



## Update on . . . Psychosocial Dimensions of Oncology Care

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The focus of this column is to present topics of interest from a variety of journals to Oncology Nursing Forum readers. The topic of this issue is psychosocial dimensions of oncology care.



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### Psychosocial Impact of Predictive Genetic Testing: Present and Future Challenges

In commemoration of the 100th anniversary of the hypothesis reported by Warthin (1913) that identified an inherited component of colorectal and gynecologic cancer, Bleiker, Esplen, Meiser, Petersen, and Patenaude (2013) wrote a clinical review of the psychosocial implications of genetic testing for Lynch syndrome (LS) and the potential impact on clinical outcomes. LS is recognized as the most common hereditary colorectal syndrome. It was first reported in 1968 by Lynch and Krush, and it currently accounts for 1%–3% of all cases of colorectal cancer. Before Lynch and Krush's (1968) report, an earlier description by Krush, Lynch, and Magnuson (1965) described an increased level of fear within families that had multiple members diagnosed with cancer.

The article by Bleiker et al. (2013) is a review of psycho-oncogenetics, which is the clinical blend of psychology, oncology, and genetics. The review addresses the psychosocial implications of genetic mapping in the high-risk population of people with LS and the implications of genetic testing in general. Studies report the prevalence of distress (e.g., anxiety, depression) ranging from 6%–30% in individuals undergoing genetic counseling for colorectal cancer (Bleiker et al., 2007). Reasons for declining genetic counseling include concerns about health insurance, cost of counseling, adverse emotional impact, low anticipated benefit, and time commitment. The psychosocial impact of genetic testing on self-concept (i.e., a cognitive construct related to how individuals think about and evaluate themselves in relation to society) has led to the theory that new information

can pose a threat to an existing self-concept. Most individuals adapt to the concept of the genetic self or genetic identity, which are terms that refer to the potential impact of genetic testing on self-concept. However, individuals who carry mutations for LS have reported feelings of stigma and health vulnerability (Esplen et al., 2011). Concerns about discrimination based on genetic testing include difficulty with obtaining health and life insurance, a mortgage, or employment (Bleiker et al., 2013). The review indicates that a majority of individuals benefit from genetic counseling and are able to cope with disseminated genetic information, but a significant subgroup experiences high levels of distress that require specific screening instruments for assessment. Families that have members with LS must be guided to make decisions focusing on preventive programs.

Future challenges with genetic testing include shortened genetic counseling sessions, no contact with genetic counseling (replaced with direct-to-consumer genetic testing), support of perceived risk rather than actual risk for screening adherence, elimination of formal pretest genetic counseling (replaced with population screening for all colorectal and endometrial cancer), and underrepresentation of cultural minorities. The review provides a historic glimpse of the evolution of the genetic and hereditary components of many cancers and the profound impact on quality of life as well as ethical, social, and emotional well-being of patients and their families.

Bleiker, E.M., Esplen, M.J., Meiser, B., Petersen, H.V., & Patenaude, A.F. (2013). 100 years Lynch syndrome: What have we learned about psychosocial issues? *Familial Cancer, 12*, 325–339. doi:10.1007/s10689-013-9653-8

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Wharthin, A.S. (1913). Heredity with reference to carcinoma as shown by the study of the cases examined in the pathological laboratory of the University of Michigan, 1895–1913. *JAMA, 12*, 546–555.

### Cancer Caregiving and Caregivers: A Global Perspective

The comprehensive review by Romito, Goldzweig, Cormio, Hagedoorn, and Andersen (2013) focused on caregiving by informal caregivers (i.e., family members and close friends) for adult patients with cancer and survivors in the United States and Europe. The literature review was derived from the PubMed and Web of Knowledge databases. The authors determined that no universal definition exists for what constitutes a caregiver. The dimensions of caregiving include psychological support, meal preparation, and living with a patient with cancer. All of those tasks have contributed to the varied definitions of caregiving. The American Cancer Society's National Quality of Life Survey for Caregivers defined a caregiver as a family-like individual, chosen by the patient, as the one individual providing consistent help (Kim, Spillers, & Hall, 2012).

According to the National Alliance for Caregiving, about four million individuals are caring for an adult patient with cancer in the United States, accounting for 8% of all caregivers (Romito et al., 2013). Most of the care occurs during distinct time periods along the cancer trajectory (i.e., at diagnosis, during treatment, and at end of life). The number of caregivers coupled with costs related to the impact on personal finances (e.g., lost wages) carries implications for policy makers and researchers. Caregiver support is needed to alleviate the burden on the public health and welfare systems. Caregivers are aged 18–90 years (with a mean age of 55), and most (65%) are women. Most caregivers are spouses (66%), but other caregivers include offspring (17%), siblings (7%), parents (4%), and friends (3%). The majority of caregivers are nominated by patients and identify as Caucasian, middle-aged women who are spouses of patients. Unmet needs and tasks of caregivers change with the patient's physical and emotional needs. Measures for assessing quality of life and support for caregivers have been developed in an attempt to provide resources (Wen & Gustafson, 2004). The daily burdens of caregiving create a profound need for assistance to avoid compromised quality of life and high levels of distress. Kim, Kashy, Spillers, and Evans (2010) identified the following domains of caregiver needs: psychosocial, financial, medical, and activities of daily living.

General caregiving in Europe has been reported using data from EUROFAM-

CARE (n.d.). Europe lacks specific data on the prevalence of cancer caregivers and interventions to support them. In Europe, the physical problems of caregivers include fatigue, sleep disturbances, weight loss, and loss of appetite. The developing European literature addresses issues such as benefits to and satisfaction of caregivers (Ruf, Büchi, Moergeli, Zwahlen, & Jenewein, 2009). These data suggest that patients and caregivers may experience positive relationship changes. However, the financial impact on caregivers can be significant despite the socialized European health-care system. Financial costs for patients and caregivers still can be substantial because some medications and homecare services are not reimbursed by state-funded health care.

The commonalities between the United States and Europe include the prevalence of the informal caregiving role; that caregivers are mostly women and spouses of the patient; and that caregiving has a similar impact on emotional, social, and physical health. The broadest difference between Europe and the United States is the lack of knowledge and data concerning caregivers in Europe compared to the data in the United States. The authors of the review suggest a combined effort to create international cancer registries to form a basis for decision making by policy makers and, ultimately, to facilitate collaborative international research focusing on the relationship between the patient and caregiver and their respective needs.

EUROFAMCARE. (n.d.). Services for supporting family carers of elderly people in Europe: Characteristics, coverage, and usage. Retrieved from <http://www.uked.de/extern/eurofamcare>

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