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Service evaluation of a breast cancer support service: a survey of people attending Breast Cancer Haven centres

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Abstract

Introduction

Breast Cancer Haven (BCH) is a national UK breast cancer charity supporting people through the physical and emotional experience of breast cancer. This service evaluation aimed to identify what people expected or hoped for from BCH, and to evaluate how well those expectations were met.

Methods

A link to an on-line SurveyMonkey survey was emailed out during November 2014 - January 2015 to 4,804 people with breast cancer who had attended BCH centres in London, Yorkshire or Hereford since 2000. Frequency analyses of pooled responses to multiple choice questions were downloaded from the SurveyMonkey website. Individual free text responses were analysed by coding into common themes, clustered into categories.

Results

A total of 980 BCH users (98.0% female, peak age 50-54 years) completed the survey; 20.4% of those invited. Most had attended a BCH centre during 2012-14, nearly half had a journey time of 30-60 minutes and most had visited 6-10 times. Emotional (77.6%) and physical (67.2%) were the most frequent concern types. Breast cancer information, nutritional therapy and the Welcome Day were considered the most helpful therapies/ group activity. Main categories of expected/hoped for factors were information and advice, emotional support, a therapeutic space and therapeutic relationships. 84.0% participants got what they expected or much more than they expected.

Conclusions

The findings suggest that BCH provides a support service that people find helpful and meets most of the expectations of those attending.

Keywords: Breast cancer; service evaluation; support service; expectations

Abbreviations: Breast Cancer Haven (BCH)

1. Introduction

At the end of 2015, an estimated 475,800 women were living up to 21 years following a diagnosis of breast cancer in the UK; this is projected to rise to 840,000 in 2030 [1]. As more people survive breast cancer, many experience physical and psychosocial problems such as fatigue, menopausal symptoms, stress, anxiety and depression, which are associated with a poorer quality of life [2, 3]. Around one-third of breast cancer survivors report one to five such unmet needs, whilst 17% report at least six concerns [4]. Consequently, long-term breast cancer survivors report significantly more healthcare utilisation than same age controls in the general population [5, 6]. 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. There is, therefore, a potential for third sector support services working in partnership with the NHS to fill this provision gap [7, 8, 9]. Increased support provided by charities to breast cancer survivors may both address their unmet needs and reduce demand on tightly stretched NHS healthcare services.

Breast Cancer Haven (BCH) is a national UK breast cancer charity supporting people through the physical and emotional experience of breast cancer. BCH provides free in-depth personalised programmes of psychological support, help with treatment side effects and supported self-management activities in five community-based centres located in London, Hereford, Yorkshire, Wessex and the West Midlands, two hospital breast units in London and Worcester and in an all cancer charity's centre, plus support days across the country. The charity has helped people live well with and beyond breast cancer since February 2000. The BCH support programme consists of an initial one-hour consultation with an experienced BCH 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 with a BCH health care professional to monitor the effectiveness of the therapies, allowing changes to be made to the treatment plan if needed. There is no time restriction for completing the programme, allowing people to fit in their therapy sessions between family and work commitments, medical treatment and hospital appointments.

A service evaluation of 1,524 BCH users showed statistically significant improvement in their two main presenting concerns and in wellbeing after receiving a personalised programme of one-to-one therapies [10, 7]. To address breast cancer related problems, the most commonly used one-to-one therapies at BCH are breast cancer information, acupuncture, counselling, nutritional therapy, aromatherapy massage, reflexology and hypnotherapy. The use of these therapies has been based upon published evidence of their effectiveness for the relief of physical and/or emotional concerns associated with a diagnosis of breast cancer

and its treatment [11-18].

In addition to the personalised support programme, BCH visitors are also able to access regular classes (e.g. yoga, Qi gong, mindful movement and meditation), a range of support groups (general, young women, living with secondary breast cancer) occasional seminars and workshops (e.g. lymphoedema awareness, Living Well, Moving On, Breast Cancer Haven in Your Kitchen) and courses such as mindfulness-based stress reduction (MBSR) and Emotional Freedom Techniques (EFT).

An eight-week MBSR programme has been shown in a large randomised trial of 229 BCH users to significantly improve mood, breast- and endocrine-related quality of life and wellbeing [19]. Preliminary evidence from a service evaluation of BCH users also suggests that EFT may be an effective self-help tool for women experiencing side effects from hormonal therapies such as mood, anxiety, depression, fatigue and hot flushes [20].

BCH aims to improve the quality of life of people affected by breast cancer by providing personalised emotional, practical and physical support. In order to ensure that everyone affected by breast cancer gets the help they need, it is important that the charity obtains feedback from their service users. A previous service evaluation using the Measure Yourself Concerns and Wellbeing questionnaire demonstrated the beneficial effects of the BCH therapy programme on the two main concerns and wellbeing of people with breast cancer [10]. The present survey was conducted to extend these findings and explore the views of people who attend BCH centres about the service as a whole, in order to understand their hopes and expectations and find out whether they have been adequately met.

The aims of the study were therefore to:

1. Identify the type of support that people with breast cancer who come to BCH expect or hope for
2. Evaluate how well the BCH support programme meets these expectations

2. Methods

This was a service evaluation, approved by the Senior Management Team of Breast Cancer Haven, of a sample of people with breast cancer who had accessed BCH support before, during or after cancer treatment. All people receiving help from BCH have given their consent, on registration, to be contacted for feedback about the charity's treatment programmes.

2.1 Participants

People with breast cancer who had attended at least one of the BCH centres in London, Hereford and Yorkshire at any time since they opened in 2000, 2004 and 2008, respectively, and for whom a valid email address was available, were invited to take part in the survey.

2.2 Survey design and distribution

The survey questions were developed by the BCH clinical (healthcare professionals and therapists) and research team, with academic support and input from the BCH Centre managers, the Marketing Manager and Directors of the charity in order to meet the study aims.

The survey included multiple choice or free text questions designed to determine:

1. travel, timing and frequency of attendance at a BCH centre.(multiple choice)
2. what participants expected or hoped for when coming to a BCH centre (free text)
3. whether participants received what they expected or hoped for (free text).
4. participants' main types of concerns/problems. The categories were as defined in the Functional Assessment of Cancer Therapy (FACT-G) questionnaire (multiple choice)
5. the individual therapies and groups/classes that participants found most helpful for their concerns/problems (multiple choice)
6. whether they still attended a BCH centre and, if not, the reasons why not. (Y/N; multiple choice)
7. whether participants sought additional help from other sources (Y/N; free text)
8. any other comments about BCH services (free text)

The age of the users was also collected.

The surveys were tested on the SurveyMonkey website (www.surveymonkey.com) for clarity, ease of use and time to complete by members of the BCH clinical staff. Five BCH London service users were contacted to request their feedback, but only one returned a response. No changes to the survey questions were required.

A total of 4,804 current and former visitors to the three BCH centres in London (N=3,027), Hereford (N=762) and Yorkshire (N=1,015) were contacted during November 2014 to January 2015. Emails were sent out using Campaign Monitor, an email marketing tool, inviting them to complete the survey via an attached link to the SurveyMonkey website. The survey was initially open to London users for 37 days, but the majority of responses were collected during the first two weeks. Subsequently, the survey was opened to Hereford and Yorkshire users for 15 days.

2.3 Data Collection

Surveys were accessed by the link provided in the invitation email, completed and the responses stored on the SurveyMonkey site. The responses were anonymous.

2.4 Data analysis

Data was downloaded from the SurveyMonkey site as pooled data for the three BCH centres. (Following separate analysis, similar results were found between centres).

Quantitative data

Summaries containing a frequency analysis of the responses (numbers and percentages) to each multiple choice question were automatically generated and exported from the website.

Qualitative data

A descriptive analysis was undertaken by BB and the themes were validated independently by DF. Open-ended free text responses were downloaded and analysed, without the use of software, by a series of analytic steps based on framework thematic analysis. Common themes were identified and clustered into categories [21].

Due to the large amount of qualitative data collected, only responses received from visitors to the London BCH were analysed. These responses represented more than half of the sample of users and were therefore expected to include a diverse range of responses.

Storage of the data collected from the survey complied with the 2018 General Data Protection Regulation.

3. Results

The link to access the survey was clicked in 1,089 of the 2,289 (47.6%) emails opened.

A total of 980 BCH users completed the survey: 531 (54.2%) London, 172 (17.5%) Hereford and 276 (28.2%) Yorkshire, plus one respondent who ticked all three centres. This represented 20.4% of the total number of emails sent out to BCH users. The number of responses to each question varied from 78.8 – 99.7% of total respondents. The participants

were predominately female (N=948 vs N=19 male; 98.0%). This is consistent with the demographics of BCH users in general across its centres (98.3-100.0%).

3.1 Age of participants and their use of BCH services

3.1.1 Age of participants

The peak age range of the 950 participants who gave their year of birth was 50-54 years (N=225, 23.7%) with 0.8 to 10.6% aged 30-49 years (Figure 1). This contrasted with the age of BCH users in general across its centres which tended to be younger with 4.6 -16.4% within the 30-49 year age range. The proportion of participants older than 54 years gradually decreased with increasing age, but there was a second peak at 65+ years.

3.1.2 Year of attendance at BCH

Most respondents who had completed the survey attended a BCH centre during 2012-2014 (N= 1087/1849 responses; 59%)(Figure 2). Some respondents attended more than one year.

3.1.3 Travel to a BCH centre

Nearly half (N=466; 48.0%) of the participants had a journey time of 30-60 minutes to their local BCH centre. Journeys of less than 30 minutes and 61-90 minutes accounted for a further 244 (25.1%) and 185 (19.1%) of responses, respectively. Travel to the London centre was mainly by Underground or bus/train, whilst car was the main mode of transport to the Hereford and Yorkshire centres, reflecting the location of the centres (data not shown).

3.1.4 Number of visits to a BCH centre

The most frequent range of number of visits to a BCH centre was 6-10 (29.7%)(Figure 3). Reasons for these visits included to attend: an individual therapy appointment; a group or class, seminar or workshop; to use the library or to have lunch in one of the kitchens. A further 183 (18.8%) and 190 (19.5%) participants attended on 2-5 or 11-15 occasions, respectively.

3.2.1 What did people with breast cancer expect or hope for from BCH?

There were free text responses from 471 (88.9%) participants that had attended the London BCH centre giving information about what they had expected or hoped to receive from BCH. In most cases, respondents gave more than one answer. Four main themes of expectations were identified (Table 1): information and advice about breast cancer and its treatment; therapeutic space, including the delivery of therapies; therapeutic relationships such as

understanding therapists and meeting others in the same situation; emotional support for anxiety, stress etc.

3.2.2 Did people with breast cancer receive what they expected or hope for from BCH?

Of those that answered this free text question (N=393, 84.0%), the majority stated that they had got what they had expected, or much more than they expected (Table 2).

Reasons given by participants who did not receive what they expected included lack of therapy-induced improvement in symptoms, not experiencing peer support, dissatisfaction with the therapist's approach/attitude and lack of availability of appointments.

3.3 Types of concerns and problems experienced by participants

Emotional concerns (77.6%), and to a lesser extent, physical concerns (67.2%) were the most frequent types of concern experienced by 889 respondents (most had more than one concern) (Figure 4). Functional concerns, such as work, sleep, quality of life were also a problem for just over half (54.7%) of the participants, whilst social support issues were less frequent (23.2%).

3.4 Most helpful therapies for concern or problems

A total of 882 respondents indicated the individual therapies and groups/classes that they had found helpful from a drop-down list of those available (more than one in most cases).

3.4.1 Individual therapies

The main individual therapies that were found to be helpful were breast cancer information (43.9%), aromatherapy massage (43.1%), nutritional therapy (42.0%), acupuncture (35.0%) and counselling (31.9%)(Figure 5).

- *"I found the aromatherapy sessions were very useful. It helped me relax before chemo."* Participant 1

3.4.2 Groups and classes

The Welcome Day, which introduces new users to the types of support offered by BCH and is probably the most commonly accessed group activity, was most frequently found to be helpful by respondents (36.6%), followed by mindfulness to reduce stress (26.6%) (Figure 6).

- *“I found the introductory session (Welcome Day) useful and the fact that there are many therapies to choose from.”* Participant 2
- *“EFT (Emotional Freedom Techniques) and the help I got to let go of fear.”*
Participant 3
- *“Mindfulness-Based Stress Reduction course changed my life.”* Participant 4

3.5 What other services would people with breast cancer have liked to receive at BCH?

Almost 40% (N=140) of the 393 participants who answered this free-text question didn't want any further services. The main categories of services that the remaining respondents would have liked were: additional types of therapies to the ones that they had already received, more individual and group therapy sessions, to live closer to a BCH centre or for more BCH centres to be opened, opportunities to meet others in a similar situation socially, extended opening hours (weekends, evenings) and better access to and more flexibility of appointments.

- *“Just wished it was closer to my home so I could've attended some of the regular workshops/classes.”* Participant 5
- *“Evening/weekend sessions would be helpful, now working full time.”* Participant 6

3.6 Current attendance at a BCH centre and reasons for no longer attending

Nearly one-third of participants stated that they still attended a BCH centre (N=257/864; 29.7%). The most frequent reason given (from a drop-down list) by those who no longer attended was that they were feeling better and did not need any further support (N=257/638; 40.3%) (Figure 7). Other main reasons for not attending were work commitments (N=200; 31.3%), had used up all free appointments (N=181; 28.4%) or lived too far from a centre (N=161; 25.2%). (In some cases respondents gave more than one reason).

3.7 Additional support from other charities or organisations

Just over 40% (N=355) of participants indicated that they had obtained additional support from other charities or organisations to help them through their breast cancer experience. When asked to specify where they obtained such support, breast care nurses and Macmillan Cancer Care were the most frequently cited, followed by Breast Cancer Care and, for London BCH users, Maggie's centre at Charing Cross Hospital. Participants also used local charities and support groups as further sources of help and support.

3.8 Other comments about BCH and its services

When asked if there was anything else the participants would like to say about BCH and its services, two-thirds of the London participants (N=354) made comments (often more than one) which were predominately positive and consisted mainly of appreciation of BCH in general and gratitude for the support it provided. The small number of negative comments (N=35/503 comments;7%) focused mainly on the distance to travel to BCH, the availability of appointments and the lack of social interaction in the centre's reception area.

- *“BCH is an amazing support facility for breast cancer affected individuals. It is a life line and much appreciated and needed resource for many. Thank you for all the services provided.”* Participant 7
- *“BCH is the door that opens when the consultation room door closes. For that reason, it is not just complementary, it's essential.”* Participant 8
- *“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 for me as an individual. It didn't matter if you became upset, everyone understood why. It was such a relief to be me.”* Participant 9

Discussion

This service evaluation was carried out to identify what people with breast cancer expected or hoped for from the free, personalised support service offered by BCH, and to evaluate how well those expectations were met. Four main themes were identified: information and advice; a therapeutic space; therapeutic relationships; emotional support. The majority of participants considered that they had received what they expected or much more than they expected.

The proportion of participants in the age group 50 -65 years was higher, and in the age group 30-49 years lower, than current BCH users (unpublished data). This discrepancy may be due to the fact that the survey was open to all previous, as well as current, users of three of the five centres. Although about 60% participants had attended a BCH centre during 2012-2014, the remainder were comprised of people who had visited up to 12 years before the date of the survey. There were also more responses from participants who had attended the London centre; this was the first BCH centre to be opened in 2000, four and eight years before the Hereford and Yorkshire centres, respectively.

Nearly three-quarters of people who attended a BCH centre lived up to 60 minutes travel away from home, suggesting that they were willing to make a significant journey to access

support. However, distance to travel to a BCH centre is likely to be a barrier to some people due to factors such as availability of transport or feeling unwell [22]. Over half of the participants made up to ten visits to a centre, but not all for therapy appointments. This is consistent with visitor data that suggests that users, on average, take up only 6 of the 10 free therapy appointments offered by the BCH centres (unpublished data).

Participants expected or hoped to obtain advice, support and information from attending a BCH centre. A recent review of the holistic needs of people with breast cancer has discussed the requirement for help and support by healthcare providers and support groups at various stages of recovery, emphasising the need to tailor cancer care to each individual [3], a unique feature of the therapy programme provided by BCH. People with breast cancer have a substantial need for information about the disease, its treatment and recovery; similarly this is most effective if tailored to each person's unique needs [23]. They obtain such information from various sources including the internet (the main source), healthcare professionals, cancer organisations and family and friends [24]. The findings of this survey suggest that people with breast cancer don't receive all the information they need from other sources such as the internet and healthcare professionals, and that cancer support services have a role to play in providing such information. Alternatively, they may access such support services to confirm the validity of information that they have collected elsewhere or to get help to make sense of conflicting data from various sources.

The importance of a calm, relaxing and safe environment was an additional aspect of the BCH service expected and appreciated by participants [22]. The contrast with the medical hospital environment was of particular importance to some participants as documented in their comments about their hopes and expectations when coming to BCH for support.

Participants also wanted access to understanding therapists and various therapies to reduce treatment side effects and support healthy living. Indeed, after advice, support and information, therapies and treatment were the services provided by BCH that people with breast cancer most frequently hoped/expected to receive. Consistent with this need for therapies to help with symptoms, women with breast cancer have been reported to be more likely to use complementary therapies compared to patients with other cancers and that their use is initiated or increased on diagnosis [25-27]. Meeting and sharing experiences with others in the same situation was also considered important by participants. Such peer support may be helpful in rehabilitation from the disease [28].

The most frequent concerns of people living with breast cancer attending a BCH centre were emotional problems such as anxiety, depression and worry about dying. This is in agreement with published studies of the unmet needs of breast cancer patients which showed psychological needs and fear of recurrence as more prevalent than physical problems during and following treatment [2, 4, 29, 30]. A previous service evaluation of the effects of the BCH

programme on the concerns and wellbeing of women with breast cancer also found that the highest proportion of concerns were psychological and emotional in nature, with fear and anxiety as the highest scoring subcategory [10].

Previous studies have shown that counselling for psychological needs in cancer survivors is preferred over anti-depressants or other medications [31]. Participants in our survey found one to one counselling, offered as part of the BCH support programme, helpful for their emotional concerns. In addition, aromatherapy massage was also considered beneficial by participants with emotional distress, consistent with the findings of randomized trials of (aromatherapy) massage therapy which reported improved emotional functioning and fatigue, and/or reduced anxiety and depression in people with breast cancer [18, 32].

Physical concerns were also frequently experienced by participants as previously reported in breast cancer survivors [2]. Acupuncture was commonly found to be helpful by participants for menopausal symptoms, fatigue, chemotherapy-induced nausea and vomiting and pain [12, 13, 33 - 35]. Nutritional therapy, which provides advice on a healthy diet tailored to the needs of the individual, was also considered beneficial by participants. The direct relationship between an unhealthy diet and lifestyle with an increase in tumour development and cancer risk, and poor adherence to dietary guidelines by cancer survivors, has emphasised the importance of eating a healthy diet to prevent cancer recurrence [36, 37].

Of the group/class sessions offered at BCH centres, the Welcome Day, which introduces new users of the service to the types of support offered by BCH, and mindfulness to reduce stress were frequently found helpful by participants. Mindfulness-based stress-reduction has been widely reported to induce statistically significant improvements in mood disturbance (anxiety, depression, fatigue, confusion) in people with breast cancer, which may persist for up to one year [19, 38, 39].

The majority (90%) of the participants indicated that they had got what they expected or much more than they expected from BCH and almost 40% didn't want any further services. Those that did wanted more of what was already being offered rather than new services. Since this survey was conducted, BCH community-based centres have been opened in Wessex and the West Midlands, and services established in two hospital breast units in London and Worcester and in an all cancer charity's centre, plus support days across the country, greatly increasing the charity's ability to help more people with breast cancer (20% more people were given support in 2018 compared to 2014). Opening hours at the centres have also been extended to include evening appointments to give people with work or family commitments the opportunity to attend. In addition, some of the lesser used therapies such as Bach Flower remedies and energy healing are no longer offered as part of the BCH support programme, allowing more therapy time for the more popular therapies such as aromatherapy massage and acupuncture.

However, limited resources (the charity raises all of its own funds and doesn't receive government funding) prevent an increase in the number and availability of free sessions offered to its users, although additional treatments can be paid for. T

The main reason given by participants for no longer attending a BCH centre was that they felt better and didn't need any further support. This may be partly due to the BCH programme that they received, but may also be a result of additional support from their breast care nurses, from other charities such as Macmillan Cancer Care, Breast Cancer Care and Maggie's or to improvement of their symptoms and problems with time.

Limitations of the study

One of the limitations of this study is that the survey was developed internally by clinical and research staff at the charity with academic support, but without external validation or testing of reliability [40]. Further, although the survey was tested by a number of clinical staff, only one of five BCH users who were asked to test it out responded. However, the number of responses to questions in the survey was high (78.8-99.7%) suggesting that the survey was clear, the questions easy to understand and that the participants didn't find it too burdensome.

Another limitation of the survey was that only 20.4% of the emailed BCH users responded and completed the survey. This is consistent with the response rate reported for postal questionnaires [41]. The low response may have been partly due to the fact that previous as well as current BCH users were invited to take part and, in some cases, their contact details may have changed. In addition, previous BCH users may have felt that they had moved on with their lives and didn't want to be reminded of their earlier diagnosis and treatment.

A further limitation is that it is unknown whether the respondents were representative of BCH users as, with the exception of their age, the demographic characteristics of the participants were not investigated. However, a large sample was surveyed which may have increased the likelihood that the demographic profile of the survey respondents reflected that of the BCH user population. Further, comments about what participants expected/hoped for from BCH were analysed from the sample of London BCH users surveyed. London BCH users generally are more ethnically diverse than those from Hereford or Yorkshire so their comments may not be representative of the survey population.

Only pooled data from the three BCH centres was presented in this paper. Although individual data was available, it was not included as responses were similar between centres.

Regular service evaluation by charities is essential to highlight any changes needed to improve the support services they provide to people with breast cancer. Future annual BCH surveys will be developed with a greater input by service users to ensure relevance, and targeted to those who had attended in the previous one or two years who might be more willing to take part than users from past years. In addition, full demographic data will be collected to allow the representativeness of samples of participants to BCH users in general to be assessed.

Conclusions

This survey shows that women who attended BCH with emotional and physical concerns following their breast cancer diagnosis found that this was an appropriate place to bring those concerns and that the interventions offered were able to meet the expectations of the majority of those that attended. Users valued the opportunity to come to a safe, welcoming and peaceful environment specifically aimed at supporting people affected by breast cancer. They also appreciated the understanding and empathy of the BCH therapy team and welcomed the opportunity to meet with other people going through a similar experience. These aspects of in-depth personalised and supportive care are often lacking in the acute NHS setting.

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