TELEPHONE HELPLINE TO SUPPORT PEOPLE WITH BREAST CANCER

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ABSTRACT

Breast cancer is the most common female cancer in the UK and those diagnosed have a variety of information and support needs. This article seeks to explore the role of Breast Cancer Care’s free telephone helpline in supporting people diagnosed with breast cancer and presents the results of a questionnaire survey of callers using the helpline during January–March 2007. Reported satisfaction levels are high and most callers would recommend the service to others. However, results suggest the helpline needs to be made more accessible for people from different black and minority ethnic groups and those in older age groups.

Approximately 44,000 women are diagnosed with breast cancer in the UK every year (Cancer Research UK, 2007).

Patients with breast cancer have a variety of information and support needs that may occur at different points along their cancer journey (Lindop and Cannon, 2001; Rees and Bath, 2000).

Not only will these information needs change over time but patients may require staggered information to avoid being bombarded with so much that they are unable to take it in (Ziegland, 2004).

Following a comprehensive literature review, Luker et al (1996) recommended that information-giving become an ongoing process, not restricted to times of diagnosis or treatment. There is evidence to suggest that long-term survivors of breast cancer may have information and support needs that may go unmet after they have been ‘discharged’ from specialist services (Vivar and McQueen, 2005). This has implications for NHS services that may already be short of resources.

Rees and Bath (2000) identified that people may seek information for several reasons including to gain control, to reduce anxiety, to aid decision-making and to facilitate coping. This is reinforced by the NICE (2002) guidance on improving outcomes for people with breast cancer, which emphasises that good communication is likely to reduce anger and anxiety, and to increase people’s confidence and their chance of receiving the best treatment for them.

IMPLICATIONS FOR PRACTICE

- The helpline needs to do more to promote access for minority ethnic groups. A lack of engagement by cultural or ethnic groups may be caused by a number of factors, including service design, which may not reflect the culturally sensitive needs of all potential users (Karlsen, 2007).
- The onus remains on the organisation to ensure that people are aware of the service and that evidence on the needs of hard-to-reach communities is used to shape the development of new services.
- Lack of awareness that the helpline is free may make some people from poorer backgrounds less likely to call and inhibit others from discussing concerns fully.
- Research is needed into whether older women have less need of a helpline service or prefer to receive information and support from alternative services.
- Increasing healthcare professional awareness of and confidence in services provided by the voluntary sector may lead to more patients being given the information about the helpline.

RESULTS

Caller profile

As might be expected the majority of respondents were women (95%); seven were men, four of whom were calling about their own breast cancer. In terms of ethnic profile of callers, 79% were white British, 1% Irish, 3% white other, 1% mixed ethnicity, 2% black Caribbean and 0.5% were Chinese. Some 12% of respondents classed themselves as disabled. Over half (58%) were over 50 years old, with approximately half of those in the 50–59 years age group.

The majority of respondents called about themselves (n=167), with the remainder calling about a family member, friend,
DEVELOPMENT

BACKGROUND

The general public is increasingly turning to telephone helplines for information and support about health and illness. Many of those funded by the voluntary sector seek to complement NHS services, giving callers information and time to explore questions about their condition.

Breast cancer patients have a variety of information and support needs that may occur at different points along their cancer journey (Lindop and Cannon, 2001).

Luker et al (1996) recommended that information-giving becomes an ongoing process, not restricted to times of diagnosis or treatment. Long-term survivors of breast cancer may have information and support needs that go unmet after being discharged from specialist services (Vivar and McQueen, 2005).

Research on the information and support needs of patients with benign breast conditions suggests that a significant proportion of them continue to feel high levels of anxiety (Meechan et al, 2005).

Access

Over one-third (35%) of respondents had called the helpline previously (n=67), while 64% (n=123) were first-time users. They heard about the helpline from a variety of sources, most commonly from their breast care nurse (28%, n=54) or the Breast Cancer Care website (23%, n=44). Only 62% (n=120) were aware it was free.

Experience of calling the helpline

The vast majority (95%, n=183) of respondents found that the information they received from the helpline was clear and easy to understand. Some 93% (n=180) felt it was relevant to their situation, and the majority (95%, n=183) felt that the helpline worker had understood their needs and 83% (n=161) felt that the information or support they received had helped them or would help to make informed choices.

Overall, the majority of respondents were satisfied with their experience of calling the helpline (93%, n=180). Five felt unsure as to whether they were satisfied, while four were not satisfied. The vast majority (95%, n=184) said they would recommend the helpline.

DISCUSSION

Satisfaction

Respondents expressed a high level of satisfaction with the service, reporting that they found the information they received relevant to their situation.

Callers often had a complex set of needs that encompassed information, emotional support and signposting to other services. This supports research from other helplines showing that callers often present with a variety of needs and that psychological and emotional needs will often coexist alongside more straightforward requests for information (Jefford et al, 2005).

Despite this wide variety of needs, as many as 95% of respondents reported that the helpline worker they spoke to had understood their needs. The high numbers who were happy with the helpline and would recommend it to others suggest it is an effective service. However, as Jefford et al (2005) pointed out, while satisfaction levels with helplines are often high, there is little research on specific patient outcomes to measure the impact of such services.

Our survey indicated that 83% of respondents felt that they were better able to make informed choices after contacting the helpline.

Other questions were structured around discovering whether respondents felt they had been given useful, easy-to-understand information and whether the tone of the call...
was helpful in encouraging them to discuss their concerns fully.

There is a possibility that the data provided could be affected by an element of selection bias. Helpline workers were encouraged to invite all callers over the duration of the survey to take part unless they felt it inappropriate. It is therefore possible that callers who appeared distressed might not always have been invited to complete the survey. While this is consistent with the approach of the helpline – to put the experience of the caller above other considerations and to handle all calls with sensitivity and tact – it might have affected the results of the survey.

Ethnicity
The high proportion of white British respondents suggests the helpline needs to do more to promote access for black and minority ethnic groups.

Breast Cancer Care is committed to providing a high-quality service to a wide range of communities and is investigating further opportunities to increase awareness of services. Previous initiatives to promote breast awareness have included visiting community groups, creating radio dramas aimed at specific audiences and translating our publications into a variety of languages.

Research from focus groups suggests that women from an Asian or Arab background may hold beliefs that inhibit them from discussing breast concerns or practising breast awareness (Scanlon and Wood, 2005). This may mean that people from some cultures would feel uncomfortable using a telephone helpline to discuss breast-related issues.

Nevertheless, the onus remains on the organisation to ensure that people are aware of the service, whether or not they choose to use it, and that research evidence on the needs of hard-to-reach communities is used to shape the development of new services.

All helpline staff attend diversity training workshops. It may also be important to raise awareness that the helpline offers the option of a translator for those not fluent or confident with English.

It was also interesting to note that around one-third of our callers were not aware that it was a free call. This raised the possibility that some people from poorer backgrounds would be less likely to call if they thought they would have to pay for the service. Moreover, it may have inhibited the 38% of respondents who were unaware of the free nature of the call from discussing their concerns fully. Promoting the fact that all Breast Cancer Care’s services are free therefore remains a priority.

Survey results indicated that 58% of respondents were over 50 years old, yet 80% of all breast cancers occur in women over 50. This suggests that older women are under-represented among helpline users, perhaps preferring to receive information and support from alternative services. This is an area that merits further research.

Breast Cancer Care is working with King’s College London on a two-year project to identify and explore potential barriers to uptake of its services. The organisation is committed to developing a strategy to address this.

While callers were most likely to have heard about the helpline from their breast care nurse, it is interesting to note that such a large percentage had heard about it from sources unrelated to their healthcare team. It is possible that there may be a fear among NHS healthcare professionals that external helplines will provide inaccurate or misleading information.

CONCLUSION
The survey has produced some reassuring results suggesting that most callers are satisfied with the service. However, it has also highlighted challenges for the future and the need to raise awareness, access and confidence among some communities and healthcare professionals.

The results have also indicated how we might alter the survey to better ascertain the psychosocial outcomes for callers. A follow-up survey could be useful to evaluate if any effects developed or altered over time. Implications for further research include the identification of potential barriers for groups often considered hard to reach in accessing services.

REFERENCES


