An Irish Breast Cancer Survivorship Study: Are We Meeting Our Patients Needs?

Abstract:

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Abstract

Irish breast cancer survivors needs have not been studied. Physical, psychological, social and spiritual concerns were investigated. Patient satisfaction with hospital discharge, GP follow-up, and the benefit of a discharge pack was investigated. A cohort of patients from the South East Cancer Centre was identified. Inclusion criteria: localized breast cancer, completion of adjuvant therapy, GP-led follow-up in the last 5 years. An anonymous questionnaire was developed, and ethical approval obtained. Subgroup analyses for age and time since diagnosis and discharge were completed. 80 patients were identified, 44 patients (55%) completed the questionnaire, (6%) were excluded. Commonest concerns included: fatigue (51%), fear of recurrence (69%) and second cancers concerns (69%). 23 (59%) and 25 patients (64%) were satisfied with discharge and GP follow-up respectively. 27 patients (67%) reported benefit from a discharge pack. Irish breast cancer survivors had concerns, and were satisfied with GP follow-up.

Introduction

Breast cancer is the commonest cancer in Ireland, with approximately 2000 cases diagnosed per year. Due to improvements in early detection, screening, diagnosis, and treatment, breast cancer mortality in Ireland has reduced by 24% in the last five years. Cancer survivorship is a concept pioneered in the 1980s by the National Coalition for Cancer Survivorship (NCCS), and refers to the stage of cancer care after completion of active anti-cancer treatment. Clinical care during this period focuses on the encouragement of healthy behaviour, management of complications of therapy, and monitoring for signs of recurrence. In Ireland, this stage of cancer care is managed primarily by hospital-based services. Discharge from these services is not a standardized process across cancer centres. It is thus a challenge for hospital-based specialists to provide ongoing care to the growing number of survivors who have completed treatment. Breast cancer services in Ireland to date have focussed on early detection and treatment to improve patient survival. As the number of breast cancer survivors continues to grow, a model of comprehensive care is needed to address the specialized needs of this cohort of patients.

A number of models of survivor care are in operation in Australia, Canada and the United Kingdom (UK). Survivorship programs in the United States (U.S) and UK divide patients needs into physical, psychological, social and spiritual . Common physical symptoms addressed by survivorship programs include: pain, fatigue, sleep disturbance, nausea/vomiting, reduced appetite, general condition, mobility/balance, ability to perform daily tasks, and hair/skin symptoms. Psychological symptoms include: anger, anxiety, sadness, loss of independence, fear of recurrence, fear of death, depression/low mood, difficulty coping, isolation, future uncertainty, stress, and change, in family roles.

Social/supportive concerns refer to financial issues, health insurance, and return to employment. Psychological needs include fear of recurrence, information sent to the GP, lifestyle, nutrition, exercise information and updates to recommended care. A number of studies have assessed how and where survivorship care can be best delivered. A Canadian randomized controlled trial demonstrated no difference in health-related quality of life and recurrence-related clinical events, when comparing GP versus hospital-based follow-up for adjuvant breast cancer. A UK study demonstrated that patient satisfaction was better with GP-delivered follow-up cancer care compared to that delivered in hospital departments.

There is no published data on survivor care in Irish patients. Knowledge of their specific survivorship needs and if these needs are currently met, is not known. The primary aim of this study was to assess the needs of an Irish cohort of breast cancer survivors, who had completed care in a hospital-based medical oncology clinic, and were recently discharged to their GP. Needs were stratified into physical, psychological, social/supportive and spiritual. Secondary aims were to assess patient satisfaction with discharge from hospital-based services, satisfaction with GP follow-up, and the possible benefit of introducing a survivorship discharge pack.

Methods

Patients discharged from a medical oncology specialist clinic of the South East Cancer Centre from 2006-2012, were identified. Inclusion criteria were: a history of localized breast cancer, completion of adjuvant multimodality therapy within the last five years, and discharge from hospital-based oncology services to the GP in the last six years. Patients with metastatic disease, second cancers and male breast cancers were excluded. An anonymous questionnaire was adapted from standardized survivorship questionnaires used in European and American survivorship studies, and websites of large cancer institutions in the U.S including MD Anderson Cancer centre and the Mayo Clinic. Ethical approval was obtained for the questionnaire from the local ethics committee.

The questionnaire was subdivided into eight subsections. Section one captured patient demographics. Sections two to five dealt with current physical, psychological, supportive/social and spiritual concerns. Sections six and seven questioned patient satisfaction with discharge from the medical oncology clinic. Section eight assessed patients view of discharge information pack. The questionnaire is available from the authors. The questionnaire and its content, and to confirm patients were still alive. Patients were contacted by the investigators prior to questionnaire posting to confirm they still had a current GP. They were managed to each patient’s GP through a postage-paid return envelope. If a patient had questions or concerns, they were encouraged in writing to contact the study investigators, the oncology unit, or their GP.

Results

Eighty patients treated for localized breast cancer were discharged over a six-year period. Forty-four patients (55%) completed and returned the questionnaire. Five patients were excluded from the study (6%): 2 patients did not complete the questionnaire in its entirety, 2 patients indicated that they still attended hospital follow-up, and 1 patient had been discharged more than ten years ago. Patient demographic data is summarized in Table 1.

Physical Needs

The commonest physical concerns in this cohort were fatigue (51%), sleep disturbance (44%) and pain (38%) (Figure 1).

Psychological Needs

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The most common psychological concern was fear of recurrence, demonstrated in 27 patients (69%). Psychological concerns are depicted in Figure 2.

Social/Supportive Care Needs

29 patients (75%) had no concerns regarding returning to work. 20 patients (52%) and 22 patients (56%) did not report any financial and health insurance-related concerns respectively.

Spiritual Needs

Spiritually, the majority of patients had no concerns regarding the need for religious support (84%) or loss of faith (89%).

Secondary aims

Table 2 outlines patient's satisfaction with discharge from the specialist clinic. 29 patients (73%) had been informed of discharge, and 23 (59%) were satisfied this. 25 patients (64%) were content with GP cancer-care follow-up. 23 patients (59%) reported that a treatment summary would have been beneficial to them. 59%, 55%, 57% and 36% of patients felt that they required additional physical, psychological, social and spiritual information respectively. The patients assessment of the services available to them was sought. 28 patients (69%) had concerns regarding second cancers, and 19 patients (48%) felt adequate services were lacking to address these concerns.

Statistical Analysis

Patients under 60 years of age were more likely to express physical concerns (p=0.01.) Rates of physical and psychological concerns decreased with increasing time from diagnosis (p-trend<0.01.) Patients had more psychological concerns in the first two years after discharge to their GP's (p=0.017.)

Discussion

The increasing survival of patients with early stage breast cancers leads to a responsibility for ongoing or "survivorship care". Irish patients are monitored by hospital-based services for a number of years after active anti-cancer therapy, and then discharged to their GP for follow-up care. This study aimed to identify the ongoing needs of these patients after discharge from hospital-based services. We identified that the majority of breast cancer survivors have ongoing concerns across a number of domains.

This study demonstrates that a median of 23% of respondents continue to experience physical problems, 28% have psychological concerns, 44% have social/supportive issues, and 12% have spiritual concerns. Similar findings have been reported in larger survivorship studies. A large UK study reported a 50% incidence of physical symptoms. Psychologically, cancer survivors have been shown to suffer more distress than those who have never experienced cancer. Interestingly, in this cohort there was a very low incidence of spiritual concerns compared to breast cancer survivors in the U.S. or Europe. This could highlight a unique aspect of Irish survivorship attitudes. In many cases, only mild concerns were expressed. However, the authors acknowledge that the divisions of mild, moderate and extreme concerns can be subjective. Fear of cancer recurrence is known to be one of the chief concerns of cancer survivors. 69% of the study cohort reported this concern. Such concerns are often most effectively addressed by specialists. Thus, the development of specialist-run survivorship programs and national cancer rehabilitation hospitals have been favoured in North America and Nordic countries respectively.

The secondary aims of this study were to assess patient satisfaction with GP-led follow-up care and the provision of a discharge pack. 64% of respondents were satisfied with GP-led cancer follow-up. Primary care could therefore be considered as a potential model of care for breast cancer survivors in Ireland. Facilitation of direct communication between GPs and specialist oncologists as well as further training and access to services, could improve GP-led cancer care. Survivor care plans have been developed in other countries based on patients' needs. The Institute of Medicines 2006 report on Cancer Surviviorship and the ASCO Survivorship Task Force, advocates for the supply of a survivorship care plan to patients on completion of primary anti-cancer therapy. This plan consists of cancer follow-up guidelines, information regarding the management of medical concerns, and links to survivorship support groups. 67% of respondents felt they would benefit from a discharge pack. Interestingly, younger patients in this cohort were more likely to report physical concerns. This finding is consistent with published data. Patients reported less psychological and physical concerns with increasing time since diagnosis, consistent with improvements in treatment-related toxicity with time. Less psychological concerns were expressed with increasing time since discharge to the GP. A possible explanation could be increased familiarity with GP-led cancer care.

There are some limitations to our findings. Our study was conducted in a geographically small area of Ireland, with all
patients discharged from the same oncology team. It is therefore possible that these patients may not be representative of all Irish breast cancer survivors. Likewise, respondents to the questionnaire could represent those patients with greater concerns. We may therefore be underestimating the concerns of Irish breast cancer survivors overall. A potential solution would be to expand the study to different sites across Ireland. The response rate of the questionnaire is comparable with survey-based studies. However, a greater response rate may be achieved by delivering questionnaires to patients at the time of discharge.

The current model of survivorship care in Ireland faces considerable challenges—increasing numbers of survivors, limited numbers of oncology specialists, multidisciplinary needs, economic constraints, and a disconnect between hospital-based care and community-based resources. This study identifies that Irish breast cancer survivors have ongoing concerns throughout their journey from hospital-based care and community-based resources. The implementation of a survivorship discharge pack including a questionnaire to patients at the time of discharge could be a potential solution. We hope that the findings of this study will support changes to the implementation and development of a comprehensive Irish survivorship care model.

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