Hospital-based support groups are unable to meet the diverse needs of patients with cancer, and are being phased out in favour of more individualised support.

**In this article...**

- How the needs of patients with cancer differ
- The limitations of hospital-based support groups
- How stratified support meets individuals’ needs

**Keywords:** Cancer care/Support groups/Survivorship/Emotional support

This article has been double-blind peer reviewed

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Support groups have been an integral component of cancer care for decades, but their value to patients living with cancer is unclear. The function and relevance of cancer support groups is now being brought into question. The plethora of resources available to serve an increasingly culturally and socially diverse population of people living with cancer and cancer survivors, which has varied needs and is growing by 3% year on year (Macmillan, 2015). The prevalence of web-based resources and expansion in social media provide easy, quick and convenient access to health information and advice. Online patient-led (and health professional-regulated) discussion forums on cancer have increased in popularity, allowing people to participate from the comfort of their own home. In particular, people with or surviving breast cancer benefit from its high profile and, compared with other tumour groups, the varied range of resources available.

National strategies and policies are focused on improving the lives of all people affected by cancer, regardless of tumour type and prognosis. Within such a context, a hospital-based cancer support group appears dated and irrelevant.

What the literature says

A small qualitative study of patients attending cancer support groups in the Midlands found that satisfaction was poor in terms of addressing survivorship (Docherty, 2004). Another study found support groups were not considered suitable forums for addressing psychosocial needs, and that most support group participants tend to be white, middle-class women (Gottlieb and Wachala, 2007). This may account for the poor representation from black, minority ethnic and ethnically diverse population and those from lower socioeconomic backgrounds, despite evidence showing that these patients express interest in attending such groups (Avis et al, 2008).

Informal evidence

An informal survey among breast cancer clinical nurse specialists within London Cancer (an amalgamation of cancer care providers within central and north-east London) showed that, in the absence of health and wellbeing clinics, most cancer units continue to run support groups. The general consensus was that they were poorly attended and participants were mainly “regulars”, making groups more of a social gathering than a practical or informative event.

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One study found support groups did not effectively address psychosocial needs.

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5 key points

1. The number of cancer survivors is rising by 3% a year
2. Fewer than one in 10 patients with breast cancer in a study at one hospital said they would attend a hospital-based support group
3. Hospital-based cancer support groups cannot provide structured, individualised care to patients with complex, varied needs from diverse backgrounds
4. Nurses should encourage patients to be active regarding their health and wellbeing
5. Stratified care pathways offer supported self-care that is responsive to the needs of the individual
To provide a structure for group meetings, guest speakers were often invited, or an informal discussion took place on a chosen topic. However, it is debatable whether there can be any positive engagement with current cancer care practices within this format. Such groups lack a wide appeal and therefore discourage active recruitment, so running them is an inefficient use of stretched and valuable hospital resources.

Our research

Patients from across the breast cancer pathway at Barts Health Trust were invited to participate anonymously in a study between January and March 2013; those attending results (new diagnosis) clinics were excluded.

The purpose of the study was to evaluate patients’ behaviour and attitudes in finding information and support throughout their cancer journey. Data was gathered by a simple questionnaire designed in collaboration with our clinical psychology team, and approved by the trust’s ethics committee.

Random selection was facilitated by inviting patients to take a questionnaire from a labelled box when they arrived in clinic to complete while waiting for their appointment. The questionnaire consisted of 17 multiple-choice questions, of which three allowed for short free text responses when ticking the choice ‘other’. It was provided in English only, but non-English speaking patients could participate through an advocate. A short description of the study was attached to the box.

Returns were sampled periodically for qualitative purposes, and spoiled or incomplete questionnaires were excluded from the final data collection. In total, 81 questionnaires returned were fit for inclusion.

Results

Most of the participants were aged between 46 and 65 years. More than half described themselves as cohabiting with a spouse or partner and 14% lived alone.

Although Barts Health provides breast cancer care for five large London boroughs with a wide social, cultural and ethnically diverse demographic profile, 74% of participants were white; 12% recorded their ethnicity as black, 10% Asian and 4% other, while 1% chose not to disclose their ethnic origin. The fact that most of the participants in the study were white is reflective of research that found women from ethnically diverse backgrounds perceive that support groups and similar services privilege white women’s experiences with cancer at the expense of their own (Barg and Gullatte, 2001).

Working and getting back to work

Most participants were in full or part-time employment (Fig 1). Some of those who were not working described themselves as a “housewife”, “carer” or “retired”. Some who had stopped working during treatment decided to retire early after treatment, which is not uncommon. However, most employed participants either continued to work throughout treatment (34%) or resumed work shortly after completing treatment (56%).

While there are obvious financial motives for continuing to work, the psychological and physical benefits of continuing with or resuming normal activities, including work, during and/or after cancer treatment should not be overlooked and, where appropriate, encouraged.

The working practices of cancer teams – particularly CNSs – and their ability to communicate information effectively, monitor patients safely during treatment and build trusting relationships with patients are essential for helping patients continue with or return to normal daily function.

Stress, anxiety and emotional support

Participants were asked about stress and anxiety. Unsurprisingly, the levels of these were recorded as highest at the point of diagnosis and during treatment; 21% said treatment side-effects caused the most anxiety, while a further 6% said management of these effects was an ongoing concern.

When asked where or from whom they sought emotional and practical support during their cancer journey, most turned to their immediate family and social circle, although 17% said they managed well on their own (Fig 2). A number (24%) gained comfort and support from their religious, spiritual and cultural communities.

The relationship between the patient and clinical nurse specialist (CNS) was valued for information giving and decision-making support (40%). For 26%, “not being rushed during appointments” was important for reducing anxiety and retaining information.

Attitudes to support groups

Although some participants found it helpful to know others were having the same experiences (37%), most did not want regular informal or formal contact with other patients. Some patients said they preferred “to keep themselves to themselves” (39%) or did “not want to appear nosy or interfering” (43%). A further 9% said they personally would not “find it helpful” to discuss their experiences with others.

Reticence to contact other patients with cancer does not mean our patients lack empathy; 9% said they had consoled other patients. Some patients said they preferred to “keep themselves to themselves” (39%) or did “not want to appear nosy or interfering” (43%). A further 9% said they personally would not “find it helpful” to discuss their experiences with others.

Figures 1 and 2

Fig 1. Participants’ work status

- Worked during treatment: 34%
- Resumed work after treatment: 56%
- Did not return to work after treatment: 9%

Fig 2. Most valued sources of support

- Family/social circle: 78%
- CNS being easily accessible: 40%
- Not being rushed during appointments: 26%
- Cope well on my own: 17%
One size does not fit all

As our research indicates, recruiting patients into a “one size fits all” support group from across the cancer spectrum is not viable. While the study focuses on the support and information needs of a breast cancer cohort, the findings and recommendations can be applied to the wider cancer patient population.

Increasing demands on services and limited finances place secondary care providers under pressure to deliver efficient but cost-effective care across a wide spectrum of patients. While cancer CNSs are valued, there are few of them, and it is vital that their working practices are effective to meet the demands of an increasing and diverse cancer population within financial and time constraints.

Regardless of cancer type, patients who have recovered well with a good prognosis will have very different needs from those with an active or advanced disease. Neither informal nor more didactic hospital-based support groups are likely to encourage patients with a good prognosis to “sever the umbilical cord” and self-manage, as being situated in hospital carries the implication that users are too vulnerable or not yet able to manage without regular secondary care input.

The best strategies for meeting the complex needs of patients living with metastatic cancer are collaborative efforts between primary and secondary care providers, with an emphasis on providing high-quality, supportive cancer care close to home and avoiding hospital attendance unless absolutely necessary.

In addition, the cultural significance of having cancer within different ethnic groups is complex and must be recognised and addressed. This is difficult to achieve within a support group context and most likely accounts for the lack of patient demand and participation from a wider demographic.

Stratified support

The National Cancer Survivorship Initiative (2008) provides structured frameworks of care that encourage collaborative working between patients, hospitals, GPs and community services. The aim is to offer a wide range of information, strategies and therapeutic interventions for improving the lives of people living with cancer. Implementing stratified cancer pathways improves patient outcomes by promoting and sustaining recovery, managing the consequences of cancer treatment, and providing comprehensive packages of care to people living with active and advanced disease. Tools such as the holistic needs assessment (HNA) (Young et al, 2012) are used early in the cancer pathway to prompt care planning to help patients meet these objectives.

Health and wellbeing clinics

CNS-led health and wellbeing clinics, which form part of the NCSI recovery package, were introduced at Barts Health in 2010, following a successful pilot study within breast and gynaecology patient cohorts in partnership with Macmillan Cancer Care.

At the end of active treatment, the CNS uses the HNA tool to prioritise and address the most pressing concerns of each patient and anticipate longer-term problems, such as managing treatment side-effects. An individualised care plan is then developed, then evaluated and reviewed by the patient, GP and other relevant health professionals. The patient is also given a resource file containing information on wellbeing services including complementary therapies, as well as generic and tumour-specific cancer organisations.

The introduction of an e-HNA tool (Bit.ly/MacmillaneHNA) has made holistic assessments less complicated and the information can now be accessed via a database by all health professionals involved in a patient’s care. In partnership with Macmillan, the tool has now been rolled out to all other tumour groups across the trust. The positive impact of the health and wellbeing clinics, along with the results of this study, validated our decision to disband our breast cancer support group, which was poorly evaluated at peer review. Although a small core of lifelong members continue to use the group socially, it is no longer affiliated with the trust, while the health and wellbeing clinics are now well established.

Patient self-management

Supported self-care with open access follow-up is a risk-stratified model designed for patients with a good prognosis. Patients are assessed for suitability and entered into the open access follow-up programme early in their treatment pathway, so they are prepared physically and psychologically to make the transition from patient to proactive cancer survivor.

Open access programmes are CNS led but multidisciplinary in approach, which facilitates movement in the system should the patient require re-entry into formal follow-up. Of course, not all patients will suit self-management, and some will require shared care or more complex case management.

Conclusion

The findings of our study suggest the traditional hospital-based support group is a tired, ineffective concept that no longer meets the needs of an increasingly diverse cancer population. It should be replaced by evidence-based and individually tailored programmes that improve outcomes for all patients living with and beyond cancer.

References


FIG. 3, ACCESSING OTHER SERVICES

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<thead>
<tr>
<th>Expessed no interest</th>
<th>For addressing survivorship issues</th>
<th>Would refer themselves for specific needs</th>
<th>Might attend a hospital-based support group</th>
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<td>37%</td>
<td>29%</td>
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Helping survivors to adjust after cancer

Bit.ly/NTCancerSurvivorAdjust