



Unmet supportive care needs of haematological cancer survivors: rural versus urban residents

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Abstract

Due to fewer cancer services in rural locations, rural survivors may have unique unmet needs compared to urban survivors. This study compared among rural and urban haematological cancer survivors the most common “high/very high” unmet supportive care needs and the unmet need scores for five domains (*information, financial concerns, access and continuity of care, relationships and emotional health*). Survivors’ socio-demographics, rurality, cancer history and psychological factors associated with each unmet need domain were also explored. A total of 1511 haematological cancer survivors were recruited from five Australian state cancer registries and 1417 (1145 urban, 272 rural) allowed extraction of their residential postcode from registry records. A questionnaire that contained the Survivor Unmet Needs Survey was mailed to survivors. *Dealing with feeling tired* was the most common “high/very high” unmet need for rural (15.2%) and urban (15.5%) survivors. The emotional health domain had the highest mean unmet need score for rural and urban survivors. Rurality was associated with a decreased unmet emotional health domain score whereas travelling for more than 1 h to treatment was associated with increased unmet financial concerns and unmet access and continuity of care. Depression, anxiety and stress were associated with increased unmet need scores for all five domains. Unmet need domain scores generally did not differ by rurality. Travelling for more than 1 h to treatment was associated with increased unmet need scores on two domains. Telemedicine and increased financial assistance with travel and accommodation may help those travelling long distances for treatment.

Keywords Haematological cancer · Rural · Supportive care · Unmet needs · Urban

Introduction

Haematological cancers include leukaemias, lymphomas and myeloma and collectively account for 6.5% of all cancers

worldwide [1]. The sub-types of haematological cancers are diverse, comprising of incurable types, highly aggressive forms or slowly progressing cancers [2]. Treatments may be intensive and include chemotherapy, radiotherapy and bone marrow transplantation [2]. The National Cancer Institute (NCI) and National Coalition for Cancer Survivorship (NCCS) define a cancer survivor as someone diagnosed with cancer, from the time of diagnosis until the end of that person’s life [3, 4]. While the cancer types and treatments vary, similar experiences that haematological cancer survivors face include an increased risk of infection, prolonged fatigue, extended recovery trajectories [5] and long-term follow-up [2]. Long-term effects of haematological cancer and/or treatment may include cognitive deterioration and adverse effects on employment, psychological wellbeing and social functioning [6]. Given the burden haematological cancer survivors experience, understanding in which areas survivors need further assistance is important for informing where services direct additional support and resources for this population.

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Supportive care needs assessment identifies the physical, informational, emotional, psychological, social, spiritual and practical needs that cancer survivors require help with [7]. Systematic reviews found that little research has examined haematological cancer survivors' unmet supportive care needs [8, 9] and that shortcomings of these studies included inadequate sample sizes and using only one or two treatment centres to recruit survivors which may limit the generalisability of findings [9]. Australian and UK studies with a heterogeneous group of haematological cancer survivors [10] or multiple myeloma survivors [11] reported that accessible hospital parking [11], acquiring life and/or travel insurance [11], handling the fear of recurrence [10, 11] and having access to an ongoing case manager [10, 11] were common unmet needs. In two other studies, haematological cancer survivors reported that dealing with feeling tired was the most common unmet need [12, 13].

Haematological cancer survivors who reside in rural areas may have unique or additional unmet needs compared to their urban counterparts, because there are fewer cancer services in rural areas [14]. Challenges faced by rural cancer survivors include travelling considerable distances to access cancer treatment, the financial cost of travel and/or staying away from home, separation from family, difficulty accessing specialists, lack of coordination between specialists and rural health professionals and difficulty accessing follow-up and support services [14, 15]. Although some studies discovered that compared to urban cancer survivors rural cancer survivors were more likely to report unmet needs for some domains such as physical/daily living [16, 17], other research has found no disparities in the unmet needs of rural compared to urban survivors [18]. However, this prior research surveyed those diagnosed with breast cancer [16], gynaecological cancer [17] or any type of cancer [18]. None of these studies focussed on a haematological cancer survivor population.

The Survivor Unmet Needs Survey (SUNS) has been found to be a psychometrically robust measure among those with various cancer types [19] and haematological cancer survivors [20]. The SUNS measures unmet needs across the following five domains: information needs, financial concerns, access and continuity of care, relationships and emotional health [19]. Given that the SUNS provides a detailed list of needs and has demonstrated acceptable psychometric properties, the SUNS is an appropriate tool for comparing the unmet needs between rural survivors and urban survivors.

There is a lack of evidence that examines the unmet needs of haematological cancer survivors residing in rural compared to urban areas. Such information could be used to inform the delivery of cancer services to these groups. Therefore, this study aimed to examine the following:

- 1) The most common “high/very high” unmet supportive care needs among rural versus urban haematological cancer survivors;

- 2) mean and median scores of rural versus urban haematological cancer survivors for each of the five SUNS' domains and
- 3) socio-demographic, rurality, cancer history and psychological characteristics associated with unmet need scores for each of the SUNS' domains.

Methods

Sample Survivors were eligible to participate if they met the following inclusion criteria: a diagnosis of haematological cancer including leukaemia, lymphoma and myeloma in the past 7 years; aged 18–80 years at enrolment; and sufficient English to complete the survey. This study used the NCI and NCCS definition of a cancer survivor as someone diagnosed with cancer, from the time of diagnosis until the end of that person's life [3, 4].

Procedure Between September 2010 and September 2013, haematological cancer survivors were recruited via five Australian state cancer registries (registries 1, 2, 3, 4 and 5). Residential postcodes were used to stratify the sample, with postcodes classified as major city/inner regional or outer regional/remote/very remote based on the Accessibility and Remoteness Index of Australia (ARIA+) [21]. All eligible haematological cancer survivors residing in an outer regional/remote/very remote location were approached due to limited numbers while survivors living in a major city/inner regional location were randomly selected.

Registry 1 recruited eligible survivors by mailing the questionnaire package directly to survivors. Non-respondents were mailed another questionnaire package after 4 weeks. Registries 2, 3 and 4 sought passive consent from the survivor's treating clinician. These cancer registries contacted the clinician via mail to seek clinician consent to contact the survivor. If the registries received consent from the clinician to contact the survivor or received no reply from the clinician within 4 weeks, the registries contacted the survivor by mail and sought the survivor's permission to provide their contact details to the research team. Registry 5 used active clinician consent to recruit eligible survivors. This registry obtained written consent from the treating clinician before contacting the survivor via mail to ask if they would give the registry permission to provide their contact information to the researchers. Survivors from registries 2, 3, 4 and 5 who agreed to being contacted by the research team were mailed a letter, survey, consent form to have their demographic and disease details released from the registry and envelope for return of the survey. Non-respondents were mailed another questionnaire package 4 weeks later. After a further 4 weeks, a reminder telephone call was made to those who did not respond.

The University of Newcastle Human Research Ethics Committee and ethics committees for the cancer registries granted ethical approval.

Measures

Survivor Unmet Needs Survey The 89-item SUNS measures the unmet needs experienced over the last month. The SUNS consists of five domains: information needs (8 items), financial concerns (11 items), access and continuity of care (22 items), relationships (15 items) and emotional health (33 items) [19]. The response options are no unmet need, low unmet need, moderate unmet need, high unmet need and very high unmet need. The SUNS has acceptable face validity and content validity with haematological cancer survivors that has been demonstrated through semi-structured interviews with 17 haematological cancer survivors [20]. Furthermore, the SUNS has acceptable construct validity (5-factor structure, all factor loadings > 0.30) and convergent validity (all five SUNS domains had correlation coefficients from 0.44 to 0.73 with all three subscales of the Depression Anxiety and Stress Scale) with haematological cancer survivors [20].

Depression, Anxiety and Stress Scale The Depression, Anxiety and Stress Scale (DASS-21) contains three subscales measuring depression (7 items), anxiety (7 items) and stress (7 items) [22].

Socio-demographic characteristics Consenting survivors had age, sex and residential postcode obtained from cancer registry records. Marital status, highest level of education and employment status were self-reported.

Cancer-related characteristics Cancer type and date of diagnosis were extracted from cancer registry records for consenting survivors. Survivors were asked about whether they had private health insurance, the treatments that they had ever or were currently receiving and time taken to travel to treatment.

Statistical analysis

SAS software version 9.4 was used to perform statistical analyses. Means, standard deviations or medians (continuous items) or frequencies and percentages (categorical items) were calculated. The five SUNS' domain scores were determined by adding the scores for all questions in that domain and dividing by the number of non-missing responses in that domain. A response of no unmet needs was scored 0, low unmet need a 1, moderate unmet need a 2, high unmet need a 3 and very high unmet need a 4. Data from survivors who completed > 70% of questions per domain were included in the analysis. As per the scoring manual, DASS-21 subscale scores were

determined by adding all questions in a subscale and multiplying by two [23]. Cut-off scores used to classify each condition were depression (> 9), anxiety (> 7) and stress (> 14) [23]. Participants with more than one item missing from the depression, anxiety and stress subscales were not included in the analysis of that subscale.

Quantile regression was used to examine socio-demographics, rurality, cancer history and psychological characteristics associated with survivors' unmet need scores for each SUNS domain. Results are presented for analysis of the median (the 50% quantile). Parameter estimates and 95% confidence intervals were calculated. Adjusted Wald *p* values for the overall effect of each variable have also been presented. Characteristics in the regression models were sex, age, education level, employment status, rurality, cancer type, time since diagnosis, time to travel to treatment, private health insurance, depression, anxiety and stress.

Results

Sample

Of 4299 eligible haematological cancer survivors identified via the five registries, 2287 survivors gave approval to be mailed the survey and 1511 returned a completed survey (66.1% of survivors mailed survey; 35.1% of eligible survivors). The ARIA+ was used to classify respondents as rural survivors (i.e. resided in outer regional/remote/very remote locations, ARIA+ > 2.4) or as urban survivors (i.e. resided in major cities/inner regional areas, ARIA+ 0–2.4) [21]. A visual illustration of the ARIA+ classifications can be found at http://www.spatialonline.com.au/ARIA_2011/ [24] where outer regional, remote and very remote locations in Australia are shaded in green, light blue and dark blue, respectively and major cities and inner regional areas are shaded in red and orange, respectively. Registry data in relation to rurality was obtained for 1417 respondents, with 1145 classified as urban survivors and 272 as rural survivors.

Survivor characteristics and treatment factors

Table 1 outlines the characteristics of rural and urban survivors and the total sample. The mean age of participants at diagnosis was 58 years and the majority were male (56.9%), married or living with a partner (78.1%) and resided in an urban location (80.8%). Most survivors were diagnosed with non-Hodgkin lymphoma (56.3%), were diagnosed more than 3 years ago (58.8%) and had received chemotherapy (82.3%). For 22.9% of survivors, it took more than 1 h to travel to treatment. More rural residents (49.2%) than urban residents (16.7%) travelled more than an hour to treatment.

Table 1 Characteristics of rural and urban survivors and the total sample

	Rural (<i>n</i> = 272)		Urban (<i>n</i> = 1145)		Total (<i>n</i> = 1511)	
	<i>n</i> ^a	%	<i>n</i> ^a	%	<i>n</i> ^a	%
Gender						
Male	153	57.3	621	56.7	778	56.9
Female	114	42.7	475	43.3	590	43.1
Age at diagnosis (years)						
Mean (SD)	59 (12)		57 (13)		58 (13)	
Marital status						
Married/living with partner	224	83.0	875	77.1	1169	78.1
Separated/divorced	18	6.7	97	8.5	126	8.4
Widowed	18	6.7	65	5.7	88	5.9
Single/never married	10	3.7	98	8.6	114	7.6
Education						
Primary/Year 6	16	6.0	36	3.2	58	3.9
Secondary/Year 10 or 12	104	39.2	400	35.6	546	36.9
Trade/vocational	96	36.2	356	31.7	478	32.3
University	49	18.5	331	29.5	397	26.8
Employment						
Employed	116	43.0	458	40.4	612	40.9
Not employed	154	57.0	676	59.6	883	59.1
Residence						
Urban	–		–		1145	80.8
Rural					272	19.2
Diagnosis						
Non-Hodgkin lymphoma	160	59.9	606	55.3	770	56.3
Leukaemia	46	17.2	194	17.7	241	17.6
Myeloma	37	13.9	178	16.2	215	15.7
Other lymphoma	24	9.0	118	10.8	142	10.4
Time since diagnosis						
≤ 1 years	25	9.6	72	6.7	97	7.2
> 1–2 years	34	13.1	137	12.8	171	12.8
> 2–3 years	62	23.8	222	20.7	284	21.2
> 3–7 years	139	53.5	643	59.9	787	58.8
Mean (SD) (years)	3.0 (1.3)		3.5 (1.5)		3.4 (1.5)	
Range (years)	(0.1–5.3)		(0.1–6.8)		(0.1–6.8)	
Private health insurance						
Yes	169	63.1	824	72.7	1053	70.4
No/Do not know	99	36.9	310	27.3	442	29.6
Treatments received (yes)						
Chemotherapy	167	77.7	772	82.7	1023	82.3
Radiation/radiotherapy	49	22.8	285	30.5	360	29.0
Bone marrow/stem cell transplant/harvest	67	31.2	263	28.2	353	28.4
Hormone/antibody treatment/targeted therapy	62	28.8	269	28.8	360	29.0
None	28	13.0	68	7.3	99	8.0
Current treatments (yes)						
Chemotherapy	24	8.8	81	7.1	112	7.4
Radiation/radiotherapy	2	0.7	14	1.2	17	1.1
Bone marrow/stem cell transplant/harvest	4	1.5	14	1.2	21	1.4
Hormone/antibody treatment/targeted therapy	27	9.9	100	8.8	137	9.1
None	164	60.3	737	64.5	964	63.9

Table 1 (continued)

	Rural (<i>n</i> = 272)		Urban (<i>n</i> = 1145)		Total (<i>n</i> = 1511)	
	<i>n</i> ^a	%	<i>n</i> ^a	%	<i>n</i> ^a	%
Time taken to travel to treatment						
< 30 min	68	27.0	434	40.4	537	37.9
30 min–1 h	60	23.8	461	42.9	555	39.2
> 1–2 h	37	14.7	130	12.1	177	12.5
> 2–5 h	66	26.2	45	4.2	118	8.3
> 5 h	21	8.3	5	0.5	30	2.1

^a May not sum to total *n* due to missing data

Most common high/very high unmet needs nominated by rural and urban survivors

Table 2 lists the most common high/very high unmet needs for rural and urban survivors separately. Seven of the most prevalent high/very high unmet needs were common to both urban and rural survivors. “Dealing with feeling tired” was the most common “high/very high” unmet need for the rural (15.2%) and urban (15.5%) survivors. “Coping with having a bad memory or lack of focus” was the second highest high/very high unmet need for urban survivors (13.1%) and the third highest for rural survivors (11.8%). “Having access to cancer services close to my home” was the second highest high/very high unmet need for rural survivors (14.3%), but was not listed among the most common high/very high unmet needs for urban survivors (6.5%). Two other items, “Dealing with feeling guilty about what I have put others through” (11.1%) and “Finding car parking that I can afford at the hospital or clinic” (11.0%) were also listed in the most common unmet needs for rural survivors only. Most items nominated as high/very high unmet needs by rural and urban survivors were from the emotional health domain.

SUNS domain scores

Table 3 outlines the mean and median scores for the five domains for the rural survivors and urban survivors, respectively. The mean and median domain scores were skewed towards no unmet needs/low unmet needs. The emotional health domain had the highest mean score for rural respondents (mean = 0.66, SD = 0.84) and urban participants (mean = 0.73, SD = 0.92). This aligns with the results described in Table 2 that demonstrated items from the emotional health domain were most commonly nominated as areas of unmet need. In contrast, the access and continuity of care domain had the lowest mean unmet need score for rural survivors (mean = 0.39, SD = 0.60) and urban survivors (mean = 0.37, SD = 0.64).

Factors associated with unmet needs in haematological cancer survivors

Characteristics associated with each of the SUNS’ five domains are outlined in Table 4.

Information needs

Being employed, aged 18–39 years, diagnosed in the last 24 months, being depressed, anxious or stressed were significantly associated with an increased unmet information needs domain score.

Financial concerns

Taking more than 1 h to travel to treatment, having depression, anxiety or stress were significantly associated with a higher unmet financial concerns domain score.

Access and continuity of care

Being diagnosed in the last 24 months, taking more than 1 h to travel to treatment and being depressed, anxious or stressed were significantly associated with an increased unmet access and continuity of care domain score.

Relationships

Characteristics significantly associated with an increased unmet relationships domain score were having a university education, being aged 18–39 years and having depression, anxiety or stress.

Emotional health

Being aged 18–39 years, having been diagnosed in the last 24 months, a myeloma diagnosis (as compared to non-Hodgkin lymphoma) and being depressed, anxious or stressed were significantly associated with a higher unmet emotional health domain score. In contrast, being a rural resident was

Table 2 Most common high/very high unmet needs identified by rural and urban survivors

Item	Rural (<i>n</i> = 272)		Domain
	<i>n</i>	%	
Q60 Dealing with feeling tired	40	15.2	Emotional health
Q25 Having access to cancer services close to my home	38	14.3	Access and continuity of care
Q83 Coping with having a bad memory or lack of focus	31	11.8	Emotional health
Q85 Dealing with changes in my physical ability	31	11.8	Emotional health
Q48 Dealing with people who expect me to be “back to normal”	30	11.3	Relationships
Q62 Dealing with feeling worried (anxious)	30	11.3	Emotional health
Q77 Dealing with feeling guilty about what I have put others through	29	11.1	Emotional health
Q15 Finding car parking that I can afford at the hospital or clinic	29	11.0	Financial concerns
Q78 Dealing with being told I had cancer	29	10.9	Emotional health
Q69 Dealing with losing confidence in my own abilities	28	10.6	Emotional health
Item	Urban (<i>n</i> = 1145) ^a		Domain
Q60 Dealing with feeling tired	174	15.5	Emotional health
Q83 Coping with having a bad memory or lack of focus	146	13.1	Emotional health
Q85 Dealing with changes in my physical ability	141	12.8	Emotional health
Q62 Dealing with feeling worried (anxious)	138	12.4	Emotional health
Q8 Dealing with not feeling sure that the cancer has gone	136	12.4	Information needs
Q68 Dealing with not being able to set future goals or make long-term plans	134	12.0	Emotional health
Q78 Dealing with being told I had cancer	132	11.9	Emotional health
Q69 Dealing with losing confidence in my own abilities	132	11.8	Emotional health
Q47 Finding someone to talk to who understands and has been through a similar experience	131	11.7	Relationships
Q48 Dealing with people who expect me to be “back to normal”	129	11.6	Relationships
Q61 Dealing with feeling stressed	129	11.6	Emotional health

^a 11 instead of 10 items are listed for the urban survivors because for the tenth ranking two items had the same percentage

associated with a decreased unmet emotional health domain score.

Discussion

This study compared the high/very high unmet supportive care needs of rural haematological cancer survivors to their urban counterparts. Although < 20% of respondents indicated high/very high unmet needs on any individual item, “dealing with feeling tired” was the most common unmet need for both

rural and urban survivors which is consistent to prior research with haematological cancer survivors [12, 13]. A systematic review has reported that aerobic exercise in supervised environments is effective in reducing cancer-related fatigue [25], which suggests that health care providers could routinely offer and encourage haematological cancer survivors to participate in exercise programs in an effort to help manage fatigue. However, access to appropriate and effective programs may be variable.

Our study also found that for both rural and urban survivors, the emotional health domain had the highest mean

Table 3 Mean and median SUNS domain scores

Domains	Rural (<i>n</i> = 272)			Urban (<i>n</i> = 1145)		
	<i>n</i> ^a	Mean (SD)	Median	<i>n</i> ^a	Mean (SD)	Median
Information needs	266	0.65 (0.82)	0.27	1094	0.67 (0.88)	0.25
Financial concerns	262	0.53 (0.77)	0.25	1106	0.50 (0.76)	0.18
Access and continuity of care	266	0.39 (0.60)	0.09	1116	0.37 (0.64)	0.05
Relationships	265	0.63 (0.82)	0.20	1117	0.66 (0.90)	0.27
Emotional health	263	0.66 (0.84)	0.27	1112	0.73 (0.92)	0.33

^a Completed > 70% of domain items

Table 4 Characteristics associated with unmet need domain scores

	Information needs		Financial concerns		Access and continuity of care		Relationships		Emotional health	
	Estimate (95% CI)	p	Estimate (95% CI)	p	Estimate (95% CI)	p	Estimate (95% CI)	p	Estimate (95% CI)	p
Education	–	–	–	–	–	–	–	–	–	–
High school or less/trade/vocational	0.00 (–0.04, 0.04)	1.0	–0.00 (–0.01, 0.01)	1.0	0.00 (–0.00, 0.00)	1.0	0.07 (0.03, 0.10)	0.0002*	0.03 (–0.02, 0.07)	0.27
University	–	–	–	–	–	–	–	–	–	–
Employment	–	–	–	–	–	–	–	–	–	–
Employed	0.12 (0.05, 0.20)	0.0005*	0.00 (–0.01, 0.01)	1.0	–0.00 (–0.00, 0.00)	1.0	0.00 (–0.03, 0.03)	1.0	0.00 (–0.04, 0.05)	0.84
Not employed	–	–	–	–	–	–	–	–	–	–
Private health insurance	–	–	–	–	–	–	–	–	–	–
Yes	–	–	–	–	–	–	–	–	–	–
No/Do not know	0.00 (–0.04, 0.04)	1.0	0.03 (–0.03, 0.09)	0.33	0.00 (–0.01, 0.01)	1.0	0.00 (–0.03, 0.03)	1.0	0.03 (–0.02, 0.08)	0.23
Sex	–	–	–	–	–	–	–	–	–	–
Male	–	–	–	–	–	–	–	–	–	–
Female	0.00 (–0.06, 0.06)	1.0	–0.00 (–0.02, 0.02)	1.0	–0.00 (–0.01, 0.01)	1.0	0.00 (–0.03, 0.03)	1.0	0.03 (–0.02, 0.08)	0.21
Residence	–	–	–	–	–	–	–	–	–	–
Rural	–0.00 (–0.04, 0.04)	1.0	–0.00 (–0.03, 0.03)	1.0	0.00 (–0.01, 0.01)	1.0	–0.00 (–0.02, 0.02)	1.0	–0.06 (–0.11, –0.01)	0.01*
Urban	–	–	–	–	–	–	–	–	–	–
Age	–	–	–	–	–	–	–	–	–	–
18–39 years	0.19 (0.01, 0.38)	0.04*	0.06 (–0.04, 0.16)	0.23	0.05 (–0.01, 0.10)	0.08	0.30 (0.16, 0.44)	<0.0001*	0.11 (0.01, 0.22)	0.03*
40+ years	–	–	–	–	–	–	–	–	–	–
Time since diagnosis	–	–	–	–	–	–	–	–	–	–
1–24 months	0.12 (0.00, 0.25)	0.04*	0.03 (–0.03, 0.09)	0.30	0.05 (0.01, 0.08)	0.004*	0.00 (–0.04, 0.04)	1.0	0.06 (0.01, 0.12)	0.02*
25+ months	–	–	–	–	–	–	–	–	–	–
Cancer type	–	–	–	–	–	–	–	–	–	–
Leukaemia	0.00 (–0.07, 0.07)	1.0	0.00 (–0.03, 0.03)	0.09	–0.00 (–0.01, 0.01)	1.0	0.00 (–0.05, 0.05)	1.0	0.03 (–0.04, 0.11)	0.001*
Myeloma	0.00 (–0.05, 0.05)	–	0.08 (0.02, 0.14)	–	0.00 (–0.02, 0.02)	–	0.00 (–0.04, 0.04)	–	0.17 (0.08, 0.26)	–
Other lymphoma	–0.00 (–0.09, 0.09)	–	0.00 (–0.06, 0.06)	–	0.00 (–0.03, 0.03)	–	0.00 (–0.05, 0.05)	–	–0.03 (–0.10, 0.03)	–
Non-Hodgkin lymphoma	–	–	–	–	–	–	–	–	–	–
Time to travel to treatment	–	–	–	–	–	–	–	–	–	–
≤1 h	–	–	–	–	–	–	–	–	–	–
>1 h	0.00 (–0.05, 0.05)	1.0	0.12 (0.07, 0.17)	<0.0001*	0.05 (0.03, 0.06)	<0.0001*	0.00 (–0.04, 0.04)	1.0	0.06 (–0.02, 0.13)	0.13
Depression	–	–	–	–	–	–	–	–	–	–
Yes	0.37 (0.21, 0.54)	<0.0001*	0.24 (0.15, 0.34)	<0.0001*	0.23 (0.17, 0.29)	<0.0001*	0.67 (0.53, 0.80)	<0.0001*	0.77 (0.63, 0.92)	<0.0001*
No	–	–	–	–	–	–	–	–	–	–
Anxiety	–	–	–	–	–	–	–	–	–	–
Yes	0.50 (0.35, 0.65)	<0.0001*	0.27 (0.17, 0.38)	<0.0001*	0.14 (0.08, 0.19)	<0.0001*	0.33 (0.22, 0.45)	<0.0001*	0.44 (0.30, 0.57)	<0.0001*
No	–	–	–	–	–	–	–	–	–	–
Stress	–	–	–	–	–	–	–	–	–	–
Yes	0.75 (0.52, 0.98)	<0.0001*	0.53 (0.33, 0.72)	<0.0001*	0.36 (0.26, 0.47)	<0.0001*	0.87 (0.66, 1.07)	<0.0001*	0.98 (0.75, 1.21)	<0.0001*
No	–	–	–	–	–	–	–	–	–	–

*p < 0.05

unmet need score while the access and continuity of care domain had the lowest unmet need score. This is similar to Canadian research with rural survivors with various cancer types that also found that the access and continuity of care domain had the lowest mean unmet need score while emotional health was ranked second after information as an unmet need [26]. However, even though in our study access and continuity of care had the lowest mean domain score, access to cancer services close to home was the second highest unmet need for rural survivors. To address emotional health unmet needs among haematological cancer survivors, health care providers should undertake distress screening regularly and ensure referral to effective and accessible psychosocial support. It may also be helpful to explore whether current forms of emotional and psychosocial support are well suited to the needs of haematological cancer survivors and accessible to survivors during and beyond the active treatment phase.

Rurality was associated with the emotional health domain only, with rural haematological cancer survivors reporting lower unmet emotional health scores than urban participants. There is evidence that factors protective of emotional health in rural cancer survivors but not urban cancer survivors include active coping and positive reinterpretation [27] and the belief that a person's health is decided by powerful others [28]. However, similar to research with survivors diagnosed with any type of cancer [18], haematological cancer survivors' scores on information, financial, access and continuity of care and relationships unmet needs did not differ by rurality. Despite the additional transport and distance-related challenges faced by rural survivors diagnosed with haematological cancer, these challenges do not appear to result in poorer overall emotional health and unmet need.

Despite the lack of differences in the unmet need domain scores between rural and urban survivors, haematological cancer survivors who travelled for more than 1 h to treatment had increased unmet need scores in the financial concerns and access and continuity of care domains. Telemedicine via video-conferencing has been successfully used in Australia to provide specialist consultations and cancer treatment [29] and may help to reduce the unmet access and continuity of care needs of those who travel long distances for treatment by allowing them to receive treatments closer to home. Given the widespread availability of video communication software such as Skype and FaceTime, such platforms could also be used to provide care to survivors who travel more than 1 h to treatment. Furthermore, cancer organisations, such as Cancer Councils, provide online peer support groups facilitated by health care professionals which may also assist in addressing the unmet access and continuity of care needs of haematological cancer survivors who travel long distances to treatment. Better coordination between cancer specialists and general practitioners may also help reduce this unmet need in those who travel more than 1 h to treatment. Despite the availability

of financial support and accommodation for haematological cancer survivors via organisations such as the Leukaemia Foundation of Australia, those who travelled for more than 1 h to treatment had increased unmet financial concerns. It is unclear from our data whether this reflects that survivors were unaware of these resources, could not access them or were able to access these but found them insufficient to alleviate the financial burden of travel. A recent study of cancer patients indicated that 74% did not use financial assistance, and more than one third of these patients did not know that financial assistance was available [30]. Future research should examine haematological cancer survivors' knowledge and ability to access financial support and also assess what type and level of financial assistance would be sufficient and beneficial to survivors, particularly those who travel long distances for treatment.

Associations were found between depression, anxiety and stress and increased unmet need scores across all five domains. These findings are similar to research with multiple myeloma patients [11] and other cancer types [31, 32] that found that there was a relationship between depression and anxiety with unmet needs. Implementing strategies such as additional assistance from health care providers, cancer organisations and peer support groups to address information, financial, access and continuity of care, relationships and emotional unmet needs among haematological cancer survivors with depression, anxiety or stress may be beneficial. Furthermore, consistent with prior research with haematological cancer survivors [10, 13, 33] and other cancer survivors [16, 34], younger age was associated with survivors reporting increased unmet need scores for information needs, relationships and emotional health. A diagnosis of haematological cancer 1–24 months ago was also associated with increased unmet need scores on three of the five domains, specifically, information, access and continuity of care and emotional health indicating that this subgroup of survivors may benefit from additional support in these areas.

To our knowledge, this study of over 1500 participants is the largest to investigate the unmet supportive care needs of a heterogeneous group of haematological cancer survivors. The strengths of this study include using rigorous sampling techniques to recruit a national sample of survivors from five Australian state cancer registries and the use of an unmet need measure shown to have acceptable reliability and validity with haematological [20] and other cancer survivors [19]. The study limitations include that although a heterogeneous sample of haematological cancer survivors was surveyed, because more than half were diagnosed with non-Hodgkin lymphoma and other haematological cancer types were represented in smaller numbers, the findings may have limited generalisability to all haematological cancer types.

While overall haematological cancer survivors reported low levels of unmet needs, particular subgroups, for example

those with depression, anxiety, stress, younger survivors and those diagnosed 1–24 months ago, were identified as a priority for targeted service provision. In contrast, generally, unmet needs did not differ for rural survivors compared to urban survivors, indicating that rural survivors (most diagnosed > 3 years ago) have managed their cancer and treatment as well as their urban counterparts.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

- International Agency for Research on Cancer - World Health Organization (2015) GLOBOCAN 2012: estimated cancer incidence, mortality and prevalence worldwide in 2012. World Health Organization, Geneva
- National Institute for Clinical Excellence (2003) Improving outcomes in haematological cancers. National Institute for Clinical Excellence, London
- Twombly R (2004) What's in a name: who is a cancer survivor? *J Natl Cancer Inst* 96:1414–1415
- National Cancer Institute (2018) NCI dictionary of cancer terms. National Cancer Institute, National Institutes of Health [Accessed 3 February 2018 from <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor>]
- Australian Institute of Health and Welfare (2010) Cancer in Australia 2010: an overview. Australian Institute of Health and Welfare, Canberra
- Allart-Vorelli P, Porro B, Baguet F, Michel A, Cousson-Gelie F (2015) Haematological cancer and quality of life: a systematic literature review. *Blood Cancer J* 5:e305
- Fitch MI (2008) Supportive care framework. *Can Oncol Nurs J* 18: 6–24
- Swash B, Hulbert-Williams N, Bramwell R (2014) Unmet psychosocial needs in haematological cancer: a systematic review. *Support Care Cancer* 22:1131–1141
- 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* 88:102–116
- Lobb EA, Joske D, Butow P, Kristjansson LJ, Cannell P, Cull G, Augustson B (2009) When the safety net of treatment has been removed: patients' unmet needs at the completion of treatment for haematological malignancies. *Patient Educ Couns* 77:103–108
- Molassiotis A, Wilson B, Blair S, Howe T, Cavet J (2011) Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. *Psycho-Oncology* 20:88–97
- Hall A, Campbell HS, Sanson-Fisher R, Lynagh M, D'Este C, Burkhalter R, Carey M (2013) Unmet needs of Australian and Canadian haematological cancer survivors: a cross-sectional international comparative study. *Psycho-Oncology* 22:2032–2038
- Boyes AW, Clinton-McHarg T, Waller AE, Steele A, D'Este CA, Sanson-Fisher RW (2015) Prevalence and correlates of the unmet supportive care needs of individuals diagnosed with a haematological malignancy. *Acta Oncol* 54:507–514
- Butow PN, Phillips F, Schweder J, White K, Underhill C, Goldstein D et al (2012) Psychosocial well-being and supportive care needs of cancer patients living in urban and rural/regional areas: a systematic review. *Support Care Cancer* 20:1–22
- Lawler S, Spathonis K, Masters J, Adams J, Eakin E (2011) Follow-up care after breast cancer treatment: experiences and perceptions of service provision and provider interactions in rural Australian women. *Support Care Cancer* 19:1975–1982
- Girgis A, Boyes A, Sanson-Fisher RW, Burrows S (2000) Perceived needs of women diagnosed with breast cancer: rural versus urban location. *Aust N Z J Public Health* 24:166–173
- Beesley V, Eakin E, Steginga S, Aitken J, Dunn J, Battistutta D (2008) Unmet needs of gynaecological cancer survivors: implications for developing community support services. *Psycho-Oncology* 17:392–400
- White KJ, Roydhouse JK, D'Abrew NK, Katris P, O'Connor M, Emery L (2011) Unmet psychological and practical needs of patients with cancer in rural and remote areas of Western Australia. *Rural Remote Health* 11:1784
- Campbell HS, Sanson-Fisher R, Turner D, Hayward L, Wang XS, Taylor-Brown J (2010) Psychometric properties of cancer survivors' unmet needs survey. *Support Care Cancer* 19:221–230
- Hall A, D'Este C, Tzelepis F, Sanson-Fisher R, Lynagh M (2014) The Survivor Unmet Needs Survey (SUNS) for haematological cancer survivors: a cross-sectional study assessing the relevance and psychometric properties. *BMC Health Serv Res* 14:211
- Australian Bureau of Statistics (2003) Australian standard geographical classification: purpose and use. Australian Bureau of Statistics, Canberra
- Antony MM, Cox BJ, Enns MW, Bieling PJ, Swinson RP (1998) Psychometric properties of the 42-item and 21-item versions of the Depression Anxiety Stress Scales in clinical groups and a community sample. *Psychol Assess* 10:176–181
- Lovibond SH & Lovibond PF (1995) Manual for the depression anxiety & stress scales. (2nd Ed.) Psychology Foundation, Sydney
- The University of Adelaide (2018) ARIA+ 2011 Australia. The University of Adelaide, Adelaide [Accessed on 3 February 2018 from http://www.spatialonline.com.au/ARIA_2011/]
- McMillan EM, Newhouse IJ (2011) Exercise is an effective treatment modality for reducing cancer-related fatigue and improving physical capacity in cancer patients and survivors: a meta-analysis. *Appl Physiol Nutr Metab* 36:892–903
- Olson RA, Howard F, Turnbull K, Munroe D, Zirul C, Manji R et al (2014) Prospective evaluation of unmet needs of rural and

- Aboriginal cancer survivors in Northern British Columbia. *Curr Oncol* 21:e179–e185
27. Schlegel RJ, Talley AE, Molix LA, Bettencourt BA (2009) Rural breast cancer patients, coping and depressive symptoms: a prospective comparison study. *Psychol Health* 24:933–948
 28. Bettencourt BA, Talley AE, Molix L, Schlegel R, Westgate SJ (2008) Rural and urban breast cancer patients: health locus of control and psychological adjustment. *Psycho-Oncology* 17:932–939
 29. Sabesan S, Larkins S, Evans R, Varma S, Andrews A, Beuttner P, Brennan S, Young M (2012) Telemedicine for rural cancer care in North Queensland: bringing cancer care home. *Aust J Rural Health* 20:259–264
 30. Paul C, Boyes A, Hall A, Bisquera A, Miller A, O'Brien L (2016) The impact of cancer diagnosis and treatment on employment, income, treatment decisions and financial assistance and their relationship to socioeconomic and disease factors. *Support Care Cancer* 24:4739–4746
 31. Schmid-Buchi S, Halfens RJG, Muller M, Dassen T, van den Borne B (2013) Factors associated with supportive care needs of patients under treatment for breast cancer. *Eur J Oncol Nurs* 17:22–29
 32. Urbaniec OA, Collins K, Denson LA, Whitford HS (2011) Gynecological cancer survivors: assessment of psychological distress and unmet supportive care needs. *J Psychosoc Oncol* 29:534–551
 33. Parry C, Lomax JB, Morningstar EA, Fairclough DL (2012) Identification and correlates of unmet service needs in adult leukemia and lymphoma survivors after treatment. *J Oncol Pract* 8:e135–e141
 34. Jorgensen ML, Young JM, Harrison JD, Solomon MJ (2012) Unmet supportive care needs in colorectal cancer: differences by age. *Support Care Cancer* 20:1275–1281