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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 marrow¹⁻³. There are over 60 sub-types^{4 5}, that are often classified into three main disease groups: myeloma, leukaemia and lymphoma^{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 world⁶. Improvements in survival rates for a number of haematological cancers have been noted in several different countries, including Europe⁷, Australia⁸ and the United States⁹. 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”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 rates³.

Haematological cancers are a unique group of cancers. There is considerable variability among the types and sub-types of haematological cancers and their treatment^{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)^{3 12 13}. Other forms are chronic in nature with frequent relapsing requiring active treatment and management for a number of years^{3 11}.

Similar to other cancers, haematological cancers affect many aspects of a person's life. Physical effects may include fatigue^{14 15}, reduced role function, insomnia, pain and dyspnoea¹⁵. Longer-term effects may include fatigue^{16 17} and poorer self-reported physical health¹⁸. Several reviews have also established associations between some haematological cancers and employment related outcomes^{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^{21 22}. Supportive care needs include the physical, informational, emotional, psychological, social, spiritual and practical concerns²³, which patients require support in addressing^{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^{25 26}. Such information can guide resource allocation, care planning and patient referrals^{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 difficulty²⁸.

Several reviews have investigated the experiences of haematological cancer patients or survivors²⁹⁻³¹; however these have largely included studies focusing on quality of life²⁹⁻³¹, 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^{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 life¹⁰. 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 al³², we adapted Fowkes and Fulton's³³ 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.

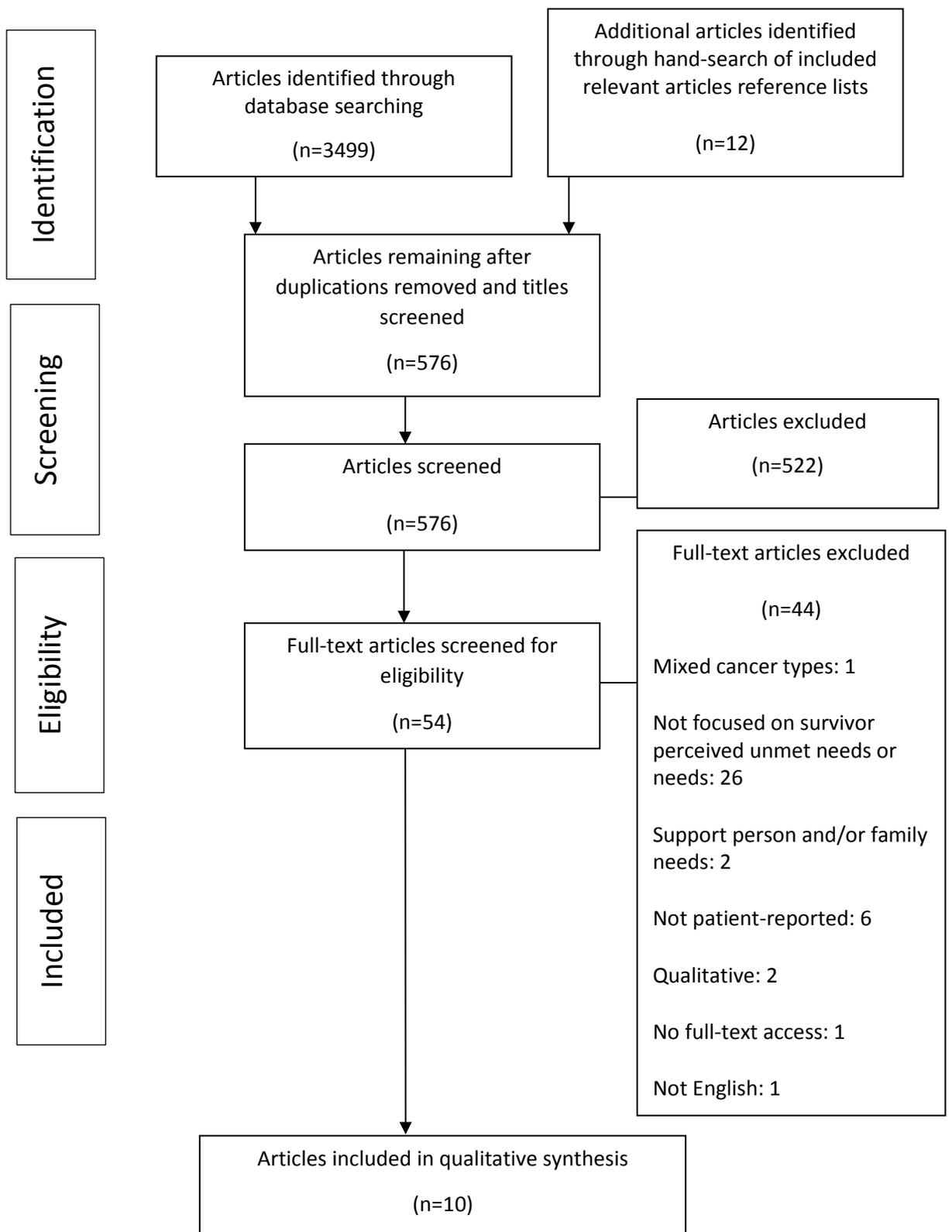


Figure 1: PRISMA³⁴ four-phase flow diagram describing process for selection of articles

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^{12 35}. Most selected patients from hospitals, cancer treatment centres or medical practices^{12 36-42}. Only one recruited survivors from a population-based cancer registry⁴³.

Four studies employed a standardized needs assessment measure^{12 38 40 42}. Two used the Cancer Survivor Unmet Needs Measure (CaSUN)^{12 38}, one the CAncer Rehabilitation and Evaluation System short form (CARES-SF)⁴² and one an adapted version of the Information Needs Questionnaire (INQ)⁴⁰. Most studies^{35-37 39 41 43} utilized researcher-derived questions.

Table 1: Methodological and sample characteristics of the nine studies assessing unmet needs of hematological survivors

Author	Sample size	Cancer type	Study design	Sample age	Recruitment setting	Needs assessed	Unmet needs Measure	Results	Study quality
Publication year	Response rate	Cancer continuum		Sex			Method of data collection		
Country									
Friedman et al[36]	67 41%	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				43% male					
USA		No evidence of cancer at last visit, survivors seen at medical centre within last 1.5 years, treated with curative intent							

								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]	29 survivors	Leukemia, lymphoma and multiple myeloma	Cross-sectional	Unknown for cancer survivors only	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 4.remision or during maintenance therapy or at relapse.	Derived questions Card sorting exercise, where cancer patients were given 13 cards listing possible information needs and asked to rank them.	-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	Poor
2010	Unkn	Mixed – included patient’s views at diagnosis, during treatment, after completion of initial treatment and at remission, or during maintenance treatment or relapse. Patients only commented on those time points they had		Unknown for cancer survivors only					
USA									

experienced

maintenance treatment or relapse, patient's ranked 'follow-up tests to detect recurrence,' 'treatment options' and 'complementary and alternative medicine' as the top three information needs.

Hammond et al[43]	250	Aggressive NHL	Cross-sectional	Aged ≥ 20 years	Population-based cancer registry	Information needs related to fertility and sexual function	Unclear	-13% of survivors wanted more information about fertility, and 28% wanted more information about sexual functioning.	Good
2008	43%	2-5 years post-diagnosis		Sex unknown			Self-report, pen-and-paper survey	-Survivors with fertility related information needs were more likely to report sexual function information needs.	
USA								-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	

								<p>univariate analysis.</p> <p>-Male gender and treatment history of bone marrow/stem cell transplant were associated with greater information needs regarding sexual function.</p>	
Hjermstad et al[42]	123 (95%)	Patient treated with high dose chemotherapy and allogeneic stem cell transplantation (SCT) for leukemia or autologous stem cell (ASCT) for malignant lymphoma	Prospective cohort surveyed at 4 time points: before, 2, 6 and 12 months post-transplant	Median age =35 (range 17-55) (SCT group) =41 (16-60) (ASCT group)	2 Hospitals	Multiple areas of need across five domains	The Cancer Rehabilitation and Evaluation System short form (CARES-SF)	<p>-Items that hematology patients most wanted help with at the first assessment were 'fear for the cancer progressing' (19%), 'anxiety' (15%), 'work-related concerns' (13%), 'bodily changes' (12%) and 'relationship with colleagues' (12%).</p> <p>-At 6 and 12 month follow-up 9% wanted help with reductions in physical energy.</p> <p>-There was a high rate of missing answers for the need for help section of the CARES-SF (range 26% to 100% of questions applicable</p>	Good

								to all patients) -No differences were found on the need for help questions in regards to transplant group, age or gender.	
Jonker-Pool et al[37] 2004 Netherlands	50 72.5 %	Lymphoma Those treated since 1977, without signs of recurrence	Cross-sectional	Median age at diagnosis = 34 years (SD = 11.6) 100% male	1 Hospital	Retrospective and current needs for information and support in relation to sexuality	Researcher-derived questions Self-reported pen-and-paper survey	-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.	Good

								-Patients who wanted information at follow-up were younger (mean 35 vs. 45 years).	
Lobb et al[12] 2009 Australia	66 50%	Mix 6 weeks to 12 months post treatment with chemotherapy or radiotherapy with the intention of cure or substantial remission.	cross-sectional	Mean age = 54 years (SD 14.07) Sex unknown	2 Hospitals	Multiple areas of need across five domains 1.Existential survivorship , 2.comprehensive cancer care, 3.information 4. Quality of life 5.relationships	CaSUN Self-reported pen-and-paper survey	-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	Good

								<p>coming back" (42%); an ongoing case manager to find out about services (33%); and communication between doctors to coordinate care (31%).</p> <p>Median number of unmet needs was 6 (SD=8.05).</p> <p>-Younger patients had a greater unmet need with concerns about cancer coming back, than older patients.</p> <p>-Patients who were not married and who were working had greater unmet need for their doctors to talk to one another in co-ordinating their care.</p>	
Molassioti et al[38]	132	Multiple myeloma	Cross-sectional	Mean age = 62 years (SD 8.8)	1 specialist hospital and 3 general hospitals	Multiple areas of need across five domains	CaSUN	-26.5% of survivors reported at least 1 unmet need. Most were described as weak or moderate.	Very good
2011	67.4 %	>1 year post-diagnosis and received chemotherapy		61.4% male		1.Existential survivorship	Self-reported pen-and-paper survey	-Most common unmet needs for patients were accessibility of hospital car	

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hensive
cancer care,
3.informatio
n
4. Quality of
life
5.relationships

parking (10.6%), obtaining
life and/or travel insurance
(10.4%) and managing
concerns about cancer
recurrence (7.9%).
-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.

Persson et al[39]	54 84%	Lymphoma and acute leukemia	Cross-sectional	Mean age = 62.8 (SD=15.7) 52% male	1 hospital	Current need for help with daily living, instrumental help and counseling	Researcher-derived questions Self-reported pen-and-paper survey	-Factor analysis of patients' current need for help in daily living resulted in a two-factor structure comprising "instrumental activity in daily living" (i.e. dressing, shopping, preparing food) and "intimate help and counseling" (i.e. someone to talk to, finances, personal hygiene). -"Help with instrumental activity in daily living" was rated most needed at the current time (16.7%). -'Patients current existential problems and sensitivity to infections,' reduced psychological and sexual energy' and low scores on the Sense of Cohesion Scale were correlated to current need for "intimate health and counseling." -'Reduced psychological and sexual energy' were related	Good
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								to need for “instrumental help.”	
Tariman[40]	20	Multiple myeloma	Cross-sectional	Mean age = 67.5 (SD unknown)	Patients referred through 2 cancer centers	Information needs across 9 topics	INQ (adapted for myeloma patients by the researchers)	-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.	Good
2011	17.7%	Newly diagnosed, older adults (≥60 years)		40% male			Self-report semi-structured interviews.		
USA	100% from site two								
Yogaparan et al[41]	31	Acute myeloid leukemia	Cross-sectional	Mean age = 64 (range 52-75)	1 Hospital	Information needs to make initial treatment decision	Researcher - derived questions	- 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%).	Poor
2009	Not reported	Newly diagnosed, older adults (≥50 years)		58% male			Self-reported pen-and-paper survey		
Canada									

-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^{12 38}. Molassiotis et al³⁸ found over a quarter (26.5%) of multiple myeloma survivors had at least one unmet need on the CaSUN³⁸, however most were described as a weak or moderate unmet need³⁸. Lobb et al¹² identified a median of 6 unmet needs on the CaSUN in a heterogeneous sample of haematological cancer survivors¹².

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^{35 36 40 41}. 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 survivors³⁶. Similarly, the top two information needs reported by older (≥60 years) myeloma survivors related to “different types of treatments,” and “likelihood of cure”⁴⁰. Yogaparan et al⁴¹ found that over two-thirds of older myeloma patients (≥50 years)⁴¹ 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)⁴¹. Leukaemia, lymphoma and multiple myeloma survivors in Gansler et al’s³⁵ 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)³⁵.

Emotional, social and psychological needs

Only four studies assessed the emotional, social and/or psychological needs of haematological cancer survivors (Table 2)^{12 38 39 42}. Concerns of cancer recurrence was ranked as the top unmet need (42%) in Lobb et al’s¹² sample of mixed haematological cancer survivors, and ranked third by Molassiotis et al’s³⁸ 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 Hjerstad et al's⁴² 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's³⁶ 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 issues³⁶.

Sexuality and fertility needs

Five studies covered sexuality and/or fertility related needs^{12 37 38 42 43}. In one study³⁷ 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 sufficient³⁷. Similarly, only 13% of NHL survivors in Hammond et al's⁴³ study wanted information related to fertility, and 28% had a need for information about sexual functioning⁴³.

Cancer care

In Lobb et al's¹² study of mixed haematological cancer survivors the authors concluded that care co-ordination was the most frequently reported area of need¹², 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 need¹². "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 need¹². 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's³⁸ study of multiple myeloma survivors³⁸. In Molassiotis et al's study³⁸ the most highly endorsed unmet need was "accessibility to hospital car parking" (10.6%).

Practical needs

Practical needs were measured in four studies^{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 CaSUN³⁸. The daily living needs of lymphoma and leukaemia survivors were assessed by Persson and colleagues³⁹. 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 27counselling (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

Areas of need assessed and identified	Studies assessing haematological cancer survivor supportive care needs									
	Friedman et al, 2010 ³⁶	Gansler et al, 2010 ³⁵	Hammond et al, 2008 ⁴³	Hjermstad et al, 2003 ^{42b}	Jonker-Pool et al, 2004 ³⁷	Lobb et al, 2009 ^{12b}	Molassiotis et al, 2010 ^{38b}	Persson et al, 1997 ³⁹	Tariman 2011 ⁴⁰	Yogapara n et al, 2009 ⁴¹
Informational ^a	✓	✓				✓	✓		✓	✓
Psychological ^a				✓		✓	✓			
Emotional ^a				✓		✓	✓	✓		
Social ^a				✓		✓	✓			
Practical ^a				✓		✓	✓	✓		
Cancer care				✓		✓	✓			
Spiritual ^a						✓	✓			
Physical ^a				✓		✓	✓			
Sexuality and /or fertility			✓	✓	✓	✓	✓			

^aCategories of supportive care needs outlined by the Supportive Care Framework²³

^bThe 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^{12 36 37 43} and male sex^{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's³⁸ 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's¹² study reported a higher level of unmet need with concerns of cancer recurrence and more Emotional and Relationship needs on the CaSUN¹². Younger (<60 years at diagnosis) B-cell NHL survivors in Friedman et al's³⁶ 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)³⁶.

Younger survivors were also identified by three studies as reporting higher levels of sexuality and/or fertility related needs^{36 37 43}. For instance, lymphoma survivors in Jonker-Pool et al's³⁷ 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)³⁷. Younger age was associated with NHL survivors need for fertility information⁴³. 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) survivors³⁶. Males were also identified by two studies as reporting higher sexual function, sexuality and/or fertility information needs in B-Cell lymphoma³⁶ and NHL survivors⁴³ (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

Sociodemographic characteristics	Areas of need									
	Overall level of need	Information	Psychological	Emotional	Relationship	Practical	Cancer care	Spiritual	Physical	Sexuality and/or fertility
Younger age			✓ ^{12, 36}	✓ ¹²	✓ ¹²	✓ ³⁶	✓ ³⁶			✓ ^{36, 37, 43}
Male										✓ ^{36, 43}
Single/not married							✓ ¹²			
Working							✓ ¹²			
Non-Anglo Saxon ethnicity										✓ ⁴³
Disease and physical characteristics										
Sensitivity to infections				✓ ³⁹						
Fewer comorbidities										✓ ⁴³
Sexual dysfunction										✓ ³⁷
Better physical functioning										✓ ⁴³
Treatment and care characteristics										
Treatment side effects	✓ ³⁸									

Bone marrow/stem cell transplant			✓ ⁴²
Less than excellent perceived care			✓ ⁴²
Helpful to speak to health care provider after treatment	✓ ¹²	✓ ¹²	
Psychological characteristics			
Anxiety	✓ ³⁸		
Depression	✓ ³⁸		
Existential problems (i.e. thoughts about death, anxiety, worry about recurrence)	✓ ³⁹		
Reduced psychological and sexual energy	✓ ³⁹	✓ ³⁹	
Low sense of coherence score	✓ ³⁹		

✓ = 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 need¹²³⁸. Fear of the cancer progressing was identified as the most prevalent need on the CARES-SF in Hjerstad's study⁴². 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 Survey⁴⁴. 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 counterparts^{24 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 survivors^{12 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^{36 38 43} impacting on the representativeness of the study sample. For instance, Molassiotis et al's³⁸ study sample of multiple myeloma patients were younger than those not selected and survived above the median survival time for this patient group³⁸. Respondents in Friedman et al's³⁶ 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^{12 36 37 43}. Ethnicity was also found to be misrepresented in Hammond et al's⁴³ study of NHL survivors, again placing questions over the external validity of these results.

Only one study utilized a population-based sample⁴³. Seven studies recruited survivors from one or two cancer centres or a specialist treatment centre^{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^{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^{12 35-37 39-41}. Small sample sizes reduce the likelihood of study samples being representative of the population in question³³. 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.³⁰

Measurement tools utilized

Only four^{12 38 40 42} of the ten studies employed a standardized needs assessment measure. In two^{12 38} studies the CaSUN⁴² was used and in one study the CARES-SF was used to assess haematological cancer survivor supportive care need across multiple domains^{49 50}. Neither the CaSUN⁴⁹ nor the CARES-SF⁵⁰ 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 INQ⁴⁰. 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^{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 assessment⁵¹. 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 conducted⁴⁴.

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. CaSUN⁴⁹ and Survivor Unmet Needs Survey (SUNS)²⁵) that assess a broad range of

supportive care needs in general cancer survivor populations⁵¹, 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 captured⁵¹. 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 considered⁵¹. 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.

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