Hall, Alix; Lynagh, Marita; Bryant, Jamie; Sanson-Fisher, Rob “Supportive care needs of hematological cancer survivors: a critical review of the literature.” Critical Reviews in Oncology/Hematology Vol. 88, Issue 1, p. 102-116 (2013)

Available from: http://dx.doi.org/10.1016/j.critrevonc.2013.03.008

Accessed from: http://hdl.handle.net/1959.13/1042848
SUPPORTIVE CARE NEEDS OF HAEMATOLOGICAL CANCER SURVIVORS:

A CRITICAL REVIEW OF THE LITERATURE

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ABSTRACT

The purpose of this review was to determine the perceived supportive care needs of haematological cancer survivors, and the patient characteristics associated with higher levels of need. Medline, PsychInfo, CINAHL, EMBASE and PsycEXTRA, were searched for eligible articles published between 1979 and 2011. Ten full-text articles were identified. Extensive variation among study populations, methodologies and needs assessment measures used, made it difficult to synthesize results. Consequently, we could not confidently determine the most prevalent perceived needs of haematological cancer survivors. However, the limited data loosely suggests that concerns surrounding cancer recurrence and survival may be predominant needs experienced by haematological cancer survivors. Younger survivors were also identified by several studies as reporting higher levels of several areas of need. Future research is needed to assess the supportive care needs of large heterogeneous, population-based samples of haematological cancer survivors, utilizing valid, reliable and standardized measures of supportive care needs.
INTRODUCTION

Haematological cancers are a diverse group of cancers that develop in the blood or bone marrow\textsuperscript{1-3}. There are over 60 sub-types\textsuperscript{4,5}, that are often classified into three main disease groups: myeloma, leukaemia and lymphoma\textsuperscript{1,3}. Collectively, haematological cancers have been estimated to be the fourth most common cancer types diagnosed in both men and women in the economically developed world\textsuperscript{6}. Improvements in survival rates for a number of haematological cancers have been noted in several different countries, including Europe\textsuperscript{7}, Australia\textsuperscript{8} and the United States\textsuperscript{9}. The *National Cancer Institute* in the United States considers a cancer survivor, as someone “from the time of diagnosis through the balance of his or her life”\textsuperscript{10}. The number of haematological cancer survivors is rising, partly due to an increase in the aging population, increasing incidence and improvement in cancer treatment and some survival rates\textsuperscript{3}.

Haematological cancers are a unique group of cancers. There is considerable variability among the types and sub-types of haematological cancers and their treatment\textsuperscript{3,11}. For some, the disease is aggressive, requiring treatment that is often extensive and debilitating, and sometimes involving long periods of inpatient care (e.g. bone marrow transplant and chemotherapy)\textsuperscript{3,12,13}. Other forms are chronic in nature with frequent relapsing requiring active treatment and management for a number of years\textsuperscript{3,11}. 
Similar to other cancers, haematological cancers affect many aspects of a person’s life. Physical effects may include fatigue\textsuperscript{14,15}, reduced role function, insomnia, pain and dyspnoea\textsuperscript{15}. Longer-term effects may include fatigue\textsuperscript{16,17} and poorer self-reported physical health\textsuperscript{18}. Several reviews have also established associations between some haematological cancers and employment related outcomes\textsuperscript{19,20}. Given the significant impact of cancer, it is vital that haematological cancer survivors are provided with health care that is patient-centred and focused on addressing their unique and specific concerns.

Assessing the supportive care needs of cancer patients is recognized as an important step in providing optimal patient-centred care\textsuperscript{21,22}. Supportive care needs include the physical, informational, emotional, psychological, social, spiritual and practical concerns\textsuperscript{23}, which patients require support in addressing\textsuperscript{23,24}. Assessing the supportive care needs of haematological cancer survivors provides an opportunity to identify the most pressing issues survivors wish to receive help with\textsuperscript{25,26}. Such information can guide resource allocation, care planning and patient referrals\textsuperscript{26,27}. Identifying patient, demographic, disease and treatment characteristics associated with higher levels of perceived needs may also assist in targeting support to sub-groups of survivors who are at increased risk of experiencing difficulty\textsuperscript{28}.
Several reviews have investigated the experiences of haematological cancer patients or survivors\textsuperscript{29-31}, however these have largely included studies focusing on quality of life\textsuperscript{29-31}, with few studies included specifically assessing supportive care needs. While important, quality of life does not provide information on patients’ perceptions of the level of assistance required to address their concerns\textsuperscript{24 25}. A review focusing on the perceived supportive care needs of haematological cancer survivors will provide important information on what areas survivors specifically feel they need help with, what sub-group of survivors may be at risk of requiring additional support and provide direction for future research in this important area. In turn, such information could be used by clinicians and researchers in determining support, services and research initiatives that may be most appropriate for this population. This review aimed to investigate the perceived supportive care needs of haematological cancer survivors, with an overall objective to identify: i) the most prevalent perceived supportive care needs of adult haematological cancer survivors; and ii) the sociodemographic, disease, physical, treatment and care characteristics associated with high levels of needs.

**METHODS**

*Literature Search*

A haematological cancer survivor was defined as an individual diagnosed with any type of haematological cancer from time of diagnosis to the end of life\textsuperscript{10}. The databases, Medline, PsychInfo, Cumulative Index to Nursing and Allied Health Literature (CINAHL),
Embase and Psychextra were searched using the following combination of terms: (Needs assessment or unmet needs or perceived need* or supportive care need* or unmet need* or needs) AND (Multiple Myeloma or multiple myeloma* or leukemia or leukemia, experimental or leukemia, hairy cell or leukemia, lymphoid or leukemia, mast-cell or leukemia, myeloid or leukemia, plasma cell or leukemia, radiation-induced or Leukemia, Myeloid, Chronic or Leukemia, Lymphocytic, Acute or Leukemia, Lymphocytic, Chronic or Leukemia, Nonlymphocytic, Acute or Leukemia, Lymphocytic or leukaemia or lymphoma or hodgkin disease or lymphoma, non-hodgkin or lymphoma, non-Hodgkin’s or lymphoma, T-Cell, cutaneous or lymphoma, B-Cell or lymphoma, Extranodal NK-T-Cell or Lymphoma, T-Cell or Lymphoma, AIDS-Related or lymphoma or Hodgkin’s disease or hematologic neoplasms or hematologic neoplasm* or haematologic neoplasm* or haematological cancer* or haematological cancer* or blood cancer*). Additional articles were sought by hand-searching the reference lists of all relevant, full-text articles.

**Inclusion criteria:** Studies were included if i) they quantitatively assessed the perceived supportive care unmet needs and/or needs of adults diagnosed with a haematological cancer; ii) employed quantitative research methods; and iii) were published in English between January 1979 and December 2011. **Exclusion criteria:** Studies were excluded if: i) they employed qualitative research methods; ii) were not a data-based research article, thesis or review (i.e. case studies, commentaries or conference abstracts); iii) focused on children, survivors of childhood cancers, people diagnosed with non-
malignant haematological disorders or support persons; iv) could not access full-text article; or v) included a small sample of haematological cancers as part of a larger heterogeneous sample of cancer survivors.

**Article Analysis**

Study title was assessed by one author (AH) to determine eligibility. Ten per cent of abstracts and 20% of full-text articles were randomly selected and assessed by a second author (ML). Any discrepancies were discussed and resolved. Two authors (AH and JB) analysed eligible full-text articles and extracted relevant data about each study. Only study characteristics and data relating to survivors perceived supportive care needs were examined. Meta-analysis was unable to be undertaken due to extensive variation among study populations, methodologies and needs assessment measures used in the studies reviewed.

**Methodological Quality**

Similar to Butow et al\(^3\), we adapted Fowkes and Fulton’s\(^3\) checklist for critically appraising quantitative research, to assess study quality. Two authors (AH and JB) independently assessed the quality of articles using 16 quality items. Any discrepancies in quality rating by the two authors were discussed until consensus was reached. The methodological quality of studies was classified as poor (encompassing <40% of quality
items), good (encompassing between 40% and 70% of quality items) or very good (encompassing >70% of quality items).32

RESULTS

The search identified 3511 articles. Of these, 54 full-text manuscripts were retrieved and ten studies met criteria for inclusion in the review. A summary of the selection process following the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) four-phase flow diagram34 is provided in Figure 1.
Figure 1: PRISMA^34 four-phase flow diagram describing process for selection of articles

Articles identified through database searching
(n=3499)

Articles remaining after duplications removed and titles screened
(n=576)

Articles excluded
(n=522)

Articles screened
(n=576)

Full-text articles excluded
(n=44)

Additional articles identified through hand-search of included relevant articles reference lists
(n=12)

Full-text articles screened for eligibility
(n=54)

Mixed cancer types: 1
Not focused on survivor perceived unmet needs or needs: 26
Support person and/or family needs: 2
Not patient-reported: 6
Qualitative: 2
No full-text access: 1
Not English: 1

Articles included in qualitative synthesis
(n=10)
*Study characteristics*

A summary of included studies is provided in Table 1. Sample size ranged from 20 to 250 participants (mean = 82). Two studies included survivors diagnosed with a range of haematological cancers\(^\text{12,35}\). Most selected patients from hospitals, cancer treatment centres or medical practices\(^\text{12,36-42}\). Only one recruited survivors from a population-based cancer registry\(^\text{43}\).

Four studies employed a standardized needs assessment measure\(^\text{12,38,40,42}\). Two used the Cancer Survivor Unmet Needs Measure (CaSUN)\(^\text{12,38}\), one the CAncer Rehabilitation and Evaluation System short form (CARES-SF)\(^\text{42}\) and one an adapted version of the Information Needs Questionnaire (INQ)\(^\text{40}\). Most studies\(^\text{35-37,39,41,43}\) utilized researcher-derived questions.
<table>
<thead>
<tr>
<th>Author</th>
<th>Sample size</th>
<th>Cancer type</th>
<th>Study design</th>
<th>Sample age</th>
<th>Recruitme</th>
<th>Needs</th>
<th>Unmet needs</th>
<th>Measure</th>
<th>Method of data collection</th>
<th>Results</th>
</tr>
</thead>
</table>
| Friedman et al[36] | 67          | Diffuse large B-cell non-Hodgkin's lymphoma | Cross-sectional | Mean Age at diagnosis = 59.6 years (SD 12.8) | 1 Hospital cancer centre tumor registry | Information needs to be included in survivorship care plans (SCP) | Researcher-derived questions | Self-report, pen-and-paper survey | -Psychosocial issues were rated as less important than medical issues in SCPs.  
-Males rated sexuality and fertility as more important to SCPs than females.  
-Younger survivors (<60 years at diagnosis) identified a plan for monitoring overall health problems, sexuality, fertility, mental health services and financial issues as more important than older adults (≥60 years at diagnosis) for SCPs.  
-The most important item identified by survivors for SCPs was “A plan to screen | Poor |
| 2010       | 41%         | USA         |              | 43% male   | 1 Hospital cancer centre tumor registry | | | | | |
for possible return of your cancer” followed by “A plan to screen for future health problems due to your cancer treatment.”

| Gansler et al[35] | USA | Leukemia, lymphoma and multiple myeloma | Three metropolitan areas using Cancer Centers, American Cancer Society National Cancer Information Centre, and local newspaper advertisements | Cancer-related information needs at four different time points: 1. at diagnosis, 2. during treatment, 3. after completion of initial treatment and at remission, or during maintenance treatment or relapse. Patients only commented on those time points they had | Derived questions | Card sorting exercise, where cancer patients were given 13 cards listing possible information needs and asked to rank them. | Poor | - At diagnosis information on ‘cancer and cancer type,’ ‘treatment options’ and ‘risk factors for cancer type’ were ranked as the top 3 information needs. | - Patients ranked ‘treatment options,’ ‘coping with side effects’ and ‘long-term side-effects’ as the three highest information needs during treatment. | - ‘Follow-up tests to detect recurrence,’ ‘long-term side effects’ and ‘insurance and financial issues’ were the three most highly ranked information needs for patients after completion of initial treatment. | - During remission or |
experienced maintenance treatment or relapse, patients ranked ‘follow-up tests to detect recurrence,’ ‘treatment options’ and ‘complementary and alternative medicine’ as the top three information needs.

| Hammond et al [43] | 2008 USA | 250 | Aggressive NHL | 2-5 years post-diagnosis | Cross-sectional | Aged ≥ 20 years | Populati\non-based cancer registry | Information needs related to fertility and sexual function | Unclear | Self-report, pen-and-paper survey | -13% of survivors wanted more information about fertility, and 28% wanted more information about sexual functioning. Sur\n

-Survivors with fertility related information needs were more likely to report sexual function information needs.

-Younger age, non-white ethnicity, fewer comorbidities, better physical function, and less than excellent perceived quality of care were associated with need for fertility information on Good
- Male gender and treatment history of bone marrow/stem cell transplant were associated with greater information needs regarding sexual function.

<table>
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<tr>
<th>Study</th>
<th>Participants</th>
<th>Methods</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Hjermstad et al [42]</td>
<td>123 (95%) Patient treated with high dose chemotherapy and allogeneic stem cell transplantation (SCT) for leukemia or autologous stem cell (ASCT) for malignant lymphoma</td>
<td>Prospectively cohort surveyed at 4 time points: before, 2, 6 and 12 months post-transplant 1-year follow-up period</td>
<td>Median age = 35 (range 17-55) (SCT group) = 41 (16-60) (ASCT group) 56% male (SCT group) 74% male (ASCT group)</td>
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</table>
No differences were found on the need for help questions in regards to transplant group, age or gender.

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Study Population</th>
<th>Study Design</th>
<th>Median Age at Diagnosis (SD)</th>
<th>Hospital</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jonker-Pool et al[37]</td>
<td>50</td>
<td>Lymphoma, Those treated since 1977, without signs of recurrence</td>
<td>Cross-sectional</td>
<td>34 years (SD = 11.6)</td>
<td>1 Hospital</td>
<td>Retrospective and current needs for information and support in relation to sexuality</td>
<td>Self-reported pen-and-paper survey</td>
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<td></td>
<td>72.5%</td>
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<td>2004</td>
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<td>Netherlands</td>
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Patients with testicular cancer were generally more dissatisfied about information and support concerning sexuality compared with lymphoma patients. 30% of lymphoma patients reported one or more sexual dysfunctions. During treatment 35.5% received insufficient or absolutely insufficient information and 38% received insufficient or absolutely insufficient support. At follow-up 27% had a need for information and 8% had a need for support.
Patients who wanted information at follow-up were younger (mean 35 vs. 45 years).

Lobb et al. [12] 2009 Australia

- Top needs included feeling “like I am managing my health together with the medical team” (85%), “to know that all my doctors talk to each other to coordinate my care” (82%) and “the very best medical care” (77%).

- Patients reporting that it would be helpful to speak to health care provider after treatment reported more ‘Quality of Life’ and ‘Emotional and Relationships’ needs.

- Younger patient’s reported more ‘Emotional and Relationships’ needs.

- Most common unmet needs were “help managing concerns about cancer...”

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Setting</th>
<th>Design</th>
<th>Age</th>
<th>Sex</th>
<th>Needs</th>
<th>Tools</th>
<th>Highlights</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lobb et al. [12]</td>
<td>66</td>
<td>Mix</td>
<td>Cross-sectional</td>
<td>Mean age = 54 years (SD 14.07)</td>
<td>Sex unknown</td>
<td>Multiple areas of need across five domains</td>
<td>CaSUN Self-reported pen-and-paper survey</td>
<td>Patients reporting that it would be helpful to speak to health care provider after treatment reported more ‘Quality of Life’ and ‘Emotional and Relationships’ needs. Younger patient’s reported more ‘Emotional and Relationships’ needs. Most common unmet needs were “help managing concerns about cancer...”</td>
</tr>
</tbody>
</table>
coming back” (42%); an ongoing case manager to find out about services (33%); and communication between doctors to coordinate care (31%). Median number of unmet needs was 6 (SD=8.05).

-Younger patients had a greater unmet need with concerns about cancer coming back, than older patients.

-Patients who were not married and who were working had greater unmet need for their doctors to talk to one another in coordinating their care.

<table>
<thead>
<tr>
<th>Molassiotis et al[38]</th>
<th>132</th>
<th>Multiple myeloma</th>
<th>Cross-sectional</th>
<th>Mean age = 62 years (SD 8.8)</th>
<th>1 specialist hospital and 3 general hospitals</th>
<th>Multiple areas of need across five domains</th>
<th>CaSUN Self-reported pen-and-paper survey</th>
<th>-26.5% of survivors reported at least 1 unmet need. Most were described as weak or moderate.</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>67.4%</td>
<td>&gt;1 year post-diagnosis and received chemotherapy</td>
<td>61.4% male</td>
<td>1.Existential survivorship</td>
<td>2.Emotional or logistical support</td>
<td>3.Social or practical support</td>
<td>4.Medical needs</td>
<td>5.Physical or mental health needs</td>
<td>1.very good</td>
</tr>
</tbody>
</table>
, 2. comprehensive cancer care, information
4. Quality of life
5. relationships

- There were no differences in level of unmet needs and age (mean as cut-point), time since diagnosis (< 5 year vs. ≥5 year) and whether patients received a blood stem cell transplant.
- Presence of “side effects of treatment” on the EORTC MY20 subscale, was associated with unmet patient needs (25% variance explained).
- Survivors with an anxiety score of ≥8 on the HADS reported significantly more unmet needs.
- Patients with signs of depression on the HADS had significantly more unmet needs.
<table>
<thead>
<tr>
<th>Study</th>
<th>Sample Size</th>
<th>Sample Description</th>
<th>Design</th>
<th>Gender</th>
<th>Mean Age (SD)</th>
<th>Hospital</th>
<th>Measurements</th>
<th>Method</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Persson et al[39] 1997 Sweden</td>
<td>54</td>
<td>Lymphoma and acute leukemia in remission, treated with chemotherapy</td>
<td>Cross-sectional</td>
<td>52% male</td>
<td>Mean age = 62.8 (SD=15.7)</td>
<td>1 hospital</td>
<td>Current need for help with daily living, instrumental help and counseling</td>
<td>Researcher-derived questions</td>
<td>Self-reported pen-and-paper survey</td>
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<tr>
<td>Study</td>
<td>Year</td>
<td>Country</td>
<td>Diagnosis</td>
<td>Study Design</td>
<td>Mean Age (SD)</td>
<td>Patient Source</td>
<td>Information Needs Across 9 Topics</td>
<td>Researcher-Derived Questions</td>
<td>Information Needs</td>
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<tr>
<td>Tariman[40]</td>
<td>2011</td>
<td>USA</td>
<td>Multiple myeloma</td>
<td>Cross-sectional</td>
<td>67.5 (unknown)</td>
<td>Patients referred through 2 cancer centers</td>
<td>INQ (adapted for myeloma patients by the researchers)</td>
<td>Self-report semi-structured interviews.</td>
<td>- Top 3 information needs related to “different types of treatments,” the “likelihood of cure” and “caring for myself at home.” - “Feelings about my body and sexual attractiveness,” was ranked as the lowest information need. - No differences in information needs across age, education, partner status, income or employment status.</td>
</tr>
<tr>
<td>Yogaparan et al[41]</td>
<td>2009</td>
<td>Canada</td>
<td>Acute myeloid leukemia</td>
<td>Cross-sectional</td>
<td>64 (range 52-75)</td>
<td>1 Hospital</td>
<td>Information needs to make initial treatment decision</td>
<td>Self-reported pen-and-paper survey</td>
<td>- Almost all patients felt they were provided with the right amount of information about the “specific medical name of their illness” (97%), the “chances of prolonging life with treatment” (86%), “major treatment options” (90%) and “how treatment works to treat illness” (86%).</td>
</tr>
</tbody>
</table>
-14% indicated being given ‘too little’ information on “chances of treatment prolonging their life” even though almost all wanted to know (77% absolutely need to know, 17% want to know).
-Although 86% felt they were given the right amount of information explaining how treatment works, with 4% reporting ‘too little’ information being given and 10% reporting no information given.
-‘Feeling informed about the side effects of treatment’ was endorsed by the lowest percentage of survivors as having been (76%) provided with the just the right amount of information.
-14% felt they were given ‘too little’ information and 7% not given any
information at all relating to “possible side effects of treatment.” Although 67% reported ‘absolutely needing to know’ and 30% ‘want to know.’
**Study quality**

Most (n=6) studies were rated as having good methodological quality, three as poor and one as very good (Table 1).

**Overall prevalence of supportive care needs**

Only two studies provided information about the overall prevalence of supportive care needs among haematological cancer survivors. Molassiotis et al. found over a quarter (26.5%) of multiple myeloma survivors had at least one unmet need on the CaSUN, however most were described as a weak or moderate unmet need. Lobb et al. identified a median of 6 unmet needs on the CaSUN in a heterogeneous sample of haematological cancer survivors.

**Areas of supportive care needs**

An overview of each study and the area of need/s they assessed are shown in Table 2.

**Informational needs**

A majority of studies assessed the informational needs of haematological cancer survivors (Table 2). Treatment, survival, side-effects and cancer recurrence were commonly identified areas of informational needs. For instance “a plan to
screen for possible return of cancer,” “a plan to screen for possible future health problems due to cancer treatment” and “the anti-cancer treatments you [patients] had” were rated as the top information needs to be included in survivorship care plans by B-Cell NHL survivors. Similarly, the top two information needs reported by older (≥60 years) myeloma survivors related to “different types of treatments,” and “likelihood of cure.” Yogaparan et al found that over two-thirds of older myeloma patients (≥50 years) reported needing to know about their chances of prolonging their life with treatment (77%) and possible treatment side-effects (67%). However, over 10% felt they were given too little or no information on these two issues (14% and 21%, respectively). Leukaemia, lymphoma and multiple myeloma survivors in Gansler et al’s study ranked “follow-up tests to detect recurrence” as their top information need after treatment and during remission or maintenance therapy or at relapse. In the same study “treatment options” was rated among the top three information needs at diagnosis (rank 2), during treatment (rank 1) and during remission or maintenance therapy or at relapse (rank 2).

**Emotional, social and psychological needs**

Only four studies assessed the emotional, social and/or psychological needs of haematological cancer survivors (Table 2). Concerns of cancer recurrence was ranked as the top unmet need (42%) in Lobb et al’s sample of mixed haematological cancer survivors, and ranked third by Molassiotis et al’s sample of Multiple myeloma
survivors (7.9%). However, there was a large difference between the percentages of survivors identifying this item as an unmet need in these two studies. This may be explained by differences in cancer types, time since diagnosis and current treatment status. Four of the five most prevalent baseline needs in Hjermstad et al’s longitudinal study were related to psychosocial concerns, with ‘fear of the cancer progressing’ (19%), ‘anxiety’ (15%), ‘work-related concerns’ (13%) and ‘relationship with colleagues’ (12%) identified. Friedman et al’s investigation of B-Cell lymphoma survivor’s informational needs found medical issues were rated as more important to survivors for inclusion in survivorship care plans than psychosocial issues.

Sexuality and fertility needs

Five studies covered sexuality and/or fertility related needs. In one study most lymphoma survivors reported no need for information (73%) or support (92%) concerning sexuality at the time of study participation, and 50% rated the information and support on sexuality they received during treatment as sufficient. Similarly, only 13% of NHL survivors in Hammond et al’s study wanted information related to fertility, and 28% had a need for information about sexual functioning.

Cancer care
In Lobb et al’s\textsuperscript{12} study of mixed haematological cancer survivors the authors concluded that care co-ordination was the most frequently reported area of need\textsuperscript{12}, with several CaSUN items relating to care coordination identified as both top needs and unmet needs in this study. Specifically, needing “to know all my doctors talk to each other to coordinate my care” was reported as the second (82\%) most prevalent need and third (31\%) most prevalent unmet need\textsuperscript{12}. “Needing to feel like I am managing my health together with the medical team” was identified as the top need (85\%), while “having an ongoing case manager...to find out about services...” (33\%) was the second highest unmet need\textsuperscript{12}. Similarly, needing an ongoing case manager and knowing that their doctors talk to one another, were rated as the fourth (7.4\%) and equal sixth (6.4\%) most prevalent unmet needs in Molassiotis et al’s\textsuperscript{38} study of multiple myeloma survivors\textsuperscript{38}. In Molassiotis et al’s study\textsuperscript{38} the most highly endorsed unmet need was “accessibility to hospital car parking” (10.6\%).

\textit{Practical needs}

Practical needs were measured in four studies\textsuperscript{12,38,39,42}. Obtaining life and/or travel insurance (10.4\%) was rated as the second highest unmet need by multiple myeloma survivors on the CaSUN\textsuperscript{38}. The daily living needs of lymphoma and leukaemia survivors were assessed by Persson and colleagues\textsuperscript{39}. In this study, factor analysis on the author-derived questionnaire revealed a two-factor structure comprising “instrumental activity in daily living” (i.e. dressing, shopping, preparing food) and “intimate help and
counselling” (i.e. someone to talk to, finances, personal hygiene). “Instrumental activity in daily living” was rated more highly by leukaemia and lymphoma survivors as a current need (16.7%), compared to “intimate help and counselling (13%)"\(^{39}\)
Table 2: The broad areas of supportive care needs assessed and identified by the ten studies investigating the needs of haematological cancer survivors

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<tbody>
<tr>
<td>Informational(^a)</td>
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<td>Psychological(^a)</td>
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<td>Emotional(^a)</td>
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<tr>
<td>Social(^a)</td>
<td>✓</td>
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<tr>
<td>Practical(^a)</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td>Cancer care</td>
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<td>✓</td>
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<td></td>
<td>✓</td>
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<td>Spiritual(^a)</td>
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<tr>
<td>Physical(^a)</td>
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<td>Sexuality and /or fertility</td>
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<td>✓</td>
<td>✓</td>
<td>✓</td>
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<td></td>
<td>✓</td>
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</table>

\(^a\)Categories of supportive care needs outlined by the Supportive Care Framework\(^23\)

\(^b\)The Cancer Survivor Unmet needs Measure (CaSUN) includes five domains (‘Existential Survivorship’, ‘Comprehensive Care’, ‘Information’, ‘Quality of Life’ and ‘Relationships’\(^49\), and the CAncer Rehabilitation and Evaluation System short form (CARES-SF) includes five domains (‘Physical,’ ‘Psychosocial,’ ‘Sexual,’ ‘Marital’ and ‘Medical Interaction’\(^50\). The items cover a range of needs that fit within other areas of supportive care.
Survivor subgroups reporting higher needs

Table 3 outlines a number of sub-groups of survivors identified as reporting higher levels of supportive care needs. However, only younger age\textsuperscript{12, 36, 37, 43} and male sex\textsuperscript{36, 43} were identified by more than one study. The level of reported unmet needs for myeloma survivors did not differ by age in Molassiotis et al’s\textsuperscript{38} study. However, younger survivors were identified by other studies as reporting higher levels of need across several (n=4) specific domains. Specifically, younger adults from Lobb et al’s\textsuperscript{12} study reported a higher level of unmet need with concerns of cancer recurrence and more Emotional and Relationship needs on the CaSUN\textsuperscript{12}. Younger (<60 years at diagnosis) B-cell NHL survivors in Friedman et al’s\textsuperscript{36} study rated information on mental health services, “a plan for monitoring overall health problems” and financial issues as more important to survivorship care plans than older survivors (≥60 years at diagnosis)\textsuperscript{36}.

Younger survivors were also identified by three studies as reporting higher levels of sexuality and/or fertility related needs\textsuperscript{36, 37, 43}. For instance, lymphoma survivors in Jonker-Pool et al’s\textsuperscript{37} study who were younger were more likely to indicate a need for information on sexuality at the current time of study participation (mean 35 years vs. 45 years)\textsuperscript{37}. Younger age was associated with NHL survivors need for fertility information\textsuperscript{43}. Similarly, younger B-Cell lymphoma survivors (<60 years at diagnosis) rated their need for sexuality and fertility information as more important in
survivorship care plans, than older (>60 years at diagnosis) survivors\textsuperscript{36}. Males were also identified by two studies as reporting higher sexual function, sexuality and/or fertility information needs in B-Cell lymphoma\textsuperscript{36} and NHL survivors\textsuperscript{43} (Table 3).
Table 3: Subgroups of survivors found to report higher levels of needs and/or sociodemographic, disease, physical, treatment and care characteristics associated with higher levels of haematological cancer survivor supportive care needs

<table>
<thead>
<tr>
<th>Sociodemographic characteristics</th>
<th>Areas of need</th>
<th>Information</th>
<th>Psychological</th>
<th>Emotional</th>
<th>Relationship</th>
<th>Practical care</th>
<th>Cancer care</th>
<th>Spiritual</th>
<th>Physical</th>
<th>Sexuality and/or fertility</th>
</tr>
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<tbody>
<tr>
<td>Younger age</td>
<td></td>
<td>✓ 12, 36</td>
<td>✓ 12</td>
<td>✓ 12</td>
<td>✓ 36</td>
<td>✓ 36</td>
<td>✓ 36, 37, 43</td>
<td>✓ 36, 37, 43</td>
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<tr>
<td>Male</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>✓ 36, 43</td>
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<tr>
<td>Single/not married</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>✓ 12</td>
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<td>Working</td>
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<td></td>
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<td></td>
<td></td>
<td>✓ 12</td>
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<tr>
<td>Non-Anglo Saxon ethnicity</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
<td>✓ 43</td>
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<tr>
<td>Disease and physical characteristics</td>
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<tr>
<td>Sensitivity to infections</td>
<td></td>
<td></td>
<td>✓ 39</td>
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<tr>
<td>Fewer comorbidities</td>
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<td></td>
<td></td>
<td>✓ 43</td>
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<td>Sexual dysfunction</td>
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<td></td>
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<td></td>
<td></td>
<td>✓ 37</td>
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<tr>
<td>Better physical functioning</td>
<td></td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td>✓ 43</td>
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<td>Treatment and care characteristics</td>
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<td>Treatment side effects</td>
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<tr>
<td>Bone marrow/stem cell transplant</td>
<td>✓ 42</td>
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<tr>
<td>Less than excellent perceived care</td>
<td>✓ 42</td>
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<td></td>
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<tr>
<td>Helpful to speak to health care provider after treatment</td>
<td>✓ 12</td>
<td>✓ 12</td>
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<table>
<thead>
<tr>
<th>Psychological characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety ✓ 38</td>
</tr>
<tr>
<td>Depression ✓ 38</td>
</tr>
<tr>
<td>Existential problems (i.e. thoughts about death, anxiety, worry about recurrence) ✓ 39</td>
</tr>
<tr>
<td>Reduced psychological and sexual energy ✓ 39 ✓ 39</td>
</tr>
<tr>
<td>Low sense of coherence score ✓ 39</td>
</tr>
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</table>

✓ = study findings indicate association or sub-group of survivors reporting higher needs
DISCUSSION

Results from this review suggest that haematological cancers survivors may experience a range of supportive care needs across multiple domains of life. However, variation in study methodologies, samples and needs assessment measures used made it difficult to synthesize study results. However, the included studies do seem to identify some relatively similar areas of perceived need for haematological cancer survivors. The data suggests that concerns about disease progression, recurrence and survival may be prevalent concerns for haematological cancer survivors, with both studies employing the CaSUN needs assessment tool identifying cancer recurrence as a top unmet need\(^{1238}\). Fear of the cancer progressing was identified as the most prevalent need on the CARES-SF in Hjermstad’s study\(^ {42}\). Four studies assessing information needs also reported a high level of need in relation to survival and disease recurrence\(^ {35 \ 36 \ 40 \ 41}\). This finding aligns with the general oncology literature, with fears about the cancer spreading previously identified as a commonly reported unmet need by cancer patients using the Supportive Care Needs Survey\(^ {44}\). Similar to all cancer survivors, haematological cancer survivors may need additional information and support for addressing concerns about disease recurrence and survival. However, as a number of haematological cancers remain incurable\(^ {3 \ 11}\) and some require prolonged and often debilitating treatments (i.e. bone marrow transplant)\(^ {3 \ 12 \ 13}\), haematological cancer survivors may need tailored or disease specific support to address these concerns. The current data also alludes to younger haematological cancer survivors as a subgroup at potential risk of experiencing a higher level of need, perhaps across several areas. This
finding is again congruent with the general oncology literature, with several studies reporting higher levels of some needs in younger cancer survivors compared to their older counterparts24 28 45-47.

Limitations of included studies

The small number of studies in this area limits our understanding of the supportive care needs of haematological cancer survivors. Several other limitations made it difficult to compare studies and draw definitive conclusions. The main limitations of previous research in this area can be summarized into two broad areas: 1) sampling bias; and 2) measurements used.

Sampling bias

nine of the ten studies concentrated on very specific sub-groups of haematological cancer survivors12 36-43, focusing on one or two specific types of cancer, or on survivors who had received particular types of treatments and/or were at explicit points on the cancer trajectory (i.e. during treatment, remission or post-treatment). Although these studies provide vital information about the needs of these specific sub-populations, the lack of research including heterogeneous samples of haematological cancer survivors restricts our understanding of the experiences of the wider population.
Certain patient characteristics were over-represented in three studies\textsuperscript{36 38 43}, impacting on the representativeness of the study sample. For instance, Molassiotis et al.’s\textsuperscript{38} study sample of multiple myeloma patients were younger than those not selected and survived above the median survival time for this patient group\textsuperscript{38}. Respondents in Friedman et al.’s\textsuperscript{36} study were significantly older at diagnosis than non-responders. Consequently, the needs reported in these two studies may misrepresent those of the wider population, particularly as younger age at diagnosis has been found to be associated with some areas of supportive care needs\textsuperscript{12 36 37 43}. Ethnicity was also found to be misrepresented in Hammond et al.’s\textsuperscript{43} study of NHL survivors, again placing questions over the external validity of these results.

Only one study utilized a population-based sample\textsuperscript{43}. Seven studies recruited survivors from one or two cancer centres or a specialist treatment centre\textsuperscript{12 36 37 39-42}. Restricting recruitment of survivors from a small number of treatment centres only allows for the inclusion of survivors from very narrow geographical locations. The predominant focus on the needs of haematological cancer survivors from cancer treatment centres has also resulted in limited research conducted on the needs of those survivors who have yet to receive treatment. This is of concern as a number of haematological cancer patients will initially undergo a regime of “watchful-waiting,” and will not require active treatment for some time after initial diagnosis\textsuperscript{3 48}. Consequently, the needs of this specific sub-group of haematological cancer survivors remains largely unknown. It is plausible that the supportive care needs of this sub-group of haematological cancer
survivors would differ to those survivors currently undergoing treatment. Future qualitative studies may be beneficial in helping us to understand the specific concerns of haematological cancer survivors undergoing “watchful-waiting.”

The sample sizes of the ten studies ranged from 20 to 250 participants, with the majority utilizing less than 100 participants. Small sample sizes reduce the likelihood of study samples being representative of the population in question. In addition, a small sample size can substantially reduce the power of a study, limiting the ability to detect significant differences between sub-groups of patients. It must be noted that small sample sizes are not an uncommon weakness of psychosocial research in the field of haematological cancer.

**Measurement tools utilized**

Only four of the ten studies employed a standardized needs assessment measure. In two studies the CaSUN was used and in one study the CARES-SF was used to assess haematological cancer survivor supportive care need across multiple domains. Neither the CaSUN nor the CARES-SF were specifically developed for a haematological cancer population and thus these measures may not adequately capture the specific concerns of this population. The remaining study that included a standardized needs assessment measure used an adapted version of the INQ. While the authors attempted to ensure this measure was specific to myeloma survivors, it
was unclear how this adaptation was performed. The small sample size (n=20) also makes it difficult to undertake an adequate psychometric evaluation of the tool.

Seven\textsuperscript{35-37,39-41,43} of the ten studies assessed very specific supportive care needs. The lack of studies assessing a broad range of supportive care needs limits our knowledge of the type, range and perceived importance of needs experienced by this population. As a result, it is difficult to use the current literature to inform resource allocation and provision of services that directly address the most prevalent and important concerns of this population.

**Strengths and limitations of the current review**

It is possible that some relevant studies were not identified. However, this review was conducted using systematic methods and a broad range of search terms. Patient need was often poorly defined. ‘Need’ was often used to describe patient symptoms, problems or preference and access to care, rather than measuring a patient’s desire for help; an issue which has previously been identified in the area of needs assessment\textsuperscript{51}. As previously stated, significant variation between the included studies made it difficult to summarize the most prevalent needs of haematological cancer survivors and restricted our ability to undertake a meta-analysis. Therefore, the results from this review must be considered preliminary data only. Despite these limitations, the main medical and psychosocial databases were searched. The time period chosen for the
search closely coincided with what has previously been argued to be the year that one of the first studies to assess the needs of cancer patients was conducted\textsuperscript{44}.

**Conclusion**

Past research has provided insight into the range of supportive care needs experienced by haematological cancer survivors. Notably, the need for support in dealing with concerns about cancer recurrence and survival appears to be a predominant concern experienced by these survivors. The current results also suggest that younger survivors may be at higher risk of reporting some supportive care needs. However, the lack of research in this area, combined with the limitations of past studies, restricts our ability to identify the most prevalent and important needs encountered by this population.

To provide patient-centred care to this unique and growing population, it is vital that future research is undertaken to identify the most prevalent supportive care needs of haematological cancer survivors. In order to identify and understand the range, type and levels of needs of this population, it is imperative that we undertake the following three steps:

1. Establish the reliability and validity of a standard measure that assesses a wide range of areas of supportive care needs, for population-based samples of haematological cancer survivors. While a number of needs assessment tools exist (e.g. CaSUN\textsuperscript{49} and Survivor Unmet Needs Survey (SUNS)\textsuperscript{25}) that assess a broad range of
supportive care needs in general cancer survivor populations\textsuperscript{51}, the relevance and psychometric properties of these measures should be assessed for use in haematological cancer populations. Qualitative methods, involving haematological cancer survivors, should be employed in this process to ensure that the specific concerns of haematological cancer survivors are adequately captured\textsuperscript{51}. If the specific concerns of haematological cancer survivors are omitted, the development of a supplementary module for use with the pre-existing measure should be considered\textsuperscript{51}. Establishing such a measure will assist in standardizing future research methods, assist in refining the definition of needs and hopefully allow for future meta-analyses to be conducted.

(2) Recruit large, heterogeneous, population-based samples. Doing so will help to reduce sampling bias associated with much of the past research, while providing an opportunity to include those sub-samples of haematological cancer survivors that have previously been under-represented in previous research.

(3) Identify survivor demographic and disease-based characteristics that are significantly associated with high levels of needs.
Undertaking these steps will importantly contribute to the collection of vital information that can be used to inform service provision and resource allocation. It will also help in addressing the specific concerns of haematological cancer survivors.
REFERENCES


34. Liberati A, Altman DG, Tetzlaff J, Mulrow C, CGotzsche PC, Ioannidis JPA, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of
studies that evaluate health care interventions: Explanation and elaboration

British Medical Journal 2009;339(b2700).


44. Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer* 2009;17:1117-28.


