

## Peer support

### MEETING THE INFORMATION NEEDS OF WOMEN CARRYING BRCA 1/2 MUTATIONS

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#### **STUDY SUMMARY: Evaluating the impact of a peer specialist program**

VandeZande D, Groff LN, Goulbourne E, Mlodzik K. "I've been there." Integrating a peer support specialist model of care into a clinical setting for breast cancer patients. Presented at CAPO conference 2018, Abstract B136.

The purpose of this study was to create and evaluate a program to address the information needs of women recently diagnosed with breast cancer or identified as carrying the BRCA 1/2 genetic mutation. The program, developed as a collaborative effort by the Canadian Cancer Society and Women's College Hospital (WCH) in Toronto, provides peer support and information, and aims to reduce patients' fear and anxiety, improve understanding of medical, practical and emotional issues, and increase coping strategies.

All patients were referred to meet with the peer support and information program specialist, who was available one day a week within the WCH Breast Centre. The goal is to provide immediate support for patients and family members/friends. The program was designed to address concerns related to coping with diagnosis, hereditary cancer risk, treatment, breast reconstruction and survivorship. The program specialist provided patients with information based on her own experience with breast cancer, previous involvement with other women, and knowledge of cancer initiatives. The peer specialist also connected patients with services offered by the Canadian Breast Cancer Foundation, psychosocial support and community-based resources.

The study recruited women to the program and collected patient feedback about the program's ability to address their concerns. Access, satisfaction, overall experience and willingness to recommend the program to others were also measured. Ninety-seven percent of patients involved in the program reported experiencing positive outcomes. Patient surveys indicated that individuals who participated felt supported, experienced a reduction in fear, and increased their knowledge, coping and communications skills. Participants unanimously agreed that they would recommend this program to other patients and rated the overall experience as very good or excellent. The initial findings from this study suggest that patients benefit from receiving a tailored program and peer support that addresses their information and emotional needs, and helps them adapt to their breast cancer diagnosis or risk.

**COMMENTARY:** Women diagnosed with breast cancer or those at genetic risk of cancer have specific information requirements. In order to learn to cope with illness, women in the early phases of treatment and treatment planning

## IN BRIEF

### Already known

- Women diagnosed with breast cancer, or found to carry the BRCA 1/2 mutation, have significant support and information needs.

### What this study showed

- A support program provided by a peer who had experienced breast cancer decreased fear and increased knowledge, communication and coping skills.

### Next steps

- Explore how peer support programs can be implemented outside the research context.
- Engage patients in research to design effective psychosocial interventions that benefit from insights gained through their experience.

typically have many questions regarding their health. Research in this area based on patient input has identified topics such as the likelihood of cure, illness spread and treatment options as some of the most important types of information women need after receiving a new diagnosis.<sup>1</sup> Women have also expressed a desire for more information about the side effects of treatment, hereditary risk and self-care.<sup>1</sup> Despite the fact that a majority of women report a need for high-level information, unmet information needs have been found to persist into primary illness treatment, with the majority of patients indicating that these informational needs have not been appropriately addressed.<sup>2</sup>

The interval between diagnosis and treatment represents a crucial time to meet women's information and support needs. Consequently, the current study describes an important and timely service to better address the emotional and educational needs of patients that have been described in the literature. The program at WCH meets patient-expressed priorities of access to information and support. Women diagnosed in early stages of cancer have an ever-increasing survival rate, which underscores the need for interventions that contribute to overall quality of life.<sup>3</sup> Research has examined the influence of perceived social support on wellbeing in a sample of 549 women with breast cancer following surgical treatment.<sup>4</sup> Women 6 months post surgery with low levels of perceived social support reported impaired quality of life with respect to general health, emotional wellbeing, role limitations, and social

functioning. By providing an intervention that functions as illness-specific social support, the WCH Breast Centre offers patients a service that meets emotional needs and likely contributes to global quality of life. Overall experiences deemed as very good or excellent are likely a further reflection that this program supports patients beyond illness-related concerns.

Positive outcomes were reported by 97% of participants in the study, who indicated they felt supported, experienced a reduction in fear, and increased their knowledge, coping and communications skills. Previous research on the effects of peer support has consistently reported high levels of participant satisfaction, yet literature in this area has been limited by varied methodologic approaches. Consequently, there have been conflicting findings about the benefits of these programs.<sup>5,6</sup> A meta-analytic review analyzed 44 methodologically varied studies of peer support programs and their participant benefits.<sup>5</sup> Of 44 studies included, only 8 employed a randomized controlled trial design, with the majority drawing on descriptive data. With minimal information about the design of many of the studies, at present there is insufficient evidence regarding the relative benefits of telephone-based and face-to-face interventions. Hoey et al suggest there is the strongest support for internet group-based interventions and one-on-one face-to-face programs, such as the WCH Breast Centre program.<sup>5</sup> Much like the outcomes in the current study, patients in past studies have reported decreased anxiety as a result of sharing their experiences and increased understanding of the cancer experience; they further drew emotional benefits, such as hope, encouragement and reassurance.<sup>6</sup>

Earlier research by Giese-Davis and colleagues examined the effects of receiving peer counseling in 43 women with breast cancer. Participants reported decreased anxious arousal symptoms after receiving breast cancer information from a peer.<sup>7</sup> The authors suggested that the opportunity to communicate with peers who have previously coped with the same illness and/or similar treatment acts as exposure, reducing the physiologic and emotional arousal related to illness. Discussing emotional experiences associated with cancer may address feelings of fear and anxiety, which are driving factors of increased need for information.<sup>7</sup> An increased need for information may reflect difficulties coping with uncertainty regarding one's health and future. In the study presented at CAPO this year by VandeZande et al, positive outcomes, including increased understanding and skills, may reflect the effects of receiving social and emotional support from the program specialist. By collaborating with a peer, individuals may be able to perceive future possibilities and consequently decrease their need for information. Peer support initiatives must strive to build the evidence base around the impact of these programs as they meet the needs of patients.

There is also evidence to suggest that peers providing support benefit themselves, as well as helping new patients. In a study of 16 women with gynecologic cancers who were providing support to women currently undergoing treatment, women reported personal satisfaction as a result

of supporting others, an increased sense of self and self-esteem, new insights into their own cancer experience, as well as the opportunity to gain closure on personal cancer-related issues.<sup>8</sup> Therefore, beyond helping patients referred to the support program, the program specialist may also benefit from providing the service, something that could contribute to the long-term sustainability of this program.

The study provides an example of patient-centred collaboration between the Canadian Cancer Society and Women's College Hospital. This initial research demonstrates the feasibility of incorporating patient knowledge and peer social support into care delivery and research. Future research could utilize standardized outcome measures to provide further insights into patient benefits from participating in the peer support program, while ensuring that patient-collaborators play a central role in the development and ongoing delivery of this intervention.

Patients who have previously received a diagnosis of or treatment for breast cancer have invaluable insight with respect to the physiologic effects of illness and the psychosocial impact of coping with breast cancer, along with experience navigating the healthcare system. Being able to offer an authentic perspective within a psychosocial intervention has clear advantages for patients. The present study further demonstrates an opportunity to use patient engagement to help strengthen research. The Canadian Institutes of Health Research (CIHR) conceptualize patient engagement as meaningful and active collaboration across many healthcare domains, including "governance, priority setting, conducting research and knowledge translation."<sup>9</sup> Moreover, utilizing patient engagement in research has been shown to have notable benefits with respect to enhancing patient participation, and the applicability and appropriateness of research.<sup>10</sup>

Research by Chiu and colleagues explored patient engagement in research by initially interviewing 6 women with breast cancer prior to developing a psychosocial measure that captured patient experience of participating in community recreation.<sup>11</sup> A portion (n=5) of these women went on to participate in the review, selection and distribution of quantitative instruments designed to measure the priority themes identified in 46 additional interviews with women with breast cancer. The authors noted that engaging breast cancer patients in the research process contributed to a greater appreciation, relevance and sensitivity to experience, which led to increased completion rates, a reduction in missing data, and improved validity and reliability of the data, while enhancing ethical research practices with a vulnerable research population. The larger evidence for patient engagement suggests that inclusion of patients in the research process increases the relevance, utility and dissemination of the research, while providing crucial insight into patient experience.<sup>12</sup> Conducted with the peer support specialist, the research by VandeZande et al represents an important step forward in conducting patient-oriented research that is better able to meet needs that have been largely unmet to date.

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