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

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

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ABSTRACT

Purpose: Increasing numbers of haematology cancer survivors warrants 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.

Methods: An integrative literature review method utilised a search of electronic databases (CINAHL, Medline, PsycInfo, PubMed, EMBASE, PsycArticles, 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.

Key Words: 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, sixteen 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]:

- 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;
- 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 five year relative survival rates [12]. The most common haematological cancers are leukaemias, 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, Larsson [6] reviewed 21 nurse-led follow-up studies and Howell et al. [19] evaluated 10 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, 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, 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.

LITERATURE SEARCH

The primary search utilised the following electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL); Medline; PsycInfo; 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 Figure 1. The initial search yielded 2907 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. Methodological characteristics documented 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, 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 reported
nurse-led studies [31, 32] and four referred to physician-led studies [33, 8, 34, 35] (Table 3). The included articles reported views from Australia (n=1), United States of America (USA) (n=10) and United Kingdom (UK) (n=3), 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, 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 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, 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 [5] 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, 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, Armes [32] provided an annual clinic with nurse contact details, whereas Gates et al. [31] delivered four consultations over a six month period. Both studies measured different outcomes and utilised different comparative groups, thereby making them difficult to compare, especially as Gates et al. [31] has only published preliminary results. John, Armes [32] prospective comparative study of 61 patients 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 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 Chubak et al. [33] reported the views of clinicians and administrators (n=40) from 10 integrated cancer centres. All respondents reported shared care was being practised. 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, Cunningham [8] qualitatively assessed the feasibility of a shared care survivorship model with 21 primary care clinicians. The overall perception was that primary carers are 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 two years, and only 42% (n=45 lymphoma) and 32% (n=10 leukaemia) are discharged after five 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 co-morbid 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 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 reported the willingness to accept exclusive care for lymphoma patients was three 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 maybe 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, Armes [32] demonstrating 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 specialist 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 that address the need for long-term follow-up that accounts for potential late treatment effects, risks of secondary cancers, 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 interests:** The authors declare no conflicts of interest relevant to this manuscript.
REFERENCES


of follow-up and preferences for methods of follow-up delivery among service users, primary care practitioners and specialist clinicians after cancer treatment. Clin Oncol 22 (10):874-884. doi:http://dx.doi.org/10.1016/j.clon.2010.06.008


Fig. 1 Flowchart of literature search results
Table 1 Levels of Evidence

<table>
<thead>
<tr>
<th>Level</th>
<th>Evidence</th>
</tr>
</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 controlled trials without randomisation</td>
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<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>
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<tr>
<td>V</td>
<td>Systematic reviews of descriptive and qualitative studies</td>
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<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>
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<tr>
<td>Setting</td>
<td>Model</td>
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<td>---------------------</td>
<td>--------------------------------------------</td>
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</tbody>
</table>
| Hospital            | Multidisciplinary survivorship clinic [7]  | Oncologist, network of consulting physicians, oncology or haematology nurse practitioner (NP), psychologist, social worker | • Can be consultative or ongoing  
• Multiple providers seen at same visit  
• Complex and resource intense  
• Co-morbid and treatment related conditions can be addressed  
• Can be extension of care, embedded in treatment team  
• Disease-specific specialist defines follow-up plan  
• NP follow-up who communicates with PCP to initiate shared care  
• Large patient cohort needed |
| Consultative clinic [27, 29] | Specialist |                                                   | • Ongoing (rarely Oncologist takes on primary carer role)                           |
| Consultative clinic [7] | Specialist |                                                   | • One-time comprehensive visit  
• Treatment summary and survivorship care plan  
• Review of recommendations – surveillance, screening, health promotion |
| Survivorship follow-up clinic [30,1] | Specialist |                                                   | • Separate from routine care  
• Holistic assessment of survivor  
• End of treatment or on maintenance therapy  
• Treatment summary, survivorship care plan and individualised information provision  
• Can have telephone follow-up |
| Late effects clinic [9] | Nurse and/or specialist | Oncology nurse or NP | • Haematology / Oncology treatment centres  
• Comprehensive, long-term follow-up to assess, |
<table>
<thead>
<tr>
<th>Primary Care</th>
<th>General survivorship clinic [28, 5]</th>
<th>Nurse collaboration with practice specialist PCP (i.e. breast care PCP)</th>
<th>Referral for services or refers to specialists</th>
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<tr>
<td></td>
<td>PCP-led [9]</td>
<td>PCP</td>
<td>Full transition to PCP after treatment completion</td>
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<td></td>
<td></td>
<td></td>
<td>Can have communication from specialist: late effects management and surveillance</td>
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<td></td>
<td></td>
<td></td>
<td>Usually low risk for recurrence or late effects</td>
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<tr>
<td>Shared Care</td>
<td>Shared care [1, 7]</td>
<td>Specialist &amp; PCP</td>
<td>Oncologist for oncology related issues</td>
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<td></td>
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<td></td>
<td>PCP for co-morbidities, other cancer screening and prevention</td>
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</tbody>
</table>

ASCO American Society of Clinical Oncology; NP Nurse practitioner; PCP primary care physician
Table 3 Methodological Characteristics of Models of Haematological Cancer Survivorship Care (n=6)

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Study Design</th>
<th>MOC Provider</th>
<th>Disease Years Post Treatment</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. [33]</td>
<td>2012</td>
<td>Exploratory study</td>
<td>Shared care</td>
<td>10 Cancer Research Network sites</td>
<td>Cancer types not identified</td>
<td>Time and lack of specialists to follow-up survivors</td>
<td>Clearer evidence to support survivorship care needed</td>
<td>Perspectives on: survivors 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>
</tr>
<tr>
<td></td>
<td>USA</td>
<td>Semi-structured telephone interviews</td>
<td>40/48 (83%) Administrator s / clinical leaders /providers in oncology, primary care</td>
<td>Survivorship care plan (SCP) - only 5 responders identified use of Support groups</td>
<td>6/10 sites survivor specific tools not being used</td>
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<tr>
<td>Study</td>
<td>Study Design</td>
<td>Sample</td>
<td>Setting</td>
<td>Key Findings</td>
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<td>DiCicco-Bloom &amp; Cunningham [8]</td>
<td>In-depth interviews on information sharing to/from specialist &amp; patients</td>
<td>21 Primary care clinicians (PCC) (11 PCP &amp; 10 NP)</td>
<td>Unknown patient types or survivorship period</td>
<td>Electronic medical records access ensures effective care transitions No guidelines or consensus for many cancers on screening, surveillance, late effects (LE) Understand nature of interactions between primary care, specialist &amp; patient Absence of systematic information sharing among PCP, patient, specialist Some patients continue to see PCC during treatment Reliance on patients to provide clinical information from specialist (not always reliable for complex conditions/treatment) Academic hospital settings were worst in communication to PCC SCP effect on patient outcomes - limited evidence</td>
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<tr>
<td>Frew et al. [34]</td>
<td>Comparison survey on models of follow up</td>
<td>Models presented for perception &amp; experience: Cancer diagnosis or treatment not disclosed</td>
<td>Non-specialist models tend to</td>
<td>Survey did not ask for survivor diagnosis &amp; Perceptions of reasons for follow-up: levels of</td>
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<td>2010</td>
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<td>Reasons for follow-up: monitoring for earlyVI</td>
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<tr>
<td>UK</td>
<td>hospital based; telephone; non-specialist; group; patient managed; no follow-up</td>
<td>Range to over 10 years</td>
<td>provide more psychological support</td>
<td>treat preference for different follow-up models; effect of individual experience on follow-up model preference</td>
<td>complications; detecting recurrence; detecting LE, providing information &amp; support (70%)</td>
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<td></td>
<td>626 (21%) survivors/carers</td>
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<td>Survey did not ask if any models would be rejected so potential deficits not identified</td>
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<td>Preference for model of follow-up experienced: 86% survivors preferred hospital based follow-up and was experienced most (84%)</td>
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<td>940 (32%) PCP</td>
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<td>Clinicians had experience of more models of follow-up</td>
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<td></td>
<td>804 specialists (including haematologist s) 558 nurses /allied health (47%)</td>
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<td>Specialists endorsed non-specialist or patient managed follow-up (87%) PCP endorsed hospital based and patient managed follow-up (83%)</td>
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<table>
<thead>
<tr>
<th>Gates et al. [31]</th>
<th>Quasi-experimental</th>
<th>Late effects MDT (haematologist)</th>
<th>HL 5 years</th>
<th>Education package</th>
<th>Health promotion SCP not given until 2nd visit (at Primary outcome: health</th>
<th>No final published results from this study</th>
</tr>
</thead>
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<td>IV</td>
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<tr>
<td>Year</td>
<td>Study</td>
<td>Comparison</td>
<td>Cohort</td>
<td>Screening Tools</td>
<td>Psychosocial Issues</td>
<td>Promotion Intervention</td>
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<tr>
<td>2012</td>
<td>Australia</td>
<td>Comparison of healthy versus Hodgkin lymphoma (HL) survivors</td>
<td>30 HL + 30 healthy participants (91%)</td>
<td>Screening tools (Late Effects Supportive Care Needs Screening Tool; The General Health Index; The Health Promoting Lifestyle Profile II)</td>
<td>Psychosocial issues identified &amp; resources given</td>
<td>Promotion intervention from nurse to improve HL survivors knowledge and motivation to adopt health promoting behaviours</td>
</tr>
<tr>
<td>2009</td>
<td>Greenfield et al. [35]</td>
<td>E-survey comparison of clinician views on long-term follow-up</td>
<td>18-45 year old breast, lymphoma, leukaemia, or germ cell survivors &gt; 2 years</td>
<td>Communication Specialist nurse support (91% most important resource)</td>
<td>Specialists can focus on acute care Lower costs</td>
<td>Potential loss of outcome data, LE information to specialists</td>
</tr>
<tr>
<td></td>
<td>UK</td>
<td>PCP-led follow-up</td>
<td>421 cancer clinicians (36% haematologist, 33%)</td>
<td>Risk stratification - low risk to PCPs, PCP: existing relationship with survivor; accessible;</td>
<td>PCP: Lack expertise in survivorship issues, increases survivor</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>
</tr>
<tr>
<td>Study</td>
<td>Location</td>
<td>Type</td>
<td>Disease</td>
<td>Length</td>
<td>Notes</td>
<td>Follow-up</td>
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<tr>
<td>John &amp; Armes [32]</td>
<td>UK</td>
<td>Prospective comparison specialist-led versus nurse-led</td>
<td>Survivorship</td>
<td>Lymphoma</td>
<td>3 years</td>
<td>50 notes audited (25 per group)</td>
</tr>
</tbody>
</table>

- LE (76%) recurrence (71%)
- Haematologist use of follow-up protocol for leukaemia and lymphoma 19%
- Discharge to PCP: 5% at 2 years 42-32% by 5 years
CNC Cancer Nurse Consultant; CNS Cancer Nurse Specialist; HL Hodgkin Lymphoma; LE Late effects; MDT multi-disciplinary team; MM multiple myeloma; NHL Non-Hodgkin Lymphoma; NP Nurse practitioner; PCP primary care provider; SCP survivorship care plan; TS treatment summary