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Frankly Speaking about advanced breast cancer: Development, implementation, evaluation, and new directions

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Frankly Speaking About Advanced Breast Cancer is a comprehensive psychosocial education program created for women diagnosed with metastatic breast cancer and their families. Created by the Cancer Support Community (CSC), formerly The Wellness Community, this program, part of the Frankly Speaking About Cancer series, provides valuable information about current treatments, side-effect management, and social and emotional challenges of an advanced breast cancer diagnosis. The program includes clinically facilitated education workshops, tailored educational booklets and website content, and an interactive CD-ROM. These evidence-based materials, developed using the Patient Active Concept[®] framework guided by Social Cognitive Theory, aim to empower patients to become actively engaged with their healthcare team. Since 2006, CSC has sponsored over 100 education workshops nationwide reaching 2036 patients and caregivers. Workshop participants completed evaluations (77% response rate), assessing participant characteristics, treatment plan, cancer information-seeking, social support, perceptions of the unique needs advanced breast cancer patients, and pre- and post-workshop knowledge of advanced breast cancer. Most workshop participants (90%) reported gaining a high or very high level of knowledge about advanced breast cancer, and increases compared with pre-workshop knowledge were significant. Nearly 90% reported intent to increase communication with their clinical team following the workshop. Data strongly suggest the success of this program and support the need for programs to address the unique needs of women with advanced breast cancer. Recently, CSC piloted a revised workshop evaluation that included a pre-test/ post-test design, and evidence-based standardized questions. This allows for research comparisons between FSAC workshop evaluations and program development.