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

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TITLE PAGE

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

1. Hewitt ME, Greenfield S, Stovall E (2006) From Cancer Patient to Cancer Survivor: Lost in Transition. The National Academies Press, Washington DC
2. McCabe MS, Faithfull S, Makin W, Wengstrom Y (2013) Survivorship programs and care planning. *Cancer* 119 Suppl 11:2179-2186. doi:10.1002/cncr.28068
3. National Coalition for Cancer Survivorship (2014) <http://www.canceradvocacy.org/>. Accessed 3 April 2014
4. Grant M, Economou D (2008) The evolving paradigm of adult cancer survivor care. *Oncology* 22 (4):13-22, 27
5. Landier W (2009) Survivorship care: Essential components and models of delivery. *Oncology* 23 (4):46-53
6. De Leeuw J, Larsson M (2013) Nurse-led follow-up care for cancer patients: What is known and what is needed. *Support Care Cancer* 21 (9):2643-2649. doi:10.1007/s00520-013-1892-6
7. Oeffinger KC, McCabe MS (2006) Models for delivering survivorship care. *J Clin Oncol* 24 (32):5117-5124
8. Diccio-Bloom B, Cunningham RS (2013) The experience of information sharing among primary care clinicians with cancer survivors and their oncologists. *J Cancer Surviv* 7 (1):124-130. doi:10.1007/s11764-012-0253-7
9. McCabe MS, Jacobs LA (2012) Clinical update: Survivorship care - models and programs. *Semin Oncol Nurs* 28 (3):e1-e8. doi:<http://dx.doi.org/10.1016/j.soncn.2012.05.001>
10. Panek-Hudson Y (2013) Survivorship care - time for innovation? *Aust J Cancer Nurs* 14 (1):7-12

11. Swash B, Hulbert-Williams N, Bramwell R (2014) Unmet psychosocial needs in haematological cancer: A systematic review. *Support Care Cancer* 22 (4):1131-1141.
doi:10.1007/s00520-014-2123-5
12. Sant M, Minicozzi P, Mounier M, Anderson LA, Brenner H, Holleczeck B, Marcos-Gragera R, Maynadié M, Monnereau A, Osca-Gelis G, Visser O, De Angelis R (2014) Survival for haematological malignancies in Europe between 1997 and 2008 by region and age: Results of EURO CARE-5, a population-based study. *Lancet Oncol* 15 (9):931-942.
doi:http://dx.doi.org/10.1016/S1470-2045(14)70282-7
13. National Cancer Institute (2006) NCI dictionary of cancer terms.
<http://www.cancer.gov/dictionary/?CdrID=45708>. Accessed 3 April 2014
14. Carey M, Anderson A, Sanson-Fisher R, Lynagh M, Paul C, Tzelepis F (2012) How well are we meeting haematological cancer survivors' preferences for involvement in treatment decision making? *Patient Educ Couns* 88 (1):87-92. doi:http://dx.doi.org/10.1016/j.pec.2011.12.014
15. Allart P, Soubeyran P, Cousson-Gélie F (2013) Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. *Psycho-Oncol* 22 (2):241-249
16. Arden-Close E, Absolom K, Greenfield D, Hancock B, Coleman R, Eiser C (2011) Gender differences in self-reported late effects, quality of life and satisfaction with clinic in survivors of lymphoma. *Psycho-Oncol* 20 (11):1202-1210
17. Hall A, Lynagh M, Bryant J, Sanson-Fisher R (2013) Supportive care needs of hematological cancer survivors: A critical review of the literature. *Crit Rev Oncol Hematol* 88 (1):102-116

18. Parry C, Morningstar E, Kendall J, Coleman EA (2010) Working without a net: Leukemia and lymphoma survivors' perspectives on care delivery at end-of-treatment and beyond. *J Psychosoc Oncol* 29 (2):175-198. doi:<http://dx.doi.org/10.1080/07347332.2010.548444>
19. Howell D, Hack T, Oliver T, Chulak T, Mayo S, Aubin M, Chasen M, Earle C, Friedman A, Green E, Jones G, Jones J, Parkinson M, Payeur N, Sabiston C, Sinclair S (2012) Models of care for post-treatment follow-up of adult cancer survivors: A systematic review and quality appraisal of the evidence. *J Cancer Surviv* 6 (4):359-371. doi:<http://dx.doi.org/10.1007/s11764-012-0232-z>
20. Sussman J, Souter LH, Grunfeld E, Howell D, Gage C, Keller-Olaman S, Brouwers M (2012) Models of care for cancer survivorship. Vol Oct 26. Cancer Care Ontario, Toronto, Ontario
21. Whittemore R, Knafl K (2005) The integrative review: Updated methodology. *J Adv Nurs* 52 (2):546-553
22. Robert Wood Johnson Foundation Glossary of Health Care Quality Terms. <http://www.rwjf.org/quality/equality/glossary>. Accessed 21 June 2014
23. Gerber LH, Stout NL, Schmitz KH, Stricker CT (2012) Integrating a prospective surveillance model for rehabilitation into breast cancer survivorship care. *Cancer* 118 Suppl 8:2201-2206. doi:[10.1002/cncr.27472](https://doi.org/10.1002/cncr.27472)
24. Weaver LC, Jessup A, Mayer DK (2013) Cancer survivorship care: Implications for primary care advanced practice nurses. *Nurse Pract* 38 (11):1-11. doi:[10.1097/01.npr.0000435784.40143.62](https://doi.org/10.1097/01.npr.0000435784.40143.62)
25. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *Br Med J* 339 (b2535)

26. Melynyk B, Fineout-Overholt E (2011) Evidence-based practice in nursing & healthcare: A guide to best practice. 2nd Ed. Wolters Kluwer, Lippincott Williams & Wilkins, Philadelphia
27. Cooper JM, Loeb SJ, Smith CA (2010) The primary care nurse practitioner and cancer survivorship care. *J Am Acad Nurse Pract* 22 (8):394-402. doi:10.1111/j.1745-7599.2010.00528.x
28. Hahn EE, Ganz PA (2011) Survivorship programs and care plans in practice: Variations on a theme. *J Oncol Pract* 7 (2):70-75
29. Leigh SA (2008) The changing legacy of cancer: Issues of long-term survivorship. *Nurs Clin North Am* 43 (2):243-258
30. McCabe MS, Bhatia S, Oeffinger KC, Reaman GH, Tyne C, Wollins DS, Hudson MM (2013) American Society of Clinical Oncology statement: Achieving high-quality cancer survivorship care. *J Clin Oncol* 31 (5):631-640. doi:10.1200/JCO.2012.46.6854
31. Gates P, Seymour JF, Krishnasamy M (2012) Insights into the development of a nurse-led survivorship care intervention for long-term survivors of Hodgkin lymphoma. *Aust J Cancer Nurs* 13 (1):4-10
32. John C, Armes J (2013) Developing a nurse-led survivorship service for patients with lymphoma. *Eur J Oncol Nurs* 17 (5):521-527. doi:10.1016/j.ejon.2013.03.001
33. Chubak J, Tuzzio L, Hsu C, Alfano CM, Rabin BA, Hornbrook MC, Spegman A, Von Worley A, Williams A, Nekhlyudov L (2012) Providing care for cancer survivors in integrated health care delivery systems: Practices, challenges, and research opportunities. *J Oncol Pract* 8 (3):184-189. doi:10.1200/jop.2011.000312
34. Frew G, Smith A, Zutshi B, Young N, Aggarwal A, Jones P, Kockelbergh R, Richards M, Maher EJ (2010) Results of a quantitative survey to explore both perceptions of the purposes

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>

35. Greenfield DM, Absolom K, Eiser C, Walters SJ, Michel G, Hancock BW, Snowden JA, Coleman RE (2009) Follow-up care for cancer survivors: The views of clinicians. *Br J Cancer* 101 (4):568-574. doi:10.1038/sj.bjc.6605160

36. Campbell MK, Tessaro I, Gellin M, Valle CG, Golden S, Kaye L, Ganz PA, McCabe MS, Jacobs LA, Syrjala K, Anderson B, Jones AF, Miller K (2011) Adult cancer survivorship care: Experiences from the LIVESTRONG centers of excellence network. *J Cancer Surviv* 5 (3):271-282. doi:10.1007/s11764-011-0180-z

37. Del Giudice ME, Grunfeld E, Harvey BJ, Piliotis E, Verma S (2009) Primary care physicians' views of routine follow-up care of cancer survivors. *J Clin Oncol* 27 (20):3338-3345. doi:10.1200/jco.2008.20.4883

38. Forsythe LP, Arora NK, Alfano CM, Weaver KE, Hamilton AS, Aziz N, Rowland JH (2014) Role of oncologists and primary care physicians in providing follow-up care to non-Hodgkin lymphoma survivors within 5 years of diagnosis: A population-based study. *Support Care Cancer* 22 (6):1509-1517. doi:10.1007/s00520-013-2113-z

39. Medical Research Council (2000) A framework for development and evaluation of RCTs for complex interventions to improve health. UK

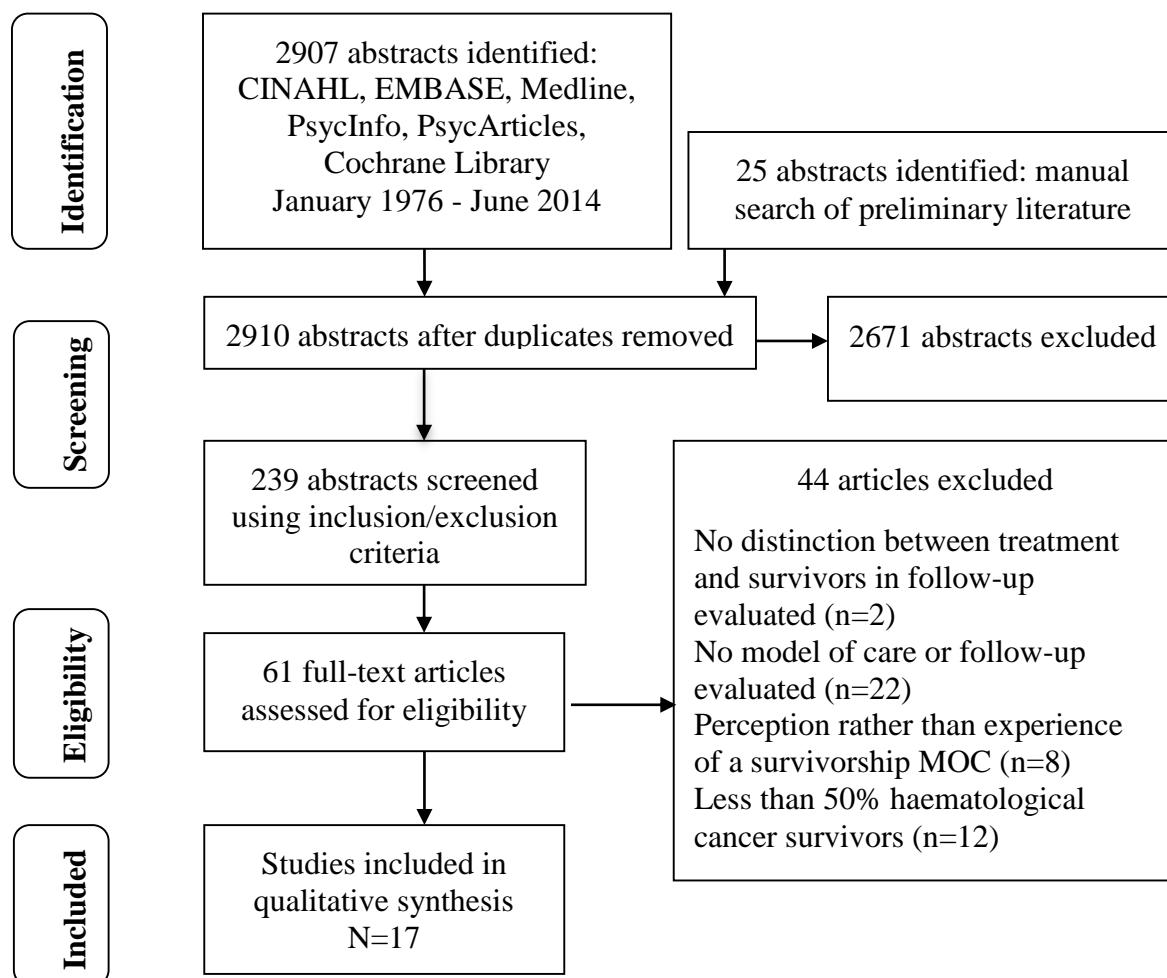


Fig. 1 Flowchart of literature search results

Table 1 Levels of Evidence

Level	Evidence
I	Systematic review of all relevant randomised controlled trials
II	At least one well designed randomised controlled trial
III	Well-designed controlled trials without randomisation
IV	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
V	Systematic reviews of descriptive and qualitative studies
VI	Single descriptive and qualitative studies
VII	Expert opinion from clinicians, authorities and/or reports of expert committees or based on physiology

Table 2 Existing or Proposed Models of Cancer Survivorship Care

Setting	Model	Provider	Model Characteristics
Hospital	Multidisciplinary survivorship clinic [7]	Oncologist, network of consulting physicians, oncology or haematology nurse practitioner (NP), psychologist, social worker	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Ongoing (rarely Oncologist takes on primary carer role)
	Consultative clinic [7]	Specialist	<ul style="list-style-type: none"> • One-time comprehensive visit • Treatment summary and survivorship care plan • Review of recommendations – surveillance, screening, health promotion
	Survivorship follow-up clinic [30,1]	Specialist	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Haematology / Oncology treatment centres • Comprehensive, long-term follow-up to assess,

	Nurse-led [27, 1]		and provide primary care needs
			<ul style="list-style-type: none"> • ASCO surveillance recommendations used • Clinic and/or telephone follow-up
Primary Care	General survivorship clinic [28, 5]	Nurse collaboration with practice specialist PCP (i.e. breast care PCP)	<ul style="list-style-type: none"> • Referral for services or refers to specialists
	PCP-led [9]	PCP	<ul style="list-style-type: none"> • Full transition to PCP after treatment completion • Can have communication from specialist: late effects management and surveillance • Usually low risk for recurrence or late effects
Shared Care	Shared care [1, 7]	Specialist & PCP	<ul style="list-style-type: none"> • Oncologist for oncology related issues • PCP for co-morbidities, other cancer screening and prevention

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)

Author	Study Design	MOC	Disease	Resources Required	Potential Benefits	Potential Deficits	Outcome Measures	Results	Level of Evidence
Year		Provider	Years Post Treatment						
Country			Sample Size (Response Rate %)						
Chubak et al. [33]	Exploratory study Semi-structured telephone interviews	Shared care	10 Cancer Research Network sites Cancer types not identified 40/48 (83%) Administrators / clinical leaders / providers in oncology, primary care	Survivorship care plan (SCP) - only 5 responders identified use of Support groups	Time and lack of specialists to follow-up survivors	Clearer evidence to support survivorship care needed 6/10 sites survivor specific tools not being used	Perspectives on: survivors needs; current survivorship practices; barriers; areas for future research	Only 2/10 sites had formal survivorship programs (1 nurse-led, 1 physician assistant-led) Responses for survivorship care needs: address fear recurrence 35%; information on long-term effects 40%; nutritional and exercise support 27%; psychosocial support 62.5%	VI
2012									
USA									
								Overall uncertainty about best models of survivorship care	

DiCicco-Bloom & Cunningham [8] 2013 USA	In-depth interviews on information sharing to/from specialist & patients	Shared care	21 Primary care clinicians (PCC) (11 PCP & 10 NP) Unknown patient types or survivorship period	Electronic medical records access SCP	Primary care perspective Information sharing 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 & patient	Absence 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	VI
Frew et al. [34] 2010	Comparison survey on models of follow up	Models presented for perception & experience:	Cancer diagnosis or treatment not disclosed	Nil described	Non-specialist models tend to	Survey did not ask for survivor diagnosis &	Perceptions of reasons for follow-up; levels of	Reasons for follow-up: monitoring for early	IV

UK	hospital based; telephone; non-specialist; group; patient managed; no follow-up	Range to over 10 years	626 (21%) survivors/care rs	940 (32%) PCP	804 specialists (including haematologists) 558 nurses /allied health (47%)	provide more psychological support	treatment which may alter model preference	preference for different follow-up models; effect of individual experience on follow-up model preference	<p>complications; detecting recurrence; detecting LE, providing information & support (70%)</p> <p>Preference for model of follow-up experienced: 86% survivors preferred hospital based follow-up and was experienced most (84%)</p> <p>Clinicians had experience of more models of follow-up</p> <p>Specialists endorsed non-specialist or patient managed follow-up (87%) PCP endorsed hospital based and patient managed follow-up (83%)</p>
Gates et al. [31]	Quasi-experimental	Late effects MDT (haematologist	HL 5 years	Education package	Health promotion	SCP not given until 2 nd visit (at	Primary outcome: health	No final published results from this study	IV

2012 Australia	comparison healthy cohort versus Hodgkin lymphoma (HL) survivors	, transplant physician, radiation oncologist, cardiologist, endocrinologis t, primary care liaison, psychologist, LE social worker, LE CNC) Nurse-led clinic for health promotion: 2 visits + 2 phone calls	30 HL + 30 healthy participants (91%)	Screening tools (Late Effects Supportive Care Needs Screening Tool; The General Health Index; The Health Promoting Lifestyle Profile II) SCP copy to survivor / PCP	Psychosoci al issues identified & resources and support given Importance of surveillanc e Survivor sees all relevant providers on same day	4 months)	promotion intervention from nurse to improve HL survivors knowledge and motivation to adopt health promoting behaviours Secondary outcomes: improved perception of health status; reduced LE unmet needs; reduced LE worry	Anecdotal analysis shows appreciation of: SCP; screening assessment	
Greenfield et al. [35] 2009 UK	E-survey comparison of clinician views on long-term follow-up	PCP-led	18-45 year old breast, lymphoma, leukaemia, or germ cell survivors > 2 years 421 cancer clinicians (36% haematologist, 33%	Communica tion Specialist nurse support (91% most important resource) Risk stratificatio n - low risk to PCPs,	Specialists can focus on acute care Lower costs PCP: existing relationship with survivor; accessible;	Potential loss of outcome data, LE information to specialists PCP: Lack expertise in survivorshi p issues, increases survivor	Compare long-term follow-up: reasons for follow-up; advantage / disadvantage of PCP-led follow-up; current practice; resources and support required	Specialists rated clinical reasons for follow-up higher Nurses and PCP rated both clinical & supportive reasons higher Reasons for follow-up: PCP rated recurrence (96%) Specialists rated	IV

			oncologist, 18% surgeon, 10% nurse, 2% other)	high risk hospital follow-up	convenient; knowledge of local support; expertise in chronic health	anxiety, time issues		LE (76%) recurrence (71%)	
			54 PCP	SCP & Treatment summary (TS)		No tumour specific follow-up guidelines		Haematologist use of follow-up protocol for leukaemia and lymphoma 19%	
								Discharge to PCP: 5% at 2 years 42-32% by 5 years	
John & Armes [32] 2013 UK	Prospective comparison specialist- led versus nurse-led	Survivorship follow-up clinic Nurse-led (replaces specialist follow-up)	Lymphoma 3 years 50 notes audited (25 per group) 120 survivors (60 per group) assessed wait time 61 (82%) survivors assessed patient satisfaction (unclear split medical-led versus nurse- led)	2 CNS Information prescription	Longer consultatio ns Written information provision Holistic needs assessment Monitoring for late effects Health promotion Post treatment contact	Annual clinic visit Preferred clinic not assessed	Documenta tion Wait time Patient satisfaction	Documentation improved – 50% of psychological & sexual issues still not recorded Wait times reduced from average 65 mins (specialist) to 10 mins (Nurse) Nurse-led was equal to specialist-led clinic and preferred in some areas Nursing telephone workload increased	IV

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