



A Review of “Family Caregivers of Women With Breast Cancer in Iran Report High Psychological Impact Six Months After Diagnosis”

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The Foreign Exchange column launches a new approach to expanding the global understanding of oncology nursing challenges and concerns. Each issue will include a review of an article that appeared in the most recent issue of the *European Journal of Oncology Nursing* that is relevant to a shared, unique, or conflicting oncology issue or practice in the United States. This column reviews an article about the shared dilemma of distress caused by caregiver burden in the ever complex and shifting setting of care delivery.

Family Caregivers of Women With Breast Cancer in Iran

An article by Khanjari, Langius-Eklöf, Oskouie, and Sundberg (2014) reported on a study of family caregivers of women with breast cancer in Iran. The purpose of the study was to explore how family caregivers describe the areas of life that are important to their quality of life (QOL) and are influenced by having a family member with breast cancer. This article was chosen because of the methodology used to capture caregiver individual responses; the well-described influence of Iranian cultural, societal, and spiritual norms on cancer care; and the parallels to the American experience.

According to the authors, breast cancer is the most common cancer in women in Iran. Like in Western countries, earlier diagnosis has led to a decline in mortality, but an increase has occurred in women diagnosed with breast cancer from ages 40–49 years. No national screening program exists, so mammography is less accessible to women with lower incomes. In keeping with other Western trends, a shift has occurred from institutional to home care, creating more demand on the entire family. Societal changes described in the article include a drift in family structure from traditional extended to nuclear

families and an increase in the age at marriage, the age of parents at birth of the first child, and the overall numbers of unmarried men and women. Women have higher levels of education and employment rates and more often contribute to family income than previously. These changes in trends in society and family life are thought to negatively influence the situation of a family caregiver.

Methods and Instruments

This longitudinal study was descriptive and prospective at two time points (i.e., 2–3 weeks and six months after a family member's breast cancer diagnosis). A previous study of the same population in Iran using a standardized QOL instrument, the Caregiver Quality of Life Index–Cancer, showed that half of family caregivers had stable QOL at six months, with some showing improvement and smaller numbers showing decreases in QOL. These findings conflicted with other Western studies that reported negative impact on QOL over time.

To further validate the experience of family caregivers in Iran, researchers chose a different instrument, the Schedule for the Evaluation of Individual Quality of Life–Direct Weighting, an interview method that allows for a caregiver to describe individual components of his or her QOL. The study results using this instrument showed that Iranian family caregivers experienced high psychological impact on QOL at the time of diagnosis and six months later. The area of psychological impact included feelings of shock and stress; feeling sad and depressed; and having fear, anxiety, and disturbed sleep, which were all well described in other caregiver studies. The study also reported other significant aspects of caregiver concern, including focus on family health, concerns about the disease, and change in family relationships.

The authors described several category findings that were particularly attributed to life in Iran. The area called “usefulness and commitment,” which is defined as being useful in society, showing respect, kindness, serving others, and being committed, had not been previously described by this instrument and was thought to include aspects natural to Iranian culture. Increased economic pressure and decreased family welfare related to the disease were other concerns identified and thought, in part, to relate to a lack of a fully financed healthcare system in Iran, a dilemma for women with lower incomes. The area named “view of life and religion” was ascribed solely of a positive nature; changed values, more empathy for others, greater optimism, and using one's capacity to deal with problems were all reported, despite an increase in family tension. Religious aspects, such as feeling a stronger connection to God and feeling hope and optimism, were expressed as enhanced. The positive effect on caregivers was not surprising to investigators because commitment to family, religion, and spirituality is a source of problem solving and part of daily life in Iran.

Reliance on Family Caregivers

As healthcare delivery in the United States has shifted away from the hospital to the homecare setting, reliance on unpaid family caregivers has grown exponentially. Cancer care and its complexities causes undue burden on patients and their families. The National Alliance for Caregiving and AARP (2009) estimated that more than 4.6 million Americans care for someone with cancer at home. Nurses routinely plan care that asks patients and

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their untrained caregivers to perform sophisticated, technical procedures and assessments to ease hospital lengths of stay measured in hours. Nurses also see firsthand the consequences of depression and anxiety with shifts in roles and relationships, impact on family welfare and employment, and overall family distress.

Conclusions

Treatment trends reveal ongoing shifts to shorter hospital stays for invasive cancer surgeries and movement of complex biologics and cellular therapeutics with nontraditional side effect profiles to outpatient infusion units or home settings. There is no question that the trend is irreversible. Economics is the driver, and nurses are forced to get onboard. How can nurses better partner with patients and caregivers to mitigate the distress of illness and treatment combined with the responsibilities and burdens of care? The literature on caregiver burden offers many reasonable interventions, which are also suggested in the Iranian article. Routine discussions with caregivers about their readiness for the role and ongoing distress screening and referral for assistance are needed. In addition to support and counseling, caregiver needs assessments indicate that knowledge

and skill acquisition are key to diminishing anxiety. Greater time and attention from health professionals and access to training programs are essential to ensure competence and confidence and achieve the desired clinical outcomes. Community- and faith-based agencies are common sources of respite and support that can be expanded to assist caregivers. Use of social media for information and outreach and electronic communication applications, such as Skype™ or FaceTime™, for coaching and professional assessment can be expanded. Growing evidence exists that well-prepared caregivers can improve recovery and clinical outcomes, resulting in reduced healthcare use, costs, and efforts. Nurses should encourage legislation that recognizes the caregiver role; provides resources, training, and support; and incorporates initiatives for temporary payment, employer support, or tax relief for caregiving, such as those implemented in some European countries and Canada (Northouse, Williams, Given, & McCorkle, 2012).

Awareness of cancer caregiving is a global issue; the article about caregiver stress in Iran highlights the influence of societal changes on the relationship to patients and families and the collective goal for higher QOL. Nurses compromise every day with what they have

known as best practice and adapt to diminished resources and regulated metrics for payment. The oncology nursing legacy of ensuring safety, quality, and comfort during chaotic times can best be applied to this new paradigm. This study from Iran raises the importance of hearing the perceptions of caregivers and the impact on their QOL and finding appropriate ways to support them.

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References

- Khanjari, S., Langius-Eklöf, A., Oskouie, F., & Sundberg, K. (2014). Family caregivers of women with breast cancer in Iran report high psychological impact six months after diagnosis. *European Journal of Oncology Nursing*, 18, 630–635.
- National Alliance for Caregiving & AARP. (2009). *Caregiving in the U.S. 2009*. Retrieved from <http://bit.ly/1qsSmL1>
- Northouse, L., Williams, A., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, 30, 1227–1234.