New research highlights the importance of third sector support for people living with breast cancer

Submitted by: Breast Cancer Haven Wednesday, 14 August 2019

A recent research study into what third sector organisations – such as national support charity Breast Cancer Haven - provide for people with breast cancer that public health services cannot, is now available in the European Journal of Integrative Medicine, September issue.

At the end of 2015, an estimated 475,000 women were living up to 21 years following a breast cancer diagnosis. By 2030, this is projected to rise to 840,000. As more people survive, many experience physical and psychosocial problems such as fatigue, menopausal symptoms, stress, anxiety and depression, all of which are associated with poorer quality of life, Around one-third of breast cancer survivors report one to five such unmet needs, whilst 17% report at least six concerns. This increase in demand for services such as breast care nurse support and oncology outpatient visits is placing increased pressure on the NHS to provide the support needed.

The research study, undertaken by Breast Cancer Haven and the College of Health and Human Sciences at Swansea University, concludes that regular service evaluations are needed to ensure that people with breast cancer receive those aspects of care that are often lacking in the NHS setting. This service evaluation aimed to identify what people expected, or hoped for from Breast Cancer Haven, and to evaluate how well those expectations were met.

A total of 980 Breast Cancer Haven service users completed the research study, most citing emotional (77.6%) and physical (67.2%) as the most frequent concerns for visiting. The four main themes of expectations were:

- information and practical advice about breast cancer and its treatment, with more advice about how to cope with the side effects of their medical treatment and prevent recurrence
- therapeutic space including a safe, calm and caring environment away from that associated with medical treatments, where they could relax and experience the therapies on offer
- therapeutic relationships with professional people who had time to listen and understand what they were experiencing, and sharing that experience with others with breast cancer to feel that they were not alone
- emotional support to manage stress, anxiety and fears so as to regain confidence and move on with their lives.

The majority of participants stated that they got what they expected, or more than they expected, from Breast Cancer Haven, with the main individual therapies found to be helpful were breast cancer information (43.9%), nutritional therapy (42%), acupuncture (35%) and counselling (31.9%).

Just over 40% of participants indicated that they had obtained additional support from other charities or organisations to help them through their breast cancer experience, with breast care nurses and Macmillan Cancer Care as the most frequently cited.

The findings of this survey indicate that people with breast cancer don't receive all the information they need from other sources such as the internet or healthcare professionals, and that cancer support

services have a role to play in providing such information. There is, therefore, a potential for third-sector support services working in partnership with the NHS to fill this provision gap. Increased support provided by charities to breast cancer survivors may both address their unmet needs and reduce demand on tightly stretched NHS healthcare services.

One participant from the survey said:

"Breast Cancer Haven is the door that opens when the consultation room door closes. For that reason, it is not just complementary, it is essential."

Breast Cancer Haven is a national UK charity supporting people through the physical and emotional experience of breast cancer. The charity – which was founded in February 2000 - provides free in-depth personalised programmes of psychological support, help with treatment side-effects and supported self-management activities in five community-based centres in London, Hereford, Yorkshire, Wessex and the West Midlands as well as two hospital breast units in London and Worcester.

The Breast Cancer Haven support programme consists of an initial one-hour consultation with an experienced Breast Cancer Haven health care professional to assess each person's needs and to mutually agree an appropriate therapy plan, followed by up to 10 hours of free individual one-to-one therapies. After six hours of therapy, each person's treatment plan is reviewed to monitor the effectiveness of the therapies, allowing changes to be made to the treatment plan if needed.

Another participant, said:

"It literally was a life changing experience for me. From the moment the girls at reception greeted you, you immediately felt safe. Everything was geared to me as an individual. It didn't matter if you became upset, everyone understood why. It was such a relief to me."

For the full research paper published in the European Journal of Integrative Medicine, please visit https://www.sciencedirect.com/science/article/pii/S1876382019302495?dgcid=author

Further information

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Notes to editors

- 1. Breast Cancer Haven is a national charity that supports women throughout or after their breast cancer treatment. When breast cancer tries to rob a woman of her individuality, confidence or strength, Breast Cancer Haven provides a tailored package of emotional, physical and practical support that helps her hold on to them.
- 2. The programme provides a unique model of care that is fully integrated with hospital medical treatment. It is a global leader in its field and cancer specialists from all over the world visit Breast Cancer Haven centres and learn from them.
- 3. Help is also available through the website breastcancerhaven.org.uk; an outreach programme, including many of the elements available at the charity's centres; and a 'Haven at Home' DVD is available to anyone who can't get to a Breast Cancer Haven centre.

- 4. It costs around £1000 to provide the Breast Cancer Haven programme for each service user and the care and support make a huge difference to their lives at a difficult time.
- 5. There are currently five Breast Cancer Haven centres in the UK in London, Yorkshire (Leeds), Hereford, Wessex (Titchfield) and West Midlands (Solihull).

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References

- 1. J. Maddams, M.Utley, H.Møller. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br. J. Cancer, 107 (2012), 1195-1202.
- K.K.F. Cheng, W.H. Wong, C.Koh. Unmet needs mediate the relationship between symptoms and quality of life in breast cancer survivors. Support Care Cancer, 24(5) (2016), 2015-2033.
- Z.X. Ng, M.S. Ong, T. Jegadeesan, S. Deng, C.T. Yap. Breast cancer: Exploring the facts and holistic needs during and beyond treatment. Healthcare, 5(2) (2017), E26.
- K.K.F. Cheng, H.L. Cheng, W.H. Wong, C. Koh. A mixed methods study to explore the supportive care needs of breast cancer survivors. Psychooncology, 27(1) (2018), 265-271.

