European Journal of Oncology Nursing 17 (2013) 521–527

Contents lists available at SciVerse ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Developing a nurse-led survivorship service for patients with lymphoma

Claire John [a,*], Jo Armes [b]

[a] 'Guy's and St Thomas' NHS Trust, Great Maze Pond, London Bridge, London SE1 9RT, UK
[b] Florence Nightingale School of Nursing & Midwifery, UK

Keywords:
Cancer
Lymphoma
Survivorship
Nurse-led services
Service development
Follow-up care

ABSTRACT

Purpose: There are two million people in the UK living with cancer and this figure is rising each year. The consequences of cancer and its treatment are devastating and many patients suffer long-term effects for years after completion of treatment. National UK policy recognises that current follow-up fails to meet patients' survivorship needs and new methods of service-delivery are required. An analysis of local service provision in a London teaching hospital demonstrated that the needs of patients with lymphoma were not being met. The aim of this project was to develop a nurse-led service that would provide comprehensive survivorship care for patients with lymphoma.
Method: A nurse-led survivorship service was implemented using a comprehensive service development framework and was evaluated through a variety of methods such as a patient satisfaction questionnaire, note audit, waiting time audit and an analysis of patients comment and suggestions.
Results: The project was successfully implemented with risk management and advanced practice requirements addressed. It was demonstrated that patients were satisfied with the new service, the quality of documentation had improved and waiting times were reduced.
Conclusion: This work adds to the current survivorship knowledge-base and provides evidence that nurses can provide safe and effective survivorship care for patients with lymphoma.

Introduction

Over 12,000 people in England and Wales develop lymphoma every year and a third die as a result of their disease (Cancer Research UK, 2010). Though these figures are concerning, it is often easy to forget that two thirds of adults are cured and still alive five years after diagnosis (NICE, 2003; National Cancer Survivorship Initiative (NCSI), 2009). As a result of improvement in diagnosis and advances in medical treatments, death rates for lymphoma have fallen more than 60% since the 1970's (Hewitt et al., 2006)

The number of cancer survivors in the UK is estimated to be over two million. (Macmillan Cancer Support, 2008a; NCSI, 2010). The increasing number of people living with cancer means it is now frequently identified as a chronic disease, with issues of 'survival' being seen as increasingly relevant (Loescher et al., 1990; NCSI, 2010). Whereas care initially focused on treatment and end-of life phases of the cancer trajectory, it is now recognised there is a need to improve services for patients in the 'survivorship' phase of their cancer journey (Hewitt et al., 2006; DOH, 2007a; Rowland, 2008; NCSI, 2010). Both the short and long-term consequences of cancer and its treatment can be devastating for patients and their family. Although the population of cancer survivors is heterogeneous, with 50–70% of patients having few effects from their treatment, others suffer permanent disabling symptoms such as psychological distress, sexual dysfunction, infertility, impaired organ function and limitations in mobility, communication and cognition (Hewitt et al., 2006; Sheldon and Sizmur, 2009; NCSI, 2010).

Current follow-up

Currently in the UK, access to comprehensive post-treatment care and late-effects monitoring is limited, and there is no standardised approach to the delivery of services (NCSI, 2009, 2010). There are no national guidelines for the follow-up of patients with lymphoma, so most clinicians follow locally developed guidance based on the best available evidence that focus on monitoring for disease relapse and to a lesser extent medical late-effects of treatment (Cunningham et al., 2004). Few make provision for the psycho-social needs of survivors (Greenfield et al., 2009). The 'Improving Outcomes Guidance for Haematological Malignancies' (NICE, 2003) states that intensive follow-up of patients offers no

---

* Corresponding author. Tel.: +44 07557 736 457.
E-mail address: eclaire106@hotmail.com (C. John).

1462-3889/$ – see front matter © 2013 Elsevier Ltd. All rights reserved.
http://dx.doi.org/10.1016/j.ejon.2013.03.001

clinical advantage and patients should only be followed-up long-term to monitor for late-effects, but offers no guidance on the recommended content or timing of follow-up care. No standardised model of service-delivery has been applied consistently across cancer networks, nor has any attempt been made to comprehensively examine the quality, content, or optimal frequency of follow-up of survivors (Devane, 2009).

There is evidence that current cancer follow-up does not always meet the needs of patients (Davies and Batehup, 2009; Torjsen, 2010), with some patients reporting feelings of abandonment during the transition from cancer patient to survivor (Cardy, 2006; NHS Confederation, 2010). There is little data to show that routine cancer follow-up has benefits in terms of early diagnosis of relapse, with evidence indicating that many recurrences are detected by patients between scheduled clinic visits (Collins et al., 2004; Montgomery et al., 2007; Torjsen, 2010). There is also little evidence of late-effect surveillance in current follow-up practice (Greenfield et al., 2009). Therefore, it has been suggested that the routine follow-up of patients by doctors in busy outpatient clinics is inappropriate and we should be looking to more innovative interventions to replace the costly hospital model of care currently in place (Moore et al., 2006; DOH, 2007a,b).

Although it is widely recognised that high-quality survivorship care should include holistic assessment of physical, psychological and social needs, this is not currently part of follow-up (Collins et al., 2004; Torjsen, 2010). The NCSI (2010) recognises that care should be tailored to meet the need of the individual, not the ‘one size fits all’ model that is currently in place.

Nurse-led survivorship care

The modernisation of health-services has given nurses the opportunity to challenge traditional roles and move professional boundaries. It is now widely recommended that nurse-led care be considered when evaluating service provision (DOH, 2004, 2007a; NICE, 2005). There have been several studies looking at nurse-led follow-up in cancer care (Helgesen et al., 2000; Moore, 2002; Koinberg et al., 2004; Beaver et al., 2009), but much of the evidence relates to survival (Moore, 2002) and patient satisfaction (Beaver et al., 2009), with few studies looking specifically at survivorship or late-effect monitoring. There is no published literature specifically about lymphoma or haematology follow-up, with the majority of the literature concentrated on breast, prostate and lung cancer.

.Evidence indicates that nurses are well placed to provide survivorship care (Davies and Batehup, 2009; NHS Confederation, 2010). Oncology nurses provide high-quality care in areas such as pain-control, fatigue, sexuality, fertility, late-effects of treatment and other areas pertaining to survivorship (Ferrell et al., 2003). Therefore, nurses appear to be well suited to lead survivorship care, but despite the obvious appeal, such a model has not been widely implemented or evaluated in the UK or the US (Greenfield et al., 2009; Hewitt et al., 2006). Therefore, the purpose of this service development project was to develop a nurse-led follow-up clinic for patients with lymphoma that provides high-quality survivorship care.

Objectives of the service were to:

- Undertake holistic assessment of patients’ medical, emotional, practical and financial needs.
- Monitor for disease relapse and detect new cancers.
- Ensure lymphoma patients are monitored for treatment late-effects and undergo appropriate investigations.
- Provide high-quality written information on a wide range of topics.
- Actively engage patients in their own health management and promote self-care behaviour.
- Provide late-effect surveillance and documentation of late-effects data.
- Provide a point of contact for lymphoma patients who have completed treatment and rapid access to specialist advice as necessary.
- Improve patient experience and reduce waiting times.

Setting

The service development took place in a large, central London teaching hospital with 1100 beds that treats over 800,000 patients each year. It has a large haematology department, with over 800 patients in the lymphoma service. With the growing incidence of lymphoma, the rising age of the population and prolonged survival of cancer patients, it is expected that these numbers will rise each year, as patients are not currently discharged from the clinic.

At the time the project was undertaken, patients were offered annual medical follow-up in a busy clinic consisting of newly diagnosed patients, those receiving treatment, and follow-up patients. The clinic space was overcrowded and patients could wait up to three hours to see a clinician. The consultation focused on disease relapse, little attention was given to psycho-social issues and there was no provision for late-effect monitoring. See Box 1 for an outline of the service development.

Advanced nursing practice

Comprehensive planning was identified as key to the project, especially pertaining to advanced practice roles. Professional development is essential to safe nurse-led services and underpins a competent service (Hatchett, 2008). It is important to ensure structures are in place to enable the practitioner to identify deficits in their knowledge-base and to rectify these (Daft and Marcic, 2004). Six methods of ensuring and maintaining competence were identified and incorporated into the development as outlined in Box 2.

Service evaluation

An essential part of the service development project was to establish how the organisation functioned prior to the intervention and gather evidence to demonstrate how it could be improved (Cummings and Worley, 2009). Resources in healthcare are limited and managers require evidence that a project will benefit

Box 1.

The nurse-led survivorship service.

Clinic: Run by two clinical nurse specialists (CNS’s) who see patients on a fortnightly basis. Patients are reviewed at least annually.
Patients: 3 years post completion of treatment for lymphoma and in clinical remission.
Intervention: 30 min consultation, comprising of physical and psychological assessment using recognised tools. Clinical investigations e.g. blood tests, ECG’s and X-rays to monitor for late-effects of treatment. Consequences of treatment and health promotion topics were addressed and patients provided with a leaflet on late-effects of treatment, an ‘information prescription’ and CNS contact details. They are encouraged to discuss any other concerns and are directed to further support if required.