Objective

Since the discovery of the BRCA1 and BRCA2 genes, great strides have been made in understanding the varied impact of testing positive or a deleterious mutation. Significant challenges remain for BRCA positive patients, which are not always addressed by their medical team. In order to educate our BRCA community regarding advancements in the field, and to address the unique medical and psychological needs of BRCA carriers, the Beaumont Cancer Genetics Program initiated an annual BRCA Symposium.

Methods

BRCA positive individuals and their families from Beaumont Health System (BHS) and the local community were invited to attend a BRCA Symposium initiated in the fall of 2012. The goals of the symposium were education, psychosocial family support, networking, and facilitate clinical decision making. A variety of relevant topics were presented including cancer risks, high risk surveillance, prophylactic surgery, gynecologic issues, and psychosocial topics. Additional topics included pre-implantation genetic diagnosis, pancreatic cancer surveillance, and male cancers. Participants were asked to complete a survey rating the quality, added benefit, and overall impact of the conference at the 2012 and 2013 meetings.

Results

Survey respondents included 48 of 58 (83%) participants in 2012, and 34 of 47 (72%) in 2013. Participants included 30 cancer survivors, 23 previvors, and 13 who had a family member who was BRCA positive but had not tested themselves. The majority were Caucasian (73%), with representation from Asian, African, and Arabic Americans. The primary reasons for attending included gathering information regarding Hereditary Breast and Ovarian Cancer syndrome (HBOC), helping with medical decision making, support, and networking with other individuals who are BRCA positive. 96% of participants felt that the conference met or exceeded their expectations. 88% felt that their knowledge about BRCA improved significantly.

Conclusion

This experience demonstrates successful implementation of an annual educational and support symposium for BRCA positive patients and their families. This approach addresses a significant need in this unique population for continued long term education and support, and serves as a model for others.