



Provision of survivorship care for patients with haematological malignancy at completion of treatment: A cancer nursing practice survey study



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A B S T R A C T

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Purpose: Many haematological cancer survivors report long-term physiological and psychosocial effects, which persist far beyond treatment completion. Cancer services have been required to extend care to the post-treatment phase to implement survivorship care strategies into routine practice. As key members of the multidisciplinary team, cancer nurses' perspectives are essential to inform future developments in survivorship care provision.

Methods: This is a pilot survey study, involving 119 nurses caring for patients with haematological malignancy in an Australian tertiary cancer care centre. The participants completed an investigator developed survey designed to assess cancer care nurses' perspectives on their attitudes, confidence levels, and practice in relation to post-treatment survivorship care for patients with a haematological malignancy.

Results: Overall, the majority of participants agreed that all of the survivorship interventions included in the survey should be within the scope of the nursing role. Nurses reported being least confident in discussing fertility and employment/financial issues with patients and conducting psychosocial distress screening. The interventions performed least often included, discussing fertility, intimacy and sexuality issues and communicating survivorship care with the patient's primary health care providers. Nurses identified lack of time, limited educational resources, lack of dedicated end-of-treatment consultation and insufficient skills/knowledge as the key barriers to survivorship care provision.

Conclusion: Cancer centres should implement an appropriate model of survivorship care and provide improved training and educational resources for nurses to enable them to deliver quality survivorship care and meet the needs of haematological cancer survivors.

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Introduction

Over the years, advances in early detection, diagnosis and treatment of cancer have resulted in a rapidly growing cancer survivor population. In the United States, five-year survival rates have increased from 49% in the 1970's to 67% in 2004 (Ness et al.,

2013). Similarly promising survival rates have been achieved in Australia, with five-year survival trends increasing from 47% in the 1980's to approximately 66% for all cancers combined between 2006 and 2010 (Australian Institute of Health and Welfare, 2012). One of the most common forms of haematological cancers, non-Hodgkin lymphoma, demonstrated the largest absolute increase in five-year survival rates, increasing by 17% over the past two decades (Australian Institute of Health and Welfare, 2012). The overall prognoses for other common forms of haematological cancers are also promising, with 87% of cases of Hodgkin lymphoma and approximately 50% of leukaemia cases, surviving five

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years post diagnosis (Cancer Council Australia, 2014; The Leukaemia Foundation, 2008). However, having better survival prospects is only part of the journey for many cancer patients, as many continue to experience a myriad of acute, chronic and late effects of cancer and its treatment (Ness et al., 2013). There has been growing interest in improving the quality of survivorship care with improved focus on the health and life of a person with cancer during the post-treatment phase until the end of life (National Cancer Institute, 2014). These efforts emphasise attention to the physical, psychosocial, and economic issues associated with cancer, that are beyond the diagnosis and treatment phases. The needs of families who are part of the survivorship experience are also being increasingly recognised (DoHA and Flinders University, 2009; Hewitt et al., 2005).

As many as 75% of cancer survivors experience physiological and psychosocial health deficits as a result of cancer and its treatment (Ness et al., 2013). Treatment of haematological cancers are often complex and can result in debilitating short- and long-term effects (Lobb et al., 2009). Some of the physiological effects include pulmonary, cardiovascular and renal complications, infertility, recurrent infections, impaired organ function, functional impairments, pain, fatigue, malignancy recurrence and risk of subsequent malignancy (Hewitt et al., 2005; John and Armes, 2013; Tichelli et al., 2008). Compared to the general population, haematological cancer survivors are at twice the risk of developing a secondary primary cancer (Loft, 2013). Psychosocially, survivors may face depression, anxiety, fear of relapse, reduced household income and associated financial stress, sexual dysfunction, relationship issues and limited capacity to engage in full-time employment, social activities and household duties (Jarrett et al., 2013; Stein et al., 2008). In addition to these physical and psychosocial effects, survivors have reported feelings of abandonment at the completion of treatment, with follow-up care rarely involving discussions addressing health promotional advice or psychosocial strategies to improve well-being (Committee on Cancer Survivorship: Improving care and quality of life, 2005; Lobb et al., 2009; Lotfi-Jam et al., 2009). Further, follow-up care is often fragmented and uncoordinated, with some cancer survivors receiving excellent follow-up care, whilst others are left to manage and seek resources as they are able (Lotfi-Jam et al., 2009).

Given the issues highlighted above, the need for a survivorship paradigm shift had become evident. The Institute of Medicine (IOM) released a seminal report, *From cancer patient to cancer survivor: Lost in transition*, recommending and challenging health-care providers to integrate survivorship care into practice. A key emphasis of the report was that the transition from active to post-treatment care is critical to long-term health and that post-treatment care should be conceptualised as comprising four key areas: prevention and detection of new and recurrent cancers, surveillance for cancer spread or recurrence, interventions for the physical, psychosocial and economic consequences of cancer and its treatment and coordination of care between providers (Hewitt et al., 2005). Several models for providing survivorship care were identified, including the suggestion “oncology nurses could play a key role” in the development and delivery of a survivorship care plan; a model of care which “appears to be promising” (Hewitt et al., 2005). Indeed, nurses have assumed essential roles in the provision of survivorship care across Europe and Australia, with a steady growth in the literature over the past decade suggesting these roles contribute positively towards post-treatment outcomes (de Leeuw and Larsson, 2013; Gates and Krishnasamy, 2009; Lee, 2008). Given nurses spend the greatest portion of time providing direct patient care and are central to any multidisciplinary effort in the delivery and coordination of survivorship care; the IOM suggests they “may be the best providers of survivorship care” (Tichelli

et al., 2008). The purpose of the current pilot study was to examine cancer nurse perspectives on the nursing responsibilities of survivorship care provision for patients with a haematological malignancy, which will inform the conduct of a large national study involving Australian cancer nurses and the feasibility of integrating the essential components of survivorship care into routine nursing care.

Method

Aims

The aims of this pilot study were (i) to identify acute cancer care nurses' perspectives on their attitudes (whether specific tasks associated with survivorship care should part of the nursing role), confidence levels (how confident they are to deliver survivorship care), and practice (how often they deliver survivorship care) in relation to post-treatment survivorship care for patients with a haematological malignancy; (ii) to examine nurses' perspectives of barriers that impede their provision of survivorship care; and (iii) to examine if there are any relationships between nurses' professional factors (years of cancer nursing experience, work setting, highest qualification) and attitude, confidence and frequency of use of survivorship practices.

Study design

A prospective cross sectional survey design was used. Potential participants were all nurses caring for patients with haematological cancer in an Australian tertiary cancer care centre. Assistants in nursing or other non-regulated nursing staff were excluded from the study. We invited all eligible nurses (approximately 200 nurses) to participate in the study. At this cancer centre, the model of survivorship care was physician-led, with supportive care services provided by nursing and allied health staff. Further, survivorship care plans were not part of standard practice at this cancer centre. This study was approved by the Research Governance Office of the Royal Brisbane and Women's Hospital as a low and negligible risk ethics research.

Procedure

All registered and enrolled nurses employed full- or part-time at the study site were invited to participate in this study. This study was discussed during in-service sessions as well as nursing leadership meetings. All eligible nurses were invited to participate by the investigators via email, or nursing unit managers and research assistants during their clinical handover time. The paper formatted study questionnaires were self-administered by participants. Participation in the study represented implied consent. It was emphasised that the survey was anonymous and that refusal to participate would not result in any negative or disciplinary consequences. Participants who completed the survey were given a free coffee voucher as an incentive.

Measurement

The 83-item survey questionnaire comprised three sections. Section 1 consisted of minimum baseline characteristics (age, gender, years of experience in cancer nursing, highest qualification, work settings and main role), while Sections 2 and 3 included an inventory of common survivorship practices and barriers influencing survivorship practices respectively. Survey items for Sections 2 were generated from recommended survivorship practices identified in the IOM seminal report *Lost in transition: From cancer*

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