familial cancer

A SURVEY OF GENETIC COUNSELLORS ABOUT THE NEEDS OF 18-25 YEAR OLDS FROM FAMILIES WITH HEREDITARY BREAST AND OVARIAN CANCER SYNDROME

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Aim: Despite evidence supporting the benefits of risk reduction, protocols for early detection and prevention among women from families affected by hereditary breast and ovarian cancer (HBOC) are not yet proven, and clinical trials have not been undertaken for patients aged 18 to 25. The absence of psychosocial data may leave genetic counsellors without uniform guidance on how to manage the care of these patients. This project sought to investigate how best to work with HBOC patients aged 18-25 given their unique developmental, familial, and medical challenges.

Methods: Certified genetic counselors were recruited through the NSGC’s Cancer Genetics Special Interest Group listserv. Researchers constructed an online survey which included 41 items and elicited information about: counsellor demographics, training, and practice settings; approaches to cancer risk assessment; and common challenges in work with 18- to -25-year-old patients. The survey was also informed by previous work by researchers with 18 to 25-year-olds with BRCA gene mutations. Researchers used a combination of grounded theory and content analysis on open-ended responses, supported and triangulated with statistical analysis.

Results: Respondents experienced 18-25-year-old patients presenting for cancer risk assessment differently than older patients, and some reported adapting their counseling style to address these differences. Respondents differed in the extent to which they felt familiar with the developmental needs of patients in this age group. Respondents aged 39 and under reported familiarity with this stage in life, having more recently completed it; respondents aged 40 and over reported less familiarity with, and more interest in learning about, this age group. A primary challenge, reported primarily by counsellors aged 39 and under, is navigating family dynamics in the counselling room and addressing the developmentally labile young adult.

Conclusions: With respect to BRCA-related cancer risk, where penetrance is incomplete and onset in early adulthood is rare, optimal screening and prevention protocols now exist. This shifts the risk management landscape from one of choice to one of adherence. A rich understanding of the trajectories of human growth over time might enhance the counsellor’s capacity to assess patients and their family members.

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