SOC, SPS, RCOPE, and HI) were assessed in the sample of family caregivers at the time of diagnosis (T1) and 6 months later (T2). In study IV consequences that were due to the breast cancer experience were investigated through semi-structured interviews at T1 and T2 using the Swedish version of the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting.

Results: The reliability of the instruments as measured by Cronbach's alpha values and intra-class correlations was highly satisfying. In addition, the majority of the hypotheses posed for validity were confirmed. A confirmatory factor analysis of the CQOLC showed a similar four-factor structure to that of the original CQOLC instrument, although with somewhat different item loadings. Hierarchical multiple regression analysis confirmed validity in that SOC was the strongest predictor of well-being and QoL in both samples. Other predictors contributing to the variance were negative religious coping, education, and severity of breast cancer. Family caregivers rated statistically significantly lesser mental burden and lifestyle disruptiveness between T1 and T2. During the same period, positive adaptation, sense of coherence, spirituality, coping were rated statistically significantly worse. None of these changes was of clinical relevance as estimated by effect size except negative religious coping. Over 50% of the family caregivers had a stable overall QoL, 15% decreased in QoL, and 34% increased their overall QoL. The multiple regression analyses of the ratings of QoL at T1 showed that negative religious coping, SOC, and severity of breast cancer explain 64% of the variance of change in overall QoL. The most frequent categories important for the QoL of family caregivers both at T1 and T2 were health in general, relationships, financial status, education, and religion. Psychological impact of disease, concerns about disease, religion, and financial situation were the most frequent categories nominated as influencing life in relation to having a family member with breast cancer. Further, positive aspects in the form of a new view of life and positive effects of relationships were mentioned.

Conclusion: Being a caregiver to a family member with breast cancer affected the life of the caregiver at both T1 and T2. Our findings indicate that some family caregivers have more difficulties than other family caregivers with adjusting to the situation, which may lead to lower QoL. Standardized instruments sometimes fail to capture all areas of importance in the life of caregivers to family members with breast cancer. This thesis calls attention to the need for nursing care to assist and support family caregivers of family members with breast cancer. This support should occur early in the disease process.

Key words: quality of life, family caregivers, breast cancer, sense of coherence, spirituality, religious coping