Effect of a nurse-led lymphoma survivorship model of care: A pragmatic phase II pilot randomised controlled trial

Karen Taylor
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Appendix A

A.1 Models of Survivorship Care Provision in Adult Patients with Haematological Cancer: An Integrative Review

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Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review

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APPENDICES

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REVIEW ARTICLE

Models of survivorship care provision in adult patients with haematological cancer: an integrative literature review

Karen Taylor · Raymond Javan Chan ·
Leanne Monterosso

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Abstract
Purpose Increasing numbers of haematology cancer survivors warrant identification of the most effective model of survivorship care to survivors from a diverse range of haematological cancers with aggressive treatment regimens. This review aimed to identify models of survivorship care to support the needs of haematology cancer survivors.
Method An integrative literature review method utilised a search of electronic databases (CINAHL, Medline, PsycINFO, PubMed, EMBASE, PsycArticles, and Cochrane Library) for eligible articles (up to July 2014). Articles were included if they proposed or reported the use of a model of care for haematology cancer survivors.
Results Fourteen articles were included in this review. Eight articles proposed and described models of care, and six reported the use of a range of survivorship models of care in haematology cancer survivors. No randomised controlled trials or literature reviews were found to have been undertaken specifically with this cohort of cancer survivors. There was variation in the models described and who provided the survivorship care.
Conclusion Due to the lack of studies evaluating the effectiveness of models of care, it is difficult to determine the best model of care for haematology cancer survivors. Many different models of care are being put into practice before robust research is conducted. Therefore, well-designed high-quality pragmatic randomised controlled trials are required to inform clinical practice.

Keywords Models of care · Survivorship · Haematological cancer · Nurse-led · Shared care · Follow-up care

Introduction
Internationally, survivorship care is recognised as a priority in the cancer care continuum. This has been principally guided by the Institute of Medicine (IOM) report in 2005, From Cancer Patient to Cancer Survivor: Lost in Transition [1]. By 2008, 16 European countries had defined national cancer plans, but to date, very few have survivorship services operating [2]. The National Coalition for Cancer Survivorship [3] defines survivorship as the experience of living with, through, and beyond a diagnosis of cancer and includes the impact on family, friends, and caregivers. It is recognised throughout the literature, based on the IOM essential components of survivorship care, that survivorship care should include the following components [4, 5]:

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• Prevention; screening and interventions for recurrence, long-term and late effects; early detection of new cancers;
• Assessment, support, management, and information provision of physical, psychological, social, and spiritual needs;
• Monitoring, information, and promotion of healthy living behaviours and disease prevention; and
• Coordination of care between providers to communicate overall health needs.

Current conventional models of survivorship care, including routine follow-up, predominately focus on surveillance for recurrence and monitoring of physical side effects, rather than provision of supportive care, health promotion, late effects monitoring, and surveillance for new cancers [6, 7]. With an increasing awareness that communication between health care professionals and patients is suboptimal and that information provided to patients and primary care providers at treatment completion is often inadequate [8, 9], there is a growing movement to redesign how survivorship follow-up care is delivered. Furthermore, cancer patients frequently experience multiple health problems earlier than the general population [10], suggesting a need for early and ongoing, comprehensive approaches to management designed to promote and support patient participation in maximising recovery.

Haematology cancer patients are underrepresented and understudied in survivorship care [11] despite international figures indicating an increase in 5-year relative survival rates [12]. The most common haematological cancers are leukemias, lymphomas, and multiple myelomas (MM) [13]. Each of these has distinctive and complex treatment regimens that commonly involve aggressive high-dose chemotherapy agents, and/or targeted therapies, radiotherapy, and haematopoietic stem cell transplants [14]. Unfortunately, the consequence of largely aggressive treatment includes long-term and late physical, practical, and psychosocial effects which include fear of recurrence, fertility, relationship, financial, employment, and insurance issues [15–17]. A qualitative study on specialist-led follow-up with haematology cancer survivors reported a lack of preparation and support in finding information and resources with poor continuity of care as patients transitioned into the survivorship phase [18]. These patients, therefore, may require models of survivorship care with specific components that differ from those designed for the more common cancers (breast, prostate, and colorectal).

Two systematic reviews [19, 20] and a literature review [6] on survivorship models of care have been recently published. Sussman et al. [20] reviewed 12 randomised controlled trials (RCTs) and four systematic reviews. De Leeuw and Larsson [6] reviewed 21 nurse-led follow-up studies and Howell et al. [19] evaluated ten practice guidelines and nine RCTs. All primary outcomes in the reviewed studies were related to recurrence detection and in some cases health-related quality of life and/or patient satisfaction [6, 19, 20]. Importantly, all studies included cancers with similar trajectories of care (breast, prostate, and colon), making generalisations to other complex cancers such as haematological cancers difficult. Therefore, the haematology focus of this integrative literature review will add to the limited body of knowledge currently available in this cohort of survivors.

This integrative literature review undertook an analysis of the literature to examine the following questions:

1. What are the common attributes of survivorship models of care developed generally for cancer patients and specifically for haematology cancer patients?
   a. What resources (human, financial, tools, and care plans) are required to support these models of care?
   b. What are the potential benefits and shortfalls of these models of care?
   c. What outcome measures have been used to evaluate these models of care and what are the findings?

Method

The integrative literature review method was chosen as the theoretical framework to guide this review. It is structured according to five stages: problem formulation, literature search, data evaluation, data analysis, and presentation. This allows for an in-depth evaluation of the issues encompassing the empirical, theoretical, and clinical approaches within a structured systematic methodology [21].

Problem formulation

To date, the term ‘Model of Care’ (MOC) has not been well defined in published literature. In this review, MOC, as defined by the Robert Wood Johnson Foundation [22], is a conceptual outline of how to plan all current and future facility and clinical services to guide and direct a patient’s experience within a health care system. Essential elements of any MOC include a clear identification of health professionals responsible for planning and coordination of care, care delivery setting [20], promotion of health maintenance, effective illness interventions, and establishing and evaluating expected clinical outcomes [23]. The medical specialist has traditionally led haematology cancer care follow-up; however, other models of cancer survivorship follow-up are now emerging [24]. Therefore, the focus of this integrative literature review was to identify models of care used by health care providers to ensure quality survivorship follow-up for haematology cancer survivors.
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Support Care Cancer

Literature search

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Psychinfo, PubMed, EMBASE, PsycArticles, and Cochrane Library from earliest records to July 2014. Combinations of the following search terms were used: (model of care or follow-up or nurse-led or shared care or primary care provider-led or General Practitioner-led or oncology-led or end of treatment or post-treatment) and (survivorship or cancer survivor or survivorship care) and (cancer or neoplasm or oncology) and (haematology or leukaemia or lymphoma or multiple myeloma). A hand search of the reference lists from full-text articles was correspondingly employed. Searches were restricted to the English language, humans and adults. Inclusion criteria used were: clinician experiences of MOC for the post-treatment phase of haematological cancer; articles that reported on models of care; and articles that reported on the structure of survivorship services. Exclusion criteria were: studies with less than a 50% haematology cancer patient/haematologist cohort; studies that reported MOC for patients who received curative surgery only (i.e. no chemotherapy and/or radiotherapy treatment); studies reporting MOC from child, adolescent, or adult survivors of a childhood cancer; non-cancer MOC studies; MOC studies that lacked provider of survivorship care information; and opinion papers, letters, editorials, commentaries, conference abstracts, conference proceedings, or case studies.

Data evaluation stage

Abstract titles were reviewed by one author [KT] to assess eligibility. A summary of the selection process [25] is provided in Fig. 1. The initial search yielded 2,907 abstracts. Following removal of duplicate articles and screening using the exclusion and inclusion criteria, 61 full-text articles were retrieved. Of these, 14 articles met the inclusion criteria and were included in this review. The documented methodological characteristics included authors, publication year, country, study design, model, provider, disease, years post-treatment, sample size and response rate, resources required, potential benefits, potential deficits, outcome measures, results, and level of evidence developed by Melynyk and Fineout-Overholt [26] shown in Table 1. Due to variations in study population and methodologies used, meta-analysis was not possible.

Results

Study characteristics

No systematic reviews of haematology cancer survivorship models of care were found. In total, 14 articles were included in this review. Eight articles described and proposed different models of survivorship care [27, 28, 1, 5, 29, 30, 9, 7] (Table 2). An additional six articles reported the use of a range of models of care for haematology cancer survivors: two

![Flowchart of literature search results](flowchart.png)
APPENDICES

Table 1  Levels of evidence

<table>
<thead>
<tr>
<th>Level</th>
<th>Evidence</th>
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</thead>
<tbody>
<tr>
<td>I</td>
<td>Systematic review of all relevant randomised controlled trials</td>
</tr>
<tr>
<td>II</td>
<td>At least one well-designed randomised controlled trial</td>
</tr>
<tr>
<td>III</td>
<td>Well-designed cohort studies without randomisation</td>
</tr>
<tr>
<td>IV</td>
<td>Well-designed cohort studies, case control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case-series</td>
</tr>
<tr>
<td>V</td>
<td>Systematic reviews of descriptive and qualitative studies</td>
</tr>
<tr>
<td>VI</td>
<td>Single descriptive and qualitative studies</td>
</tr>
<tr>
<td>VII</td>
<td>Expert opinion from clinicians, authorities and/or reports of expert committees or based on physiology</td>
</tr>
</tbody>
</table>

Table 2  Existing or proposed models of cancer survivorship care

<table>
<thead>
<tr>
<th>Setting</th>
<th>Model</th>
<th>Provider</th>
<th>Model characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital</td>
<td>Multidisciplinary survivorship clinic [7]</td>
<td>Oncologist, network of consulting physicians, nurse practitioner (NP), psychologist, and social worker</td>
<td>Can be consultative or ongoing</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Multiple providers seen at same visit</td>
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<td></td>
<td>Complex and resource intensive</td>
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<td></td>
<td>Co-morbid and treatment-related conditions can be addressed</td>
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<td></td>
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<td></td>
<td>Can be extension of care, embedded in treatment team</td>
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<td></td>
<td>Disease-specific specialist defines follow-up plan</td>
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<td></td>
<td></td>
<td></td>
<td>NP follow-up who communicates with PCP to initiate shared care plan</td>
</tr>
<tr>
<td>Consultative clinic [27, 29]</td>
<td>Specialist</td>
<td>Ongoing (weekly) Oncologist takes primary cancer role</td>
<td></td>
</tr>
<tr>
<td>Consultative clinic [7]</td>
<td>Specialist</td>
<td>One-time comprehensive visit</td>
<td></td>
</tr>
<tr>
<td>Survival clinic [1, 30]</td>
<td>Specialist</td>
<td>Treatment summary and survivorship care plan</td>
<td></td>
</tr>
<tr>
<td>Survival clinic [1, 30]</td>
<td>Specialist</td>
<td>Review of recommendations — surveillance, screening, and nutrition</td>
<td></td>
</tr>
<tr>
<td>Survival clinic [1, 30]</td>
<td>Specialist</td>
<td>Separate from routine care</td>
<td></td>
</tr>
<tr>
<td>Survival clinic [1, 30]</td>
<td>Specialist</td>
<td>Holistic assessment of survivor</td>
<td></td>
</tr>
<tr>
<td>Late effects clinic [9]</td>
<td>Nurse and/or specialist</td>
<td>End of treatment or maintenance therapy</td>
<td></td>
</tr>
<tr>
<td>Late effects clinic [9]</td>
<td>Nurse and/or specialist</td>
<td>Treatment summary, survivorship care plan, and individualised information provision</td>
<td></td>
</tr>
<tr>
<td>Late effects clinic [9]</td>
<td>Nurse and/or specialist</td>
<td>Can have telephonic follow-up</td>
<td></td>
</tr>
<tr>
<td>Nurse-led [1, 27]</td>
<td>Oncology nurse or NP</td>
<td>Haematology/oncology treatment centre</td>
<td></td>
</tr>
<tr>
<td>Nurse-led [1, 27]</td>
<td>Oncology nurse or NP</td>
<td>Comprehensive, long-term follow-up to assess and provide primary care needs</td>
<td></td>
</tr>
<tr>
<td>Nurse-led [1, 27]</td>
<td>Oncology nurse or NP</td>
<td>ASCO surveillance recommendations used</td>
<td></td>
</tr>
<tr>
<td>Nurse-led [1, 27]</td>
<td>Oncology nurse or NP</td>
<td>Clinic and telephone follow-up</td>
<td></td>
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</tbody>
</table>

reported nurse-led studies [21, 32] and four referred to physician-led studies [33, 8, 34, 35] (Table 3). The included articles reported views from Australia (n = 1), the US (n = 10), and the UK (n = 3) as shown in Table 3. The eight articles that described and proposed various models of survivorship care were categorised into three main settings: hospital-based, primary care-based, and shared care and included models, providers, and characteristics. The results are shown in Table 2. These included articles used multiple terms to describe clinicians. For clarity, the following terms have been used: primary care provider (PCP) to denote community-based general practitioners (GP) or family physicians; specialist to represent the main hospital consultant oncologist (medical, radiation, and surgical) or haematologist; and nurse which includes nurse specialist, nurse practitioner (NP), or nurse coordinator.

Of the six studies that reported the use of specific models of survivorship care, four were quantitative and two were qualitative studies. Studies reflected moderate (IV) to low (VI) levels of evidence.

Data analysis and presentation

Cancer survivorship MOC

The first component of this integrative literature review was to identify different models of survivorship care (Table 2). Characteristically, hospital-based follow-up care is commonly specialist-led, with often no end point [27, 29]. Survivors may acquire an impression the specialist has become their primary carer, particularly if they have assessed and treated co-morbid conditions during the treatment phase [7]. Multidisciplinary disease-specific clinics [5, 9, 7] and survivorship clinics were most often a one-time consultation for an assessment, plan of follow-up care provision and referrals to other health care providers [1, 30]. Clinics within this framework frequently

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consulted on one aspect of post-treatment care, such as late effects [9].

Nurse-led survivorship clinics, as described, were mostly hospital-based and delivered a number of interventions including information, symptom management, psychosocial support, allied health referrals, and health promotion strategies [27]. They can involve longer consultations and more frequent patient contact [27, 6]. PCP-led models involved a complete transition of all care from the hospital specialist to PCP [28, 5, 9]. This can be challenging for specialists who decide to transition care, as the level of knowledge and experience amongst PCPs can differ [5, 30].

Shared care models involved more than two providers sharing care and responsibility [1, 9]. According to Oeffinger and McCabe [7], after treatment completion, the PCP assumes responsibility for maintenance of survivor health, management of any co-morbid conditions, ongoing physical and psychosocial concerns, and health promotion. The medical specialist provides a survivorship care plan and treatment summary and ongoing consultation for recurrence or problematic late effects if required. Both providers are to undertake monitoring, therefore, a clear delineation of responsibility for particular screening and surveillance is important [5]. Landier [3] identified shared care as appropriate for low-risk and even some moderate-risk patients, however, intensively treated patients (i.e. haematological cancers) require specialist monitoring.

Nurse-led

The two studies that evaluated nurse-led follow-up in lymphoma survivors predominately targeted late effects and health promotion. Gates et al. [31] studied a nurse-led component of a haematology late effects survivorship multidisciplinary team, whereas John and Armes [32] reported on nurses replacing specialist-led follow-up, independently delivering comprehensive survivorship care. Both clinics assessed for supportive care needs and concerns and delivered health promotion and information [31, 32]. John and Armes [32] provided an annual clinic with nurse contact details, whereas Gates et al. [31] delivered four consultations over a 6-month period. Both studies measured different outcomes and utilized different comparative groups, thereby making them difficult to compare, especially as Gates et al. [31] have only published preliminary results. A prospective comparative study of 61 patients by John and Armes [32] concluded that patient satisfaction was equivalent in the nurse-led clinic cohort compared with the medical-led clinic cohort and was, in some cases, preferred. However, the number in each group was not reported, and it is possible that patient satisfaction was related more to the decrease in wait times. It would likewise be difficult to attribute lifestyle changes to the clinic as patients were seen annually.

Physician-led

The included physician-led studies (n=4) presented comparisons of self-reported practices in survivorship follow-up [8] and clinician perceptions of survivorship follow-up [33–35]. A qualitative exploratory study by Chabuk et al. [33] reported the views of clinicians and administrators (n=40) from ten integrated cancer centres. All respondents reported shared care being practiced. This was based on the assumption that all survivors have a PCP and despite respondents reporting a lack of standard approaches to sharing care between clinicians. Support for survivorship-specific care appeared lacking, with 22 % (n=9) observing it would not add to current care and may decrease care integration. The authors concluded that interviewing respondents from sites without survivorship care would give an unbiased account. However, there may have been a lack of awareness related to the benefits of survivorship care.

Dicicco-Bloom and Cunningham [8] qualitatively assessed the feasibility of a shared care survivorship model with 21 primary care clinicians. The overall perception was that primary care is already involved in survivor follow-up, despite poor information provision from specialists. They perceived electronic medical records are often inaccessible. The authors further concluded survivorship care plan research is limited. PCPs felt excluded once patients entered the hospital system, especially when follow-up extended well past treatment to healthy patients with no recurrent cancer. This was reflected in the study by Greenfield et al. [35] who reported the views of clinicians (n=475) regarding long-term follow-up and found only 5 % (n=14) of haematology cancer survivors are discharged after
Table 3  Methodological characteristics of models of haematological cancer survivorship care (n=6)

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Study design</th>
<th>MCC provider</th>
<th>Disease, years post-treatment, sample size (response rate %)</th>
<th>Resources required</th>
<th>Potential benefits</th>
<th>Potential deficits</th>
<th>Outcome measures</th>
<th>Results</th>
<th>Level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chubak et al. [13], 2012, USA</td>
<td>Exploratory study</td>
<td>Shared care</td>
<td>Ten Cancer Research Network sites Cancer types not identified</td>
<td>40/48 (83 %) Administrators, clinical leaders, providers in oncology, primary care and patients</td>
<td>Survery care plan (SCP) — only five responders identified use of support groups Time and lack of specialists to follow up survivors</td>
<td>Clearer evidence to support survivorship care needed</td>
<td>Perspectives on: survivorship needs; current survivorship practices; barriers; areas for future research</td>
<td>Only 2/10 sites had formal survivorship programs (1 nurse-led, 1 physician assistant-led)</td>
<td>VI</td>
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<tr>
<td>DiGiacomo-Bloom and Cunningham [9], 2013, USA</td>
<td>In-depth interviews on information sharing to/from specialist and patients</td>
<td>Shared care</td>
<td>21 Primary care clinicians (PCP) (11 PCP and 10 NP) Unknown patient types or survivorship period SCP</td>
<td>Information sharing ensures effective care transitions</td>
<td>No guidelines or consensus for many cancers on screening, surveillance, late effects (d.I)</td>
<td>Absence systematic guidance sharing among PCP, patient, specialist</td>
<td>Understand nature of interactions between primary care, specialist, and patient</td>
<td>Some patients continue to see PCP during treatment</td>
<td>IV</td>
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</tbody>
</table>
### Table 3 (continued)

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Study design</th>
<th>MOC provider</th>
<th>Disease, years post-treatment, sample size (response rate %)</th>
<th>Resources required</th>
<th>Potential benefits</th>
<th>Potential deficits</th>
<th>Outcome measures</th>
<th>Results</th>
<th>Level of evidence</th>
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</thead>
<tbody>
<tr>
<td>Frew et al. [34], 2016, UK</td>
<td>Comparison survey on models of follow-up</td>
<td>Models presented for perception and experience: hospital-based; telephone; non-specialist; group; patient-managed; no follow-up</td>
<td>Cancer diagnosis or treatment not disclosed</td>
<td>Nil described</td>
<td>Non-specialist models tend to provide more psychological support</td>
<td>Survey did not ask for survivor diagnosis and treatment which may alter model preference</td>
<td>Perceptions of reasons for follow-up: levels of preference for different follow-up models; effect of individual experience on follow-up model preference</td>
<td>Preferences for model of follow-up experienced: 86% of survivors preferred hospital-based follow-up and was experienced most (84%)</td>
<td>Clinicians had experience of more models of follow-up</td>
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<td></td>
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<td>Range to over 10 years</td>
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<td></td>
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<td>626 (21%) survivors/ rates</td>
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<td>946 (12%) PCP</td>
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<td>804 specialists (including haematologists)</td>
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<td></td>
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<td>556 nurses allied health (47%)</td>
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<tr>
<td>Gies et al. [31], 2012, Australia</td>
<td>Quasi-experimental comparison healthy cohort versus Hodgkin lymphomas (HL) survivors</td>
<td>Late effects MDT (haematologist, transplant physician, radiators oncologist, radiation oncologist, endocrinologist, primary care liaison, psychologist, LE social worker, LE CCC)</td>
<td>HL Education package Health promotion SCP copy to survivor/PCP</td>
<td>Primary outcomes: health promotion intervention from nurse to improve HL survivors knowledge and motivation to adopt health promoting behaviours</td>
<td>No final published results from this study</td>
<td>No final published results from this study</td>
<td>IV</td>
<td></td>
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<tr>
<td>Author, year, country</td>
<td>Type of study</td>
<td>MOC provider</td>
<td>Disease years post-treatment, sample size (response rate, %)</td>
<td>Resources required</td>
<td>Potential benefits</td>
<td>Potential deficits</td>
<td>Outcome measures</td>
<td>Results</td>
<td>Level of evidence</td>
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<tr>
<td>Greenfield et al. [15], 2009, UK</td>
<td>E-survey comparison of clinicians views on long-term follow-up</td>
<td>PCP-led</td>
<td>18-45 years old breast, lymphoma, leukemia, or germ cell survivors</td>
<td>Communication Specialist nurse support (91% most important resource)</td>
<td>Potential loss of outcome data, LE information to specialists</td>
<td>Compare long-term follow-up: reasons for follow-up; advantage/disadvantage of PCP-led follow-up; current practice; resources and support required</td>
<td>Specialists rated clinical reasons for follow-up higher</td>
<td>IV</td>
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<td></td>
<td></td>
<td></td>
<td>&gt;2 years</td>
<td>Specialist nurse support (91% most important resource)</td>
<td>Lower costs</td>
<td>PCP lack expertise in survivorship issues, increases survivor anxiety, time issues</td>
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<td>421 cancer clinicians (36% haematologist, 33%)</td>
<td>Risk stratification: low risk to PCPs, high risk</td>
<td>PCP existing relationship with survivor; accessible; convenient</td>
<td>No tumour-specific follow-up guidelines</td>
<td>Reasons for follow-up PCP-rated recurrence (96%)</td>
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<td></td>
<td>30 HL - 30 healthy participants (91%)</td>
<td>SCP copy to survivor/PCP</td>
<td>Psychosocial issues identified and support given</td>
<td>Secondary outcomes: improved perception of health status; reduced LE unmet needs; reduced LE worry</td>
<td></td>
<td></td>
<td>Anecdotal analysis shows appreciation of SCP screening assessment</td>
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<tr>
<td></td>
<td></td>
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<td></td>
<td>Health promotion; two visits + two phone calls</td>
<td>Supportive Care Needs Screening Tool the General Health Index, the Health Promoting Lifestyle Profile II</td>
<td>Second visit (at 8 months)</td>
<td>Intervention from nurse to improve HL survivors knowledge and motivation to adopt health promoting behaviours</td>
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</table>
### Table 3 (continued)

<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Study design</th>
<th>MOC provider</th>
<th>Disease, years post-treatment, sample size (response rate %)</th>
<th>Resources required</th>
<th>Potential benefits</th>
<th>Potential deficits</th>
<th>Outcome measures</th>
<th>Results</th>
<th>Level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>John and Armos [22], 2013, UK</td>
<td>Prospective comparison specialist-led versus nurse-led Survivability follow-up clinic</td>
<td>Lymphoma</td>
<td>2 CNS</td>
<td>Longer consultations</td>
<td>Annual clinic visit</td>
<td>Documentation improved</td>
<td>Patients rated LE (76 %) recurrence (71 %)</td>
<td>Hematologist use of follow-up protocol for leukemia and lymphoma 30 %</td>
<td>IV</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Information prescription</td>
<td>Written information provision</td>
<td>Preferred clinic not assessed</td>
<td>Wait time reduced from average 55 min (specialist) to 10 min (nurse)</td>
<td>Nurse-led was equal to specialist-led clinic and preferred in some areas Nursing telephone workload increased</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>50 notes audited (25 per group)</td>
<td>Holistic needs assessment</td>
<td>Patient satisfaction</td>
<td></td>
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<td>120 survivors (60 per group) assessed wait time 61 (82 %) survivors assessed patient satisfaction (unclear split medical-led versus nurse-led)</td>
<td>Monitoring for late effects</td>
<td></td>
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<td>Health promotion</td>
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</tbody>
</table>

CNC cancer nurse consultant, CNS cancer nurse specialist, HL Hodgkin lymphoma, LE late effects, MDT multidisciplinary team, MM multiple myeloma, NHL non-Hodgkin lymphoma, NP nurse practitioner, PCP primary care provider, SCP support care plan, TS treatment summary
2 years, and only 42% (n = 45 lymphoma) and 32% (n = 10 leukaemia) are discharged after 5 years. This finding may be explained by the complex and ongoing late effect sequelae in haematology patients and their expectation of long-term specialist follow-up. Although respondent numbers were not reported, it was perceived that long-term specialist follow-up gave survivors false reassurance and perpetuated the illness role. Whereas the PCP-led model was perceived as normalising the survivors’ experience, with a corresponding increase in comorbid disease management. The authors concluded by proposing a risk stratification process whereby low-risk survivors are transitioned early to PCP and high-risk survivors stay within the hospital model or become part of a shared care model supported by survivorship care plans.

Frew et al. [34] studied survivor (n = 626) and clinician (n = 2302) views on different models of care. Respondents could choose from a number of follow-up models but were not asked if they would reject a particular model. What was evident in the study by Frew et al. [34] was specialist follow-up, which was the most experienced by survivors (84% n = 528) and clinicians (95% n = 2167). However, specialists who had experienced non-specialist models of follow-up (60% n = 819) preferred this model over all others including specialist-led (87%).

Discussion

Deciding upon a model of survivorship follow-up care for haematology cancer survivors is difficult due to the considerable variability between the types of haematological cancers, range of treatment regimens, and long-term and late effects that impact the survivorship phase of the cancer continuum [17]. For haematology cancer survivors, different models have been proposed and utilised. However, we are unable to determine the best or the most appropriate model. This finding is consistent with those of Campbell et al. [36], reporting that no model was identified as better than any others. The reasons for these findings are that most of the articles were not evaluative in nature and do not allow comparison. Patients who have only received a single model of care would not be able to comment on potential benefits of other models of care; therefore, further research in understanding survivors’ perspectives of follow-up care is required.

The transition of survivor care to the PCP requires PCP willingness. A study involving PCP views that reported the willingness to accept exclusive care for lymphoma patients was 3 years after treatment completion [37]. This may be due to the complex nature and length of the treatment regimens [15] and a lack of tumour specific follow-up protocols used by haematologists [35]. With a lack of guidance and comprehensive information communicated from the haematologist [8, 35], PCPs may be reluctant to accept exclusive care of what they perceive as complex and ‘high risk’ patients [37]. Shared care may be more satisfactory to haematologists, survivors, and PCPs as it encompasses the strengths and expertise of providers from more than one discipline. As a study of follow-up care providers has reported, a high proportion of survivors are followed up by multiple providers [38]. Therefore, it is important that good coordination and communication is in place to reduce the possibility of either incomplete or duplication of services between multiple providers. Cooper et al. [27] proposed that patients’ transition into survivorship phase and out to primary care through specialist nurses so that monitoring for recurrence, psychosocial needs, and health promotion are addressed and communicated to survivors and health care providers. This too has implications with John and Armes [32] who demonstrated that increased nurse workload occurred with patients utilising telephone contact between the scheduled clinic visits.

Establishing survivorship care provision will require careful planning and robust prospective evaluations. It is important to note that coordinated survivorship care interventions are complex interventions [39] and can be resource intensive, requiring robust evaluations using patient and system outcomes. This integrative review identified the three models of care: physician-led, nurse-led, and shared care models. Ultimately, high-quality pragmatic RCTs are required to test the effectiveness of these models. There is an urgent need for health research funders to understand the need for good survivorship cancer care and fund the development and evaluation of the effects of various models of survivorship care.

To the best of our knowledge, this review is the first that examines the characteristics, resources required, and effectiveness of survivorship care models specifically for patients with haematological cancer. A number of limitations of this review are acknowledged. The search revealed only a relatively small number of articles that met the inclusion criteria. Furthermore, the variation of study methodology, range of measures, populations, and follow-up approaches made it difficult to compare models of care and enabled only tentative conclusions [31, 32]. Additionally, short-term follow-up or the timing of interventions may have been insufficient to report whether different models have impacted survivorship care. Finally, an inherent bias in interpretation might be due to the evaluator.

Conclusion

There is a paucity of effectiveness research related to haematology cancer survivors and specifically models of survivorship care in this cohort. Shared care models have been suggested as an alternative to exclusive specialist care. For shared care to work effectively, ongoing communication channels need to be established and maintained. Nurse-led models have been proposed as another feasible model, where a
specifies nurse intervenes directly and acts as the conduit between patient, hospital-based treatment team, and PCP. However, more research is needed to define how these models should be best configured and evaluated for their effectiveness. For future development, a haematology-specific survivor-based needs assessment tool, individualised treatment summary and survivorship care plan would be integral. These would assist in guiding survivor-centred screening, health promotion, and identification of needs to be monitored and managed. This approach may address many of the barriers that have been postulated.

Future research will need to account for increasing cancer incidence and survival rates, making extensive specialist follow-up care more difficult to maintain for new patients and survivors. To provide quality survivorship care, new and innovative models of haematology survivorship follow-up are required which address the need for long-term follow-up that accounts for potential late treatment effects, risks of secondaries, development of treatment-related co-morbid conditions, and psychosocial well-being. This review revealed a lack of high-quality evidence suggesting the effectiveness of any single model of care. A well-designed pragmatic randomised controlled trial, assessing patient and system outcomes including costs, is required to inform clinical practice.

Conflict of interest None

References


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A.2 Survivorship Care Plans and Treatment Summaries in Adult Patients with Hematologic Cancer: An Integrative Literature Review

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Survivorship Care Plans and Treatment Summaries in Adult Patients With Hematologic Cancer: An Integrative Literature Review

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Survivorship, as defined by the National Coalition for Cancer Survivorship (2014), is the experience of living with, through, and beyond a diagnosis of cancer, including the impact on family, friends, and caregivers. Survivorship care is recognized as a priority in the cancer care continuum and has largely been driven by the Institute of Medicine (IOM) report From Cancer Patient to Cancer Survivor: Lost in Transition (Hewitt, Greenfield, & Stovall, 2005). A key recommendation of this report was the provision of a survivorship care plan (SCP) and treatment summary (TS) for all survivors (Palmer et al., 2014). Following the release of the report, many countries around the world developed and initiated national cancer initiatives (McCabe, Faithfull, Makin, & Wengström, 2013). Survivorship care should include the following components (Grant & Economou, 2008; Landier, 2009; Rechis, Arvey, & Beckjord, 2013).

- Coordination of care among providers to communicate overall health needs
- Monitoring, information about, and promotion of healthy living behaviors and disease prevention (e.g., guidelines for diet and exercise, alcohol consumption, tobacco cessation, sun protection, and healthy weight management)
- Prevention, screening, and intervention for recurrence, as well as long-term and late effects; early detection of new cancers or second malignancies by adherence to recommended surveillance guidelines (e.g., colonoscopies, mammograms, Papanicolaou tests, skin checks); and awareness of comorbidities
- Psychosocial well-being assessment, support, management, and information provision for physical, psychological, social, and spiritual needs

Routine follow-up care focuses largely on surveillance for recurrence and the monitoring of physical side effects, neglecting supportive care, health promotion, late-effects monitoring, and surveillance for new cancers (de Leeuw & Larsson, 2013). Awareness of the suboptimal communication that occurs between healthcare professionals, including primary care providers (PCPs), and patients is increasing; important information is often not provided at treatment completion (Dicosola-Bloom & Cunningham, 2013; McCabe & Jacobs, 2012). In addition, patients with cancer frequently experience multiple health problems earlier than the general population (Panek-Hudson, 2013). As such, a need exists for comprehensive early and ongoing approaches to management; these should take advantage of teachable moments at the end of active treatment to promote and support patient participation in maximizing recovery.
by the adoption of healthy lifestyle behaviors (Alfano, Ganz, Rowland, & Hahn, 2012; Grant & Economou, 2008; Hewitt et al., 2005; Panek-Hudson, 2013).

The provision of SCPs or TSs has been seen as an important element of communication with survivors and multidisciplinary healthcare providers. What appears to be an obvious solution to ensuring optimal follow-up and recommendation adherence is hampered by the complexity of cancer types and treatment. This problem is particularly evident within hematologic cancers, which are made up of diverse blood, immune, and bone marrow diseases that make standardization of inclusion very difficult (Rechis et al., 2013). This survivor cohort lacks clear guidelines for follow-up care (Earle, 2007; Phillips & Currow, 2010; Rechis et al., 2013).

The three main types of hematologic cancer are leukemia, lymphoma, and myeloma (American Society of Hematology, 2015). Each cancer type has distinctive and complex treatment regimens that commonly involve high-dose chemotherapy agents, as well as targeted therapy, radiation therapy, and hematopoietic stem cell transplantation (Carey et al., 2012); these regimens often take place at different institutions. Unfortunately, a number of long-term and late physical, practical, and psychosocial effects that commonly include fear of recurrence, fatigue, and issues related to nutrition, exercise, fertility, relationships, finances, employment, and insurance can result from these largely aggressive treatments (Allard, Souleyman, & Coxossen-G Ile, 2013; Hall, Lynam, Bryant, & Hansson-Pitzer, 2013). Patients with hematologic cancer require SCPs or TSs that reflect disease-specific differences instead of those designed for patients with more common cancers (e.g., breast, prostate, colorectal) that follow similar patterns of survivorship and are widely available.

Patients with hematologic cancer are understudied and underrepresented in survivorship care (Swash, Hubert-Williams, & Bramwell, 2014), despite internationally increasing five-year relative survival rates (Sant et al., 2014). The hematology focus of this integrative review will add to the limited body of knowledge available regarding this cohort of survivors.

This review undertook an analysis of the literature primarily to examine the common attributes of SCPs and TSs developed for patients with hematologic cancer, including (a) resources (e.g., human, templates) required to develop SCPs and TSs, (b) potential benefits and limitations of SCPs and TSs, and (c) outcome measures that have been used to evaluate SCPs and TSs, as well as the findings of those measures.

**Methods**

The integrative review method was chosen because it allows for an in-depth evaluation of the issues encompassing the empirical, theoretical, and clinical approaches within a structured systematic methodology (Whittemore & Knaf, 2005). The method is structured according to five stages: problem formulation, literature search, data evaluation, data analysis, and presentation (Whittemore & Knaf, 2005).

**Problem Formulation**

In the current review, an SCP is defined as a personalized document that guides and coordinates follow-up care (e.g., recommended surveillance, screening, health-promoting behaviors) in addition to providing information, education, and resources for the management of potential long-term and late effects of cancer treatment (Hausman, Ganz, Sellers, & Rosenquist, 2011; Salz et al., 2014). Within cancer survivorship, a TS specifically refers to comprehensively summarized information regarding disease, procedures, and treatments received for a particular cancer (Hausman et al., 2011; Jabson & Bowen, 2013). The aim of these tools is to provide written communication from the treatment team to survivor, as well as clear delineation of responsibility of care to current and future healthcare providers (Earle, 2006; McCabe, Bhatia, et al., 2013). A number of components have been proposed for inclusion in SCPs and TSs based on recommendations from the IOM (Hewitt et al., 2005).

An overview of relevant components for survivors of hematologic cancer are listed in Table 1 and have been adapted from the published literature.

Much of the responsibility for the creation and dissemination of SCPs and TSs rests with the treating team (Earle, 2007; Hausman et al., 2011; Hewitt, Bambino, Day, & Harvey, 2007; McCabe, Faithfull, et al., 2013; Salz et al., 2014; Stricker et al., 2011). However, the development of such individualized tools is time consuming, particularly if treatment occurs across multiple sites and if a lack of integration or absence of electronic records exists (Earle, 2007; McCabe, Bhatia, et al., 2013; Parry, Kent, Forsythe, Alfano, & Rowland, 2013; Rechis et al., 2013; Salz et al., 2014). Nurses have been suggested as the logical choice to create and deliver SCPs and TSs, not only to free up specialists’ time but also because of their well-established role in providing holistic, individualized information to patients (Jackson, Scheid, & Rolnick, 2013; Marbach & Griffith, 2011).

Templates can reduce the time required to complete SCPs and TSs, providing that the required information is readily accessible. The American Society of Clinical Oncology (ASCO) and Lippincott’s NursingCenter.com provide three-page downloadable templates (McCabe, Partridge, Granfeld, & Hudson, 2013). Once the pertinent information is provided, Internet-based SCP tools, such as the Journey Forward Survivorship Care Plan Builder and the LIVESTRONG® Care Plan
A hand search of reference lists from full texts was also employed. Searches were restricted to the English language, humans, and adults. Exclusion criteria were (a) studies that reported on SCP and TS use during the post-treatment phase of hematologic cancer survivorship and (b) studies that reported usage perceptions of SCPs and TSSs experienced by healthcare providers and survivors. Exclusion criteria were (a) studies with less than a 25% cohort of patients

**Survivorship Care Plan**

- Follow-up schedule (includes responsibilities of all relevant healthcare providers)
- Monitoring for potential physical, psychological, and social issues, as well as referrals for
  - Anxiety and depression
  - Counseling
  - Employment, financial assistance, insurance, and legal aid
  - Fear of recurrence
  - Fertility and sexual functioning
  - Relationship issues (e.g., family and friends, marital, parenting)
- Promotion of healthy lifestyle behaviors
  - Alcohol reduction
  - Dietary modifications and weight reduction
  - Physical activity
  - Smoking cessation
- Recovery time frames for treatment toxicities
- Resource list and where to find information regarding
  - Offered by health providers
  - Specific disease and treatment information
  - Support groups
- Responsibilities of healthcare providers (in addition to provision of referrals and tests)
  - Consent conditions
  - Monitoring of long-term effects and the onset of potential late effects
  - Monitoring and screening for recurrence and second cancers
  - Recommended cancer screenings (e.g., colonoscopies, mammograms, Pap smear/colposcopy tests, skin checks)

**Treatment Summary**

- Adverse reactions or complications
- Blood product support
- Chemotherapy or targeted therapy (alterations, amount, cycles, and drugs)
- Clinical trials
- Contact information for each modality
- Coordinator of continuing care contact information
- Date of treatment initiation and completion
- Diagnosis, tests performed, and results
- Disease characteristics, site, and stage of classification
- Maintenance treatments and impact on health
- Psychosocial, nutritional, and other supportive services used
- Radiation therapy (dosage, site, and time frame)
- Transplantation (allologenic or autologous)
- Type of surgery (if applicable)

**Figure 1. Recommended Components of Hematologic Cancer Survivorship Care Plan and Treatment Summary**

Note: Based on information from Ganz et al., 2008; Hewitt et al., 2005; McCabe, Bhalla, et al., 2013; Palmer et al., 2014; Salz et al., 2014.
with hematologic cancer or hematologist viewpoint; (b) studies that reported perceptions of, rather than experiences with, SCP and TS use; (c) studies reporting SCPs and TSs from child, adolescent, adult survivors of a childhood cancer, or non-cancer populations; and (d) opinion papers, letters, editorials, commentaries, conference abstracts, conference proceedings, or case studies.

**Data Evaluation Stage**

Abstract titles were reviewed to assess eligibility. A summary of the selection process (Moher, Liberati, Tetzlaff, & Altman, 2009) is provided in Figure 2. The initial search yielded 697 abstracts. Duplicate articles were removed, and abstracts were screened against the inclusion and exclusion criteria. Abstracts that did not provide cancer or provider type were sought for further screening. Twenty full-text articles were retrieved; of those, four articles were reviewed. Documented methodologic characteristics included author information, study design and intervention, sample characteristics (e.g., participant details, response rate, years post-treatment), outcome measures, results, limitations and comments, and level of evidence as developed by Melnyk and Fineout-Overholt (2011) (see Table 1). Because of variations in study population and methodologies used, meta-analysis was not possible.

The hematology component in the majority of studies was low. No systematic reviews on studies related to SCPs and TSs were identified. The four included studies were all from the United States. They assessed survivor and clinician views on the experience of receiving or disseminating SCPs and TSs. Included articles used various terms to describe treating clinicians. For clarity in this article, the term “specialist” will refer to the following treating consultants: hematologist and medical or radiation oncologist. The research studies all used quantitative approaches and reflected a low level (IV) of quantitative evidence. Reviewed studies were related to the survivorship phase of the cancer trajectory. Characteristics of reviewed articles are detailed in Table 2.

**Data Analysis and Presentation**

Sabatino et al. (2013) reported a subset of survivors (n = 407) who were within four years of diagnosis—a time frame corresponding with the IOM report’s recommendation that all survivors receive SCPs and TSs. Survivors were asked if they had ever received a SCP or TS. The authors found that 38% (n = 155) of survivors acknowledged receipt of a TS, and that 38% (n = 256) had received written follow-up instructions. Written follow-up instructions were received more often by those patients who were part of a clinical trial (65%, n = 346) and by those who were reported as having a higher income (67%, n = 274). Survivors who had undergone hematopoietic stem cell transplantation were included; however, numbers were not reported.

Curcio, Lambe, Schneider, and Kahn (2012) studied survivors and clinicians. Survivors of hematologic cancer accounted for 26% (n = 8) of the overall survivor cohort studied (n = 30). Survivors were highly satisfied with the provision of SCPs and TSs and reported an increase in knowledge. Anxiety levels decreased, although levels were not high at baseline and may have decreased naturally with time. Survivor satisfaction may have been related to the survivorship visit and follow-up telephone call rather than SCP provision. PCCs were reported as being satisfied (100%, n = 10 with SCPs and TSs). The authors reported that PCCs appreciated the content, which aided communication and was useful in providing clarification of the survivor’s follow-up plan.
APPENDICES

Friedman, Coan, Smith, Herndon, and Abernethy (2010) studied survivors of non-Hodgkin lymphoma (n = 67) and physicians (n = 22) involved in survivorship care. Informational needs in the SCP were reported as being congruent between the PCP and survivor. All respondents rated medical content as more important than psychosocial issues, perhaps reflecting survivor expectations in the current model of survivorship follow-up. In addition, survivors ranked the plan to monitor overall health the sixth most important element of the SCP as compared to physicians who ranked it 13th. This led the authors to conclude that survivors view follow-up as part of general health maintenance, whereas physicians separate cancer survivorship care and non-cancer-related care.

Merport, Lemon, Nyambrose, and Prout (2012) evaluated clinicians (n = 108) and PCPs (n = 400) receipt of SCPs and TSS. About 54% (n = 216) of PCPs received a TSS. However, the study reported that only 42% (n = 46) of specialists, including hematologists, prepared a TSS. SCP preparation by specialists was low at 14% (n = 15); however, the authors reported that all SCPs were sent to survivors and PCPs. Barriers identified in this study included the lack of a template and of training given to healthcare professionals regarding the development of SCPs and TSSs, as well as specialists’ perceived absence of financial reimbursement for their time spent developing and delivering SCPs and TSSs. The absence of support from treating clinicians may mean that development and dissemination remain low, with the possibility that SCPs stay medically focused.

These four studies all showed a lack of routine use of SCPs and TSSs, although survivors and PCPs reported that they valued the tools and the direction for survivorship follow-up care that they provided.

Discussion

Published hematologic research regarding SCPs and TSS is limited. No randomized, controlled trials or literature reviews exist for this understudied cohort of survivors, despite the belief that SCPs and TSS are beneficial to complex and rare survivor groups (e.g., hematology) (Shalom, Hahn, Casilles, & Ganz, 2011) in which health problems may take many years to develop (Sabatino et al., 2013). With the increased risk of psychosocial, physical, and economic long-term and late effects from disease and cancer therapy, patients often experience difficulties accessing post-treatment follow-up, which may lead to poorer overall health outcomes (Friedman et al., 2010).

Within the literature that reported the development and dissemination of the SCP and TSS (Curcio et al., 2012; Merport et al., 2012), a lack of information regarding resources used by the specialist to develop the SCP and TSS was observed (Merport et al., 2012). Similarly, information concerning how generic templates were tailored by the specialist and nurse practitioner to different survivors was not provided (Curcio et al., 2012). Details on any evidence-based guidelines for follow-up care used in SCPs (Merport et al., 2012) and the clinical expertise of the health professionals creating SCPs and TSSs was equally lacking.

Standardized templates linked to electronic health records that would directly populate TSS have been proposed to provide health providers with diagnosis and treatment information (Merport et al., 2012; Salz et al., 2014); doing so would be particularly relevant when survivors have had treatment across a number of sites (Merport et al., 2012). Sabatino et al. (2013) found low TS and SCP delivery when survivors had more than one treatment modality. The long duration of treatment that occurs in some hematologic cancer regimens can make difficult the finding and summarizing of modifications and issues that have occurred during the entire treatment phase. Guidelines and templates for SCPs and TSS specific to hematologic cancers are necessary because generic cancer templates cannot convey all of the appropriate information required, adding to the complexity of this issue (Friedman et al., 2010). Curcio et al. (2012) and Sabatino et al. (2013) noted that the provision of SCPs and TSSs soon after treatment completion is required to assess the need for information and resources.

Friedman et al. (2010) argued that providing extra information to survivors could overload and dilute the impact of the most important information that

Table 1. Levels of Evidence

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<tr>
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<tr>
<td>I</td>
<td>Systematic review of all relevant randomized, controlled trials</td>
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<tr>
<td>II</td>
<td>At least one well-designed, randomized, controlled trial</td>
</tr>
<tr>
<td>III</td>
<td>Well-designed, controlled trials without randomization</td>
</tr>
<tr>
<td>IV</td>
<td>Well-designed cohort studies, case-control studies, interrupted time series with a control group, historically controlled studies, interrupted time series without a control group or with case series</td>
</tr>
<tr>
<td>V</td>
<td>Systematic reviews of descriptive and qualitative studies</td>
</tr>
<tr>
<td>VI</td>
<td>Single descriptive and qualitative studies</td>
</tr>
<tr>
<td>VII</td>
<td>Expert opinion from clinicians or authorities, reports of expert committees, or based on physiology</td>
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Note: Based on information from McInery & Fineout-Overholt, 2011.
Table 2. Methodologic Characteristics of Hematologic Cancer Survivorship Care Plans and Treatment Summaries

<table>
<thead>
<tr>
<th>Study</th>
<th>Design and Intervention</th>
<th>Sample Characteristics</th>
<th>Outcome Measures</th>
<th>Results</th>
<th>Limitations and Comments</th>
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<tr>
<td>Carico et al., 2012</td>
<td>Pre- and post-test questionnaire. Survivorship protocol with SCPs and TSs developed by specialist and NP (40-75 minutes to complete); delivered by NP using ASCO generic template</td>
<td>30 survivors (convenience sample included patients with breast cancer [53%], NHL [21%], lung cancer [10%], and gastrointestinal cancer [10%], less than two years post-treatment); 10 (41%) RR PCPs; 8 (30%) RR staff</td>
<td>Improved disease knowledge; decreased anxiety; satisfaction with NCCN follow-up guidelines; cost-benefit analysis</td>
<td>Survivors reported increased knowledge of disease, treatment, follow-up, signs of recurrence, and LEs, as well as decreased anxiety and consistent fidelity to follow-up frequency as per NCCN guidelines. High satisfaction with SCPs and TSs was noted by survivors (70%), PCPs (100%), and staff (100%).</td>
<td>Limitations included low anxiety scores at baseline, small sample size, and a lack of cost-benefit analysis.</td>
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<tr>
<td>Friedman et al., 2010</td>
<td>Mailed questionnaire. Rating of the most important informational needs in SCPs</td>
<td>67 (41%) RR: survivors of NHL (9 months-12.6 years post-treatment); 22 (29%) RR: physicians involved in survivorship care</td>
<td>Survivors’ and physicians’ informational needs in SCPs: congruence in needs between survivors and physicians</td>
<td>Survivors’ informational needs include information about recurrence screening, LTs, treatment, overall health monitoring, nutrition, exercise, insurance, and finances. Physicians’ informational needs include treatment complications. Survivors and physicians rated medical issues as more important than psychosocial issues.</td>
<td>Limitations included small sample sizes, as well as having the same questions asked of survivors and physicians and a disease-specific cohort.</td>
</tr>
<tr>
<td>Anport et al., 2012</td>
<td>Mailed questionnaire. SCPs and TSs developed and delivered by specialists. TSs reported diagnosis, stage, treatment, start dates, treatment fields, and drugs</td>
<td>101 (29%) RR specialists, of which 35 (32%) were hematologists; 400 (11%) PCPs. Reported cancers were breast (64%), prostate (35%), colorectal (35%), lung (31%), and hematologic (20%).</td>
<td>SCP and TS use and obstacles among specialists: SCP and TS receipt and informational preferences among PCPs</td>
<td>Of the specialists, 56% reported requiring TSs, and 14% reported requiring SCPs, both of which were sent to the PCP and patient. About 47% of specialists had no training in doing so, 46% have no template, and 40% receive no reimbursement. Of the PCPs, 54% reported receiving a TS, SCP receipt was not reported. Among the PCPs, informational needs from highest to lowest were TS (93%), follow-up schedule (89%), recommendations (69%), potential side effects (84%), and treatment-related health risk (67%).</td>
<td>Limitations included low response rates, self-reported practices, and responder bias (potential overestimation of use). The study showed a reported lack of routine use of SCPs and TSs.</td>
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<tr>
<td>Saluturo et al., 2013</td>
<td>2010 National Health Interview Survey. Survivor-reported receipt of TS or written follow-up instructions</td>
<td>1,345 (61% RR): survivors (i.e., breast cancer [20%], prostate cancer [14%], cancer of the cervix or uterus [13%], melanoma [11%), colorectal cancer [9%], other cancer, including hematologic [31%]) less than and more than four years post-treatment</td>
<td>Receipt of TS or written follow-up instructions; recent surveillances for recurrence or other cancer screening</td>
<td>Of the survivors who were less than four years post-treatment, 38% had received a TS, 58% had received written follow-up instructions, 29% had received both, and 33% had received neither. More treatment modalities meant lower provision of TSs, whereas higher income and clinical trial participation meant higher provision of written follow-up instructions.</td>
<td>Limitations included an unspecified number of respondents who had been diagnosed with hematologic cancer, as well as self-reported data’s failure to reflect the actual documents received. The study included separate reporting of survivors diagnosed after the IQM report (less than four years).</td>
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Note: All four studies reflected a low level (IV) of quantitative evidence based on information from Melnyk and Fineout-Overholt (2011).

ASCO—American Society of Clinical Oncology; IOM—Institute of Medicine; LE—Late effect; NCCN—National Comprehensive Cancer Network; NHL—non-Hodgkin lymphoma; NP—nurse practitioner; PCP—primary care physician; RR—response rate; SCP—survivorship care plan; TS—treatment summary.
needs to be conveyed. This view is supported by Cox and Faithfull (2013) who reported that clinicians consider late-effects information to affect psychological adjustment and increase the amount of late effects through autosuggestion. However, these authors reflect the perception of clinicians rather than patients, and, as Hill-Kayser et al. (2013) argued, this paternalistic approach is no longer acceptable. Providing tailored SCPs and TSSs to survivors empowers individuals to learn about their disease and treatment and assume responsibility for future surveillance and disease management, facilitating engagement in a future healthy lifestyle (Jackson et al., 2013). This is particularly vital for younger survivors, given the expectation of a longer survivorship period (Jabson & Bowen, 2013).

Multidisciplinary collaboration has been suggested (Shalom et al., 2011) as a strategy for developing SCPs and TSSs. Interdisciplinary education must acknowledge the value of each provider’s contribution within the team. Recommendations clearly detailing provider responsibilities can help ensure that survivors are not over- or undertreated and that they adhere to evidence- or consensus-based recommendations (Curcio et al., 2012). However, caution must be exercised when using consensus-based recommendations.

Nurses can be a key component in implementing care plans and providing comprehensive information, education, and resources, particularly in preventive health and screening (Curcio et al., 2012). Shalom et al. (2011) revealed that nurse practitioner-developed SCPs may not be read by PCPs—100% (n = 15) of PCPs reported that they would not act on expensive testing recommendations. Consequently, specialists must reinforce the importance of nurses as an essential component of survivorship care planning (Hewitt et al., 2007).

SCP and TSSs should be developed in conjunction with a robust model of hematologic cancer survivorship follow-up care that will address the issues and barriers related to implementation. Many professional organizations are calling for SCP development for accreditation. However, cancer programs that develop SCPs solely to meet professional requirements may be reluctant to make the organizational changes necessary to actually deliver the SCPs to survivors and PCPs (Birken, Mayer, & Weiner, 2013). Institutions and specialists perceiving a lack of financial reimbursement and support for the additional time required to prepare and deliver SCPs and TSSs may be disinclined to support widespread implementation (Earle, 2007; McCabe, Partridge, et al., 2013; Salz et al., 2014).

The authors acknowledge several limitations of the current review. The search revealed a small number of articles meeting inclusion criteria. All studies reviewed had low sample numbers and response rates, particularly those studies that explored PCP experiences of SCPs and TSSs. The numbers of survivors of hematologic cancer were limited, decreasing the applicability of findings to survivors of hematologic cancer. The reliance on self-reported practices in all four of the studies and a lack of comparison groups restrict the conclusions that can be drawn. Study participants may have had more experience with SCPs and TSSs, as well as a bias toward or against SCP and TSS implementation. This lack of standardization makes comparing studies and drawing conclusions regarding benefits to survivors difficult. In addition, an inherent bias in interpretation may be related to the evaluator.

**Implications for Nursing**

This integrative review identified published literature on SCPs and TSSs and their applicability to survivors of hematologic cancer. Treatment advances in hematologic cancer mean that patients are living longer (Sant et al., 2014); however, the extended recovery trajectory involves a heavier symptom burden and post-treatment complications because of the aggressive nature of the hematologic disease and the treatment required. These hematologic cancers are unlike the other cancers that are often used as benchmarks (e.g., breast cancer, prostate cancer) (Parry, Morningstar, Kendall, & Coleman, 2011).

Nurses can influence and guide the development of relevant survivorship care recommendations, thereby facilitating a paradigm shift to encompass all aspects of the cancer trajectory. Nurses with advanced research skills (e.g., PhD prepared) would be well placed to take the lead in adopting and translating follow-up guidelines for patients with hematologic cancer into evidence-based and disease-specific templates. Nurses are in a unique position to provide and disseminate SCPs and TSSs comprising individualized and relevant resources, information, and education to ensure that the needs of survivors of hematologic cancer are met. Nurses must also support and empower survivors to take control of and, ultimately, self-manage their ongoing needs.
The current review revealed a lack of high-quality evidence related to the care of survivors of hematologic cancer. Addressing the specific and ongoing concerns of these patients, along with disseminating this information to survivors and clinicians, particularly in primary care, is important. As survival rates continue to increase, the successful integration of hematologic cancer survivorship care into the cancer continuum is vital.

Conclusion

Further research will need to account for the inclusion of each component of the SCP, the survivor’s desire for this knowledge and information, and the best way to develop and deliver SCPs and TSs that are specific to hematologic cancer. Research is required regarding the models of care that are most suitable for delivering SCPs and TSs to survivors of hematologic cancer, including their perspectives on follow-up provision. Nurse-led hematology survivorship clinics that facilitate shared care between the treating team and PCPs may be the most appropriate model to deliver SCPs and TSs. This may help to achieve the best outcomes for patients transitioning into the survivorship period but requires further evidence-based research. Methods that will optimize communication and clarity with provider responsibility, decreasing overuse or underuse of surveillance and screening tests, are fundamental aspects of this research. Research in how best to decrease the amount of time needed to prepare SCPs and TSs and the ideal time to effectively deliver SCPs and TSs is necessary. Well-designed, pragmatic, randomized, controlled trials are required to inform clinical practice. As the amount of outcome-based research increases, so too will the understanding of providing optimal survivorship care.

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References

Appendices


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A.3 Systematic Review of the Tools Used to Assess the Informational and Practical Needs of Acute Leukaemia and Lymphoma Survivors

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Systematic review of the tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors

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Abstract
Purpose: To identify validated measurement tools to assess the informational and practical concerns of leukaemia and lymphoma survivors. Cancer nurses have the potential to lead the way in providing quality post-treatment survivorship care.

Method: This systematic review utilised a search of electronic databases for eligible articles published to March 2014. Included articles described a tool to assess informational and/or practical concerns of leukaemia and/or lymphoma survivors.

Results: Seven full text articles were identified that described cancer-specific tools used to assess informational and/or practical needs of this survivor cohort. There was variation in the use of cancer survivor-specific tools and generic cancer tools.

Conclusions: No haematology-specific needs assessment tools were identified. Therefore only tentative conclusions on the best tool for this cohort can be made. Further research is required to develop reliable and validated tools that will support the selection of the most appropriate tool for leukaemia and lymphoma survivors.

Keywords: Leukaemia and lymphoma cancer; survivorship; instruments; measures; tools; supportive care needs; unmet needs; perceived needs.

Introduction
Leukaemia and lymphoma are the most common blood and bone marrow cancers. Effective treatments are largely aggressive and cause a number of long-term and late physical, practical and psychosocial effects, which significantly impact lifestyle in the survivorship phase. Survivorship is defined as the experience of living with, through and beyond a diagnosis of cancer. As with other cancers, the haematology cancer health professional role has extended to include provision of patient care in the survivorship phase. This important step forward has been driven largely by the 2005 Institute of Medicine (IOM) report From Cancer Patient to Cancer Survivor: Lost in Transition, considered the seminal paper for cancer survivorship. The report recommended survivorship care as a priority in the cancer trajectory with a number of specific issues relevant to the survivorship phase. These issues can be categorised according to the seven domains of Fitch’s supportive care framework: physical, informational, emotional, psychological, social, spiritual and practical concerns. The framework can be used across the cancer continuum including haematology survivorship care. Whilst survivorship care is developing for other cancers, haematology cancers remain understudied in survivorship literature, despite increasing five-year relative survival rates internationally.

The purpose of this review was to source tools that could be used to assess two domains from the supportive care framework: informational and practical concerns. These were chosen as a result of our findings from a qualitative study undertaken with leukaemia and lymphoma patients that revealed a number of unmet needs, predominately informational and practical, thought to relate in part to the extensive nature of the treatment and the uncertainty around long-term remission and potential late effects.

The terms ‘informational needs’ and ‘practical needs’ are rarely considered or defined as separate entities in the literature. For clarity and consistency, Fitch’s definitions of needs have been used. Informational needs are defined as information to
assist in decision-making and acquiring of skills to decrease fear, anxiety and misperception. Fear of recurrence is often reported as an informational need for this cohort. Two recent systematic reviews on this topic reported tools used to measure fear of recurrence; tools to measure other informational needs were not reported. Practical needs are defined as direct interventions or help that support the survivor to complete a task or meet a concern. Insurance and employment issues are often cited as unmet needs for leukaemia and lymphoma survivors. Other common informational and practical needs reported in haematology survivorship literature include late effects, fatigue, nutrition, exercise, fertility and sexual concerns, relationship issues, financial issues, personal care and accessing support services.

Gates et al. argued that haematology cancer nurses have an important role in this changing dynamic, especially in developing sustainable, nurse-led survivorship care. If nurses are to take on a greater role in survivorship care they require accurate, reliable and validated tools to assess patients entering the post-treatment phase. Hawkins et al. proposed that tools designed for patients to self-identify perceived needs are required to support survivorship care. These tools could then guide the development of appropriate models of care, resources and tailored support that are patient-centred rather than based on the perceptions of health professionals. The timing of patient needs assessments is equally important. Research showing interventions and assessments undertaken in the early survivorship phase (up to two years post-diagnosis) can lead to fewer unmet needs moving into the extended survivorship phase over five years.

There is a dearth of published literature that has critically evaluated tools used to measure the perceived unmet needs of leukaemia and lymphoma survivors. Tools specifically developed for these patients in the treatment phase such as the Functional Assessment of Cancer Therapy: Lymphoma or Leukaemia (FACT-LYM, FACT-Leu) have also been used in the survivor population. Hence, it is possible that survivor-specific needs may not be captured.

Given that each cancer patient’s journey is unique, it is important to measure individual needs and match practical support to meet those needs. Therefore, the leukaemia and lymphoma-specific focus of this paper will add to the limited body of knowledge currently available in this survivor cohort.

The following questions guided this systematic review:

1. What reliable and valid measurement tools are currently available to measure the informational and practical needs of acute leukaemia and lymphoma cancer survivors?
2. What are the implications of the findings from this review for future research and clinical practice?

Method
A systematic review methodology was chosen to guide this review. To guide literature searches and analysis of articles, a study protocol was devised. As the use of needs assessment tools dictates a quantitative study method, qualitative studies and the qualitative component of quantitative studies were excluded. Mixed methods research was included with only the quantitative element evaluated.

Literature search
The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychInfo, PubMed, EMBASE, PsychArticles, and the Cochrane Library from earliest records to March 2014. Search terms related to leukaemia and lymphoma cancers, assessment, survivorship and needs (see Appendix 1 for the search strategy). A hand search of the reference lists from full text articles was also employed. Searches were restricted to English and adult acute leukaemia or lymphoma survivors. Inclusion and exclusion criteria are shown in Table 1. Studies with only multiple myeloma participants were excluded as these patients have an incurable cancer and could therefore be termed “living with cancer”. Likewise, studies with only allogeneic transplant participants were excluded as they have ongoing conditions such as graft-versus-host-disease.

Quality appraisal and data extraction
One author (KT) reviewed abstract titles to assess eligibility. KT and LM then appraised the instrument/tool(s) used in eligible full text articles to determine whether they measured informational and/or practical needs of the leukaemia or lymphoma survivor. A summary of the selection process using the PRISMA 2009 Flow Diagram is provided in Figure 1.

Table 1: Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of a cancer survivor-specific or generic cancer tool or instrument</td>
<td>Tools used in the treatment or diagnostic phase</td>
</tr>
<tr>
<td>Validity and reliability of tool tested with leukaemia and/or lymphoma cancer survivors only</td>
<td>Tools used with relapse or secondary leukaemia or lymphoma cancer survivors only</td>
</tr>
<tr>
<td>Informational and/or practical needs reported</td>
<td>Studies reporting survivors of a childhood leukaemia or lymphoma cancer</td>
</tr>
<tr>
<td>Adult leukaemia and lymphoma cancer survivors only</td>
<td>Studies related to caregivers, or comparative studies between caregivers and survivors</td>
</tr>
<tr>
<td>Adults aged 18 years or older</td>
<td>Studies with less than 50% leukaemia or lymphoma cancer survivor cohort</td>
</tr>
</tbody>
</table>

Opinion papers, letters, editorials, commentaries, conference proceedings, or case studies
Inclusion criteria:

- 5234 abstracts identified: Cochrane Library, CINAHL, EMBASE, Medline, PsychINFO, PsychArticles January 1970 - March 2014
- 98 abstracts identified: manual search of preliminary literature
- 5286 abstracts after duplicates removed
- 9016 abstracts excluded
- 269 abstracts screened using inclusion/exclusion criteria
- 32 full-text articles assessed for eligibility
- 25 articles excluded: abstracts only (n=3), haematology patients comprised < 50% study population or cohort not identified specifically (n=8), treatment or clinical trial related (n=2), focus not relevant (i.e. distress, age, late effects, transplant spirituality, adaptation, tool only comparisons (n=5), literature review did not target informational/practical needs (n=3)

Studies included in qualitative synthesis: N=7

Figure 1: Flow chart of literature search results

The methodological characteristics documented included: authors; publication year; country; study design; comparison group; outcome measures; disease; sample size and response rate; survivorship period; cancer-specific and non-cancer-specific tools; reported unmet informational and practical needs; results and study quality, as shown in Table 2. Due to variations in study population, methodologies and tools used, meta-analysis was not possible. Study quality was assessed using Fowkes and Fulton’s guidelines and checklist for critically appraising quantitative research. Assessment of the methodological quality of studies utilised a classification system of poor (under 40% of quality items), good (40-70% of quality items) or very good (over 70% of quality items) as reported by Hall et al. In addition, the validity of each tool was assessed according to: how the tool covered the informational and/or practical needs of the participants; correlation with other generic cancer or survivor-specific tools; and whether results confirmed study outcomes.

Tool reliability was determined by internal consistency of the items and whether test-retest reliability had been performed. Generalisability of the tool to leukemia or lymphoma survivors was gauged from the study results, along with the clinical usefulness of the tool for these survivors.

Data analysis

The initial search yielded a large number of abstracts (n=5234).

Following removal of duplicate articles and abstract screening using exclusion and inclusion criteria, 32 full text articles were sought and further appraised. Of these, seven articles were reviewed and referred to one or more relevant tools.

No tool had been specifically developed for exclusive use with leukaemia or lymphoma survivors. Two studies reported researcher-developed questionnaires.

The seven included articles reporting haematological cancer survivor cohort studies were from Australia (n=2), Canada (n=1), the United States of America (USA) (n=3), Norway (n=1) and United Kingdom (UK) (n=1). The periods of survivorship ranged from six weeks post-treatment through to 12 years after diagnosis.

Of the reviewed studies, four utilised comparative groups related to unmet needs among different: treatment types; countries; gender; and survivors and physicians. Outcome measures varied across all studies, although the majority related to unmet needs after treatment completion (Table 2). The assessment of methodological quality revealed most studies (n=5) were “good”; two were classified as “poor”. Two studies utilised mixed method designs, six studies were cross-sectional and one was prospective. Methodological quality varied with sample sizes ranging from 22 to 477 participants and response rates varying from 29% and 94%.
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Country</th>
<th>Study design</th>
<th>Comparison group</th>
<th>Outcomes measured</th>
<th>Disease</th>
<th>Sample size</th>
<th>Response rate</th>
<th>Tools</th>
<th>Cancer-survivor-specific Non-cancer tools</th>
<th>Investigator questions</th>
<th>Unmet information/practical needs</th>
<th>Results</th>
<th>Study quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ander-Oliz et al.</td>
<td>2011</td>
<td>UK</td>
<td>Cross-sectional</td>
<td>Administration of questionnaires</td>
<td>Gender comparison Health-related quality of life, late effects and perceived vulnerability, satisfaction with care, expectations and satisfaction of clinic visit</td>
<td>Lymphoma n=15 10%</td>
<td>Yes</td>
<td>QLQ-C30 (Quality of Life Cancer Survivor) Yes, SF-36 (Medical Outcomes Study Health Survey Short Form 36 version 2, Premorbid Marginal Hospital Satisfaction with Doctor Questionnaire</td>
<td>Only questions related to discussion of treatment, late effects</td>
<td>No gender difference in late effects or perceived vulnerability, more late effects, worse health-related quality of life. wanted to discuss more topics (women discussed fewer topics) shorter wait time; more topics discussed. Health-related quality of life dependent on whether survivor, follow-up expected. More topics were discussed.</td>
<td>Good</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radnax et al.</td>
<td>2011</td>
<td>USA</td>
<td>Cross-sectional</td>
<td>Mailed questionnaire</td>
<td>Comparison of survivors and physicians Informational support needed by cancer patients; needs of survivors and physicians Comparisons between survivors’ physicians</td>
<td>Non-Hodgkin lymphoma n=340</td>
<td>Yes</td>
<td>Investigatory questionnaire</td>
<td>Information needs to be included in survivorship care plan</td>
<td>Information needs to be included in survivorship plan</td>
<td>Poor</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sin et al.</td>
<td>2011</td>
<td>Australia, Canada</td>
<td>Cross-sectional</td>
<td>Mailed questionnaires</td>
<td>Comparison of Australian and Canadian haematology survivors Percentage of survivors reporting unmet needs: domain scores 10 to 24</td>
<td>Leukemia, lymphoma multiple myeloma</td>
<td>Australia n=118 (70%) 5 years Canada n=81 (85%) 3-5 years</td>
<td>BUMS (Survivors’ Unmet Needs Survey) Yes</td>
<td>Information needs</td>
<td>Cancer recurrence and survival Work and financial needs</td>
<td>Similar levels of unmet needs. Is fatigue highest concern across both cohorts. Multiple areas of need found in females, younger age, expected changes in vocation education level, seeing doctor about treatment or concerns Work and financial needs higher for Australian survivors.</td>
<td>Good</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hjernested et al.</td>
<td>1999</td>
<td>Norway</td>
<td>Perspective cohort of 4159 post</td>
<td>Mailed questionnaires</td>
<td>Comparison of subgroups of lymphoma with autologous blood and autologous bone marrow transplant recipients</td>
<td>Lymphoma, lymphoma</td>
<td>n=110 94%</td>
<td>Yes</td>
<td>CARMS-4 (Cancer Rehabilitation Evaluation System Short Form) No</td>
<td>CARMS-4 (Cancer Rehabilitation Evaluation System Short Form) (European Organization for Research and Treatment Quality of Life Questionnaire) No</td>
<td>Information needs</td>
<td></td>
<td>Few patients reported help with any kind. CARMS-4 useful for assessing sexual, marital, medical intervention to address specific issues. Follow-up</td>
<td>Good</td>
</tr>
<tr>
<td>Lofstedt et al.</td>
<td>2009</td>
<td>Australia</td>
<td>Cross-sectional</td>
<td>Mailed questionnaire</td>
<td>No comparison group Assessment of unmet informational and emotional needs after treatment</td>
<td>Leukemia, lymphoma multiple myeloma</td>
<td>n=12 78% 6 months to 3 years post-treatment</td>
<td>CSOM (Cancer Survivors Unmet Needs Survey) Yes</td>
<td>Concerns, fear of recurrence, care coordination, information on services</td>
<td>Care coordination after treatment important, significant for unmet or working patients. Fear of recurrence, emotional and relationship needs greater in younger patients.</td>
<td>Good</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pues et al.</td>
<td>2012</td>
<td>USA</td>
<td>Mixed methods</td>
<td>Cross-over</td>
<td>Mixed questionnaires</td>
<td>Health service and psychosocial needs of adult leukemia and lymphoma survivors</td>
<td>Lymphoma, leukemia</td>
<td>n=86 6%</td>
<td>Hours et al. Service Need Inventory, refined by Korklitz et al. 14 items</td>
<td>Practical needs, child care, financial</td>
<td>Unmet need highest in sexual issues; handling medical and living expenses; emotional, difficult employment, health insurance; Women were likely to report unmet child care needs</td>
<td>Poor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sieben et al.</td>
<td>2000</td>
<td>USA</td>
<td>Mixed methods</td>
<td>Cross-over</td>
<td>Mixed questionnaires, semi-structured interviews</td>
<td>Leukemia, lymphoma</td>
<td>n=15 10%</td>
<td>Yes</td>
<td>QLQ-C30 (Quality of Life Cancer Survivors) Yes</td>
<td>Fear of recurrence, fatigue, employment, support, financial family</td>
<td>Forgetting, pain, fear of recurrence — ongoing issues Family dynamics and finances continue to impact survivors. Financial issues were more in survivors. Lack of relation to quality of life. Income is significantly to quality of life. Positive associations with ability to cope after Cancer</td>
<td>Good</td>
<td></td>
<td></td>
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Results

Five tools were identified and could be dichotomized as either those designed for cancer survivors (survivor-specific) or those developed for cancer patients undergoing treatment and used with a cancer survivor cohort (generic cancer tools). Utilising the definitions of informational and practical needs as previously described ensured consistency with the data extracted from the articles. Comparisons of the five main assessment tools identified in this review are shown in Table 3.

The generic cancer tools: Cancer Rehabilitation Evaluation System Short Form (CARES-SF) and European Organization for Research and Treatment Quality of Life Core questionnaire (EORTC QLQ-C30) were not survivor-specific and no data in relation to previous use in any haematology survivor cohorts was described. Reliability scores and validity information was variable in the detail reported. Similarly, the three cancer survivor-specific tools: Cancer Survivors Unmet Needs Survey (CaSUN); Quality of Life Cancer Survivors (QoL-CS), and Survivors’ Unmet Needs Survey (SUNS) provided variable reliability and validity data.

All studies documented tool domains and scoring scales. Only two tools addressed both informational and practical needs (CaSUN, SUNS). The SUNS is the only tool developed using a mixed cohort that included haematological cancer survivors. All reviewed articles reported the clinical usefulness of the tools to the haematological cohort studied.

The majority of studies (n=5) assessed the informational needs of survivors (Table 2). Of the survivor-specific tools used to assess informational needs, the CaSUN includes an explicit information domain with response items such as “I need up to date information”; “I need understandable information”: It is assumed that follow-up is required for those patients who score highly for such items. The SUNS tool similarly includes an informational domain with questions targeted to “Finding information…” or “Dealing with fears…or feelings…” In general, a high score allows the assessor to identify areas of need. However, neither tool explicitly asks if the survivor would like help with their issue or concern.

Acker-Close et al. measured gender-related informational needs using the cancer survivor-specific tool QoL-CS. Although this article made gender-specific recommendations, it did not provide insight into what assessment tools best identify gender differences. Friedman et al. developed a questionnaire that focused on information that should be included in survivorship care plans such as: specific information about cancer recurrence; nutrition and exercise; screening plan; and information for family members. This questionnaire both identified needs and

Table 3: Comparison of assessment tools

<table>
<thead>
<tr>
<th>Tool</th>
<th>Cancer survivor-specific</th>
<th>Content</th>
<th>Scale Scoring</th>
<th>Information needs</th>
<th>Practical needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>CARES-SF (Cancer Rehabilitation Evaluation System Short Form)</td>
<td>No</td>
<td>59 items – degree problem applies</td>
<td>5 point</td>
<td>Lower scores = fewer problems</td>
<td>No</td>
</tr>
<tr>
<td>CaSUN (Cancer Survivors Unmet Needs Survey)</td>
<td>Yes</td>
<td>35 supportive care needs; items: 6 positive outcome items; 1 open-ended item</td>
<td>5 point</td>
<td>Higher scores = greater needs</td>
<td>Yes</td>
</tr>
<tr>
<td>EORTC QLQ-C30 (European Organization for Research and Treatment Quality of Life Core questionnaire)</td>
<td>No</td>
<td>5 functioning scales: physical; role; emotional; social; cognitive</td>
<td>8 point</td>
<td>Function: higher scores = better function</td>
<td>No</td>
</tr>
<tr>
<td>QoL-CS (Quality of Life Cancer Survivors)</td>
<td>Yes</td>
<td>4 domains: physical well-being (8 items); psychological well-being (6 items); social well-being (8 items); spiritual/religious well-being (7 items)</td>
<td>10 point</td>
<td>Higher scores = best QoL</td>
<td>No</td>
</tr>
<tr>
<td>SUNS (Survivors’ Unmet Needs Survey)</td>
<td>Yes</td>
<td>5 domains: informational needs (8 items); financial concerns (1 item); access and continuity of care (2 items); relationships (1 item); emotional health (5 items)</td>
<td>5 point</td>
<td>Higher scores = greater need</td>
<td>Yes</td>
</tr>
</tbody>
</table>
enquired whether respondents wanted information. On the other hand, the CARES-SEP does enquire if patients would like assistance with their concerns. However, it does not explicitly identify survivor informational needs. In contrast, Parry et al. used a non-validated survey that identified informational and practical needs of haematology survivors examining if participants received the help they required.

The definition of “practical need” differed between authors, making identification of suitable tools somewhat difficult. The QoL-CS tool examined practical concerns including: employment; sexuality; financial burden and fatigue. Unlike the other cancer survivor-specific tools, a higher score indicated a better quality of life outcome. It was unclear if the tool recommended users to follow up concerns that generated low scores. Similarly, the EORTC QLQ-C30 assessed the practical need of financial concerns, but focused on more treatment-related concerns that are unlikely in the survivorship phase. Needs relating to fatigue management, fertility, sexuality, nutrition, exercise, insurance, finances and employment were explored by the majority of tools or investigator-derived questionnaires to varying degrees. The late effects of treatment were reported as both an informational need and a practical area where a plan for screening should occur. Likewise, fear of recurrence issues were similarly reported.

Although a variety of tools was used, there was consensus regarding the most prevalent leukaemia and lymphoma survivor informational and practical needs. The commonly reported informational needs were: treatment late effects; cancer recurrence including fear of recurrence; care coordination; and information on available resources. The most consistently identified practical needs were: fatigue management; employment; finances; insurance; family; and sexuality. Arden-Close et al. addressed potential differences in gender and found men wanted more information; however, they were often unable to receive this from the medical consultation. Women, on the other hand, were able to discuss the topics they wanted. Other studies found women had higher unmet needs related to family issues; similarly younger survivors had higher unmet informational and practical needs. Conversely, disease and treatment type did not identify those with greater unmet needs.

Discussion

Providing information across the cancer continuum is one of the most important aspects of care, yet it is a frequently reported unmet need, especially in the survivorship phase. Leukaemia and lymphoma patients differ from other cancer patients in the considerable variability between their cancer types and the range of treatments affecting many aspects of their lives. With improving survival rates, those diagnosed younger (18–45 years) can now expect to live longer, raising additional concerns and unmet needs. Information provision must be individualised and tailored to specific patients’ needs. As highlighted by Friedman et al., survivorship care plans need to account for differing informational and practical needs of survivors, primary care providers and haematologists.

Generic cancer tools include items related to diagnosis and treatment issues, which are not necessarily specific to the survivorship phase. This review has shown that survivor-specific tools can be used to assess unmet needs of leukemia and lymphoma participants in the survivorship phase. Therefore, tools specific to the survivorship phase would be more appropriate to assess for unmet needs and concerns in this cohort.

Arden-Close et al. and Aziz have argued that survivors should be afforded the opportunity to obtain support and access resources earlier in the survivorship continuum. They assert survivors need information about immediate and long-term impacts of the cancer, together with practical needs related to fatigue, exercise, nutrition, fertility, sexuality, insurance, finances, employment, and late effects. Leukaemia and lymphoma survivors may also want resources to address healthy lifestyle choices or support to deal with the psychosocial aspects such as relationships, anxiety, and fear of recurrence, reported in many studies as the highest unmet needs.

We acknowledge a number of limitations. There was variation in tools used across a wide range of survivors from the early survivorship phases (under two years) through to 12 years post-diagnosis. This made comparative generalisations of informational and practical needs difficult and enabled only tentative conclusions. Our findings are limited to comparing those areas surveyed with the assessment tools. As such, the review could not determine a broader range of supportive care needs for all haematological cancer survivors. Further, the relatively low response rate reported for some studies reduces the likelihood of the sample being representative of leukaemia and/or lymphoma survivor populations, and sampling bias could result in distorted conclusions. Extracting the psychometric properties of the tools was hampered by a lack of detailed data to support validity and reliability. Finally, an inherent bias in interpretation might be considered.

Notwithstanding the limitations, this review identified a consensus on the most prevalent informational and practical needs of leukaemia and lymphoma survivors. This important finding can assist haematology cancer nurses when making decisions regarding the most appropriate tools to use and may assist in the development of haematology cancer survivor-specific tools that measure perceived informational and practical needs; the extent to which needs are being met; and the survivors’ need for support across all supportive care domains. In this way nurses are ideally positioned to provide individualised information and resources to these survivors and further this area of research.
APPENDICES

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Conclusion

There is a paucity of studies related to leukaemia and lymphoma survivors and specific validated tools that can be used to identify and measure the informational and practical needs of this cohort. While cancer survivor-specific needs assessment tools do exist and have been used with more common cancer groups, further research is required to determine their relevance and applicability to leukaemia and lymphoma survivors to ensure specific concerns are heard and addressed via appropriate support and information. Equally, generating psychometric data will ensure valid and reliable tools are utilised. As the only tool developed that included a haematology cohort, the use of the SUNS tool in further leukaemia and lymphoma survivor populations will allow a greater body of knowledge to be developed.

Appendix: Combinations of search terms used

| Haematology | cancer OR haematology (hematology) malignancy OR hematologic neoplasm OR haematological (hematological) cancer OR blood cancer OR acute leukemia (leukaemia) OR myeloid acute OR lymphoid acute OR nonlymphocytic acute OR lymphoma OR Hodgkin disease/lymphoma OR Non-Hodgkin OR T-Cell OR B-Cell OR oncology |
| AND tool/s OR screening tool/s OR instrument/s OR measurement tool/s OR measurement scale/s OR psychological test/s OR questionnaire/s |
| AND survivor OR survivorship OR cancer survivor/s OR after cancer |
| AND supportive care need/s OR unmet need/s OR need/s OR needs assessment OR perceived need OR information need OR practical needs |

References


Appendices

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A.4 Protocol for Care After Lymphoma (CALy) Trial: A Phase II Pilot Randomised Controlled Trial of a Lymphoma Nurse-led Model of Survivorship Care

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Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care

Karen Taylor,1,2 David Joske,3,4 Max Bulsara,5 Caroline Bulsara,2 Leanne Monterosco2,6,7

ABSTRACT

Introduction: Lymphoma is the sixth most common cancer diagnosed in Australia and internationally. Owing to the aggressive nature of the disease and intensity of treatment, survivors face long-term effects that impact on quality of life. Current models of follow-up post-treatment fail to address these complex issues. Given that 74% of patients with lymphoma cancer now survive 5 years beyond diagnosis and treatment, it is important to address this gap in care.

Aim: To determine self-reported informational and practical needs, anxiety, depression, stress, coping and empowerment at baseline, 3 and 6 months.

Methods and analysis: A pilot randomised controlled trial will test the effect of a nurse-led lymphoma survivorship clinic compared with usual post-treatment care at a large tertiary cancer centre in Western Australia. The intervention will comprise three face-to-face appointments with delivery of tailored resources, a survivorship care plan and treatment summary (SCP TS). The SCP TS will be given to the participant and general practitioner (GP). Intervention participants will be interviewed at completion to explore the perceived value of the intervention components and preferred dose. An evaluation developed for GPs will assess receipt and use of SCP TS. The primary intent of analysis will be to address the feasibility of a larger trial and requisite effect and sample size.

Ethics and dissemination: Ethics approval has been granted by the University of Notre Dame Australia and Sir Charles Gairdner Hospital in Western Australia. Peer-reviewed publications and conference presentations will report the results of this phase II trial.

Trial registration number: ANZCTR12615008530527; First results.

INTRODUCTION

Lymphoma is a general term for over 20 blood cancers that originate from T and B cells in the lymphatic system1 where lymphocytes undergo a malignant change and multiple uncontrollably. Lymphomas, when combined, represent the sixth most commonly diagnosed cancer worldwide,2 with Hodgkin’s lymphoma (HL) and non-Hodgkin’s lymphoma (NHL) the two main forms. HL represents 11.5% of all lymphomas and is the third most common cancer in the adolescent and young adult population.3 With the exception of HL, incidence increases with age; thus, NHL is predominantly a cancer of the older population (over 65 years).3,4

The incidence of lymphoma in Australia is increasing, with a projected diagnosis of 5680 cases in 2015. This will equate to 4.5% of all cancer cases.5 In Australia, the overall survival rate has improved, and ~74% of people diagnosed with lymphoma are reported as being alive at 5 years compared with 49% in the 1980s.6 Despite these encouraging results,5 this group of cancers remains understudied and subsequently under-represented in survivorship care.7 Lymphoma treatment regimens commonly involve aggressive high-dose chemotherapy and/or targeted therapy agents, radiotherapy
and haematopoietic stem cell transplants. Such treatments result in a long-term impact of physical, practical and psychosocial effects, which can produce ongoing unmet needs. These needs relate to physical and psychosocial impacts such as fear of recurrence, fatigue, poor nutrition, exercise, fertility, relationships, financial, employment and insurance issues. Furthermore, these patients commonly experience related health problems earlier than the general population and are at risk of specific late effects. Cardiovascular disease is particularly pertinent in this cohort due to chemotherapies combinations and cumulative dosing, as well as mediastinal radiotherapy. Patient health and lifestyle behaviours, for example, smoking, likewise have an effect on disease development.

Patients with lymphoma have an increased relative risk of second cancers, higher when diagnosed at a younger age and further elevated when treatment includes radiotherapy. The potential for the development of bone marrow disease is greater in the first decade; however, unlike second cancer risk, this decreases and then plateaus in the second decade. Patients who require a haematopoietic stem cell transplant have additional transplant-related late-effect risks. Although patients may be unable to modify some late-effect risks, awareness of relevant potential late effects may ensure timely follow-up for symptomology.

The traditional model of haematological cancer care follow-up has largely been haematologist led within the acute hospital setting. Information at treatment completion is often inadequate, with a lack of clear guidelines for the ongoing management of survivors. This has led to an emerging focus on redesigning survivorship follow-up care and delivery.

Lolli et al. demonstrated patient-reported needs among Western Australian haematological cancer survivors (n=66) not addressed during routine follow-up post-treatment completion and thereby classified as unmet needs. Almost two-thirds of respondents (59%) would have found it helpful to talk with a health professional at treatment completion. A recent qualitative study conducted by the authors with lymphoma and leukaemia cancer survivors (n=19) in Western Australia found unmet needs relating to information, practical support, coping strategies and transitioning from active treatment into the survivorship phase. Findings suggested that tailored, end-of-treatment interventions should form a key component of survivorship care. Participants suggested a nurse coordinator nurse as an important element to initiate and transition patients into the survivorship phase.

Nurse-led models of care have demonstrated potentially satisfactory outcomes and are proposed as an acceptable pathway to transition into the survivorship phase. A dedicated nurse-led survivorship clinic to administer patient-centred survivor-specific needs assessments is an important aspect of survivorship care to address patient concerns and empower survivors to manage their own health and ongoing symptoms.

Empowering patients enables them to become more responsible for the management of their own health and well-being, and can contribute to the influence and control patients have over their own health which has the advantage of improving quality of life. Bandura’s theory of self-efficacy, the principal concept in self-management education, teaches patients to identify their problems and provides skills in decision-making and developing an appropriate action plan. It is anticipated that increasing empowerment and providing healthy lifestyle resources will result in a reduction in the patient-perceived need for support from the healthcare system.

Survivorship care plans (SCPs) and treatment summaries (TS) have been recommended as facilitators to deliver holistic survivorship follow-up care by the Institute of Medicine, the American Society of Clinical Oncology, the UK National Cancer Survivorship Initiative and the proposed Clinical Oncology Society of Australia survivorship guidelines. A personalised SCP would guide follow-up care by including recommendations, information and resources for surveillance, screening of potential long-term and late effects and health-promoting behaviours. The TS would comprehensively summarise information on diagnosis and treatments. Cancer nurses have established expertise in the areas of health promotion, information, support and resource provision, and therefore can develop and disseminate SCPs and TS to facilitate communication between the survivor, specialist and primary care.

AIM

The aim of the Care After Lymphoma (CALy) study is to develop and empirically test an evidence-based nurse-led lymphoma survivorship clinic to transition participants into the survivorship phase, using a pilot randomised controlled trial (RCT) design. This phase II trial of an intervention is aimed at reducing the immediate and long-term physical and psychosocial consequences of haematological cancer treatment and to enable the participant to return to normal functioning sooner. The nurse-led lymphoma survivorship clinic has three core components: (1) needs assessments to determine individual informational or practical issues or concerns; (2) provision of a tailored survivorship care plan and treatment summary to enhance communication between the participant and all other health professionals with whom the patient has contact post-treatment; and (3) provision of individualised evidence-based education, information and resources to address patient-reported needs, likely post-treatment physical and emotional concerns and maximising participant involvement in healthy lifestyle behaviours. The aims are aligned with the Australian national research priority for preventative healthcare to reduce comorbid diseases in cancer survivors.

The Medical Research Council framework for the development and evaluation of complex interventions
APPENDICES

RESEARCH QUESTIONS
The following research questions guide this pilot RCT:
1. Do participants assigned to the nurse-led lymphoma survivorship clinic demonstrate a reduction in self-reported anxiety, depression and stress and an increase in patient self-management behaviours compared with participants randomly assigned to usual care?
2. Do participants assigned to the nurse-led lymphoma survivorship clinic demonstrate a reduction in self-reported anxiety, depression and stress and an increase in patient self-management behaviours compared with participants randomly assigned to usual care?
3. What is the perceived efficacy and value of the nurse-led lymphoma survivorship clinic from the perspective of a subset of survivors in the intervention group?
4. To what extent does the provision of an SCP TS to general practitioners (GPs) improve the communication between the treating hospital, GP and the participant?
5. Does the SF-SUNS demonstrate stability and reliability over time?

METHODS
Design
The evidence to support the development of the phase II CAlly trial comprised a qualitative study using a focus group methodology with lymphoma, leukaemia and multiple myeloma survivors. The evidence also encompassed three systematic reviews regarding models of haematological survivorship care; SCPs and TS in patients with haematological cancer; and tools used to assess the informational and practical needs of acute leukaemia and lymphoma survivors. Information gained from this preliminary work guided the development of intervention components and the operationalisation of the feasibility and acceptability of a nurse-led RCT.

The RCT framework has been developed using the Consolidated Standards of Reporting Trials (CONSORT) statement and checklist. Outcomes will be measured using validated needs assessment instruments. Reporting will include inclusion and exclusion criteria; missing data; dropout; and early closure of the trial if required (figure 1). The survivorship cancer

nurse coordinator (CNC) is a specialist cancer nurse with an extensive background in haematology and formal counselling qualifications, including motivational interviewing techniques.

Population and setting
A convenience sample of patients with lymphoma cancer from a specialised haematology department in a comprehensive cancer centre of a large acute tertiary hospital in Perth, Western Australia, will be used. Follow-up by a haematologist occurs every 3 months for the first 12 months. The nurse-led survivorship clinic will be an additional care activity to the medical haematology follow-up and will involve three appointments over 6 months. It will start at 3 months post-treatment completion and cease at 9 months post-treatment.

Inclusion criteria
1. Pathologically confirmed new diagnosis of HL or NHL.
2. Completed first-line curative intent chemotherapy or second-line curative intent autologous stem cell transplant within the previous 3 months.
3. No evidence of lymphoma disease on mid-treatment interim positron emission tomography (PET) scan or post-treatment PET scan where these are performed.
4. Able to understand and read English.
5. Over 18 years.

Exclusion criteria
1. Diagnosis of other haematological malignancy.
2. Did not undergo chemotherapy.
3. Further treatment and follow-up at another hospital.
4. Intellectually impaired or experiencing an acute mental health condition that precludes the ability to provide informed consent.
5. Comorbid condition requiring monthly visits with GP.

To measure selection bias, minimal data will be completed on eligible participants who decline to participate. Reasons for refusal will be recorded to gain valuable information for future research.

Recruitment
Identification of eligible participants will be undertaken by haematology clinicians who will provide details to the survivorship CNC. Ongoing education of clinicians (haematologists and nurses) regarding all aspects of the study, its progress and recruitment will facilitate cooperation and support. Eligible participants will be met after treatment completion by the CNC who will discuss the study and provide a Participant Information and Consent Form (PICF). Consenting participants randomised to the intervention group (n=30) will be offered the opportunity to consent to a qualitative interview at completion of all time points. Approximately one-third of participants (n=10) will be required for this phase. Participants’ names and contact details will be entered
APPENDICES

Figure 1  Trial flow chart.
DASS-21, Depression Anxiety Stress Scale; GP, general practitioner; MINI-MACM, Mini-Mental Adjustment to Cancer Scale; PES, Patient Empowerment Scale; PET, position emission tomography; SCP TS, survivorship care plan and treatment summary; SF-SUNS, Short-Form Survivor Unmet Needs Survey.

Identification of eligible patients
Inclusion: understand English; completed curative intent chemotherapy or autologous transplant for new Hodgkin or non-Hodgkin lymphoma; no evidence of lymphoma on PET scan; over 18 years of age.
Exclusion: diagnosis of other haematological malignancy; undergoing active treatment; intellectually impaired; experiencing an acute mental health condition that precludes ability to provide informed consent; committed condition requiring monthly visits with GP.

Intervention group (N=30)
Nurse-led lymphoma survivorship clinic
- Consultation with Cancer Nurse Coordinator to normalise end of treatment concerns
- Delivery and discussion of tailored SCP TS
- Discussion of identified needs and goal setting
- Tailored resource pack
- SCP TS sent to GP

Time 1 (3 months post treatment completion)
Informed consent and register (N=45)
Baseline measures
Demographics and medical records, SF-SUNS (pre-test), DASS21, MINI-MACM, PES

Randomisation

Control group (N=30)
Care provided according to treating hospital usual practice

Time 2 (3 months after baseline)
Measures sent for self-reporting: SF-SUNS; DASS21, MINI-MACM, PES

Time 3 (6 months after baseline)
Measures sent for self-reporting: SF-SUNS; DASS21, MINI-MACM, PES

Interview (N=10)
- Assessment of perception of nurse-led lymphoma survivorship clinic

DP evaluation (N=20)
- Evaluation of SCP TS use

Treatment completion visit to haematology consultant
- Patient refusal (collected reason for refusal)

SCP and TS
An extensive review of the literature and available SCPs and TS was undertaken. Many institutions in Australia are using US-based templates that are large (up to 20 pages), not tailored to the individual and provide resources that are not contextualised to the Australian healthcare setting. Therefore, we developed a lymphoma SCP TS in collaboration with a haematology consultant, GP and other multidisciplinary team members (eg, consumers, psychologists, cancer nurses and academic cancer researchers). This has been created as a word document template to be filled in by the nurse. The perspectives of lymphoma survivors (n=6) and clinicians (including GPs; n=6) were sought to determine the relevance of the proposed SCP TS items. Each item was assessed for content and apparent internal consistency (whether items should be included and the general fit with other items) using either yes or no responses to the items. Content validity used a rating scale (1=not relevant to 4=highly relevant). The content validity index (CVI) was generated for each item by adding the number of ‘yes’ scores (content, clarity and apparent internal consistency) and scores of 3 or 4 (content validity). The mean CVI consumer results were as follows: clarity 0.98, apparent internal consistency 1.00, content validity 0.95. Consumers demonstrated complete agreement of 1.0 for internal consistency items. The mean CVI clinician results were as follows: clarity 0.98, apparent internal consistency 0.95, content validity 0.84. Feedback in the comments section of the evaluation interestingly indicated GPs did not value or
require a large TS document. Consensus of the research team was achieved for the TS (half a page in length) and SCP (one and a half pages in length).

The TS is completed using existing medical record information such as diagnosis, treatment, complications and use of allied health providers. The first section of the SCP includes a table for the inclusion of individualised potential late effects. This table comprises the late effect; information for the GP about tests or follow-up required and when; and the symptomology the participant needs to be aware of, with encouragement to follow these up with the GP. Prior to recruitment, a comprehensive list of potential late effects and follow-up required was developed for each lymphoma type using available published literature and guidelines (KT). This list was circulated, discussed and amended by the haematologists who were aware these would be used to guide their population of the table. Tailored individualised potential late effects will be documented based on treatments administered, participants’ demographics and health characteristics. Once the TS and this aspect of the SCP are completed, it will be emailed to the haematologist for final approval. Once amendments (if any) are made, the haematologist signs the TS. The second page of the SCP is patient centred and populated by the nurse in consultation with the participant. Participants will be asked to identify three main concerns, health goals and proposed actions to achieve these goals.

**Sample size**

The calculation of a sample size is not required for pilot RCTs as effect size is not yet known. Rather the purpose of the pilot is to determine variability in measures from which effect sizes can be calculated. Approximately 75 patients are seen per year at the study setting; however, this figure is inclusive of new and existing patients. Therefore, a consecutive sample of 60 participants will be recruited and randomised 1:1 to either control or intervention group (30 participants are expected in each group). It is necessary to establish test–retest reliability for the SF-SUNS by demonstrating a minimum intraclass correlation (ICC) of 0.8. Therefore, a sample size of 39 (rounded up to 40 participants) administered on two consecutive occasions no more than 3 days apart (baseline and 3 days later) is required to achieve 80% power to detect this ICC of 0.8.56

**Patient-reported outcome measures**

A review of the literature46 has resulted in four assessment instruments being selected to measure the outcomes proposed: SF-SUNS; Depression Anxiety Stress Scale (DASS21); Mini-Mental Adjustment to Cancer Scale (Mini-MAC); and Patient Empowerment Scale (PES). These instruments have demonstrated reliability and validity with haematological cancer survivors as shown in Table 1.

**Baseline data collection**

Baseline data collection from consenting participants will occur 3 months after treatment completion. All participants will self-report demographic information and complete the four assessment instruments. In addition, they will receive a second SF-SUNS instrument to complete no later than 2 weeks after the baseline testing. These will be returned via a pre-paid envelope to allow the researchers to undertake test–retest reliability testing. Medical demographic information obtained will include type of haematological cancer, stage of disease, type of treatment received (chemotherapy, immunotherapy, radiotherapy), date of diagnosis, time since diagnosis, treatment complications or dose modifications, and comorbidities. Personal demographic information collected will include sex, age, marital status, age of children (if any), postcode, occupation, income level, education level and health behaviours such as smoking, alcohol consumption and weight.

**Randomisation**

After baseline assessment, participants will be randomised to either the current standard of care or intervention group. Computer-generated random numbers using a four-digit sequence have been generated and linked to group allocation by an independent statistician. An independent member of the research team, to ensure confidentiality and offset bias in randomisation, has sealed a hard copy of each individual number and group in an opaque envelope. The envelopes are consecutively numbered and will be distributed to consenting participants in this order. Control group participants will be made aware that another researcher will follow-up non-questionnaire return with a telephone call to the participant after 2 weeks.

**Control group**

Control group participants will receive follow-up care as per haematologists’ usual practice. At 3 and 6 months after baseline, the same four assessment instruments will be sent to the participant, and they will self-report any issues or unmet supportive care needs. An addressed reply paid envelope will be provided to return assessments. Participants who score high unmet needs will be encouraged to discuss these with their haematologist at their usual follow-up appointment.

**Intervention group**

Following baseline data collection, intervention group participants will have an appointment at the nurse-led lymphoma survivorship clinic. The first page of the SCP TS will be populated prior to this appointment. At the first nurse-led lymphoma survivorship clinic, any concerns the participant has regarding the end of treatment will be discussed and normalised. The nurse will discuss the TS and potential late effects. The second page of the SCP will be completed by the nurse using an electronic template in collaboration with the participant.
### Table 1: Outcomes assessment instruments

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Use</th>
<th>Internal consistency</th>
<th>Additional issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>SPU (PSQI)</td>
<td>Uses 30-item scale; assesses sleep quality</td>
<td>Cronbach's alpha: 0.85</td>
<td>0.70 indicating SPU validity</td>
</tr>
<tr>
<td>UCQ (PSQI)</td>
<td>Uses 20-item scale; assesses sleep quality</td>
<td>Cronbach's alpha: 0.80</td>
<td>0.60 indicating UCQ reliability</td>
</tr>
<tr>
<td>DASS</td>
<td>Measures depression, anxiety, and stress</td>
<td>Cronbach's alpha: 0.90</td>
<td>Used to support SPU validity and UCQ reliability</td>
</tr>
<tr>
<td>MINI-Mental State Examination (MMSE)</td>
<td>Measures cognitive function</td>
<td>Cronbach's alpha: 0.80</td>
<td>Used to support SPU validity and UCQ reliability</td>
</tr>
<tr>
<td>Patient Empowerment Scale (PES)</td>
<td>Measures patient empowerment and self-efficacy</td>
<td>Cronbach's alpha: 0.85</td>
<td>Used to support SPU validity and UCQ reliability</td>
</tr>
</tbody>
</table>
time, the importance of follow-up recommendations will be emphasised. The SCP TS will then be copied, signed, and dated by the participant and the nurse. The completed SCP TS will then be sent, with the original given to the participant, a copy placed in the participant’s medical records, and a copy sent to their GP. Motivational interviewing techniques will be employed for healthy lifestyle behaviour and to assess for readiness to make behavioural change. Participants will be encouraged to identify and explore behaviours they would like to modify using a chart that enables them to list likes and dislikes of specific behaviours and potential impacts of perceived behavioural change. By listening to concerns, highlighting conflicts arising from behaviour and documenting on the chart, participants can control decision-making related to lifestyle change. Participants will be encouraged to set realistic time frames and identify habits and beliefs that may possibly hinder change. Tailored, evidence-based information and advice in a resource pack will then be issued. It is anticipated that a consultation of 60 min will be required in a private clinical room.

A further two appointments will be made at 3 and 6 months after baseline where the same four assessment instruments will be completed by the participant, and they will self-report any issues or unmet supportive care needs. These will be discussed and the appropriate resources, support and information provided. Participants will be encouraged to discuss their health concerns, goals and progress with any action they may have taken. Participants will be asked if they have seen their GP in the last 3 months and if they took the SCP TS and discussed any of the late-effect screening recommendations, their participant-identified concerns or goals. This will aid the transition to GP follow-up where the benefits of shared care will be explained. A checklist for each participant of the resources provided will be kept.

**DATA ANALYSIS**
Quantitative data will be analysed using univariate and multivariate statistical techniques with SPSS data analysis software. Descriptive statistics will be used to analyse the demographic variables collected. Responses to the SF-12 and SF-36, DASS21, Mini-MAC and PES will be scored according to the algorithms in the instrument manuals. Measures from all instruments will be checked for normal variance within the two groups. Within each group, paired t-test comparisons will be made between baseline measurements and at each time point: baseline, 3 months and 6 months. Differences between intervention and control groups will then be assessed at each time point. Test-retest reliability using ICC will be undertaken on the SF-12 instrument. The minimum ICC value required for this scale is 0.8. Participants who drop out or are lost to follow-up or accrue to be excluded after the start will be accounted for by intention-to-treat analyses. CIs will reflect the contrast between groups to show treatment effect. Missing data, incomplete answers and non-response will be recorded.

**Qualitative Interviews**
Supplementary in-depth, semistructured interviews will occur with ~10 consenting participants when they have completed all intervention components (after 6 months). This number will allow for saturation of themes. Telephone interviews will be digitally recorded and undertaken by an independent researcher to ensure participants are given the opportunity to freely express positive and negative perceptions of their experience. The use of a qualitative approach will provide depth of information regarding the personal impact of the nurse-led lymphoma survivorship clinic on the participant. The interviews will also highlight any issues or challenges for this group that could be better addressed in the future.

Interviews will be transcribed verbatim and thematic analysis used to determine themes and patterns within the text. NVivo qualitative analysis data management software will be used to manage interview data.

**GP Evaluations**
A non-validated evaluation will be sent to GPs who have received the SCP TS. This was developed in consultation with a GP and will ascertain if GPs made use of the SCP TS and to elicit perceptions of the value and effectiveness of this document in facilitating communication between the treating hospital and GP and GP and participant. This will guide future refinement of the SCP TS. Analysis will use descriptive statistics and distribution analysis techniques. Open-ended questions will use content analysis techniques. GPs will be called by the researcher after 2 weeks for non-return of the questionnaire to remind them to fill in and return the evaluation in the reply-paid envelope.

**DISCUSSION**
A significant culture change is required for providers to recognise survivorship care as a standard component of quality cancer care that involves all health professionals, participants and families. The gap in knowledge contributes to a current model of survivorship care that is fragmented, with inadequate service provision at treatment completion, leading to unmet needs along the survivorship continuum. The cancer specialist is not necessarily required for routine screening and follow-up. However, the involvement of other health professionals, including primary care, necessitates the need for an awareness of the treatment delivered and the long-term and late-effect risks. This study will address the lack of robust empirical evidence in haematology survivorship care. A nurse-led model of care would assist patients transitioning from the end of treatment to the survivorship phase. Furthermore, the provision of an individualised SCP TS
is a means to empower individuals with knowledge about their illness and treatment and to assume responsibility for future surveillance and disease management. It will likewise take advantage of ‘teachable moments’ at the end of active treatment to support and promote patient participation in healthy lifestyle behaviors. This is particularly vital for younger survivors, given the expectation of a longer survivorship period.

The intervention has been timed to occur in the early survivorship phase. This has been supported by preliminary focus group work including lymphoma cancer survivors who indicated they often felt abandoned at treatment completion. This timing also concords with McDowell et al., who found assessments and interventions undertaken in the early survivorship phase (up to 2 years post diagnosis) led to fewer unmet needs moving into the extended survivorship phase (over 5 years).

The CALy trial will examine the impact and effectiveness of the nurse-led lymphoma survivorship clinic intervention through an assessment of the important clinical outcomes: unmet informational and practical needs; depression, anxiety and stress; coping; and self-empowerment as measured by the instruments chosen. It is therefore designed to improve the identification of unmet needs. Testing of such an intervention by an RCT has not been published in lymphoma survivorship studies to date. Consequently, it will make a significant contribution to the planning and delivery of survivorship care. Likewise, it represents a substantial and original contribution to knowledge and support for haematology survivorship care as few studies aim to improve the psychosocial and supportive care of this cohort. If the intervention achieves its intended outcomes, it may potentially lead to the development of nurse-led haematology survivorship clinics across the tertiary health sector in Western Australia that could ultimately be expanded to all cancer survivors.

Ethics

Ethics approval has been gained from the relevant hospital (2015-029) and university (015007E) Human Research Ethics Committees (HRECs). The trial is registered at the Australian and New Zealand Clinical Trials Registry (ACTRN 126130053027) and the Western Australia Cancer Clinical Trials Registry. The trial is open to patient recruitment. It is not expected participants will be exposed to any undue risks or harm by participation. Participant information will remain confidential and deidentified where appropriate. Economic harm will be minimised by providing appointments when the participant is already attending the hospital. Exploring concerns may be distressing and if this occurs, participants will be referred to the appropriate counselling services as per usual clinical practice. Collected data will be securely stored at the university for 15 years after study completion and will only be accessible with written permission from the researcher and relevant university and hospital sites.

Dissemination

We plan to complete the study by December 2017 and report trial results in 2018. It is anticipated the main trial outcomes will be published in a single paper in a refereed cancer journal. Further publications will explore the qualitative data and the test-retest reliability measures of the SF-36 in WA. We will correspondingly present findings at national and international conferences.

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Protocol for Care After Lymphoma (CALy) trial: a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care
Karen Taylor, David Joske, Max Bulsara, Caroline Bulsara and Leanne Monterosso

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A.5 Qualitative Results from a Phase II Pilot Randomised Controlled Trial of a Lymphoma Nurse-led Model of Survivorship Care

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Qualitative results from a phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care

Karen Taylor, Leanne Monterosso, Caroline Bulpuls

Keywords: Lymphoma cancer Survivorship Qualitative interviews Nurse-led clinic intervention Survivorship care plans and treatment survivorship

Abstract

Purpose: To explore and describe lymphoma survivors' thoughts and perceptions of the components of a nurse-led lymphoma survivorship clinic intervention.

Methods: An exploratory, qualitative descriptive study using interviews from ten participants who had transitioned post-treatment into the survivorship phase via a nurse-led lymphoma survivorship clinic intervention. Thematic analysis revealed three major themes: Reassurance and individualised care; Information and support; and Empowerment. Participants described the reassurance they gained from having contact with a health professional post-treatment who individualised information and support. A survivorship care plan and treatment summary was developed for this study and was believed to be very patient-centred and helpful. This enabled participants to take back control of their health and well-being and to rebuild confidence.

Conclusions: In this study, participants expressed a need for patient-centered follow-up care that addressed their concerns and supported them in the survivorship phase to get their life back on track. Nurse-led follow-up may offer a viable model of post-treatment survivorship care to lymphoma cancer survivors.

1. Introduction

Lymphomas are haematological cancers that originate from the lymphatic system, and are mainly categorised as either Hodgkin (HL) or non-Hodgkin lymphoma (NHL) (American Cancer Society, 2014). Worldwide, lymphomas represent the sixth most commonly diagnosed cancer (Surveillance Epidemiology and End Results (SEER), 2014). Australian incidence is increasing with an estimated 6333 cases expected in 2017, which will equate to 4.6% of all cancer cases (Cancer Australia, 2017a, 2017b). However, developments in treatment and supportive care options such as chemotherapy, haematopoietic stem cell transplantation, radiotherapy and targeted therapies have improved five year survival to 76% (Cancer Australia, 2017a). With increased remission and survival rates, many survivors experience issues and concerns, called unmet needs, which can impact quality of life and well-being (Gaynor et al., 2012; Sent et al., 2014). These can relate to issues such as: fatigue; poor nutrition; exercise capacity; cognition impairment; fear of recurrence; fertility; relationships; finances; employment; and insurance (Taylor et al., 2015; van der Poel et al., 2014). Health can be further compromised by late effects of treatment such as cardiovascular disease and second cancers (Fitzpatrick, 2010; Ng et al., 2011; Travis et al., 2012), often experienced earlier than the general population (Fack-Mahoney, 2013).

Haematological survivorship studies often report on mixed haematological samples regardless of variations in clinical features, treatment, curability and relative survival (Hall et al., 2013; Lobbe et al., 2009; McGraith, 2014). A study of lymphoma (n = 230) and myeloma (n = 178) survivors on anxiety, depression and unmet needs in the early survivorship period (under two years) reported decreasing anxiety and depression rates in the myeloma cohort and increasing rates in the lymphoma cohort (Oberti et al., 2017). The authors indicated a need for cohort specific studies, especially in the early survivorship period (Oberti et al., 2017) to ensure targeted support. Lymphoma only studies often reflect a survivorship period beyond 2 years at assessment (Ferone et al., 2011; Friedman et al., 2010; O’connor et al., 2014), which may not reflect the unique needs of those who have recently completed treatment, limiting generalisability. A recent study by the authors (Monterosso et al., 2017) reported on focus groups with lymphoma survivors (n = 17), the majority (n = 13, 76%) who were 12-30 months post-treatment completion. Participants recounted unmet needs related to information, coping strategies and support, especially when transitioning into survivorship. Findings suggested cancer nurse
APPENDICES


coordinators could be a feasible approach to delivering structured, individualised support early post-treatment (Monteiro et al., 2017). Nurse-led models of survivorship care have been proposed to transition patients post-treatment and have demonstrated acceptable outcomes in haematology cohorts (Gaines et al., 2015; Howell et al., 2012; John and Armas, 2013). As a minimum, nurse-led models should include: administration of survivor-specific needs assessments to identify patient concerns (McHewell et al., 2016; Siedle et al., 2013); development and delivery of a survivorship care plan and treatment summary (SCPTs), to guide holistic follow-up (Clinical Oncology Society of Australia, 2016; Macmillan Cancer Support & NSW Improvement, 2010; McCabe et al., 2013); and support to assist survivors to take ownership of their health and well-being (Meadallin et al., 2002; Kuijpers et al., 2013). To date, studies that have tested nurse-led models of care have focused on survivors of common cancers (breast, prostate, colon) (Jefford et al., 2016; Mah et al., 2017; Taylor et al., 2013), been based in acute care settings, used long consultations, and involved more frequent patient contact (Cooper et al., 2015; De Lucca and Larson, 2013), which may preclude generalisability to other cancers or limit economic viability.

In order to provide lymphoma survivors with supportive and relevant supportive care, the unique issues and unmet concerns of this cohort need to be assessed in the early survivorship period (under one year). The aim of this sub-study was to provide qualitative semi-structured interview data from a sample of participants who had been randomised to the intervention group of the Care After Lymphoma (CALy) phase II randomised controlled trial study (RCT) (Taylor et al., 2016). The RCT aimed to develop and test a nurse-led lymphoma survivorship clinic (NLSC) intervention to assist participants transitioning from treatment completion into the early survivorship phase. This study will add to the limited literature that exists in lymphoma specific early survivorship.

2. Methods

2.1. Methodological framework

A qualitative descriptive methodology was utilised to provide a comprehensive summary of a specific experience by the participants (Neergaard et al., 2009; Sandelowski, 2000), using a semi-structured interview design. The interview schedule consisted of the same open-ended questions and was developed by the researchers. To ensure participants felt able to express themselves and their perceptions freely, interviews were conducted by an experienced independent researcher.

2.2. Sample and setting

A purposive sample of lymphoma patients from a large tertiary hospital cancer centre in Perth, Western Australia were recruited from the intervention group of the RCT. A non-probability purposive sampling provides rich information from participants who have the greatest amount of in-depth knowledge and experience of a particular circumstance or event (Patton, 2011). Only participants who had completed all aspects of the NLSC intervention were approached by the survivorship nurse conducting the clinic intervention. These participants had completed four measures: Short Form Survivor Umeå Needs Survey (SF-SUNS); Depression Anxiety Stress Scale (DASS21); Mini Mental Adjustment to Cancer Scale (Mini-MAC); and Patient Empowerment Scale at three time points: baseline (prior to randomisation), 3 months and 6 months. At the first NLSC appointment (approximately one week after baseline), participants completed and received an individualised lymphoma SCPTs, developed for this study (Taylor et al., 2016). Participants’ GP were sent a copy. A motivational interview technique was used to provide evidence-based information, advice and support at the first intervention appointment and reinforced with additional resources and support as required over the next two appointments.

All participants approached agreed to be interviewed. Each participant was nine months post-treatment completion and the sample reflected an equal gender distribution and range of ages. Data saturation was achieved after ten interviews.

2.3. Interviews

The study was approved by the relevant hospital and university human research ethics committees. Informed written consent was obtained by all participants prior to interview scheduling. Interviews were conducted from February 2016 to May 2017 and occurred after the last NLSC appointment. Telephone interviews were conducted at a time convenient for the participant and were digitally recorded. The following are examples of the interview questions: ‘Did you have any concerns or needs not addressed by any of the questions?’; ‘What aspects of the clinic would you want to change?’; ‘Would you recommend the clinic to other patients finishing treatment?’; ‘How do you feel about having the health concerns, goals and actions individualised to yourself?’; and ‘Overall how useful was the SCPTs to you?’ Interviews were transcribed verbatim, de-identified and an identifier code applied. Digital recordings and transcribed interviews were saved in a password-protected file on a secure server. After the first three interviews, the question order was slightly altered to enhance the flow of the interview.

2.4. Data analysis

Interview transcripts were imported into NVivo 11 to facilitate management of data and completion of the analysis. Theme analysis was used to establish patterns and themes within the text (Grubich, 1998; Patton, 2014, Smith, 2007). Theme analysis allows for participant diversity of ideas and perceptions (Smith, 2007), thus providing a depth of information regarding the personal impact of the NLSC on the participant. Sub-themes were developed from the data, and allowed for a logical organisation of the themes that emerged. The criteria of credibility, auditability and fitlessness were applied to the data analysis process to ensure rigor (Beck, 1993). Credibility was maintained by triangulation with another member of the research team (Beck, 1993) to ensure independent reading and analysis of the transcripts by KT and CB who allocated codes and themes to the generated data (Braun and Clarke, 2006). The researchers met to discuss the codes and any discrepancies before consensus on emerging themes was reached. The sample use of extracts or quotes from the data demonstrated fitlessness to the agreed codes. A comprehensible audit trail maintained auditability, demonstrated by documentation of research planning through to analysis, and through a reflective discourse and debrief process with colleagues.

3. Results

3.1. Participants

Ten semi-structured interviews were conducted with all participants willing to share an opinion for each of the interview guideline areas. Demographic and disease information is shown in Table 1. There were equal numbers of males and females, with similar age range (24-74 years) and lymphoma type. The majority of participants resided within the metropolitan area (n = 8, 80%), were working (n = 6, 60%), were married or de facto (n = 6, 60%) and had a university degree or trade qualification (n = 8, 80%).

Time elapsed from end of study to interview ranged from 1 to 26 days (mean 5.5 days, SD 7.8 days). The majority of interviews (n = 8) were done within 5 days. No time limit was set and interviews ranged from 17 min through to 48 min (mean 30.5 min).
### Table 1
Demographic characteristics for interview participants (n = 10).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Males n = 5 (50%)</th>
<th>Females n = 5 (50%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group at baseline</td>
<td>2-25</td>
<td>2-25</td>
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<tr>
<td></td>
<td>40</td>
<td>40</td>
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<td></td>
<td>60-74</td>
<td>60-74</td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td></td>
<td></td>
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<tr>
<td>Non-Hodgkin</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Hodgkin</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Highest level of education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary or less</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Trade/vocational college</td>
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<td>2</td>
</tr>
<tr>
<td>University</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Employment status</td>
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<td></td>
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<td>2</td>
</tr>
<tr>
<td>Retired</td>
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<td>2</td>
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<tr>
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<td>1</td>
</tr>
<tr>
<td>Marital status</td>
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<tr>
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<td>1</td>
<td>2</td>
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<tr>
<td>Married/defacto</td>
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<td>2</td>
</tr>
<tr>
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<tr>
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<tr>
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</tr>
<tr>
<td>Rural</td>
<td>-</td>
<td>-</td>
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<tr>
<td>Total</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

### 3.2. Themes

Three major themes emerged from analysis and coding of data: Reassurance and individualized care; Information and support; and Empowerment. Subthemes have been included to add clarity.

### 3.3. Reassurance and individualized care

Overall, the NSLC was well-received and deemed a positive experience for participants, although it would have been reassuring to know about the clinical intervention during treatment. The needs assessment questionnaires and the SCPTS were perceived to facilitate individualized care.

#### 3.3.1. Timing of support

Most participants indicated they would have liked knowledge of the clinical intervention during treatment so they could feel reassured that someone was still interested in supporting them and they were "not going to be abandoned." This would take the form of a contact person they could trust.

"Just knowing that I was still going to get some support" F.24yo,HL

"But to know that look, don’t worry, after treatment you are going to see a nurse, that would have been very calming for me" F.64yo,HL

#### 3.3.2. The use of questionnaires to elicit unique needs and concerns

Questionnaires were used to elicit unique needs and areas of concern that could be discussed with participants at the NSLC appointment. Participant responses served as a focus for the follow up appointment. Feedback about the questionnaires indicated some questions were hard to answer.

"Sometimes I found that I couldn’t say yes or no to the questions, because they didn’t apply I suppose, and I had to answer" F.64yo,HL

Nonetheless, the questionnaires were able to cover aspects thought to be important to participants’ overall wellbeing, as one said,

"They covered a multitude of the different things like your emotional well-being, mental well-being and physical well-being, all the things that you know you can struggle with" F.24yo,HL

#### 3.3.3. The supportiveness of the intervention

All participants wanted the intervention structure to remain the same, describing the one-to-one, personalized nature of the intervention as valuable opportunity to talk to someone who was not family, friends or a doctor. They described being listened to and ‘feeling safe’ to ask questions on a range of topics, especially questions they felt they could not ask their haematologist. Participants indicated support was individualized and felt reassured they could get their life back on track.

"The one-on-one was really helpful because then you felt like you could pretty much ask anything, or talk about anything, and you didn’t feel like there would be other people around to listen to your private conversations. A safe space, ask questions and get reassurance and the right answers. That was good" F.24yo,HL

"Someone that you can speak to and address the problems that you don’t get the time with the doctors to talk about" F.64yo,HL

Another participant also commented on how he could discuss other aspects of the cancer experience. He said,

"What I particularly liked was the opportunity to have a conversation around things other than treatment. Dealing with some of the fears that you may have that you didn’t feel like you could ask your specialist about. Or where do I go for complementary therapies. The kind of questions that specialists don’t necessarily need for. Or don’t have time really so cover. The ability to have a chat to a nurse that can help you through the next part of the journey" M.48yo,HL

A couple of participants indicated that the intervention should have been conducted according to patient preferences. This included a preference for the NSLC to be away from the hospital and closer to their home.

"We should be providing services close to home where possible and I think there are some really great opportunities for the mindfulness study to get out into the community even though they are still run by the hospital" M.48yo,HL

Although two participants found returning to the hospital traumatic, they felt the NSLC experience helped them to overcome their aversion as it was felt to be a safe place they could communicate their fears and receive reassurance.

"The torture as a result of the treatment – going back to the hospital made me feel all that. It actually helped me deal with the fact that I can go to the hospital and not feel sick – so there was a positive" M.48yo,HL

#### 3.3.4. Nurse contact and support

It was also felt contact should have been more frequent with telephone support between face to face visits, to provide extra support and to ‘check-in’ with the participant.

"I think you need to make them a bit closer together – a bit more frequent. And also make where patients can choose. Make it more patient-driven – where the patient tells you how often they want to see or talk to someone" F.48yo,HL

There was also an indication that many wanted the contact to go beyond the study timeframe. As one participant said,

"I don’t feel like I am on my own anymore yet. I am thinking 2 years before I have got my confidence and hopefully my health back" F.64yo,HL

All participants described the relationship with the nurse who ran the intervention as comfortable and flexible, and felt they could call or speak to her with any issues if they wanted to. Participants provided comment and perceptions of the nurse as follows:

"And she did explain things so that I understand them more. She was really good at making you feel relaxed" F.48yo,HL

11
"You felt like you had enough time to talk about and ask questions you didn’t feel rushed and I think that was really good" F.23y_HL.

3.3.3. Survivalship care plan and treatment summary

The written patient-centred SCPTS was described as reassuring when it guided follow-up and for keeping on track with healthy lifestyle behaviours.

"Yes, it was good because it is reassuring, it is a guideline of what to do which I needed and knowing what to look out for and should be doing" F.54y_HL.

Feedback from participants regarding the SCPTS being sent to the GP indicated only two GPs discussed the SCPTS with them. Other participants indicated they either had not seen the GP or the GP acknowledged receipt but did not discuss.

3.4. Information and support

Participants appreciated the opportunity to discuss, record and receive written individualised information, support and resources. Although some information such as late effects was confronting at the time, it was nevertheless appreciated. All felt the information received at the NSLC was relevant and appropriate because it was tailored to their unique needs. Most felt they had not received this information or support from the treating team, however, it was acknowledged that possibly verbal information had been given but not retained.

3.4.1. Individualisation of the SCPTS

Participants liked the individualisation of the health concerns, goals and actions, and the accompanying written information and/or contacts.

"When I did have a concern, I was given printed notes about those issues and I think that is really good. Because I do have trouble with my memory now, and I can go back over those notes and sometimes it is like, reading it anew, you know" F.64y_HL.

The treatment summary was well-received with most participants describing it as ‘good to have’, especially as a tool for communication with other health professionals.

"I think it was useful to sit down and have that initial meeting. I think it was really good that it was sent to my GP" F.23y_HL.

However, one participant was unsure of the value to himself.

"But I think this kind of treatment summary is the sort of thing I would give to my GP, or if I was seeing a new Dr, or if I was travelling and I got sick. I almost feel like it’s less useful for me, but more useful for other people" F.64y_HL.

One participant felt the terminology related to the disease location could have been put in simpler language and this helpful recommendation was utilised for subsequent treatment summaries.

"Sometimes you don’t always understand the medical terms so I think putting it into more simpler language would be a bit more helpful" F.46y_HL.

3.4.2. Late effect information

The potential late effect information given on the SCPTS was individualised to each participant. It came as a shock to many that heart disease and other cancers, for example, were possible consequences of the treatment received.

"Well that was a bit of a shock to me, because they hadn’t been mentioned prior to the treatment. ... but at the same time, it was probably easier on me not knowing anyway" F.65y_HL.

Participants appreciated having the information and felt it could help with GP consultations, specifically around planning of health management into the future.

"That gave me something to go to my GP with and go okay I think I need to monitor this and this. And it helped me set out a care plan with my Dr as well" F.46y_HL.

"It’s always a bit overwhelming, but I think it is a good way to highlight the possible things that could happen. I think it reduces you’re stress because you are not just in the dark about it. I think it is really important for yourself and the GP. If anything does change you know at least you are going to get a early" F.24y_HL.

One participant indicated they had heard the potential late effect information at diagnosis and another described being told there were some possible late effects after she had completed treatment.

"Oh, he just briefly spoke about you just need to be careful, you need to look after your skin, you need to do annual breast checks, you need to look after your heart. You know there is a possible risk you could get these problems in the future. That is sort of how he mentioned it" F.24y_HL.

Neither participant had received written information and did not feel they knew how to follow-up these risk factors. This was an important consideration when developing the SCPTS to ensure follow-up suggestions for the GP and participant were given.

"[GP] just asked me to come in and discussed it with me and then be kind of just saved it and then he linked me in with support services to make sure I was monitoring all of my side-effects, so I think he thought it was good" F.23y_HL.

3.5. Empowerment

Most participants perceived the intent of the NSLC was to assist with transitioning away from reliance on the treating team, to taking responsibility for monitoring and seeking support.

3.5.1. Nurturing empowerment

All participants described the SCPTS as useful and perceived it as a means to remind them to ‘stay on track’ with healthy lifestyle behaviours or for encouragement with achieving their goals.

"It just kind of helped remind me of my goals, and every time I had the meeting with [RT], it was like a kind of thing to remember my goals and I thought it was a really beneficial thing" M.24y_HL.

Although one participant described the initial discussion and plan as helpful, she felt she should have had to seek out services and arrange appointments.

"Maybe actually getting linked into the services they talk about. Rather than just getting the information and being left with it, it was kind of like I had to go and seek it out myself. I think it would have been really helpful to have someone contact me" F.25y_HL.

It appeared she did not want to take responsibility for her follow-up care. The remaining participants described understanding and appreciating the need to take back control of their health and well-being. They described the opportunity to discuss and write down their own health concerns, health goals and the actions they planned to take with a health professional as confidence building and assisted in increasing their positivity post-treatment completion.

"There are definitely days where you go thru and you start to question yourself, but being able to talk to someone about it made me feel more confident about being finished" M.25y_HL.

"I started thinking a bit more positive" M.27y_HL.
Participants noted that having the opportunity to record and discuss participant-specific issues had personalised both the appointment and the SCPTS.

"It identified what you personally were worried about and it wasn’t just a general thing that everyone can be worried about, but it was specific to you. And then having the specific needs addressed with a certain plan or the actions column that you could put in place. I think that was really helpful because you see how you could be proactive about things" F.24yo, NIL.

3.5.2. Monitoring progress

Participants felt the follow-up over the next six months in the NSCT allowed them to monitor their progress and see how they were going.

"That was good. It was something to monitor my progress and it feels more personal" M.23yo, NIL.

"It sort of crystallises your thinking for the future. If you don’t do something like that you tend to drift along day to day" F.74yo, NIL.

Receiving written and contact information for support allowed participants to engage and take ownership for how and when they dealt with their goals and concerns. Even when issues remained unmet, having the issue normalised was equally important.

"Well the fatigue and the memory problems I have still got. It was useful to find that other people suffer the same things, that I am not alone on that" F.64yo, NIL.

3.5.3. Usefulness of general health information

Participants received general health and screening information and felt it was helpful. More read it at home, then put it aside. They felt the value was in having it to refer to if needed.

"I think that it is really good to get the information and just have it there. I thought that was very handy" F.24yo, NIL.

This document was not sent to the GP, as GPs involved in evaluating the SCPTS for content clarity, internal consistency and content validity, indicated they knew this information and did not want it. It was noteworthy that two participants had given it to the GP and it had guided follow-up care.

"I basically took all the information into my GP and let him read thru it and he used it to help guide my care plan in the right direction" F.48yo, NIL.

4. Discussion

This study contributes to the growing body of cancer-specific survivorship literature. The current model of specialist follow-up care for cancer survivors is inadequate, with many survivors experiencing unmet needs that can remain poorly addressed throughout the survivorship continuum (De Larena and Larson, 2013). It is essential survivorship care incorporates an awareness of treatment and disease, long-term and late effect risks, as well as healthy lifestyle behaviours (Taylor et al., 2013), and facilitates communication amongst all health professionals and the patient and family. Expertise in the provision of health promotion, support and information has always been the purview of cancer nurses (Jackson et al., 2013). Therefore nurse-led models should be considered within any proposed model of survivorship care.

This study involved a cohort of lymphoma participants and specifically targeted those in the early survivorship phase (first nine months post-treatment). Studies that involve a single subtype of haematological cancer are important in ascertaining the psychosocial and supportive care interventions that are specific and most appropriate (Ohnoro et al., 2017). Assessing and providing an intervention in the early survivorship period has been shown to lead to a reduction in the unmet needs as survivors continue beyond five years (McGowen et al., 2010).

Participants described having time within the NSCT appointment to ask questions and seek individualised support as fundamentally helpful. An important point of difference with medical follow-up where participants perceived the specialist as too busy, or perhaps not interested when they were seeking reassurance and support. Interestingly, some participants would have preferred a follow-up appointment away from the hospital, an important consideration with future planning of nurse-led clinics. Participants had not previously met the nurse who provided the intervention; she is, however, a cancer nurse coordinator with extensive haematology/oncology nursing and counselling experience and qualifications. A health professional who can quickly build a strong and positive rapport allows participants a greater opportunity to explore their own unmet needs (Ross, 2013). This may be why participants responded favourably to the intervention and is important when considering nurse-led models of survivorship care.

Empowering participants with an individualised SCPTS that provided disease and treatment knowledge, and allowed them to assume responsibility for their future health and well-being (Taylor and Montgomery, 2013), was described as helpful from all participants. The expectation of younger survivors living longer with potential issues is important (Johnson and Bowen, 2013), nevertheless all participants in this study, regardless of age, appreciated the follow-up guidance they could discuss and implement with their GP. Information on general health and screening allowed participants a sense of independence of when and how they would seek follow-up. Of particular importance to participants was the opportunity to personalise the SCPTS and concentrate on what was important to them as they moved forward after treatment had completed. Conversely, our study revealed a small subset of participants who were not ready to take back control of their future health and well-being. It is important to acknowledge those patients, and provide individualised support that meets their needs at the time, without building further dependency in the survivorship phase.

Survivorship literature highlights the concept of ‘teachable moments’ (Alfano et al., 2012; Grant and Economou, 2008; Hewitt et al., 2005; Pannell-Hadden, 2013) at the end of active treatment to support and promote patient participation in healthy lifestyle behaviours. It was thought that participants in this study would need to be encouraged to engage in healthy lifestyle behaviours. However, it was evident that participants did feel a need to improve their health, and for some, change their lifestyle to adopt healthier lifestyle behaviours they had not been able to do during the stress of treatment. These participants particularly described the opportunity to revisit the SCPTS over the preceding months allowed them to monitor and reflect on their achievements and help them to keep focused on their goals.

4.1. Limitations

This study reflects the views of a subset of lymphoma participants who underwent a nurse-led clinic survivorship intervention and therefore could not be generalisable to the wider survivorship population who have experienced a nurse-led clinic. Nonetheless, the use of qualitative research allowed an opportunity to gain a deeper understanding of the experiences of this select group. The findings are presented to help build research that is based on patient experience and feedback. The small number of participants is not a methodological limitation in qualitative research when data saturation is reached.

5. Conclusion

The interviews were conducted to ascertain the participants’ perception of the efficacy and value of the components of the nurse-led intervention and to highlight any issues or challenges for this cohort that could be better addressed in the future. Survivorship care offered by nurses may address the patient-perceived unmet needs at the
conclusion of active treatment. Participants indicated the need for security in knowing there would be support when treatment completed, and would likewise value the opportunity to have their concerns heard. An individualised SCC75 questionnaire surveys to address healthy lifestyle issues, and provide a follow-up guide for late effects of the disease and treatment assists in refocusing responsibility back to the patient. Nurse-led survivorship care may offer an acceptable model to deliver patient-centred post-treatment follow-up. This model allows the time required to individualise and tailor supportive survivorship care.

Conflicts of interest

There are no competing interests. No conflict of interest has been declared by the authors in relation to this study.

Funding

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References

A.6 Test–Retest Reliability of the Short-Form Survivor Unmet Needs Survey

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APPELLICES

Original Article

Test-Retest Reliability of the Short-Form Survivor Unmet Needs Survey

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ABSTRACT

Objective: Reliable and valid needs assessment measures are important assessment tools in cancer survivorship care. A new 30-item short-form version of the Survivor Unmet Needs Survey (SF-SUNS) was developed and validated with cancer survivors, including hematology cancer survivors; however, test-retest reliability has not been established. The objective of this study was to assess the test-retest reliability of the SF-SUNS with a cohort of lymphoma survivors (n = 40).

Methods: Test-retest reliability of the SF-SUNS was conducted at two time points: baseline (time 1) and 5 days later (time 2). Test-retest data were collected from lymphoma cancer survivors (n = 40) in a large tertiary cancer center in Western Australia. Intraclass correlation analyses compared data at time 1 (baseline) and time 2 (5 days later). Cronbach’s alpha analyses were performed to assess the internal consistency at both time points. Results: The majority (33/36, 77%) of items achieved test-retest reliability scores 0.45-0.74 (fair to good). A high degree of overall internal consistency was demonstrated (time 1 = 0.92, time 2 = 0.95), with scores 0.65-0.94 across subscales for both time points. Conclusions: Mixed test-retest reliability of the SF-SUNS was established. Our results indicate the SF-SUNS is responsive to the changing needs of lymphoma cancer survivors. Routine use of cancer survivorship specific needs-based assessments is required in oncology care today. Nurses are well placed to administer these assessments and provide tailored information and resources. Further assessment of test-retest reliability in hematology and other cancer cohorts is warranted.

Key words: Cancer survivorship, Internal consistency, lymphoma, short-form Survivor Unmet Needs Survey, test-retest reliability

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**Introduction**

Lymphoma blood cancers are malignant T or B cell lymphocytes in the lymphatic system and are categorized under two main types: non-Hodgkin lymphoma (NHL) and Hodgkin lymphoma (HL). NHL represents approximately 88% of all lymphomas, while HL is predominately diagnosed in the adolescent and young adult population. Combined, they represent the sixth most common cancer diagnosis worldwide. Consistent with worldwide trends, the incidence of lymphoma in Australia is increasing, and with a projected diagnosis of 6232 cases in 2017, this equates to 4.6% of all cancer cases. An estimated mortality rate of 1481 equates to 3.1% of all deaths from cancer in 2017. Projected figures for 2017 in the USA have a similar projected incidence of lymphoma of 4.8% and mortality of 3.6%. Treatment for lymphoma generally comprises high-dose chemotherapy and/or targeted immunotherapy agents and may include radiotherapy and hematopoietic stem cell transplants. These treatments have resulted in an improvement to overall survival of approximately 76% at 5 years compared with 52% at 5 years in the 1980s. Notwithstanding the positive impact treatment has had on survival rates, the consequences of disease and treatment continue long after treatment completion. Long-term and late effects may produce ongoing unmet needs such as fear of recurrence, fatigue, poor nutrition, exercise, fertility, relationship, financial, employment, and insurance issues.

To provide optimal supportive care to lymphoma survivors, the identification of patients’ perceived concerns and level of support needed is required. This is especially important for younger patients (18–45 years of age) where the expectation of long-term remission can raise additional concerns and unmet needs. Receiving relevant information and practical support soon after treatment ends, especially resources related to healthy lifestyle behaviors, can help mitigate the impact of disease and treatment and lead to fewer unmet needs further along the survivorship continuum. A qualitative study with lymphoma cancer survivors (n = 17) undertaken in Western Australia reported unmet informational and practical needs as participants transitioned from treatment to the survivorship phase. The findings suggested tailored post-treatment support and interventions are fundamental components of excellent survivorship care.

The measures used to assess unmet needs are equally important. Generic cancer measures which comprise items related to diagnosis and treatment are often not specific enough for the survivorship phase. Comprehensive, relevant, reliable, and validated needs assessment measures that are survivor-specific are essential to capture unmet needs that become evident when treatment ends. These measures can guide health professionals in providing individualized information, support, and resources. Two recent systematic reviews revealed that needs assessment tools are varied and may not capture all the possible unmet needs patients may have. The reviews likewise found validity and reliability evidence limited. The Survivor Unmet Needs Survey (SUNS) was identified as a measure that had strong psychometric properties and was developed and psychometrically tested with a large cross-sectional sample of cancer survivors (n = 550) including a small cohort of hematology cancer participants (n = 31, 5.6%). Campbell et al. confirmed a high overall internal consistency of items for their study with an overall Cronbach’s alpha of 0.90. The authors also reported high test–retest reliability although the results were not published. Internal consistency of the SUNS was further tested in two studies of hematological cancer survivor cohorts. A cross-sectional study with 529 hematological cancer survivors demonstrated overall Cronbach’s alpha values >0.9, and a weighted Kappa coefficient score of >0.6 for test–retest reliability; acceptability was reported for 40/89 (45%) items. Qualitative data from 17 semi-structured interviews indicated that the SUNS was considered relevant by this cohort of hematological cancer survivors. A cross-sectional study of hematological cancer survivors from Australia and Canada (n = 437) reported similar levels of unmet needs across the two cohorts using the SUNS, with fatigue (α = 0.26, 17%) and financial concerns (n = 39, 8%) rated as high unmet needs. Despite the clinical utility of the original SUNS, it was considered potentially burdensome for use in the clinical setting given the large number of items (n = 89). In 2014, the 30-item short-form-SUNS (SF-SUNS) was developed and validated with a mixed sample of cancer survivors (n = 1589), including hematological cancer survivors (n = 84, 5%). Construct validity and intraclass correlation coefficients (ICCs) of the SF were similar to those of the original SUNS. Cronbach’s alpha scores for the final four domains were ≥0.85, and ICCs for the three domains from the original SUNS (financial concerns, information, and access and continuity of care) and the SF-SUNS were high (>0.9). Discriminant validity demonstrated the SF-SUNS ability to discriminate between individuals who had recently received treatment and those who had not. The authors recommended further testing of the SF-SUNS for test–retest reliability. The 30-item SF-SUNS was therefore judged to be more practical and likely to be completed by participants in our larger study, particularly as the SF-SUNS was one of four instruments to be administered to participants in a pilot randomized trial to measure the effect of a nurse-led survivorship model of care.
For researchers and clinicians to develop targeted follow-up support for cancer cohorts underrepresented in survivorship literature, such as lymphoma, cohort-specific studies in the early survivorship phase are required. Therefore, this study recruited only those with a lymphoma diagnosis who had completed treatment. Discerning the issues and concerns of this group requires survivor-specific measures that are psychometrically sound and fully tested. The SF-SUNS has been used within the clinical setting; however, since test–retest reliability of the SF-SUNS had not been established, the aim of the present study was to establish test–retest reliability of the SF-SUNS to add to the psychometric data available in the published literature on this instrument.

Methods

Design

Test–retest reliability of the SF-SUNS was conducted at two time points: baseline (time 1) and 5 days later (time 2). This time frame was chosen to reduce recall bias and change in the level of unmet needs. Ethical approval to conduct the study was obtained from the human research ethics committee of the study site (2015-020) and university (015007F).

Population and setting

A convenience sample of 40 lymphoma cancer patients who were 3 months’ posttreatment completion were recruited from the hematology department of a large tertiary hospital in Western Australia. Inclusion criteria were pathologically confirmed new diagnosis of NHL or HL; completed first-line curative intent chemotherapy or second-line curative intent autologous stem cell transplant within the previous 3 months; no radiological evidence of lymphoma posttreatment (on positron emission tomography [PET] scan); able to understand and read English; and over 18 years of age. Participants were excluded if they had not been treated with chemotherapy; had received further treatment at another hospital (as experiences or interventions may have introduced bias); or were cognitively impaired or experiencing an acute mental health condition that prohibited the provision of informed consent.

Sample size

The sample size calculation was derived from Walter et al. and used a fixed alpha of 0.05 from two observations with reliability values of R0 = 0.6 (acceptable) and R1 = 0.8 (expected), indicating a minimum sample size of n = 39.

Short-form Survivor Unmet Needs Survey

The SF-SUNS assesses unmet needs across four domains: information needs (3 items); work and financial needs (8 items); access and continuity of care needs (6 items); and coping, sharing, and emotional needs (13 items). Patient self-reported concerns and the level of support required are measured using a Likert-type scale: 0 = no unmet need, 1 = low unmet need, 2 = moderate unmet need, 3 = high unmet need, and 4 = very high unmet need. Domain scores are generated by adding each item score and dividing by the total number of domain items.

Procedure

The researcher identified and approached eligible participants after treatment completion to discuss the study and provide them with a participant information and consent form. Following informed consent, demographic and baseline (time 1) SF-SUNS questionnaires were then administered to participants. After completion of the questionnaires, participants were provided with another blank copy of the SF-SUNS accompanied by instructions to complete the questionnaire at home 5 days later and postback using the supplied reply-paid addressed envelope. Participants were advised to record the date of completion if this differed from the specified due date.

Data collection

At the request of the research team’s hematologist, baseline demographic and SF-SUNS data were collected from consenting participants 3 months posttreatment completion and PET scan to confirm the absence of disease. Demographic information obtained included lymphoma type, stage of disease, type of treatment received (chemotherapy +/- radiotherapy), date of diagnosis, time since diagnosis, comorbid conditions, gender, age, weight, marital status, age of children (if any), postcode, occupation, income level, education level, and health behaviors such as smoking and alcohol consumption. Participants then completed the SF-SUNS at time 2 (5 days following time 1 completion) at home.

Data analysis

All analyses were performed using IBM SPSS Statistics Version 25 data analysis software (IBM Corp. Released 2017. IBM SPSS Statistics for Macintosh, Version 25.0. Armonk, NY: IBM Corp.). Descriptive statistics were used to analyze all data. Descriptive analyses were used to analyze and describe demographic data. To assess for absolute consistency of SF-SUNS items for test–retest reliability data, an ICC with a random-effects model was used to compare each item at time 1 and time 2. The ICC measure was chosen for its ability to discriminate between sets of scores ranked in the same order but not necessarily in agreement and adjusts for the degree of test–retest agreement expected by chance. The closer the value of the ICC
to 1.0, the greater the reliability of the item or measure.\textsuperscript{13} The guidelines developed by Cicchetti and Sparrow\textsuperscript{10} were used to determine the level of clinical significance of the ICC values obtained: <0.40 = poor, 0.40–0.59 = fair, 0.60–0.74 = good, and >0.75 = excellent. For this study, items classified as achieving “fair to excellent” reliability, ICC >0.40,\textsuperscript{19} were reported. Cronbach’s alpha, a measure of internal consistency, was used to measure the scale reliability.

To examine the distribution of unmet needs, the five levels of unmet need were collapsed to three levels. A score of 0 (no unmet need) remained the same. Scores of 1 or 2 (low and moderate unmet need) were reclassified as 1 (low–moderate unmet need), and scores of 3 or 4 (high and very high unmet need) were classified as 2 (high–very high unmet need).

**Results**

**Participant characteristic**

There were slightly more male \((n = 22, 55\%)\) participants, and a greater number of participants with NHL \((n = 29, 72.5\%)\) compared with HL \((n = 11, 27.5\%)\) \([\text{Table 1}]\). This was in keeping with the current disease statistics which reflect a greater number of NHL than HL diagnoses.\textsuperscript{11} Almost one-third of participants were aged between 18 and 39 years \((32.5\%)\), and a greater proportion had a university qualification \((n = 16, 40\%)\) \([\text{Table 1}]\). Although the majority of participants were currently working \((n = 15, 37.5\%)\) and had been throughout their treatment, 30% \((n = 12)\) were looking for work or had no return to work data set. Over half the participants had a partner \((n = 25, 62.5\%)\). Forty participants completed both time 1 and time 2 SF-SUNS. The majority of participants \((n = 35, 87.5\%)\) completed time 2 SF-SUNS 5 days after time 1 \(\text{range} 4–7\) days.

**Test–retest**

ICCs, 55% confidence intervals, and clinical significance are shown in Table 2. One (3%) item met the “excellent” criteria for clinical significance; Finding car parking I can afford at the hospital or clinic. Twelve (40%) items met the “good” criteria \((0.40–0.74)\) and 11 (37%) items met the “fair” criteria \((0.30–0.40)\). In summary, test–retest data showed “fair” to “good” reliability for the majority of items \((23/30, 77\%)\).

**Internal consistency**

Overall Cronbach’s alphas were 0.92 at time 1 and 0.94 at time 2, with subscales \([\text{Table 2}]\) ranging from 0.74 and 0.69 for information needs, 0.65 and 0.83 for work and financial needs, 0.89 and 0.85 for access and continuity of care, and 0.90 and 0.94 for coping, sharing, and emotional needs, respectively. These results support strong internal consistency for the overall scale. Item-to-total correlations between 0.40 and 0.70 indicate that items are not redundant or measuring needs similar to other items within the instrument.\textsuperscript{19} Using this criterion, the SF-SUNS demonstrated item-to-total correlations between 0.40 and 0.70 at time 1 for 24 items \((80\%)\) and at time 2 for 19 items \((63\%)\) \([\text{Table 2}]\). The majority of items were considered relevant and to be measuring unique needs.

**Discussion**

Our study is the first to report test–retest data for the SF-SUNS. The majority of items met absolute consistency for reliability ICC scores of >0.40 for test–retest, categorized as “fair” to “good.” An “excellent” clinical significance score was achieved for only one item \((3\%)\), related to car parking costs which are unlikely to change over time. Needs-based instruments such as the SF-SUNS measure the degree of an individual’s perceived unmet need at one point in time. Importantly, Cronbach’s alpha scores at time 1 and time 2 demonstrated a high degree of internal consistency and high item-to-total correlations, confirming that items in the tool were reliable.

A criterion for psychometrically sound needs-based tools is the requirement for an instrument to be responsive to changes over time.\textsuperscript{21,22} Although our ICC results may reflect the responsiveness of the SF-SUNS to changes in need over the data collection period, further research is required.
### Table 2: Item test-retest reliability and internal consistency (n=40)

<table>
<thead>
<tr>
<th>Domain (n=4)</th>
<th>Item description</th>
<th>ICC (95% CI)</th>
<th>Level of clinical significance</th>
<th>Cronbach’s alpha</th>
<th>Item-to-total correlation</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information needs</td>
<td>Items (n=3)</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Finding information about complementary or alternative therapies</td>
<td>0.69 (0.49-0.83)</td>
<td>Good</td>
<td>0.74</td>
<td>0.69</td>
<td>0.20</td>
<td>0.50</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Dealing with fear about cancer spreading</td>
<td>0.56 (0.30-0.74)</td>
<td>Fair</td>
<td>0.39</td>
<td>0.63</td>
<td>0.03</td>
<td>0.71</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dealing with worry about whether treatment has worked</td>
<td>0.57 (0.32-0.75)</td>
<td>Fair</td>
<td>0.65</td>
<td>0.71</td>
<td></td>
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<tr>
<td>Work and financial needs</td>
<td>Items (n=8)</td>
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<tr>
<td>Worrying about earning money</td>
<td>0.63 (0.40-0.79)</td>
<td>Good</td>
<td>0.49</td>
<td>0.47</td>
<td>0.45</td>
<td>0.38</td>
<td></td>
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</tr>
<tr>
<td>Having to take a pension or disability allowance</td>
<td>0.70 (0.50-0.83)</td>
<td>Good</td>
<td>0.55</td>
<td>0.60</td>
<td>0.67</td>
<td>0.71</td>
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<tr>
<td>Finding the right type of financial assistance available and how to obtain it</td>
<td>0.76 (0.59-0.85)</td>
<td>Excellent</td>
<td>0.62</td>
<td>0.71</td>
<td></td>
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<tr>
<td>Finding family funding that I can afford at the hospital or clinic</td>
<td>0.71 (0.55-0.81)</td>
<td>Good</td>
<td>0.70</td>
<td>0.71</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Understanding what is covered by my medical insurance or benefits</td>
<td>0.71 (0.53-0.80)</td>
<td>Good</td>
<td>0.55</td>
<td>0.60</td>
<td>0.67</td>
<td>0.71</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Knowing how much time I would need away from work</td>
<td>0.74 (0.53-0.85)</td>
<td>Good</td>
<td>0.55</td>
<td>0.60</td>
<td>0.67</td>
<td>0.71</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Doing work around the home (cooking, cleaning, home repairs, etc.)</td>
<td>0.77 (0.67-0.86)</td>
<td>Good</td>
<td>0.55</td>
<td>0.60</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Access and continuity of care</td>
<td>Items (n=6)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Having access to cancer services close to my home</td>
<td>0.45 (0.16-0.66)</td>
<td>Fair</td>
<td>0.44</td>
<td>0.62</td>
<td>0.50</td>
<td>0.70</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting appointments with specialists quickly enough (e.g., oncologist, surgeon, etc.)</td>
<td>0.50 (0.28-0.72)</td>
<td>Fair</td>
<td>0.51</td>
<td>0.67</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting test results quickly enough</td>
<td>0.66 (0.44-0.81)</td>
<td>Good</td>
<td>0.57</td>
<td>0.71</td>
<td></td>
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<tr>
<td>Having access to care from other health specialists (e.g., cardiologist, physical therapist, occupational therapist)</td>
<td>0.53 (0.32-0.72)</td>
<td>Fair</td>
<td>0.51</td>
<td>0.67</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making sure I had enough time to ask my doctor or nurse questions</td>
<td>0.59 (0.37-0.77)</td>
<td>Fair</td>
<td>0.59</td>
<td>0.68</td>
<td>0.70</td>
<td>0.77</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting the health care team to attend promptly to my physical needs</td>
<td>0.53 (0.32-0.72)</td>
<td>Fair</td>
<td>0.59</td>
<td>0.68</td>
<td>0.70</td>
<td>0.77</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping, sharing and emotional needs</td>
<td>Items (n=12)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telling others how I was feeling emotionally</td>
<td>0.42 (0.14-0.65)</td>
<td>Fair</td>
<td>0.42</td>
<td>0.65</td>
<td>0.58</td>
<td>0.88</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Finding someone to talk to who understands and has been through a similar experience</td>
<td>0.32 (0.02 to 0.58)</td>
<td>Poor</td>
<td>0.45</td>
<td>0.57</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Dealing with people who expect me to be “back to normal”</td>
<td>0.62 (0.34-0.78)</td>
<td>Good</td>
<td>0.57</td>
<td>0.77</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dealing with people accepting that having cancer has changed me as a person</td>
<td>0.51 (0.34-0.71)</td>
<td>Fair</td>
<td>0.68</td>
<td>0.81</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Dealing with reduced support from others when treatment has ended</td>
<td>0.67 (0.46-0.81)</td>
<td>Good</td>
<td>0.82</td>
<td>0.82</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Dealing with feeling depressed</td>
<td>0.73 (0.55-0.85)</td>
<td>Good</td>
<td>0.53</td>
<td>0.72</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dealing with feeling nervous</td>
<td>0.49 (0.21-0.69)</td>
<td>Fair</td>
<td>0.57</td>
<td>0.71</td>
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<tr>
<td>Dealing with feeling anxious</td>
<td>0.55 (0.33-0.74)</td>
<td>Fair</td>
<td>0.78</td>
<td>0.69</td>
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<tr>
<td>Dealing with feeling lonely</td>
<td>0.72 (0.53-0.84)</td>
<td>Good</td>
<td>0.63</td>
<td>0.61</td>
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<tr>
<td>Dealing with not being able to feel “normal”</td>
<td>0.47 (0.20-0.68)</td>
<td>Fair</td>
<td>0.57</td>
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<tr>
<td>Trying to stay positive</td>
<td>0.63 (0.45-0.79)</td>
<td>Good</td>
<td>0.55</td>
<td>0.61</td>
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<tr>
<td>Coping with having a bad memory or lack of focus</td>
<td>0.64 (0.43-0.79)</td>
<td>Good</td>
<td>0.50</td>
<td>0.86</td>
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<tr>
<td>Dealing with changes in how my body appears</td>
<td>0.78 (0.64-0.89)</td>
<td>Good</td>
<td>0.73</td>
<td>0.84</td>
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ICC: Intraclass correlation, CI: Confidence interval

To detect clinically meaningful change for patients, all participants completed the time 2 questionnaire at home, well away from the hematolymphoma clinic where the time 1 questionnaire was completed. It is possible that participants may have had additional time to more accurately reflect on the level of unmet need. Similarly, time 1 scores may have been impacted by participants’ anxiety at the hospital appointment where patients often worry about test results and potential relapse. In addition, fatigue is a recognized effect of lymphoma treatment and may have potentially...
affected participant responses at either time point. Finally, most items were similarly balanced for both time points from "no unmet need" to "low unmet need" or "low unmet need" to "no unmet need."

It is important to allow cancer survivors the opportunity to self-identify unmet needs and issues of concern. Survivorship needs-based instruments provide a consistent method for this purpose.[36] Furthermore, it is important that any tool is responsive to change as individuals’ issues, concerns, thoughts, and feelings can change from day-to-day.[36] Particularly during survivorship transition as individuals move on with their lives after cancer treatment. Such reliable and valid instruments can facilitate individualized survivorship care and tailored support and resources.[35]

It is important to note that the original SF-SUNS demonstrated low test–retest reliability acceptability,[35] with the authors suggesting that the test–retest timeframe was too long at 28 days. Since our study was part of a larger study involving an intervention group, a 3-day later test–retest assessment was deemed an appropriate timeframe to ensure completion of the time 2 SF-SUNS before the implementation of any needs-based interventions associated with the larger study.[36] Importantly, this time period was also in keeping with the recommended 2–14-day time period for test–retest procedures.[36–38]

A limitation of this study may have been the sample size of 40 participants, despite sample size calculations indicating that this number would be sufficient to adequately perform test–retest reliability with confidence. Many participants (n=16, 40%) attended the baseline appointment, where time 1 SF-SUNS was administered, accompanied by a support person (partner or family member). We acknowledge that this may have influenced time 1 responses. Likewise, time 2 responses may have similarly been influenced as the SF-SUNS was completed at home. We can confirm that participants did not receive any needs-based interventions between time 1 and time 2 completion of the SF-SUNS.

Conclusion

We suggest that needs-based assessments should be used routinely during the survivorship period to facilitate survivorship care that is tailored and responsive to individuals’ changing needs. Valid and reliable survivor-specific measures are essential for routine screening and follow-up. Nurses in particular are a valuable resource in the survivorship phase to assess for areas of concern or unmet needs and for the provision of information, support, and resources that are tailored to the individuals’ unique needs. Further testing of the SF-SUNS is recommended in hematology and other cancer populations to further understand and demonstrate the responsiveness of this instrument to changes in need over the survivorship period.

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Conflicts of interest

There are no conflicts of interest.

References

Appendix B

B.1 A Qualitative Study of the Post-treatment Experiences and Support Needs of Survivors of Lymphoma

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A qualitative study of the post-treatment experiences and support needs of survivors of lymphoma

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ABSTRACT

Purpose: To explore the post-treatment experiences and preferences for follow-up support of lymphoma survivors.
Methods: Two focus groups were conducted with 17 participants to explore informational, psychosocial, emotional, social, practical and physical needs, 6–30 months post-treatment for lymphoma. Perceptions regarding a potential model of survivorship care were also elicited.
Results: Thematic content analysis revealed five key themes: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normalcy, and Person-centred post-treatment care. Participants described a sense of loss as they transitioned away from regular interaction with the hospital at the end of treatment, but also talked about the need to find a "new normal". Establishing post-treatment support structures that can provide individualised information, support, reassurance and referrals to community and peer support were identified as a helpful way to navigate the transition from patient to post-treatment survivor.
Conclusions: Participants in our study articulated a need for a flexible approach to survivorship care, providing opportunities for individuals to access different types of support at different times post-treatment. Specialist post-treatment nurse care coordinators working across acute and community settings may offer one effective model of post-treatment support for survivors of haematological malignancies.

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1. Introduction

Lymphomas are complex, potentially life limiting haematological (blood) malignancies that have a marked impact on quality of life and long-term health as a consequence of the aggressive or chronic nature of the treatments required to manage them (Carey et al., 2012). Lymphomas are immune-related cancers, broadly categorised as non-Hodgkin or Hodgkin lymphoma, and can be indolent or aggressive in nature (National Cancer Institute, 2016). Advances in treatment efficacy, including haematopoietic stem cell transplants, bone marrow support with blood component transfusions and white cell stimulation, along with advances in decreasing severity of infection risk, remission rates have improved (Lichtman, 2008).

In Australia, the context for this study, the 2012 estimated age-standardised rates (ASRs) of Hodgkin lymphoma incidence and mortality were 2.7 and 0.3 respectively (Cancer Australia, 2017a). These figures compare favourably with the European Union (EU-27) estimated ASRs of Hodgkin lymphoma incidence (2.3) and mortality (1.04) for the same period (Ferlay et al., 2013). The estimated Australian ASRs of incidence and mortality for Non-Hodgkin lymphoma were 16.1 and 5.4 respectively compared with EU-27 estimated ASRs of 11.6 and 3.8 respectively (Cancer Australia, 2017b; Ferlay et al., 2013).

Late and long-term side effects of treatment for lymphoma are common and can include fatigue; nutritional and physical activity deficits; fertility, sexuality and relationships concerns; and financial, employment and insurance issues (Allart et al., 2013; Arden-Close et al., 2011; Hall et al., 2013). As advances in remission and cure rates improve, survivors are living longer with the consequences of their disease and treatment (Sart et al., 2014), and many experience unmet needs that impact long-term health and well-being (Arden-Close et al., 2011). In a study of 53 long-term survivors of leukaemia and lymphoma (Zehrbach, 2000), issues such as fatigue (n = 23, 42%), remained an ongoing problem. The authors indicated fear of recurrence and financial concerns were also predominant factors in long-term survivors (no figures given). In a study of 437 haematology survivors in Australia and Canada, fatigue was identified as the greatest unmet concern (n = 76, 16%), with the Australian cohort only (n = 208, 61%) reporting a higher level of unmet financial concerns (n = 39, 15%) (Hall et al., 2013a). Survivors of haematological malignancies have been shown to experience ongoing issues up to a decade or more post-treatment completion (Ferber et al., 2011). Severe fatigue impacting functional capacity, emotional well-being and ability to return to work (Ferber et al., 2011; Kangas et al., 2008; Orelmans et al., 2011), and persistent cognitive impairment have been reported as debilitating long-term effects of treatment (van der Poel et al., 2014).

There is limited evidence available to inform the development of patient-focused haematology survivorship services in Australia. However, some evidence exists to indicate patients’ preferences for post-treatment follow-up care. In a study of 66 cancer survivors representing the major haematological diagnostic groups (non-Hodgkin lymphoma 48%, Hodgkin lymphoma 12%, multiple myeloma 28%, leukaemia 14%), help with managing the fear of recurrence (42%) and ongoing case management (33%) were identified as unmet needs in the post-treatment period (Lubo et al., 2009). The opportunity to discuss experiences with a health care professional at treatment completion was identified as potentially helpful by 59% of participants. McGrath (2014) reported findings from a qualitative study of 50 haematology survivors that explored use of routine telephone follow-up as a supportive care strategy. The sample represented the haematologic diagnostic groups of multiple myeloma (n = 15), lymphoma (n = 14) and leukaemia (n = 17). Although telephone follow-up support was perceived by the majority of participants as potentially beneficial, many individuals did not support the idea as they wanted more assurance from cancer and would not have welcomed any contact.

Unlike more common malignancies such as breast and prostate cancer, evidence to inform the development of optimal follow-up guidelines for haematological survivorship care is lacking. This study set out to explore the experiences of and preferences for post-treatment support in Australian survivors of lymphoma 6–10 months post-treatment completion. For the purpose of the study, participants were deemed ‘lymphoma survivors’ if their haematologist had documented ongoing remission at least six months from treatment completion as our intent was to better understand post-treatment support needs.

2. Methods

2.1. Methodological framework

We undertook a qualitative, descriptive study (Neergaard et al., 2009; Sandelevski, 2000) utilising focus groups to explore and better understand the post-treatment experiences and support needs of lymphoma survivors. Focus groups allow for collection of a broad range of information and insight when little is known or understood about a topic (Neergaard et al., 2009; Sandelevski, 2000), while providing peer support and normalisation of experiences that group participants may share. Excellent facilitation is important to ensure all participants have an opportunity to contribute as they wish, avoiding dominance of one or two experiences (Tausch and Menedez, 2016). For the purpose of our study, a PhD prepared haematology clinical psychologist experienced in conducting focus groups with vulnerable populations, facilitated the digitally recorded focus groups and was supported by a specialist cancer nurse who acted as scribe to support detail and accuracy of interpretation of the digitally recorded focus group data.

The study was approved and undertaken in accordance with the ethical standards guiding the Human Research Ethics Committees of the relevant study site and university. Informed written consent was obtained from all participants prior to study participation.

2.2. Sample and setting

The study was undertaken at a large tertiary hospital with a comprehensive cancer centre in Western Australia. Between 1 July 2009 and 1 December 2013, 479 patients were referred to the hospital for treatment of lymphoma. Potentially eligible study participants were identified through a manual search of the hospital cancer registry patient records. Eligibility criteria included: i) aged over 25 years (in Australia Youth Cancer Services provide specialist, age-appropriate treatment and support for young cancer patients aged 15–25); ii) currently residing in Western Australia; iii) fluent in English; iv) completed treatment at least 6 months prior to study; and v) no cognitive impairment (as indicated in the medical record or during recruitment process where participants’ ability to understand the study details and provide consent was assessed). Exclusion criteria were patients who: i) had relapsed after first-line therapy; ii) were receiving care or follow-up or had undertaken an allogeneic transplant at another hospital; and iii) were undergoing work-up for autologous transplant. These exclusion criteria ensured experiences from other hospital sites and continuing treatment experiences did not influence the data collected.
2.3 Focus groups

Two digitally recorded focus groups were carried out and data from each group transcribed verbatim. The transcriptions were checked for accuracy by the facilitator and support nurse, drawing on the notes taken during the groups and by listening to the recordings. Digital recordings of interviews and transcribed interviews were saved in password-protected files on a secure server.

A semi-structured interview guide was developed by the research team based on previously reported study data and clinical experience. Interview questions allowed for exploration of informational, psychological, emotional, social, practical, physical and spiritual aspects of post-treatment support needs. Participants were also asked to talk about what they thought would have been or could be of help to them in the post-treatment period.

2.4 Data analysis

The focus group transcript data were imported into NVivo to enable management of data, and the process of data analysis. Thematic content analysis methodology was applied to explore and organise data into codes and themes (Braun and Clarke, 2006). Transcripts were initially coded by CE. Subsequently each transcript was read independently by two other members of the study team (TM, KT). Thematic content analysis is a widely used analytical approach to qualitative data where themes, identified through coding, reflect key patterns within the textual data. This inductive approach was regarded as the most appropriate for our data, allowing themes to emerge from the content of the focus groups rather than considering data in response to questions pre-constructed by the researchers (Sarantakos, 2013). Data saturation point was reached following analysis of the two focus groups.

2.5 Rigour

Researchers (KT, CB and TM) met to discuss outcomes from the independent coding process and agreed on emerging themes. Discrepancies were discussed until consensus was reached. This allowed for development of a coding system that ensured a strategy of reliability throughout the process (Morse, 2015). Rigour of data analysis was ensured by applying the criteria of credibility, auditability and fittingness (Beck, 1993). Credibility was obtained through use of researchers to complete independent coding whereby ensuring categories accurately captured issues being discussed. Decisions related to allocation of discrete data elements to codes and fittingness of the codes, were demonstrated through extensive use of quotes or extracts from the data. Fittingness was further achieved by reflecting on the core concepts of unmet survivorship needs as confirmed by the research team (van Manen, 1997). Documentation of all steps in the analysis process, including opportunities for reflection on the codes and debriefing about the content of the transcriptions ensured a coherent audit trail and therefore maintained auditability.

3. Results

3.1 Participants

Of the 79 eligible lymphoma participants, 11 returned opt-out forms without providing a reason for this decision. The remaining 68 participants were contacted to further explain the study and provide focus group details. Of these 22 (32%) agreed to participate in a focus group, however five people did not attend on the day. Reasons for non-participation included: migrating overseas/inter-state (n = 2); recently relapsed or other cancer (n = 5); bereavement (n = 1); working fulltime (n = 1); declined to provide a reason when contacted by telephone (n = 20); did not respond to voicemail message (n = 13); severe symptom burden (n = 1); unable to arrange transport (n = 1); family objection (n = 1); deceased (n = 1).

The disease and demographic characteristics of the participants who did not take part in a focus group were comparable with those who participated. The age range of participants was 27–85 years with a mean age of 63.6 years (SD 14.5). The average time since last treatment was 14.6 months (SD 8.2) with a range of 6–30 months (Table 1).

3.2 Themes

Five themes emerged from analysis and coding of data: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition; connectivity and normalcy, and Person-centred post-treatment care.

3.3 Information

Participants described difficulty in obtaining information from some members of the health care team after treatment had finished, feeling that professionals sometimes didn’t understand or pre-empt the type of information and support they required post-treatment:

“My GP doesn’t even really know that much about cancer, I think I’ve been telling him ... but you could phone the Cancer Council and get quite a bit of information if you wanted to ...”
F, 48yo, NH.

Participants indicated that a generic list of services and written information describing what to expect post-treatment would be helpful:

“An instruction sheet, so basically you’ve just had your last chemotherapy session one month ago, you’ve done your test, you’re in remission, here’s what you need to do for the next 12 months”
M, 48yo, JL.

<table>
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<th>Demographic variable</th>
<th>Focus group 1</th>
<th>Focus group 2</th>
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APPENDICES

Compounding the issue of information support was recognition that retention of information given in preparation for end of treatment was challenging and that being given important information at different times or repeatedly may be helpful:

"I don't think anyone explains it all to us, is there a rule book? After 3 months, you should...." M. 48y, HL.

"I think about things in between visits. I have questions, so every three months I come back." F. 75y, NHL.

that was a twice a week thing which was really good. So then I thought if I can go to weight lifting I can go to rademission, and I did that twice a week and that kept my mind occupied, something to do and being active and I think it is something that's very useful." F. 46y, NHL.

"I think having kids around brings you up a lot and makes you realise that life isn't so tough." F. 28y, NHL.

...but also you need to be busy mentally and do things for the future and I really amazed myself in two months after chemo when I planted my vegetables and I thought 'will I be alive to eat it?' F. 46y, NHL.

3.4. Loss and uncertainty

Post-treatment side effects were spoken about in terms of loss; a loss of strength and physical function, a loss of control around nutrition and sustenance, a loss of energy and interest, and a loss of concentration. Comments around what to expect indicated most would have found it helpful to know how long side effects continue for, and what was normal:

"I just think, for me the chemotherapy has left me this neuropathy and I mean I'm learning to walk again, and stuff like that, I can't feel my legs so it's like I'm on air cushions..." F. 46y, NHL.

For some, the changes post-treatment were noticed when trying to get back to exercise and movement. They felt their physical abilities had declined:

"Yeah, I mean I walk the streets but I don't like doing that, I can go one block and then I'm exhausted. But I do feel better when I do something, but I can't do it long enough for it to benefit me." F. 75y, NHL.

Many participants spoke about coping with the emotional experience and impact of their cancer treatment through avoidance:

"I can personally say that I did have my down moments... but it's so hard and I thought it's worse being in this state, just get out--just get going, just don't think about it -- it's easier to just get on with it rather than get depressed -- I know that's easier said than done." F. 28y, NHL.

Living with the fear of cancer recurrence was described as a common experience and although one or two participants talked about seeking help and reassurance to address their fear, most described getting on with living alongside the uncertainty and fear:

"I don't think you ever quite get rid of the shadow... I don't think you ever forget of that slightly depressed feeling that's in the back of your head that it could come back." F. 46y, NHL.

"I just want to be living well...if I'm going to live for only 5 more years, I just want to live well for those 5 years and extract as much as I can..." M. 48y, HL.

The most commonly mentioned strategies used post-treatment to try and cope with the impact of their diagnosis, its treatment and on-going uncertainty included exercise, having children around, and hope for the future:

"[Weight lifting exercise class] I went twice a week and after 3 months I was really feeling much better and almost back to my energy level and I'm not even back to it now after a year, and..."
But for others a group situation was difficult, at times overwhelming, leaving them feeling uncomfortable:

“You’re always identified as the cancer person or with the cancer group… but sometimes it weighs a bit heavy, like the people there you don’t necessarily want to broadcast it in the whole world.” F.75yo, NHL.

3.6. Transition, connectivity and normality

The relationships established during treatment and the security that came through knowing they were being treated and monitored closely by an expert team or centre who genuinely cared for them was greatly valued:

“I just had this feeling of ‘wow’ I am so privileged to have the treatment and the knowledge of the professional care here, the medical staff, all of them…” F.73yo_NHL.

“I was under Dr X and they always said that you know, if you ever have any problems, ring me personally and you can come straight in, don’t bat an eyelid. So I was very confident in the team and I knew there was support if I needed it.” F.52yo, NHL.

But with completion of treatment and the transition to a different relationship with the hospital and treating team, some participants felt that although their medical needs were met, they did not feel connected or understood holistically:

“…. my specialist is great, excellent doctor, but I walk in there and you get nothing other than your um, medical moment for want of a better term - there’s no, you know, like [the doctor’s] just happy that you’ve got a remission so [the doctor’s] done the job, you know, and it was literally, ok so what happens now? I’ll see you in 3 months.” M.68yo, NHL.

Leaving the support of the hospital was experienced as a loss. Some felt their safety net and reassurance had gone along with the camaraderie of other patients who were undergoing a similar experience. Many were left wondering what their purpose was moving forward:

“I used to be this guy that had a sense of purpose and a reason for doing - all of a sudden all of that is taken away and no-one’s telling you what to do next, it’s just come and see me in 3 months’ time … for me, a massive sense of loss. It’s a loss of purpose and identity, actually. … You know I used to call them my chemo buddies and yeah you’d sit with the same people every time and the nurses, everybody that you just had a connection with and it’s just severed.” M.48yo, NHL.

Participants spoke about being so focused on getting through treatment they had not had time to process what would happen when treatment finished. There was a sense of adjusting to this new normal post-treatment without adequate preparation. One participant talked about having to take responsibility for herself again:

“…. but I felt um hang on, they’re spewed me out the door and I thought, now I’m going to have to do something for myself.” F.46yo, NHL.

Overwhelmingly, participants wanted things to return to normal or a new normal post-treatment. They wanted to get on to with their lives, get back to work and move forward; to put cancer to one side or leave it behind:

“…. and I got to a point after treatment where I just told my friends to stop talking about it and stop asking I felt like it was taking over my life and I wanted other things to focus on.” F.28yo_NHL.

But moving from the structure of treatment and hospital support back into “normal life” was difficult. Some expected to return to their life as it was pre-diagnosis and found it challenging when this did not happen:

“…. when your chemo’s finished they kept telling me it would take a year to get back to normal and I’m like ‘you don’t know me, that’s not going to happen, I’m going to walk out of here and flip a switch and I’m going to be back to normal’ well it’s not the case.” M.51yo_NHL.

The need to find a new meaning or purpose post-treatment and a realisation that one had changed and that what matters in life had changed were strong elements in the data gathered:

“You lose kind of like your purpose in life, you’re not the same like you used to be before your cancer.” F.49yo, NHL.

“You’re not so cocky now, … I really have sympathy for others, whereas before — now I really listen to them.” M.63yo_NHL.

“I never want to be a CEO again, I never want to be in that place, I want to be there for me and my family. … it certainly makes you more empathetic - makes you have more empathy for others, it certainly gives you that gene, because I certainly didn’t have much at all before.” M.48yo, NHL.

Moving away from the “cancer label” and not wanting to be stigmatised was important for many participants as they transitioned into the post-treatment phase:

“When I went to the gym with the cancer group … I would have really benefited from having an individual membership and being by myself … you get a card and ‘oh, are you with the cancer group??’ I don’t want to be labelled all the time … even though you’re looking for support.” F.52yo, NHL.

3.7. Person centred post-treatment care

Participants recognised that support needs varied from diagnosis through treatment and on into follow-up, the post-treatment stage. But when discussion was guided during the focus groups to services or support that would have been useful post-treatment, participants talked about the need for this to be individualised, stating it would be difficult to get a “one size fits all” approach to their support needs:

“A group is great. But if you were ringing up asking for help you’d probably want one-on-one.” M.70yo, NHL.

However, most participants felt that some sort of “check-up” (follow-up) appointment at the hospital around one month post-treatment would be helpful where the focus was on the experience of the individual rather than the disease:

“I think a follow-up would be a good idea because there aren’t any follow-ups as such. A formal follow-up, either with a clinical..."
psychologist or nurse when you come for your cancer follow-ups." M_70-NHL.

Some participants suggested this appointment should be mandatory, a logical transition from hospital care to a "new normal":

"I also don’t think that if you make someone available it will do any good. You got to send me there. You’ve got to have an appointment for me to go there otherwise I’ll use tomorrow as an excuse not to go." M_70yo-NHL.

Wanting a personal connection with a qualified professional was a strong theme, a person to seek reassurance from and check worrying symptomology:

"Where you can phone somebody who is there for you right then and there specifically for that reason, to say well if you’re worried, yes go and see - because you doubt yourself, you think am I being neurotic about every little ache or pain ... and being silly or should I see the doctor, maybe I’m just being silly. It would just be nice to have that support that you know that there’s the cancer nurse there for you, somebody in the know that can say ‘don’t worry about it’ or ‘yes come in and see your specialist.’" F_40yo-NHL.

Peer support was also described as valuable when the peer had undergone a similar experience and for some people it was important to get away from "the medics":

"... probably the best thing that could happen to those other people is not go and see the specialist, but sit in a room with us." M_70yo-NHL.

"... I would have appreciated a formal session like this, talking to people who’ve already been where I was and where I’m going.” M_51yo-NHL.

4. Discussion

This research contributes to a small but growing body of literature reporting on post-treatment experiences and support needs of survivors of lymphoma. Data from our study identified five key themes of relevance to the post-treatment experience of lymphoma survivors: Information; Loss and uncertainty; Family, support and post-treatment experience; Transition, connectivity and normality, and Person-centred post-treatment care.

Information needs varied across participants in our study, reflecting findings from other qualitative studies of haematological cancer survivors (Gauler et al., 2010) and emphasising the importance of flexibility in services developed if they are to successfully address the information needs of post-treatment survivors. Participants in this study described difficulty in accessing the kind of information they needed from tertiary and community health professionals once the acute treatment period was over, a finding commonly reported in studies of non-haematological cancer survivors (Taylor and Monterosso, 2016). Participants described a sense of loss in terms of support, connectivity and reassurance when they transitioned away from active care to the post-treatment phase, indicating that there is opportunity to develop and implement tailored post-treatment preparation interventions to enhance the experience and wellbeing of haematology survivors, Living with fear of cancer recurrence was a common experience for participants in our study, and is widely recognised as one of the most distressing or prevalent concerns of cancer survivors (Batistou et al., 2015; Park et al., 2013). Helping people find strategies to live with fear of recurrence is a key issue in the advancement of post-treatment survivorship care.

Dealing with the side effects of treatment was described as one of the most difficult aspects of the post-treatment phase. Participants in our study felt they weren’t adequately prepared to manage the issues they faced, and suggested that information on the duration of side effects, what to expect and how to cope with them would have been helpful. This finding offers an important and achievable target for improvement in post-treatment care of survivors of lymphoma.

Some participants described difficulty in adjusting to a "new normal" post-treatment and actively sought a new sense of purpose and identity. A clear sense of moving away from cancer and putting it to one side so that a new norm could be established was evident for some. This finding suggests that working with patients ahead of treatment completion to prepare a "new narrative" for themselves may better support people to transition from their identity as a cancer patient.

Although there was a general recognition of the value of support provided through existing family and friend networks, some participants felt that once they started to look and feel better, family or significant others’ expectations of what they were capable of doing exceeded what they felt ready or able to do. The need to develop survivorship services that directly support families or important others so they can be effective partners in the transition to life post-treatment, as well as keep themselves well, is evident.

In response to questions about helpful components of post-treatment care, many participants described the ability to contact a health professional to seek reassurance, check in about concerning symptoms and get advice and information as an important element in enabling confident transition to survivorship. Specialist post-treatment nurse care coordinators working across tertiary and community settings may offer an effective model to address this need for survivors of haematological malignancies.

A follow-up appointment post-treatment focusing on reflection of the diagnosis and treatment experience as a way of being able to "move on" to the next phase of life was also recommended as a potentially useful intervention and is worthy of consideration as one component of person-centred post-treatment care.

4.1 Limitations

The limitations in this study include the small sample size and the single site recruitment. However, the findings do offer valuable insight into the post-treatment experiences and support needs of participants in our study, and offer tangible opportunity for the development of post-treatment services and interventions targeted to the needs of survivors of lymphoma, although more works needs to be done to establish the credibility of our findings to other haematological cancer patients' post-treatment. Participants chose to opt-in and therefore it is not possible to assess whether those with greater needs or worse experiences of post-treatment care excluded themselves. However, experiences of those people who gave their time to take part have provided a valuable addition to a small but growing body of research in this area. The use of a clinical psychologist as the facilitator for the focus group (disclosed to participants at the beginning of the focus group) may have influenced the issues participants chose to share or withhold dependent on previous access to or attitudes toward a psychologist.
APPENDICES

5. Conclusion

Survivors of lymphoma experience many and complex post-treatment issues that require tailored intervention as part of a comprehensive package of person-centred post-treatment care. Data from our study suggest that integration of professional, peer and family/important other support strategies may prove to be most effective. Specialist haematology nurse care coordinators working across territory and community settings could offer a feasible and efficient way of coordinating tailored programs of support around survivors of haematological malignancies.

Funding

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Conflict of interest

The authors have no funding or conflicts of interest to disclose.

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References


B.2 Living with Multiple Myeloma: A Focus Group Study of Unmet Needs and Preferences for Survivorship Care

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Research Article

Living With Multiple Myeloma: A Focus Group Study of Unmet Needs and Preferences for Survivorship Care

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Abstract

**Purpose:** To describe the unmet informational, psychological, emotional, social, practical, and physical needs and preferences for posttreatment survivorship care of individuals living with multiple myeloma to inform the development of relevant, person-centered, survivorship services. **Methods:** An exploratory, descriptive study using 2 focus groups with 14 participants, 6 to 49 months postdiagnosis. **Results:** Thematic analysis revealed 7 key themes: information needs, experience with health-care professionals, coping with side effects, communicating with family and friends, dealing with emotions, support needs, and living with the chronicity of myeloma. Participants described key characteristics of survivorship care relevant to their needs and indicated they would like a more whole of person approach to follow-up when the main treatment phases had completed. **Conclusion:** Participants in this study described unmet needs across a breadth of domains that varied over time. The development of flexible, person-centered approaches to comprehensive survivorship care is needed to address the considerable quality-of-life issues experienced by people living with multiple myeloma. Nurse-led care may offer a viable model to deliver enhanced patient experience—providing the vital “link” that people described as missing from their survivorship care.

**Keywords**
normalized, multiple myeloma, survivorship, focus groups, unmet needs, support

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**Introduction**

Around 1700 people are diagnosed with multiple myeloma (myeloma) each year in Australia with approximately 840 people dying from the disease annually (1). Myeloma is a malignant incurable plasma cell disorder (2). Treatment depends on disease stage, general health and age, aiming to suppress disease and control symptoms through chemotherapy, radiotherapy, immunotherapy regimens, including autologous transplantation (3,4). Symptoms of myeloma include bone pain, fractures, renal disease, anaemia, infection, and fatigue, all of which have considerable impact on lifestyle, role functioning, and quality of life (5,6).

In a qualitative study of 20 people with myeloma 5 years after diagnosis (7), the considerable impact on emotional, social, role and work-related areas of life, and fears regarding uncertainty of the future was described (7). In a survey of 113 hematological cancer survivors, including myeloma patients in the first 12 months following initial treatment (8), managing fear of recurrence was the most frequently endorsed unmet need ( \( n = 42, 73\% \) ). This was followed by the need for care coordination ( \( n = 22, 33\% \)) with two-thirds ( \( n = 39, 59\% \)) reporting the opportunity to discuss diagnosis and treatment experiences with a health-care professional would have been helpful (8).

We set out to explore the experiences of a cohort of patients living with myeloma. In accordance with the definition of a cancer survivor as articulated by the National Coalition for Cancer Surviviorship (9), patients recruited to this study were cancer survivors living with, through, and beyond a diagnosis of myeloma. Despite the recognized profile of chronic, complex symptoms and treatment side effects experienced by people living with myeloma, little is known about their preferences for support and survivorship care. This project aimed to establish the unmet needs and preferences for survivorship support in a cohort of patients 6 to 49 months post-diagnosis of myeloma.

**Methods**

**Design**

A descriptive, exploratory study was chosen, as it allowed for in-depth investigation of experiences and survivorship care needs of participants, while maintaining a focus on study aims, through the use of semi-structured focus group prompts (10,11). Thematic content analysis was chosen as the approach to focus group data, ensuring issues of importance to participants were revealed (12). The study was undertaken in accordance with the ethical standards of the Human Research Ethics Committees of Sir Charles Gardiner Hospital (Ref. 2012-135) and the University of Notre Dame Australia (Ref. 013030f).

**Sample**

The local Cancer Registry recorded 248 new cases of myeloma between July 1, 2009 and December 1, 2013 from the study site. A manual search of patient hospital records determined the date of diagnosis and treatments received to ascertain study eligibility. The Death Registry was searched to avoid contacting families of deceased patients. Sixty-three eligible participants were sent a letter of invitation from the study site hematologist; a participant information and consent form and an opt-out form to be returned within 2 weeks. Six opt-out forms were returned, 5 without indicating a reason and 1 objection to recruitment. The research assistant telephoned remaining eligible participants (n = 57) 1 week later to further explain the study and provide focus group location and time details.

**Inclusion Criteria**

- Aged between 25 and 85 years.
- Fluent in English.
- No cognitive impairment (as indicated by medical record or during recruitment process).
- May be receiving oral chemotherapy considered as disease maintenance.

**Exclusion Criteria**

- Receiving care or follow-up at another hospital (where experiences could have potentially influenced interview data).
- Undergoing an autologous transplant (exposure to a group setting considered a potential health risk).

**Focus Groups**

Two 90-min focus groups were conducted at a large tertiary cancer center in Western Australia. All participants provided written informed consent prior to participation. Focus group questions were derived from a comprehensive literature review of key issues and concerns in this cohort and research team clinical experience (Table 1). They prompted participants to discuss informational, psychological, emotional, spiritual, social, practical, and physical needs, along with views about survivorship support and care.

Focus groups were facilitated by a hematology clinical psychologist experienced in facilitating focus groups with vulnerable populations, digitally recorded, and transcribed verbatim. Codes replaced participant names, and clinician identifiers were removed to ensure anonymity of responses prior to analysis. Electronic transcriptions were stored in a password-protected file on a secure server.

**Data Analysis**

NVivo 11 was used to manage data and undertake analysis. Transcripts were read and analyzed independently by C.B., T.M., and K.T. with content assigned to codes and themes generated from the data (12). These researchers discussed the coding and reached consensus on emerging themes. Rigor of the data analysis process was ensured by applying the criteria of credibility, auditability, and fitfulness (13).
Table 1. Guiding Questions for Myeloma Focus Groups.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>General introduction questions</td>
<td>- What have been your key “moments” since diagnosis and commencing treatment?</td>
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<tr>
<td></td>
<td>- What have been the most important things you needed since you began living with myeloma?</td>
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<tr>
<td></td>
<td>- What do you think could be put into place to support people who are living with myeloma?</td>
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<tr>
<td></td>
<td>- What were your key concerns about finishing your first treatment phase?</td>
</tr>
<tr>
<td>Informational</td>
<td>- What have been your biggest informational needs?</td>
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<tr>
<td></td>
<td>- How would you like to access this information?</td>
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<tr>
<td></td>
<td>- What is the best way you could be supported now that you are living with myeloma?</td>
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<tr>
<td></td>
<td>- What advice would you have for another patient who is living with myeloma?</td>
</tr>
<tr>
<td>Psychological</td>
<td>- What was most distressing to you after treatment phases?</td>
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<tr>
<td></td>
<td>- What things, if any, are you worried about now?</td>
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<td></td>
<td>- What things, if any, do you look forward to when you finish a particular treatment phase?</td>
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<tr>
<td></td>
<td>- If you have experienced worry and fear about myeloma returning</td>
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<tr>
<td></td>
<td>- How did you need to manage this worry/fear?</td>
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<tr>
<td>Emotional/spiritual</td>
<td>- What have been your biggest emotional needs?</td>
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<tr>
<td></td>
<td>- positive impact</td>
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<tr>
<td></td>
<td>- negative impact</td>
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<tr>
<td></td>
<td>- How did you feel at the end of each treatment phase?</td>
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<td></td>
<td>- relieved, scared, adrift?</td>
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<tr>
<td></td>
<td>- did these feelings change over time?</td>
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<td></td>
<td>- How do you feel when you don’t need to see the hematologist as frequently?</td>
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<td></td>
<td>- Can you describe any spiritual issues or concerns since you began living with myeloma?</td>
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<tr>
<td>Social</td>
<td>- How has your life changed since you began living with myeloma?</td>
</tr>
<tr>
<td></td>
<td>- Has your social life changed since you began living with myeloma?</td>
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<tr>
<td></td>
<td>- How does/did your treatment affect your relationships with the people closest to you?</td>
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<tr>
<td>Practical</td>
<td>- What have been your biggest practical concerns!</td>
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<tr>
<td></td>
<td>- How would you like your care to be handled after you complete a treatment phase?</td>
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<tr>
<td></td>
<td>- How would you like your care to be communicated or coordinated when you complete a phase of treatment?</td>
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<tr>
<td></td>
<td>- Have you made any plans to change your life?</td>
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<td></td>
<td>- Has anyone told you where to access help or support after treatment if you need it?</td>
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<tr>
<td>Physical</td>
<td>- What have been your biggest physical concerns?</td>
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<tr>
<td></td>
<td>- Do you recall speaking to a member of the health team about the possible effects some treatments can have?</td>
</tr>
<tr>
<td>Perceptions on a survivorship model of care</td>
<td>- If you could design a model of care to best support myeloma patients, what would it look like?</td>
</tr>
<tr>
<td></td>
<td>- who would be in the care team?</td>
</tr>
<tr>
<td></td>
<td>- how would you access this care and how would they communicate with you?</td>
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<tr>
<td></td>
<td>- what services would be provided?</td>
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<tr>
<td></td>
<td>- how often would you like to contact/access this care model?</td>
</tr>
</tbody>
</table>

Independent coding and researcher checking to ensure categories accurately captured issues being discussed maintained credibility. Extensive use of examples from the data demonstrated fit/ness. Auditing was maintained by documenting research planning through to analysis, and through a reflective process of discussion, and debrief with colleagues. The merging of individuals with and without haematology expertise added to the richness of interpreted data and provided a balance to the analytical process.

Results

Participants

Eighteen (31.5%) of 57 eligible individuals agreed to participate. Fourteen participants attended on the scheduled day (Figure 1). On average, 31 months (standard deviation [SD]: 13.8; range: 6–49 months) had elapsed since diagnosis. Thirteen participants had a partner and 5 indicated at least 1 child <20 years of age living at home. Participants in focus group 1 had received 1 line of treatment and an autograft transplant (n = 5). Seven participants in focus group 2 had received at least 2 lines of treatment. Five participants had received 1 autograft transplant, and 1 participant had received a second autograft transplant.

Age range and time since diagnosis were comparable with those who did participate. The majority of nonresponders preferred not to provide a reason (Figure 1).

Main Themes

The following 7 themes emerged and reflect data from both groups: information needs, experience with health-care
professionals, coping with side effects, communicating with family and friends, dealing with emotions, support needs, and living with the chronicity of myeloma.

Information Needs (Box 1)

Participants had differing views about the amount of information they had received at diagnosis and most had never heard of myeloma before. Some were overwhelmed and felt they couldn’t absorb the information, others felt they were not given enough. All participants reported using the Internet. Many felt a list of reputable and reliable sites to search would have been helpful and may have made the diagnosis less confronting.

[I] typed in multiple myeloma and read something about ‘it’s not curable’ and turned the computer off and went ‘no’…the average person out there who goes online doesn’t get the full medical details…that’s the information you want. (MM2-7)

Experiences with Health-Care Professionals (Box 1)

Participants suggest, in the main, their experiences of medical care were positive, but some said it was difficult to obtain “holistic support.” Participants discussed ways to maximize the value of their consultation appointments. Some indicated they would have liked to review blood results prior to appointments, to process the information and determine the “right questions to ask,” agreeing this would help reduce anxiety.

…but if you’re told that [out of remission] at an appointment, you’re just in shock, you’re useless. So yes [before appointment] it does make a much better consultation. (MM2-2)

Participants spoke positively about general practitioners (GP) when cancer symptoms were recognized and communicated effectively. Negative experiences were described as those where a GP had not recognized symptoms of a serious illness resulting in a delayed diagnosis.
APPENDICES

Box 1. Information Needs and Experiences of Health-Care Professionals.

| Information needs | “You get a package of books and stuff. There’s a limit to how much you can absorb; I think, especially initially you know, you’re kind of reeling.” MM1 -1 |
| Experiences of health-care professionals | “I think in a way, because [the consultant] didn’t say I never got around to asking some things that I would’ve [liked to].” MM1.4 |
| | “I think the nurses are quite knowledgeable … but a lot of them don’t have the time to sit with you, I mean while they’re in the room they’ll talk a little bit like that’s how the one nurse told me about the plastic knife and fork when I said everything tastes like metal.” MM2.7 |
| | “I don’t know if the doctors realize how anxious we get waiting for these results … I just couldn’t wait, I was just a bit of a wreck, because you never know — it’s like waiting to find out if you’re sick again, so I got them to send the results to my house.” MM2.7 |
| | “My GP actually picked me up … and she’s very good, I was very fortunate to have that doctor.” MM1.7 |
| | “My GP didn’t pick anything up! And I’d been having these symptoms for about a year and a half, I’ve had a broken rib and it don’t heal …” MM1.5 |

Box 2. Coping With Side Effects.

| Side effects | “I can’t just go out and kick a footy, do all those hard sorts of sports that I loved to do, but now I just can’t do those sorts of things, too much of a risk.” MM2.3 |
| Others expectations | “. . . all of a sudden you look good, you look normal, you know. People look at me and think ‘you can’t possibly be sick’.” MM1.6 |
| | “I feel tired a lot . . . My muscles have all gone. Whereas, I was working manually, I would spend a half hour doing office work in the day, then 10 hours of lifting and stuff . . . I’m trying to swim every day and walk and things and people say, ‘you’ve got a good life, going to the beach every day.’” MM1.5 |
| Hair loss | “I’m proud of it, you know, I’d always say ‘I’ll never be bald, I’ll never be bald’ and, I’d no control over it. And waking up and seeing your pillow covered with hair just absolutely ruined my mind, and I was just really really impacted by that.” MM1.1 |
| | “You are someone who has cancer, from that point [losing hair] onwards. I found it very confrontational.” MM2.2 |
| | “… I’m a hairdresser by trade, so for me to have no hair it’s like ‘I can’t possibly have no hair’!” MM1.2 |
| Peripheral neuropathy | “I couldn’t even get toothpaste out of a tube, it affected my strength in my hands and feet. I was driving along I day, and I couldn’t feel the controls, the pedals, so, I’ve given up driving, which, again, is a very frustrating thing to do.” MM1.4 |
| | “And with the feet problem, exercising is tough, because I get to the point where I don’t trust my feet anymore, you know . . . Even making a run to cross the road, the green man . . . you think “will I get it? Will I get it? Will my feet listen to what my brain’s telling them to do?” MM1.1 |
| Fatigue | “I think that’s the most frustrating thing, when you’ve had some sort of treatment, or when your whole system’s down, when you’re really weary and tired, and you can’t do . . . even simple chores are a real hassle. And you’re so frustrated that you can’t do . . . just the normal things.” MM1.4 |

Coping With Side Effects (Box 2)

Most participants struggled with treatment side effects, described as “the most difficult part of their experience.” Participants felt health professional support and guidance in preparing for, coping with, and managing side effects were inadequate.

I found one of the challenging things is understanding and dealing with the side effects. My issue is about coping . . . so I never quite know if it’s an important side effect or not. I don’t want to waste the doctor’s time on unimportant things. (MM2 -1)

A number of side effects were mentioned; however, hair loss, peripheral neuropathy, and fatigue were most widely experienced and discussed. All participants described hair loss as difficult; besides the emotional impact to self-image and identity, it labeled them as having cancer. Peripheral neuropathy impacted day-to-day functioning and well-being. Fatigue was described as
Box 3. Communicating With Family and Friends and Dealing With Emotions.

| Family support | “But it’s the after, once you look OK—don’t get me wrong, my family’s still there and they still know I’m sick ... but people look at you and go ‘you look fantastic’ you know, and you do, you look good, you’ve got your hair back, so people don’t assume you’re sick, they don’t know your journey, and it’s a physical thing.” MM1-2 |
| Children       | “My grandchildren didn’t recognize me, they don’t think I’m the same person (laughs) ... we were so close, you know they did everything with me and after I spent 5 weeks in hospital I’m like a stranger and I think like they’ve just got to get to know me again.” MM2-4 |
| Hope and positivity | “You know, how many birthdays have I got left? How many things like teaching them how to drive? Basic things like that.” MM2-3 |

excessive and long lasting; however, some found physical exercise beneficial.

Participants described a sense of loss, as the disease and treatment had changed their life. They discussed the difficulty of appearing “well on the outside,” while dealing with challenging side effects not physically obvious to others. In a sense, the cancer was viewed as “forgotten,” and there was an expectation to resume normal duties and roles. Support from loved ones wavered when participants began to improve and look better.

Communicating with Family and Friends (Box 3)

Families were supportive; however, at times the ways in which they tried to help was not useful or even wanted. There was a sense that family and friends were uncomfortable or unable to cope when the participant was “down” or wanted to talk about prognosis. One participant spoke of the difficulty in having to refuse advice perceived as helpful.

... and in the end with all the herbal things and stuff I just had to say, ‘I’ve chosen conventional treatment, I’m happy, it’s working for me, just leave me alone’ ... you’re trying to manage yourself but also all those people around you it’s really hard work. (MM2-2)

Participants described talking to their children about myeloma as a key difficulty and “stressful.” Regardless of children’s ages, participants wanted to talk honestly using age-appropriate language during conversations without frightening them.

It’s very hard, she was only 9 when I was diagnosed, so, to try and tell her what was going to happen to me, we have to sort of tread lightly, because she’s known cancer to be deadly ... both her grandparents [died] ... to say those words that her mum had it, would’ve been just traumatic. I had to try and find ways to explain it to her, that I wasn’t going to end up in a coffin, you know? (MM1-2)

Dealing With Emotions (Box 3)

Many participants perceived stress was a contributing factor to their diagnosis and response to treatment.

... stress, I think that’s a massive part of my diagnosis, I was separated [at diagnosis ... I have noticed that when it’s stressful ... that’s when my levels go up. (MM2-3)

Similarly, participants talked about their emotional response to diagnosis and how emotions fluctuated with disease status. There was the feeling they should be able to express the good and had aspects without pressure to be continually positive. Coping strategies were discussed generally and specifically, especially those that helped maintain hope for the future such as better treatment options or having something to look forward to. Exercise, a positive frame of mind, and not “giving in” were identified as helpful strategies.

Food and exercise. Book a holiday. Always have something to look forward to. (MM2-3)

For many participants, there was a sense that living with myeloma had a positive impact on their well-being, forcing them to “live in the now” and “appreciate the moment.” A reluctance to accept professional psychological support was described and a few felt by the time they had an appointment the need had passed. Participants who had accessed an
Box 4. Support Needs and Living With the Chronicity of the Disease.

| Support needs | “It’s not that you want to go and see a psychologist out in the suburbs cos maybe they’ve never dealt with somebody [with cancer] like that.” MM2-7 |
| Peer support | “You don’t want to upset anybody and that’s why I started going to the meetings… because you actually got to talk about it! With your family you don’t sit like this and have a discussion. I mean initially I found it a bit sort of ‘oh my god’ but then once you start talking it’s like here, I mean everybody’s in the same boat. I think it’s a great opportunity for us to get our story out.” MM1-2 |
|              | “And you wanted empathy not sympathy… But you could only get empathy from someone who was exactly where you are.” MM1-6 |
|              | “Well maybe if there was a contact register… specific to people who did want to help, and you could be told this person is more than happy for you to contact them, you know, please do or would you like us to get them to contact you? Because sometimes… if X had’ve rung me, I would’ve been perfect with that, but I just couldn’t do it myself.” MM1-6 |
| Link person  | “I know of other people at other hospitals and I’ve said ‘you done that?’ and they’re saying ‘no, haven’t done that, what’s that all about?’ and I’m thinking surely there’s got to be a common path that we tread down, with slight branches off depending on individuals, but there’s got to be a common path—that’s right or not?” MM2-8 |
| Living with myeloma | “One thing I have thought about that I would really have liked is one person that I had the phone number of that I knew that I could ring if my appointment was wrong, if I was feeling depressed and wanted to arrange counselling, just one person. That was mine in this hospital somewhere.” MM2-2 |
| Remission    | “Yeah, just knowing that at any point you can ring up and you know, not get a message press this press that and get through to someone who couldn’t help you anyway.” MM2-3 |

I don’t think any of us really forget about it, there’s not a day that goes by that I don’t anyway” MM1-2

Support Needs (Box 4)

Gaps in service provision were identified during discussions, and participants made suggestions on what they would have found helpful. Participants described changing needs with regard to individual or group support at different stages in their cancer journey. They recognized individual differences existed in the types of support they may choose to access or want provided. Some found support groups useful to share experiences and gain informational, emotional, and social support. Others felt the group environment would be intimidating, or they would be unable to connect with others. Another issue was hearing about different treatment regimens, making them feel insecure about their treatment. However, for most there was a longing to be connected with others of a similar age and life stage.

I found it really hard to go to the clinic and have my treatment because I didn’t want to be sitting next to people who were quite a bit older than me. I couldn’t talk to them because I felt like I didn’t have anything in common. Obviously I did, because I had the disease… MM1-2

The suggestion was made that a contact register in the hospital could be beneficial, where individuals could approach others who had myeloma to talk through their shared experiences. Although, participants felt those overwhelmed by negative experiences would be unhelpful to connect with.

Participants felt a health professional link/support person was required, who had expert knowledge, be able to offer information, advice, and provide reassurance. This person could also act as the contact between participants and the wider support team and help facilitate communication.

Living With the Chronicity of the Disease (Box 4)

Participants discussed the chronicity of myeloma, living with an incurable disease and inevitability of relapse.

Well, they say ‘it’s going to come back, it’s not curable, it’s treatable, but don’t kid yourself because we can’t cure you’, so there’s always this ‘oh my god’. It’s tough because you know you’ve got to go through it all again [treatment]. (MM1-6)

Many participants had experienced a relapse and spoke about dealing with recurrence. For some, the recurrence was as devastating as the initial diagnosis.
I’m not on drugs, I’m on a roll, and then you get symptomatic again and it was confirmed it was bad. It was devastating. (MM2-2)

Death and dying was not discussed in depth during the focus groups. Conversely, participants discussed periods of remission as a time when life returned to a sense of normality. This was expressed as comforting and liberating.

**Discussion**

Reports of the experiences of people living with myeloma and a description of their unmet needs are limited in published literature (14,15). Our study contributes to an understanding of the experiences of care and treatment for this group of people. Consistent with recent work (16,17), our findings indicate that support is required for people to adjust to living with an incurable disease has an unpredictable trajectory of remission, relapse, and refractory disease (18,19). This is an important area for future intervention. Most of the people in our study had never heard of myeloma before their own diagnosis, and as such, the need to ensure that patients and their support networks are well informed about the disease and what they can do to keep themselves well is an important consideration for enhancing survivorship experience (20,21).

Treatment side effects were described as one of the worst aspects of the experience, with many people reporting feeling unprepared to recognize or cope with them (20,22). Preparation and strategies for self-management of side effects were identified as a priority area where more intervention is required. Fatigue and peripheral neuropathy were reported as particularly challenging, as they impact negatively on daily functioning and the quality of life (16). These present important areas for future multidisciplinary, survivorship research. Developing effective, feasible resources that enable prompt, access to information about the disease, its treatments, and side effects is an important focus for survivorship innovation to minimize or ameliorate these unmet and highly burdensome needs. Survivorship research to minimize the physical and psychological impact of the complex symptoms and side effects of myeloma is urgently needed.

System issues highlighted as opportunities to improve posttreatment experiences included knowing blood results prior to an appointment, as a way of reducing anxiety and maximizing time for discussions at hospital appointments (16), and ensuring a focus on addressing emotional needs as well as medical issues.

Participants spoke about having to manage family’s feelings and reactions while they tried to cope with their own. Development of survivorship services or resources targeted at family members/support networks may enhance posttreatment experiences for all affected by this disabling and complex disease.

Given the rarity and incurability of myeloma (23), some patients identified myeloma support groups as an important component of their survivorship care, providing information, emotional support, and a venue for shared understanding of their experience. A health professional “link” person was consistently identified as an important component of supportive survivorship care.

**Limitations**

This study reflects the views of a specific cohort of myeloma patients who self-selected to participate in our qualitative, exploratory study. The intent was to offer deeper understanding of the experiences of an underresearched group of people about whom we know little about their experiences. Given the intent of the work, the small number of people who took part and the heterogeneity across participants does not present methodological limitations as they would in a quantitative study. The findings are offered as an opportunity to build further research informed by patients’ experiences. We acknowledge that disclosure by the focus group facilitator of her role as a psychologist may have influenced the content participants chose to share and issues discussed, but the similarity of our data with that reported from other studies undertaken with this group of patients indicates that this did not influence the information shared.

**Conclusion**

Participants in this study described unmet needs across a breadth of domains that varied over time. The development of flexible, person-centered approaches to comprehensive survivorship care is needed to address the considerable quality-of-life issues experienced by people living with multiple myeloma. Nurse-led care may offer 1 viable model to deliver enhanced patient experiences—providing the vital “link” that people described as missing from their survivorship care.

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**Declaration of Conflicting Interests**

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**References**


Author Biographies

Leanne Monterossa, professor, is the inaugural Chair of Nursing (Clinical Nursing) at the University of Notre Dame Australia (Fremantle) and St John of God Hospital Murdoch. Her research interests include cancer and palliative care. Leanne is particularly interested in understanding the experiences of people living with cancer and undertaking implementation research to test nursing interventions to support these individuals and their families.

Karen Taylor is an experienced Cancer Nurse Coordinator with the Western Australian Cancer and Palliative Care Network and a PhD candidate in cancer survivorship research at the University of Notre Dame Australia. Karen has a professional background in haematology, oncology, bone marrow transplant nursing across public and private hospitals in Australia. Karen is interested in research related to nurse-led models of survivorship care and supporting haematological cancer survivors.

Violet Platt is the co-director and director of Nursing of WA Cancer and Palliative Care Network. Violet is responsible for the delivery of all Statewide Cancer and Palliative Care Strategic Initiatives and operationally responsible for the Statewide cancer nurse coordination service.

Elizabeth Lob is the Cunningham Centre for Palliative Care’s Professor of Palliative Care based at Calvary Health Care Sydney and adjunct professor in the Faculty of Medicine at the University of Notre Dame Australia (Sydney). Elizabeth has established national and international research collaborations.

Toni Muscatello is an experienced Clinical and Research psychologist, who holds a Doctorate and Masters degree in Health psychology. Toni has an interest in psycho-oncology research.

Caroline Bussara, associate professor, is a research coordinator in the School of Nursing and Midwifery, University of Notre Dame Australia (Fremantle). Caroline works primarily with qualitative research methods and community participatory research and provides leadership to universities, primary health care and non-government organizations to build research capacity.

Kendall Stratton is a Cancer Nurse Specialist in the Western Australia Youth Cancer service and project manager of survivorship research at the University of Notre Dame Australia. Kendall has a professional background in paediatric and adolescent...
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**David Joske** is a Clinical haematologist and Medical co-director at Sir Charles Gairdner Hospital and holds a clinical professor role at the University of Western Australia. David was head of Department from 1994-2013 and has had two NHMRC Fellowships. He has research interests in Supportive Care in cancer, psycho-oncology and lymphoma and is the founder and Chairman of the Solaris Cancer Care Foundation, which offers support to cancer patients and survivors in Western Australia.

**Meenir Krishnasamy** is chair in Cancer Nursing at the University of Melbourne and Research and Education lead for Cancer Nursing at the Victorian Comprehensive Cancer Centre. Mei is chief investigator on several national and international research grants, and sits on several national expert cancer policy committees.
Appendix C

Joint Authors’ Declarations

Statement of Co-Authorship

Survivorship care plans and treatment summaries in adult patients with hematologic cancer: An integrative literature review. Oncology Nursing Forum, 2015, 42(3), 283–291

List of Authors: Taylor, K., & Monterosso, L.

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Contribution of the PhD candidate to the paper:
The candidate undertook the search terms lists, literature search, review of journal articles, analysis of the journal articles, writing of the manuscript, revision for reviewers, and editing prior to publication. The co-author contributed search strategy, corrections, clarity with discussion, recommendations, review of revisions.

Karen M Taylor 04/02/2018

Leanne Monterosso 04/05/2018
Statement of Co-Authorship

Publication: Models of survivorship care provision in adult patients with haematological cancer: An integrative literature review. *Supportive Care in Cancer*, 2015, 23(5), 1447–1458

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Statement of Co-Authorship

Protocol for Care After Lymphoma (CALy) trial: A phase II pilot randomised controlled trial of a lymphoma nurse-led model of survivorship care. BMJ Open, 2016, 6(e010817, 1–10

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Appendix D

Patient Information and Consent Form

SIR CHARLES GAIRDNER HOSPITAL

Participant Information Sheet/Consent Form

Effect of a Nurse-Led Lymphoma Survivorship Clinic: A Pilot Randomised Controlled Trial

Protocol Number: 2015-020
Project Sponsor: University of Notre Dame Australia
Coordinating Principal Investigator: Professor Leanne Monterosso
Principal Investigator: Karen Taylor
Associate Investigators: Dr David Joske, Violet Platt, Kendall Stratton, Professor Max Bulsara

What does my participation involve?
You are invited to take part in this research project, which is called the effect of a nurse-led lymphoma survivorship clinic. You have been invited because you have received treatment for lymphoma cancer: either Hodgkin’s lymphoma or Non-Hodgkin’s lymphoma. This research is specifically for patients who have completed treatment and are entering into the post treatment or ‘survivorship’ phase. Your haematologist has recommended you and has provided your contact details as you are about to, or have already finished treatment.

This Participant Information Sheet/Consent Form explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in this study.

Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or your treating doctor.

Your participation is voluntary. If you don’t wish to take part, you don’t have to. If you decide you want to take part, you will be asked to sign the consent section. By signing it you are telling us that you:
• Understand what you have read
• Consent to take part in this research
• Consent to be involved in the research described
• Consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.

Participant Information Sheet/Consent Form 22 August 2016 Version 6
What is the purpose of this research?
“Survivorship” is a term that is commonly used to describe the experience of living with, through and beyond a diagnosis of cancer. People who have completed treatment for a blood (haematological) cancer such as lymphoma can have problems that impact on the practical, physical and emotional quality of their life. This study will test a nurse-led lymphoma survivorship clinic that will provide information, education and practical support to people like yourself who have just finished treatment. This will help in moving (transitioning) on from hospital care. Information will also be passed onto your General Practitioner (GP) about the treatment you have received and what to expect in the future. This will be in the form of a survivorship care plan treatment summary, which has been suggested as a way to help patients and GPs find out about the treatment received and the issues that may require further assessment and support with.
Western Australia has no formal survivorship care and this research aims to identify whether a survivorship clinic would be acceptable to patients like yourself to help reduce the number of problems encountered after treatment ends and to provide information to enable a healthy lifestyle. This pilot research will form the basis for future expansion of survivorship care for all blood cancer survivors across Western Australia.

Who is organising and funding the research?
This research is being conducted by Karen Taylor who is a PhD student at the University of Notre Dame Australia, under the supervision of the coordinating principal investigator Professor Leanne Monterosso. Karen is an experienced haematology cancer nurse. Other members of the research team include Dr David Joske from the SCGH Haematology Department, Violet Platt, Director of Nursing at the WA Cancer and Palliative Care Network, Kendall Stratton from the Youth Cancer Service and Professor Max Bulsara who is a leading biostatistician. This research is funded by the University of Notre Dame Australia.
No member of the research team will receive a personal financial benefit from your involvement in this research project.

What does participation in this research involve?
Consent
If you decide to participate in this study, please sign the consent form and bring it to your next haematologist appointment at SCGH. Karen will contact you on that day either before or after your appointment. Karen will need to check that you are eligible for the study by asking about your diagnosis and treatment. Your medical records will need to be accessed, but this will not occur without your consent.
Once you have consented, Karen will ask you to fill out four (4) questionnaires. These will be used to assess whether you have any particular needs related to practical, physical, emotional or social issues that are known to possibly affect patients after treatment for cancer such as lymphoma. These questionnaires may take up to an hour to complete.