



## 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

Bleiker, E.M., Menko, F.H., Kluij, I., Taal, B.G., Gerritsma, M.A., Wever, L.D., & Aaronson, N.K. (2007). Colorectal cancer in the family. Psychosocial distress and social issues in the years following genetic counseling. *Hereditary Cancer in Clinical Practice*, 5, 59–66. doi:10.1186/1897-4287-5-2-59

Esplen, M.J., Stuckless, N., Gallinger, S., Aronson, M., Rothenmund, H., Semoitiuk, K., . . . Wong, J. (2011). Development and validation of an instrument to measure the impact of genetic testing on self-concept in Lynch syndrome. *Clinical Genetics*, 80, 415–423. doi:10.1111/j.1399-0004.2011.01770.x

Krush, A.J., Lynch H.T., & Magnuson, C. (1965). Attitudes toward cancer in a "cancer family": Implications for cancer detection. *American Journal of the Medical Sciences*, 249, 432–438. doi:10.1097/00000441-196504000-00011

Lynch, H.T., & Krush, A.J. (1968). Genetic counseling and cancer: Implications for cancer control. *Southern Medical Journal*, 61, 265–269. doi:10.1097/00007611-196803000-00012

Warthin, 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).