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## **Prevalence and associates of psychological distress in haematological cancer survivors**

### **Short title: Psychological distress in haematological cancer survivors**

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## **ABSTRACT**

**Purpose:** To explore outcomes of psychological distress, including anxiety, depression and stress, among adult haematological cancer survivors, with a specific focus on potential differences between rural and urban survivors.

**Methods:** 1,414 urban and rural survivors were recruited from five Australian population-based cancer registries and completed a self-report pen-and-paper survey on their wellbeing, including the Depression Anxiety and Stress Scale-21 item version.

**Results:** A quarter of survivors were identified as reporting above normal levels of anxiety and depression respectively, and almost one fifth (17%) reported above normal levels of stress. There were no statistically significant differences in the percentage of rural and urban survivors reporting above normal levels of anxiety, depression or stress. Survivors who had experienced financial burden due to their cancer or were of middle age had higher odds of reporting multiple domains of psychological distress, compared to their counterparts.

**Conclusions:** Haematological cancer survivors diagnosed during middle age or who experience increased financial burden as a result of their diagnosis, may require additional support and care with regards to psychological distress.

**KEYWORDS:** Cancer, Oncology, Distress, Haematological Cancer, Geographical Location

## **INTRODUCTION**

Haematological cancer survivors may experience increased symptoms of psychological distress compared to other cancer populations[1,2]. This is of concern as psychological distress such as anxiety and depression has been found to be related to poorer quality of life[3], greater functional impairment[4], greater barriers to accessing and receiving cancer care[4] and reduced adherence to recommended medical care, including treatment and preventive related medical recommendations (e.g. medications, exercise, diet, screening, vaccinations, appointments and health related behaviours), in studies including cancer populations[5].

For health care services to be well equipped to provide support to those experiencing significant distress, robust estimates of the prevalence of psychological outcomes are needed. Understanding the risk factors associated with high levels of psychological distress, will also allow services to provide relevant and timely support to those who need it most. Unfortunately, research concerning the prevalence of psychological distress in haematological cancer survivors is limited.

Most previous studies have focused on specific sub-populations of haematological cancer survivors, focusing only on several types of haematological cancers, [6-8] or particular treatments [9,8,10]. Consequently, the data available to inform service development and delivery for this population is only based on specific sub-groups, which may not be applicable to everyone. While there are few studies that have included a heterogeneous sample of haematological cancers, most did not recruit from a population-based sample and included only small sample sizes of less than 350 [11-13]. Small sample sizes are likely to reduce the accuracy of the prevalence estimations, as well as reduce the power to explore the risk factors associated with high levels of psychological distress. In particular small sample sizes are likely to affect the ability to adequately assess certain factors that may affect psychological outcomes and deserve special consideration, but are otherwise difficult to study due to only a small proportion of the population experiencing them. Such characteristics include, rurality and rarer haematological cancers.

Given the significant differences between haematological cancers and other cancers, it may not be appropriate to generalise data from other cancer populations to haematological cancers[14] [15]. Likewise, the disease presentation, progression and treatment of haematological cancers are all highly variable[14]. Thus, generalising data from only sub-populations of haematological cancers to inform the delivery of care and services to the entire population may not be appropriate. To understand which haematological cancer survivors may benefit from what services, it is essential that population-based studies of large heterogeneous samples are conducted. Such studies will allow for accurate prevalence estimates of psychological distress, while allowing for examination of how such outcomes differ across sub-populations.

It is also important to assess the impact of other characteristics that may affect survivor's wellbeing but have received little focus in the past, such as rurality. Several previous studies with other cancer types have shown higher rates of psychological morbidity among rural compared to urban cancer survivors[16,17], although these results are mixed[18,19]. For haematological cancer survivors it is believed that the impact of rurality on psychological outcomes may be particularly pertinent, as much of the care they require is only offered in large, urban treatment centres where specialists are readily available[15]. Consequently, many rural haematological cancer survivors are required to travel for over an hour, or relocate[20], in order to receive specialist treatment. As a result of having to travel great distances or relocate, living in a rural location may compound financial strain, social isolation and reduce availability of social support, which are factors found to be related to poorer psychological outcomes in cancer survivors[21,22].

We aimed to estimate the prevalence of anxiety, depression and stress experienced by haematological cancer survivors, and:

- (1) Compare the percentage of rural survivors reporting above normal levels of anxiety, depression and stress, to urban survivors; and
- (2) Identify other characteristics associated with survivors reporting above normal levels of anxiety, depression and stress.

## **METHODS**

Cross-sectional survey.

### **Participants**

The inclusion criteria was: adults  $\geq 18$  years at the time of recruitment and diagnosed with a haematological cancer, including: non-Hodgkin's lymphoma, leukemia, myeloma and other lymphomas. A haematological cancer survivor was defined as anyone diagnosed with cancer, from the time of diagnosis until the end of their life[23,24].

### **Sampling**

Survivors with a residential postcode at diagnosis classified by the Australian Bureau of Statistics Accessibility and Remoteness Index of Australia (ARIA+) categories of: outer regional, remote and very remote were defined as rural[25]. Urban survivors were defined as a postcode categorised as major cities of Australia and inner regional Australia[25].

All eligible rural survivors were informed by the registries about the study. Where possible, a random sample of urban survivors were approached. However this was not always possible, as some registries require that cancer survivors are only contacted about research once, and some specific haematological cancer types were already being recruited for other studies.

### **Recruitment**

Survivors were recruited from five Australian state population-based cancer registries (Registry A, B, C, D and E). Registry-specific eligibility and recruitment procedures were employed. Registry A identified and mailed a study package directly to eligible survivors. Completed surveys were returned to the registry and passed onto the researchers. Non-responders were mailed a second study package from the registry approximately three weeks later. These methods are described elsewhere[26].



Registries B, C and D notified each eligible survivor's clinician of their intent to contact the survivor. Clinicians were given approximately one month to indicate whether any survivors should be excluded. All remaining survivors were informed of the study by the registry, and asked to provide informed consent to pass on their contact details to the researchers. This procedure is reported elsewhere[27].

Registry E gained written clinician consent to contact eligible survivors about this study. Survivors with clinician consent were asked to provide informed consent for the registry to pass on their contact details to the researchers. These methods are described elsewhere[28].

Survivors consenting to registries B, C, D and E were mailed a questionnaire package by the researchers. Non-responders were sent a second package after three weeks and contacted via telephone after a further three weeks. Return of a completed survey was taken as informed consent to participate.

This study received approval from the University of Newcastle Human Research Ethics Committee and from the relevant committees associated with each registry.

## **Measures**

*Participant and non-participant data:* De-identified data on: age at diagnosis, cancer type, postcode or rural/urban location at diagnosis and sex were collected from the registries.

*Psychological distress:* was measured using the Depression Anxiety and Stress Scale 21-item version (DASS-21). Seven items assess each of the three constructs, depression, anxiety and stress. Respondents indicate the level to which they have experienced each item over the last seven days, using a four point Likert scale ranging from: 0 ("not at all") to 3 ("very much")[29]. The DASS has evidence of several indicators of reliability and validity[30,31].

*Independent variables:* Independent variables included in this study are listed in Table 1. The following were obtained from the self-report survey: treatment type and status, phase in the survivorship continuum, cancer recurrence, diagnosis with another cancer type, education level, health insurance, financial difficulties as a result of cancer (which included a range of indicators with varying impact), employment status, marital status, travel time to treatment, participation in a support group in the last month and access to home care services in the last month. For survivors who consented the following were obtained from the registries: age at diagnosis and/or date of birth, sex, cancer type, date of diagnosis, postcode and/or location of residency at diagnosis.

## **Statistical analysis**

Missing items were left as missing.

### *Participant characteristics*

Participant and non-participant characteristics, and sociodemographic characteristics of urban and rural haematological cancer survivors were compared using Chi-Squared tests.

### *Prevalence of anxiety, depression and stress*

The DASS-21 was scored by adding all items in a subscale, dividing by the number of non-missing items in the sub-scale and multiplying by two[29]. A sub-scale score was only calculated for survivors who responded to least 6 of the seven items in each sub-scale[32]. Respondents were classified based on population norms, with above normal levels defined as the following: anxiety ( $\geq 8$ ), depression ( $\geq 10$ ) and stress ( $\geq 15$ )[29]. The percentage and 95% Confidence Intervals (CI) of survivors classified as experiencing above normal levels of anxiety, depression and stress were calculated.

### *Characteristics associated with above normal levels of psychological distress*

Logistic regression analyses were conducted to assess the differences in psychological distress between urban and rural haematological cancer survivors, and identify other characteristics associated with psychological distress. Separate analyses were conducted for above normal levels of: (1) anxiety; (2) depression; and (3) stress. Each independent variable

(listed in Table 1) was examined for association with the outcome by adding it into a simple logistic regression model along with urban/rural location as a covariate. Independent variables with a  $p$ -value of 0.1 or less in this initial analysis, as well as the urban/rural variable, were included in the final logistic regression models. Variables in the final models that had a  $p$ -value less than 0.017 on the Wald statistic were considered statistically significant. The conservative alpha level was used to account for multiple testing between three correlated outcomes. A  $p$ -value more than 0.05 on the Hosmer-Lemeshow goodness of fit test indicated an appropriate fit to the model.

### **Power calculations**

We aimed to recruit a sample size of 750 urban and 750 rural haematological cancer survivors. A sample of this size would allow for detection of an 8% difference in proportions, at an alpha level of 5% with 90% power. However, the final sample consisted of 1,144 urban and 270 rural survivors, which allowed for the detection of a 13% difference in the proportion of participants experiencing psychological distress, at an alpha level of 0.017%, with 90% power. To assess associates of psychological distress this final sample size provided 90% power, at an alpha level of 0.017% to detect differences of 12% in the proportions experiencing psychological distress between levels of factors, allowing for differences in numbers of participants across level of variable of 2:1.

## **RESULTS**

### ***Participants***

A total of 4,299 eligible survivors were contacted by the registries; of which 1,511 returned a completed survey (35% participation rate) (Figure 1). Of the 4,299 eligible survivors contacted by the registries, information relating to survivor's location at diagnosis was available for 4,049 survivors; of which 677 were from a rural location and 3,372 were from an urban location. Of the 1,511 eligible survivors who returned a survey 1,414 had a relevant postcode at diagnosis and were included in this study (1,144 (81%) urban; and 270 (19%) rural). Participant characteristics are described in Table 2. Rural and urban survivors differed in terms of their time since diagnosis, marital status and education level (Table 2).

Of the data obtained from the registries, 0% to 11% of the participant data was missing, and 0% to 45% of non-participant data was missing. There were differences between participants and non-participants with regards to: age at diagnosis ( $p<0.001$ ), rural/urban location ( $p=0.002$ ), cancer type ( $p=0.001$ ) and the state-based cancer registry survivors were recruited from ( $p<0.001$ ). Survivors aged between 50 and 59 years at diagnosis (44%) recorded the highest participation rates and those aged between 15 and 39 years at diagnosis (23%) recorded the lowest. A higher percentage of rural survivors returned a completed survey (42%) compared to urban survivors (35%). Myeloma survivors recorded the highest participation rates (44%) and other types of haematological cancers recorded the lowest (32%). Registry E recorded the highest participation rate (54%) and registries C and D the lowest (33%).

### ***Prevalence of psychological distress***

Missing data for the DASS-21 ranged from 1.9% to 3.0%.

A quarter of survivors reported above normal levels of anxiety ( $n=344$ ; 95% CI: 0.23, 0.27) or depression ( $n=342$ ; 95% CI:0.23, 0.27); while 17% ( $n=232$ ; 95% CI:0.15, 0.19) reported above normal levels of stress.

### ***Psychological distress of urban and rural survivors***

Twenty five percent ( $n=274$ ), 24% ( $n=268$ ), and 17% ( $n=194$ ) of urban survivors reported above normal levels of anxiety, depression and stress; respectively. Comparatively, 27% ( $n=70$ ), 28% ( $n=74$ ) and 15% ( $n=38$ ) of rural survivors reported above normal levels of anxiety, depression and stress; respectively. When controlling for other characteristics there were no significant differences between the percentage of urban and rural haematological cancer survivors reporting above normal levels of anxiety (Table 3), depression (Table 4) or stress (Table 5).

### ***Characteristics associated with above normal levels of distress***

#### ***Anxiety***

As shown in Table 3, survivors who: were single (vs. in a coupled relationship), aged between 40 and 59 years at diagnosis (vs. 70 years and over), recruited from registry A (vs.

registry E), had less income as a result of their cancer; and did not have to take off work, had higher odds of reporting above normal levels of anxiety compared to their counterparts. This model was an adequate fit to the data ( $p=0.522$ ).

### *Depression*

Survivors who: were aged between 40 and 49 years at diagnosis (vs. 70 years and over), diagnosed with non-Hodgkin's lymphoma and other types of lymphoma (vs. myeloma); currently receiving active treatment (curative or palliative) and at another phase in the cancer journey (vs. undergoing follow-up appointments only); had used up their savings due to cancer; and did not have or were unsure of their private health insurance, had higher odds of reporting above normal levels of depression compared to their counterparts (Table 4). This model was an adequate fit to the data ( $p=0.674$ ).

### *Stress*

Survivors who: were aged between 50 and 59 years at diagnosis (vs. 70 years and over); reported difficulties in paying their bills due to cancer; and having used up their savings due to cancer had higher odds of reporting above normal levels of stress compared to their counterparts (Table 5). The final model was an adequate fit to the data ( $p=0.9648$ ).

## **DISCUSSION**

A quarter of participants reported above normal levels of anxiety and depression, and almost a fifth reported above normal levels of stress. As a substantial proportion of our sample were several years post diagnosis, this finding indicates the need to address psychosocial concerns across the disease trajectory for this population. These findings are somewhat consistent with previous studies of haematological cancer survivors, with prevalence rates of anxiety ranging from 11% to 18% and depression from 14% to 51% [18,11,2,13]. However, comparison across such studies are difficult due to differences in the measures used, population included and the definition of 'high' distress. Nevertheless, together these data suggest that a substantial minority of this population experience psychological distress. Health care providers should

follow recommendations in current guidelines for the treatment of anxiety, depression and stress[33]. However, methodologically rigorous studies are needed to further investigate the effectiveness of treatments for psychological outcomes in cancer survivors[22,34], particularly haematological cancer populations.

We found no difference in the percentage of rural and urban haematological cancer survivors reporting above normal levels of psychological distress. Previous results are mixed such as studies have found poorer psychological outcomes among rural compared to urban survivors of other cancer types[16,17]. While other studies including both haematological and heterogeneous populations of cancer survivors, have failed to find a significant association between geographical location and psychological distress[18,11]. For approximately the last decade there has been a push to improve the delivery of and access to cancer services to Australian rural cancer patients[35]. It is possible that such initiatives are having an effect on some of the psychosocial outcomes of rural cancer patients. It is also possible that other characteristics have a larger impact on survivor's psychological wellbeing than rurality. Further research is needed to explore these possibilities. It must be noted, that similar to this study, the majority of these previous studies have assessed survivor self-reported levels of anxiety and depression via validated screening tools, rather than including those with a clinical diagnosis of psychological distress. The relationship between clinical diagnoses of psychological distress and rural/urban location should be investigated in the future.

Indicators of financial hardship were associated with above normal levels of psychological distress. Specifically, survivors who reported having to use their savings as a result of their cancer, had difficulty paying their bills, had less income and did not have to take time off work had greater odds of experiencing above normal levels of one or more of the outcomes assessed. Financial difficulties are likely to reduce survivors' access to available services, especially supportive care services that may not be offered as routine treatment. Whilst not taking time off may be an indication of some survivors having to maintain their employment due to financial pressure, regardless of their level of health and wellbeing. Surprisingly, survivors without or unsure of their health insurance coverage only reported significantly higher odds of experiencing above normal levels of depression. Many treatments for haematological cancers are intensive and are administered over long periods of time, some

for up to a period of two years[15]. Consequently, the incidental costs experienced by haematological cancer survivors that are not covered by private health insurance are likely to be substantial regardless of insurance status[36]. Practical support such as providing subsidised or free accommodation, have been reported to alleviate some of the financial difficulties faced by haematological cancer survivors[36]. As some haematological cancer survivors have reported being unaware of available support or difficulties accessing them[37], it is important that proactive systems are in place to inform and support survivors in accessing such services. Research into the impact different financial stressors have on haematological cancer survivor's wellbeing is needed to help inform the delivery of financial services.

Middle aged survivors predominately between 40 and 59 years at diagnosis had higher odds of experiencing elevated psychological distress, compared to older adults aged 70 years or above. This finding is consistent with previous studies of cancer survivors, which have identified younger age at diagnosis to be associated with increased levels of psychological distress[18]. However, the youngest age group (15 to 39 years) was not found to be associated with higher psychological distress. This finding is in contrast with the current belief that cancer diagnosed during young adulthood is a risk factor for increased psychological distress[38]. Midlife has been described as a period of significant demands and responsibilities, filled with social and financial obligations[39]. A diagnosis of haematological cancer is likely to disrupt a person's ability to manage and fulfil such responsibilities, which may result in increased stress and burden. More research is needed to assess the differences in psychological distress across different age groups.

Other characteristics assessed were also found to be associated with one of the outcomes of psychological distress. For instance being single and the registry from which survivors were recruited were all found to be associated with survivors reporting above normal levels of anxiety. Whereas, being in active treatment or another time in the cancer trajectory and being diagnosed with lymphoma were all associated with above normal levels of depression, compared to receiving follow-up appointments only and being diagnosed with myeloma, respectively. These data suggest that the psychological impacts of a haematological cancer diagnosis may differ across sub-populations; thus the services and support relevant to one sub-group may not be appropriate to everyone.

## **Limitations**

At 35% the response rate was low; although this is comparable to other psychosocial registry-based studies, which have reported response rates less than 50% [40,41]. There was evidence of response bias, with differences found between a number of participants and non-participant characteristics. Of particular note, was the significantly higher percentage of rural survivors who returned a completed survey compared to urban survivors. It is difficult to ascertain why such differences in the response rates of rural and urban survivors exist. It has been suggested that people residing in larger, more urban areas may be less available, harder to reach and more socially isolated than those residing in less urbanised locations, which has been argued to potentially contribute to differences in research response rates by location [42]. However, it is likely that numerous factors are at play, and future research should strive to explore more closely what factors specifically impact on differences in response rates of haematological cancer survivors. These two limitations may affect the generalizability of findings. However, the comparisons made between participants and non-participants should be interpreted with caution due to the large percentage of missing data from some registries.

There were insufficient numbers of rural haematological cancer survivors in the population to allow us to meet our a-priori sample size, with only 270 rural survivors recruited out of the target 750. As a result the non-significant results found from the comparisons between urban and rural survivors may be due to reduced statistical power rather than a lack of difference. However, our post-hoc power calculations indicated that the sample was sufficient to detect a 12% difference in the prevalence of psychological distress among rural and urban survivors. However, as less than 20% of the Australian population [43] reside in a rural location, it is unlikely that a recruitment of a much larger sample of rural participants would be possible.

The cross-sectional design only provides an indication of psychological distress experienced by haematological cancer survivors at one time-point. While relying on self-report for the main outcomes and some of the clinical variables may be subject to error. However, use of objective measures for these variables, such as clinical interview and clinical records, was impractical and beyond the scope of this study. Some characteristics that may impact on the



main outcomes were not assessed (e.g. symptoms or disease progression) or did not have adequate numbers to allow for inclusion in the analyses (e.g. specific type of treatment currently received). Future research should strive to assess the impact of these characteristics on the prevalence of psychological distress in haematological cancer survivors.

## CONCLUSIONS

The results of this study indicate that psychological distress affects a substantial minority of haematological cancer survivors. It also suggests that the prevalence of above normal levels of psychological distress is similar for both rural and urban survivors. Characteristics such as middle age at diagnosis and increased financial burden as a result of cancer were associated with an increased risk of poor psychological outcomes. Health care providers should be alert to the increased vulnerability of such survivors and regularly assess their psychosocial support needs, and offer timely and targeted support as required.

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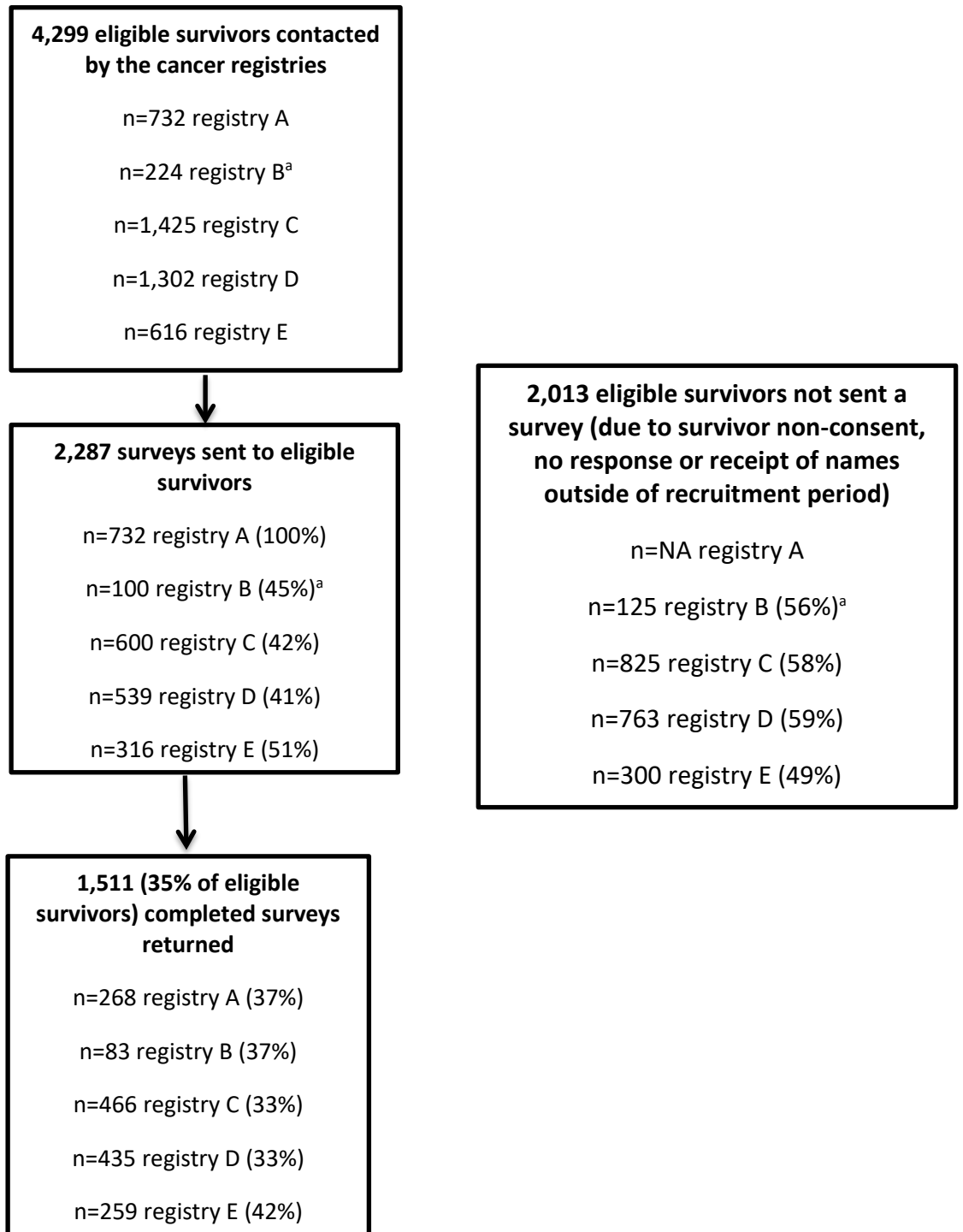
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**Figure 1. Number and percentage of survivors at different stages of recruitment**

<sup>a</sup>Totals do not add up due to missing information

**Table 1. Characteristics assessed for association with haematological cancer survivors reporting above normal levels of anxiety, depression and stress**

<b>Characteristic assessed</b>	<b>Response categories</b>
Location at diagnosis	<b>Rural</b> <b>Urban</b>
Cancer types	Non-Hodgkin's lymphoma Leukaemia Multiple myeloma Other lymphoma
Currently receiving active treatment, including: chemotherapy, radiotherapy, stem cell/bone marrow transplant and/or hormone/drug therapy	Yes No
Cancer recurrence	Yes No/not sure
Diagnosed with another form of cancer	Yes No/not sure
Time since diagnosis (months)	1-12 months 13-24 months 25-36 months 37-60 months 60+ months
Phase in cancer journey	Watchful waiting Receiving active or intensive treatment including palliative treatment Follow-up appointments only No follow-up needed Other (open-ended response by respondent)
Age at diagnosis	15-39 years 40-49 years 50-59 years 60-69 years 70+ years

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Sex	Male
	Female
Marital status	In a partnered relationship (married or living with a partner)
	Single (including widowed, divorced, seperated, never married)
Education level	High school or below
	Trade or vocational training
	University degree
Employment status	Paid employment
	Non-paid employment
Had to take time off work as a result of cancer and treatment	Yes
	No
Had less income as a result of cancer and treatment	Yes
	No
Had to resign of close my business as a result of cancer and treatment	Yes
	No
Had difficulty paying bills as a result of cancer and treatment	Yes
	No
Used up my savings as a result of cancer and treatment	Yes
	No
Had trouble meeting day to day expenses as a result of cancer and treatment	Yes
	No
Had to seel an assest to get extra cash as a result of cancer and treatment	Yes
	No
Participated in a support group (face-toface, online or telephone) in the last month	Yes
	No
Received home care services (personal, housework, meal delivery) in the last month	Yes
	No
Travel time to tretament	1 hour or less
	More than 1 hour
Cancer Regustry recruited from	A
	B

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	C
	D
	E
Private health insurance	Yes
	No/not sure

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**Table 2. Demographic and disease characteristics of haematological cancer survivors**

Characteristics	Urban survivors (n = 1,144) <sup>a</sup>		Rural survivors (n= 270) <sup>a</sup>		p-value
	n	%			
<i>Sex</i>					0.915
Male	620	57	151	57	
<i>Cancer type</i>					0.534
Non-Hodgkin's Lymphoma (NHL)	606	55	159	60	
Leukemia	193	18	45	17	
Myeloma	178	16	37	14	
Other lymphoma	118	11	24	9.1	
<i>Age at diagnosis</i>					0.117
15-39	120	11	25	9.4	
40-49	120	11	40	15	
50-59	323	30	61	23	
60-69	357	33	93	35	
70+	175	16	46	17	
<i>Approximate time since diagnosis (months)</i>					<0.001*
1-12	72	6.7	24	9.3	
13-24	137	13	33	13	
25-36	221	21	62	24	
37-60	457	43	132	51	
60+	186	17	7	2.7	
<i>Marital status</i>					0.043*
Partnered (married or living with a partner)	875	77	222	83	
<i>Education</i>					0.002*
High school or below	435	39	119	45	
Vocational training or other	356	32	95	36	
University	331	30	49	19	
<i>Employment</i>					0.423
Currently employed	461	41	116	43	
<i>Currently receiving chemotherapy, radiotherapy, stem cell/bone marrow transplant and/or hormone/drug therapy</i>					0.275
Yes	241	21	65	24	

<sup>a</sup>the total number for each characteristic may not add to equal the total sample size due to missing values

\* Significant difference at p<0.05.

**Table 3. Characteristics associated with haematological cancer survivors reporting above normal levels of anxiety<sup>a</sup>**

Variable	Multiple regression analysis	
	Odds Ratio (95% CI)	p-value for Wald statistic
<i>Location at diagnosis<sup>b</sup></i>		
Urban	1	
Rural	1.14 (0.68, 1.92)	0.546
<i>Age at diagnosis</i>		
15-39 years	1.48 (0.58, 3.76)	0.310
40-49 years	2.59 (1.10, 6.07)	0.007*
50-59 years	2.07 (1.02, 4.20)	0.014*
60-69 years	1.39 (0.73, 2.65)	0.222
70 years and over	1	
<i>Marital status</i>		
Partnered	1	
Single	1.65 (1.06, 2.56)	0.006*
<i>Less income</i>		
No	1	
Yes	1.81 (1.10, 2.99)	0.004*
<i>Time off work</i>		
No	1.76 (1.02, 3.02)	0.012*
Yes	1	
<i>Registry</i>		
A	2.16 (1.02, 4.54)	0.013*
B	0.90 (0.25, 3.16)	0.835
C	1.11 (0.62, 1.99)	0.669
D	1.10 (0.56, 2.17)	0.727
E	1	

\*Variables associated with haematological cancer survivors reporting above normal levels of anxiety on the DASS-21 at a p-value <0.017

<sup>a</sup>Characteristics included in the final model but not found to be significant include: cancer type, currently receiving treatment, time since diagnosis, phase in the cancer journey, sex, education level, trouble meeting day-to-day expenses, difficulty paying bills, used up savings,

stopped work, less income, travel time to treatment, private health insurance, use of home services in the last month. Other independent variables were excluded at the univariate level as they were found to have a p-value  $>0.1$ .

<sup>b</sup>Location at diagnosis is reported despite not being found significant as differences between urban and rural survivors was a main aim of this paper.

**Table 4. Characteristics associated with haematological cancer survivors reporting above normal levels of depression<sup>a</sup>**

Variable	Multiple regression analysis	
	Odds Ratio (98.4% CI)	p-value for Wald statistic
<i>Location at diagnosis<sup>b</sup></i>		
Urban	1	
Rural	1.38 (0.84, 2.27)	0.112
<i>Cancer type</i>		
Non-Hodgkin's Lymphoma (NHL)	2.07 (1.15, 3.72)	0.003*
Leukemia	1.38 (0.68, 2.79)	0.274
Myeloma	1	
Other lymphoma	2.98 (1.33, 6.69)	0.001*
<i>Phase in cancer journey</i>		
Waitful watching	1.49 (0.51, 4.34)	0.367
Active or intensive treatment (curative and palliative)	2.24 (1.18, 4.23)	0.002*
Follow-up appointments only	1	
No follow-ups	1.45 (0.79, 2.67)	0.141
Other	3.26 (1.19, 8.94)	0.005*
<i>Age at diagnosis</i>		
15-39 years	1.29 (0.51, 3.25)	0.501
40-49 years	2.40 (1.02, 5.62)	0.014*
50-59 years	1.84 (0.87, 3.88)	0.049
60-69 years	1.73 (0.86, 3.49)	0.059
70 years and over	1	
<i>Used up savings</i>		
No	1	
Yes	1.79 (1.10, 2.92)	0.004*
<i>Private health insurance</i>		
Yes	1	
No/not sure	1.60 (1.06, 2.41)	0.006*

<sup>a</sup>Variables associated with haematological cancer survivors reporting above normal levels of depression on the DASS-21 at a p-value <0.017

<sup>a</sup>Characteristics included in the final model but not found to be significant include: currently receiving treatment, marital status, education level, employment status, trouble meeting day-to-day expenses, difficulty paying bills, stopped work, less income, participation in a support group in the last month, travel time to treatment, use of home services in the last month. Other independent variables were excluded at the univariate level as they were found to have a p-value >0.1.

<sup>b</sup>Location at diagnosis is reported despite not being found significant as differences between urban and rural survivors was a main aim of this paper.

**Table 5. Characteristics associated with haematological cancer survivors reporting above normal levels of stress<sup>a</sup>**

Variable	Multiple regression analysis	
	Odds Ratio (95% CI)	p-value for Wald statistic
<i>Location at diagnosis<sup>b</sup></i>		
Urban	1	
Rural	0.87 (0.50, 1.52)	0.560
<i>Age at diagnosis</i>		
15-39 years	1.87 (0.67, 5.24)	0.142
40-49 years	2.19 (0.81, 5.90)	0.057
50-59 years	2.69 (1.10, 6.56)	0.008*
60-69 years	1.80 (0.75, 4.31)	0.107
70 years and over	1	
<i>Used up savings</i>		
No	1	
Yes	1.81 (1.07, 3.05)	0.006*
<i>Difficulty paying bills</i>		
No	1	
Yes	1.94 (1.03, 3.67)	0.012*

\*Variables associated with haematological cancer survivors reporting above normal levels of stress on the DASS-21 at a p-value <0.017

<sup>a</sup>Characteristics included in the final model but not found to be significant include: currently receiving treatment, phase in cancer journey, trouble meeting day-to-day expenses, stopped work, less income, had to take time off work, participation in a support group in the last month, registry recruited from. Other independent variables were excluded at the univariate level as they were found to have a p-value >0.1.

<sup>b</sup>Location at diagnosis is reported despite not being found significant as differences between urban and rural survivors was a main aim of this paper.