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Unmet needs of Australian and Canadian hematological cancer survivors: A cross-sectional international comparative study

# Running title: Hematological cancer survivor unmet needs

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#### ABSTRACT

**Objective:** Few population-based studies have assessed the needs of hematological cancer survivors or conducted international comparisons. We aimed to assess and compare the unmet needs of Australian and Canadian hematological cancer survivors.

**Methods:** Two cross-sectional data-sets were analyzed. Survivors were recruited from population-based cancer registries and sent a self-report survey containing the Survivors Unmet Needs Survey. Australians were aged 18-80 years at the time of study, and diagnosed in the last three years. Canadians were diagnosed 1 to 5 years prior and aged 19 years and over at diagnosis.

**Results:** 268 Australian and 169 Canadian survivors returned a completed survey. "*Dealing with feeling tired*" was identified as the highest concern by survivors. Country ( $LR\chi^2=4.0(1)$ , p=0.045) was associated with survivors reporting a 'high/very high' unmet need with "*worry about earning money*," with Australians reporting marginally nonsignificantly higher odds than Canadians (OR 2.1; 95% CI: 0.99, 4.3). Country was not significantly associated with any other outcome. Having a personal expense in the last month as a result of having cancer, younger age at diagnosis, female sex, vocational or other level education and consulting a health care professional for cancer treatment or concerns about cancer in the last month were associated with multiple areas of need.

**Conclusions:** Australian and Canadian hematological cancer survivors were found to experience similar level of unmet needs. Overall, hematological cancer survivors may require additional assistance in dealing with feeling tired.

#### **INTRODUCTION**

The burden of cancer continues to increase world-wide[1], more than doubling in almost three decades[2]. In a number of countries mortality rates for some cancer types have decreased[1]. Consequently, the number of people living beyond a diagnosis continues to increase, emphasizing the importance of recognizing and addressing the concerns of cancer survivors.

Supportive care needs refer to the informational, physical, practical, psychological, spiritual and social concerns patients may have[3, 4]. Needs based assessment provide an opportunity to investigate the gap between patient concerns and the help they receive[5, 6]. Needs assessment can be used to identify specific concerns and areas that could be improved for cancer survivors[6].

Hematological malignancies encompass cancer types that develop in the blood and bone marrow (e.g. leukemia, lymphoma and myeloma)[7-9]. The 2008 World Health Organization (WHO) estimates indicated leukemia, myeloma and lymphoma (Non-Hodgkin and Hodgkin) made up approximately 7% of worldwide cancer incidence (excluding non-melanocytic cancer)[10]. The WHO projected that the estimated incidence rate of these cancers would increase by approximately 28% from 2008 to 2020[10]. However, limited research has focused on the specific unmet needs of this population.

Researchers often rely on international data to help understand the psychosocial experiences of cancer survivors in their own country. This is often done with limited understanding as to the generalizability of data. An international comparison of cancer

survivor psychosocial outcomes from two culturally and economically similar countries, such as Australia and Canada allows us to assess the generalizability of findings. International comparisons also provide an indication of the burden of illness and how it varies between populations[11], as well as specific areas of care that could be improved in the different countries[12]. Australia and Canada both offer universal health care[13]. In 2008, WHO five-year prevalence estimates of adult (aged 15-75 years) lymphomas (Hodgkin and non-Hodgkin) leukemia and multiple myelomas for both countries were reasonably similar: 133.9 per 100,000 in Australia and 141.9 per 100,000 in Canada[10].

This study aimed to assess and compare the unmet needs of Australian and Canadian hematological cancer survivors.

#### METHOD

#### Study Design

This study compared two cross-sectional, self-administered surveys, of Australian and Canadian adult hematological cancer survivors.

#### Participants and procedure

*Australian sample:* Data from a sub-sample of respondents participating in a larger, national study were analyzed. Survivors diagnosed in the last three years (between 1 July 2007 and 30 June 2010) with a hematological cancer (including: leukemias, lymphomas and myelomas) and aged between 18 and 80 years at time of study, were identified from one Australian state-based cancer registry. Survivors were sent a

questionnaire package from the cancer registry. Non-responders were mailed a second questionnaire package approximately 4 weeks later.

*Canadian sample:* All hematological cancer survivors who participated in the *Canadian Survivors Unmet Needs* study were included. The *Canadian Survivors Unmet Needs* study is a large, cross-sectional study assessing the unmet needs of a heterogeneous sample of 1,589 Canadian cancer survivors from three provincial cancer registries. Survivors were aged 19 years and over at diagnosis and diagnosed 1 to 5 years previously. A cover letter and survey were mailed to survivors from the cancer registries. Two registries sent a pre-notification letter to survivors 7 to 10 days prior to mailing the survey. A follow-up reminder was sent 3 to 4 weeks later, with a second reminder sent after a further 10 to 21 days.

In both countries, return of a survey was taken as voluntary consent to participate. Ethics approval was provided by the relevant administrative institutions.

#### Measures:

*Unmet needs:* The Survivors Unmet Needs Survey (SUNS) was used to assess the level of unmet need experienced by cancer survivors over the last month[5]. The SUNS contains 89 items across 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)[5]. Each item is scored from '0' (no unmet need) to '4' (very high unmet need)[5]. The SUNS was developed using a heterogeneous sample of Canadian cancer survivors and has demonstrated reliability and validity[5].

*Cultural relevance*. To ensure the SUNS was linguistically appropriate for the Australian culture it was reviewed by a convenience sample of Australian researchers and people from the general population. As a consequence four items were changed. For example, "Doing yard work (cutting grass, snow shoveling etc.)" in the Canadian version was changed to "Doing yard work (lawn mowing etc.)" in the Australian version. "Being told I had cancer" was changed from the Canadian version to "dealing with being told I had cancer" in the Australian version. The final Australian version of the SUNS was then reviewed by a sample of Canadians to ensure consistency and appropriateness of the altered questionnaire.

*Sociodemographic and disease characteristics:* For consenting Australians, age at diagnosis, sex, date of diagnosis, cancer type and other disease and demographic characteristics were obtained directly from the cancer registry. Canadian survivors' age group at diagnosis, sex, months since diagnosis, cancer type and other disease and demographic characteristics were collected from the cancer registries. Other variables assessed in both Australian and Canadian survivors, including, employment, education, who survivors currently live with most of the time, consulting a health care professional for cancer treatment or concerns about cancer in the last month, experiencing a personal expense in the last month as a result of having cancer and travel time to treatment, were obtained from the survey.

#### Statistical analysis

Three outcomes were assessed in this study: (1) percentage of survivors reporting no unmet needs on all 89 items; (2) domain scores; and (3) the 10 most prevalent 'high/very' unmet needs items.

#### Outcome one: No unmet needs

A total unmet needs score was calculated by summing participants' responses to the 89 items. A score of zero was classified as reporting no unmet needs. Percentage of Australians and Canadians reporting no unmet needs were compared using Chisquared analyses. Only survivors who completed all 89 items were included in this analysis.

# Outcome two: Domain scores

Domain scores were calculated by summing the scores for all items and dividing by the number of non-missing responses for that domain. Only data from participants who completed more than 70% of items in each domain were included in this analysis, which is a more conservative method than recommended[14]. Due to the skewed distribution, the Wilcoxon rank-sum test was used to compare Australian and Canadian median domain scores.

#### Outcome three: Ten most prevalent 'high/very high' unmet needs

The percentage of participants reporting a 'high/very high' level of unmet need was calculated for each of the 89 items and ranked from the highest to lowest percentage[5] for both countries. Chi-squared analyses were used to compare the percentage of Australian and Canadian survivors' top 10 'high/very high' unmet needs. Missing and uncodeable data were excluded from these analyses[14].

Multivariable analyses (linear regression for domain scores and logistic regression for unmet needs) were conducted to examine factors associated with each of the three main outcomes, adjusting for potential confounders. Explanatory variables (country, age at diagnosis, time since diagnosis, travel time to treatment, sex, cancer type, employment status, education level, living with others, consulting a health care professional for cancer treatment or concerns about cancer in the last month and reporting a personal expense in the last month as a result of having cancer) with a p-value of  $\leq 0.2$  on univariate analyses were included in the regression analyses. A backwards stepwise method was used to exclude variables from the models, until only variables with a p-value <0.1 on the maximum likelihood statistic for logistic regression and Wald statistic for linear regression analyses, remained. As country was the variable of most interest it was included in all multivariable analyses regardless of the p-value. A significance level of 5% was used. The residuals of the final linear regression models were assessed for normality and homoscedasticity.

Post hoc power calculations were undertaken for this study. A total of 169 hematological cancer survivors were identified from the *Canadian Survivors Unmet Needs* study and 268 survivors participated in the Australian study, providing a total of 437 survivors. This number provided at least 80% power, with a significance level of 5%, to allow detection of differences in the percentage of Australian and Canadian survivors reporting no unmet needs and differences in the top high/very high unmet needs of approximately 14%. This sample size also allowed detection of a difference of 0.32 standard deviations in mean domain scores, with 90% power for parametric analysis, or approximately 80% power for non-parametric tests.

# RESULTS

#### **Participants**

*Australian sample:* Of 732 eligible survivors, 268 (37%) returned a completed survey (Figure 1). Participant and non-participant age group at diagnosis, sex, year of diagnosis, cancer type and urban/rural location at diagnosis, were compared. Adults 50 years and over at diagnosis had higher odds of participating compared to survivors 15 to 39 years at diagnosis[15].

*Canadian sample*: Of the 375 eligible survivors 169 (45%) returned a completed survey (Figure 1). Responder and non-responder sex and age-group from two of the three registries were compared. A higher percentage of survivors aged 50 to 69 years were responders, and survivors under 40 years and over 70 years at diagnosis were more likely to be non-responders.

The Canadian sample had a significantly higher consent rate compared to the Australian sample ( $\chi^2$ =7.42, df(1), p=0.006).

Demographic and disease characteristics were similar for Australian and Canadian survivors, except that a higher percentage of Australians were currently employed, while time since diagnosis was longer for Canadians (Table 1). Of the ten personal expenses listed, expenses in the last month relating to parking while at hospital or clinic appointments (31%, n=130), travelling to appointments (28%, n=119) and drugs or treatment (21%, n=90) were the three most highly endorsed by survivors.

#### Outcome one: No unmet needs

Three hundred and thirty four (76%) participants (207 Australians and 127 Canadians) completed all 89 items of the SUNS (Figure 1). Of these, 21% (n=71) reported no unmet needs on all 89 items. Over a quarter of Canadians reported no unmet needs (n=35; 28%) compared to only 17% (n=36) of Australians ( $\chi^2$ =4.86, df(1), p=0.027). Age group at diagnosis (LR $\chi^2$ =11.1(2), p=0.004), consulting a health professional for cancer treatment or concerns about cancer in the last month (LR $\chi^2$ =5.0(1), p=0.025), having a personal expense in the last month as a result of having cancer (LR $\chi^2$ =10.1(1), p=0.002) and country (LR $\chi^2$ =2.9(1), p=0.091) were included in the final logistic regression model for this outcome. Survivors 60 years and over (OR 2.6, 95% CI: 1.2, 5.9) had significantly higher odds of reporting no unmet needs compared to survivors 15-49 years at diagnosis. Those who did not see a health professional (OR 2.2, 95% CI: 1.1, 4.5) or did not have a personal expense (OR 3.2, 95% CI: 1.5, 6.9) in the last month reported higher odds than survivors who did. Although, Canadians had slightly higher odds of reporting no unmet needs than Australians this was not statistically significant (OR 1.7, 95% CI: 0.92, 3.0).

#### Outcome two: Domain scores

On univariate analyses Australians reported a higher level of *'financial concerns'* and *'relationships'* needs compared to Canadians (Table 2). However, after controlling for other variables these differences were no longer significant (Table 3). Table 3 illustrates the characteristics associated with survivor's domain scores. Country was not significantly associated with any domain score following linear regression analyses. Having a personal expense in the last month as a result of having cancer, younger age at diagnosis, female sex, vocational or other level education and

consulting a health care professional for cancer treatment or concerns about cancer in the last month were associated with multiple domains of need (Table 3). The regression diagnostics for all final models demonstrated slight to moderate skew and some heteroscedasticity.

# Outcome three: Most prevalent 'high/very high' unmet needs

Missing and uncodeable data for SUNS items ranged from 2.1% to 6.0%.

The highest unmet need item for both samples was "*dealing with feeling tired*," with a similar percentage reporting a 'high/very high' unmet need in this area (Table 4). Sex (LR $\chi^2$ =6.1(1), p=0.014), consulting a health professional about cancer treatment or concerns about cancer in the last month (LR $\chi^2$ =6.4(1), p=0.011), reporting a personal expense in the last month (LR $\chi^2$ =2.8(1), p=0.094) and country (LR $\chi^2$ =0.26(1), p=0.611) were included in the final logistic regression model for this outcome. Females reported higher odds of reporting a 'high/very high' unmet need with this item than males (OR 1.9; 95% CI: 1.1, 3.2). Survivors who consulted a health professional in the last month reported higher odds than survivors who did not (OR 2.1; 95% CI: 1.2, 3.9).

On univariate analyses a significantly higher percentage of Australians reported a 'high/very high' unmet need for '*finding someone to talk to who understands and has been through a similar experience*' (Table 3). Country (LR $\chi^2$ =2.1(1), p=0.14), sex (LR $\chi^2$ =4.4(1), p=0.036), age at diagnosis (LR $\chi^2$ =14.8(2), p=0.001), living with others (LR $\chi^2$ =2.9(1), p=0.087) and a personal expense in the last month due to cancer (LR $\chi^2$ =10.2(1), p=0.001) were included in the final logistic regression model for this

outcome. Females had significantly higher odds than males of reporting a 'high/very high' unmet need with this item (OR 1.9; 95% CI: 1.0, 3.5). Survivors 15-49 (OR 3.6; 95% CI: 1.7, 7.7) and 50-59 (OR 3.1; 95% CI: 1.5, 6.3) years at diagnosis had higher odds than survivors 60 years and over. Survivors reporting a personal expense in the last month had higher odds of reporting a 'high/very high' unmet need for this item than those who did not (OR 2.6; 95% CI: 1.4, 4.9).

On univariate analyses a significantly higher percentage of Australians reported a 'high/very high' unmet need with '*worry about earning money*' (Table 3). Country (LR $\chi^2$ =4.0(1), p=0.045), age at diagnosis (LR $\chi^2$ =25.5(2), p<0.001) and having a personal expense in the last month as a result of having cancer (LR $\chi^2$ =15.4(1), p<0.001) were included in the final logistic regression model for this outcome. Australians reported marginally nonsignificantly higher odds than Canadians (OR 2.1; 95% CI: 0.99, 4.3). Survivors aged 15-49 (OR 4.8; 95% CI: 2.0, 11.5) and 50-59 (OR 6.5; 95% CI: 2.9, 15.0) years at diagnosis had significantly higher odds of reporting a 'high/very high' unmet need for this item than survivors aged 60 years and over. Survivors who reported a personal expense in the last month had significantly higher odds than survivors reporting no personal expense in the last month (OR 3.7; 95% CI: 1.9, 7.4).

#### DISCUSSION

This is one of the largest population-based studies of hematological cancer survivor unmet needs and the only international comparison. Australian and Canadian hematological cancer survivors appear to report similar levels and types of unmet needs. However, Australians illustrated marginally higher odds of reporting a 'high/very high' unmet need for "*worry about earning money*," compared to Canadians, which was of borderline statistical significance. Canadians also had marginally non- significantly higher odds of reporting no unmet needs than Australians. Given the similarities in health care services between Australia and Canada additional international comparative studies are needed to further explore potential cross-cultural differences in the psychosocial outcomes of cancer survivors. Additional data in this area will help determine whether psychosocial data from one country can be generalized to a similar population in another country.

This study also provides vital insight into the unmet needs of hematological cancer survivors, a population where such information is scarce. '*Dealing with feeling tired*' was the highest unmet need for both Australian and Canadian survivors. There is an abundance of research assessing the unmet needs in other cancer populations. However differences in the needs assessment measures used in these studies make it difficult to compare with the current results. Despite this, a number of previous studies have identified feeling tired or a lack of energy as a top unmet need of cancer patients[6, 16-21]. Strategies aimed at reducing fatigue in hematological cancer survivors should be assessed using methodologically rigorous intervention studies.

Australian survivors identified a need to talk to someone who has been through a similar experience and finding affordable car parking as their second and third most prevalent unmet needs. Accessible/easy car parking[6, 22-26] and needing to talk to other cancer patients[22-24] have previously been reported as prevalent unmet needs in studies of hematological and other cancer survivors. Again, the use of different needs assessment measures in these studies make it difficult to compare to our results.

Nevertheless, low cost peer support services that aim to match hematological cancer survivors to those going through similar experiences may be an intervention strategy worth future investigation. Such services may be particularly beneficial for survivors experiencing personal expenses due to cancer, females and younger survivors. While affordable car parking was only identified as a top unmet need by Australian survivors, parking while at hospital or clinic appointments was endorsed by both samples as the greatest personal expense in the last month due to cancer. Providing free or subsidized parking may help alleviate hematological cancer survivors unmet needs.

There is increasing recognition that the psychosocial outcomes of cancer survivors are impacted by a multitude of factors including: individual-level, disease/treatment, social and health care factors[27]. Results from the multivariable analyses provide some provisional insights into factors associated with hematological cancer survivor unmet needs.

# Individual characteristics

Similar to previous findings in other samples of cancer survivors[16, 17, 19, 21, 28] and hematological samples[22, 29], younger survivors were found to experience higher levels of some unmet needs. Females, survivors with a vocational level education, survivors experiencing a recent personal expense as a result of cancer and survivors who have recently consulted a health care provider about their cancer may also be sub-groups of hematological cancer survivors that require additional assistance in addressing some areas of need.

#### Disease and treatment characteristics

No disease characteristics assessed, including cancer type and time since diagnosis, were found to be associated with any of the outcomes. Unfortunately variation between survey coverage and items prevented comparisons between other disease and treatment characteristics that have previously been found to be associated with some cancer survivor needs, including remission status[17, 20, 28] and some treatment types[17, 20, 21, 26, 30]. We suspect such characteristics to be associated with hematological cancer survivor unmet needs, particularly treatment status and type, which can be highly variable between hematological cancer patients. For instance some will undergo an initial period of "watchful-waiting" where treatment will not be required for some time after diagnosis[7], while others undergo intensive and often debilitating treatments (i.e. bone marrow transplant)[7]. In a previous study the presence of treatment side effects was associated with multiple myeloma survivors reporting unmet needs[23].

#### Limitations

The low consent rates of both samples (below 50%) could affect the generalizability of the results. However, both the Australian[15] and Canadian samples were found to be fairly representative of the sample population on variables available for comparison, except age-group at diagnosis. The response rate is also comparable to other psychosocial survey studies that have recruited from population-based cancer registries[17, 31].

There were variations in the eligibility criteria of the two samples. The Canadian sample included those diagnosed 1-5 years prior, whereas the Australian sample

included survivors diagnosed in the last 3 years. The age range of survivors also differed. Other variables that may have impacted on survivor's level of unmet needs, such as current treatment, remission status and marital status, were unable to be compared and included in multivariable analyses due to differences in the wording and/or coverage of survey items. Future international comparative studies should strive to employ identical research protocols where possible. Finally, distribution of the residuals from the final linear regression models were slightly to moderately skewed, with some heteroscedasticity. However given the sample size, parameter estimates should be unbiased, but variance may be underestimated[32].

# Conclusions

The current data extends our understanding of the specific concerns faced by hematological cancer survivors. The unmet needs of Canadian and Australian hematological cancer survivors appear similar in most areas. Dealing with tiredness seems to be a significant concern faced by hematological cancer survivors. A number of subgroups may require additional support in addressing multiple areas of need, including those who are younger, female, have experienced a recent personal expense due to cancer, have a vocational or other level education or have recently consulted a health care professional about cancer.

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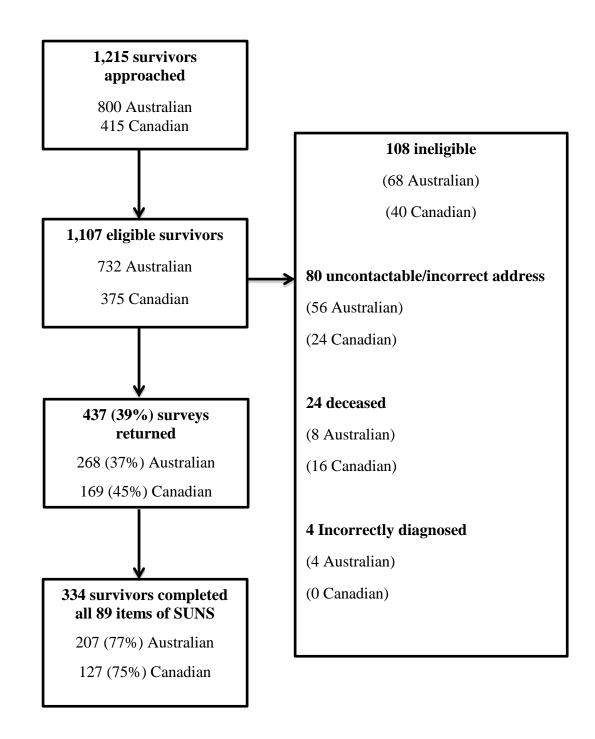


Figure 1. Recruitment and data collection process for Australian and Canadian study samples

| Characteristics                           | Australian<br>survey sample<br>(n = 268) |     | Canadian survey<br>sample<br>(n = 169) |    | Chi-squared<br>test statistic<br>(df) | p-value |
|---|--|-----|--|----|---------------------------------------|---------|
|   |  |     |  |    |                                       |         |
|   |  |     |  |    |                                       |         |
|   | n  | %   | n                                      | %  |                                       |         |
| Gender                                    |  |     |  |    | 0.73 (1)                              | 0.394   |
| Male                                      | 157                                      | 59  | 92                                     | 54 |                                       |         |
| Cancer Type                               |  |     |  |    | 6.16 (3)                              | 0.104   |
| Non-Hodgkin's Lymphoma                    | 134                                      | 50  | 88                                     | 52 |                                       |         |
| Leukemia                                  | 72                                       | 27  | 32                                     | 19 |                                       |         |
| Myeloma                                   | 42                                       | 16  | 27                                     | 16 |                                       |         |
| Other (incl. other lymphoma and           | 20                                       | 7.5 | 22                                     | 13 |                                       |         |
| myeloproliferative disorder)              |  |     |  |    |                                       |         |
| Age at diagnosis                          |  |     |  |    | 2.57 (2)                              | 0.276   |
| 15-49                                     | 56                                       | 21  | 28                                     | 17 |                                       |         |
| 50-59                                     | 74                                       | 28  | 41                                     | 24 |                                       |         |
| 60+                                       | 138                                      | 51  | 100                                    | 59 |                                       |         |
| Approximate time since diagnosis          |  |     |  |    | 129.89 (2)                            | < 0.001 |
| (months) <sup>a</sup>                     |  |     |  |    |                                       |         |
| 1-24                                      | 171                                      | 72  | 50                                     | 30 |                                       |         |
| 25-36                                     | 63                                       | 26  | 39                                     | 23 |                                       |         |
| 37-60                                     | 5  | 2.1 | 80                                     | 47 |                                       |         |
| <i>Education<sup>a</sup></i>              |  |     |  |    | 2.93 (2)                              | 0.231   |
| High school or below                      | 110                                      | 41  | 71                                     | 44 |                                       |         |
| University or higher                      | 53                                       | 20  | 41                                     | 25 |                                       |         |
| Vocational training or other              | 103                                      | 39  | 51                                     | 31 |                                       |         |
| Employment <sup>a</sup>                   |  |     |  |    | 4.11(1)                               | 0.043*  |
| Current paid employment                   | 124                                      | 47  | 58                                     | 37 |                                       |         |
| Current non-paid                          | 141                                      | 53  | 100                                    | 63 |                                       |         |
| Travel time for treatment <sup>a</sup>    |  |     |  |    | 0.05(1)                               | 0.822   |
| Less than 2 hours                         | 213                                      | 87  | 139                                    | 86 | - \ /                                 |         |
| 2 hours or more                           | 33                                       | 13  | 23                                     | 14 |                                       |         |
| Live with others <sup>a</sup>             | 225                                      | 84  | 124                                    | 79 | 1.56(1)                               | 0.212   |
| Consulted a health care professional for  | 130                                      | 49  | 71                                     | 46 | 0.44(1)                               | 0.505   |
| cancer treatment or concerns in last      |  | -   | . –                                    |    |                                       |         |
| month <sup>a</sup>                        |  |     |  |    |                                       |         |
| Personal expense as a result of cancer in | 119                                      | 45  | 70                                     | 45 | 0.03(1)                               | 0.868   |
| last month <sup>a</sup>                   |  | -   | ~ ~                                    |    |                                       |         |

 Table 1: Socio-demographic, disease and health care characteristics of Australian and

 Canadian hematological cancer survivors

<sup>a</sup>Numbers may not add to total sample size due to missing values \*Significant at p<0.05

|                                  |     | Australian | sample                    | Canadian sample |        |                           |         |             |
|----------------------------------|-----|------------|---------------------------|-----------------|--------|---------------------------|---------|-------------|
| Domain                           | n   | Median     | Quartile 1,<br>Quartile 3 | n               | Median | Quartile 1,<br>Quartile 3 | z-score | p-<br>value |
| Information needs                | 259 | 0.57       | 0, 1.4                    | 164             | 0.38   | 0, 1.4                    | 0.54    | 0.591       |
| Financial concerns               | 259 | 0.27       | 0, 1                      | 163             | 0.18   | 0, 0.7                    | 1.97    | 0.049*      |
| Access and<br>continuity of care | 260 | 0.14       | 0, 0.9                    | 165             | 0.09   | 0, 0.7                    | 1.12    | 0.262       |
| Relationships                    | 259 | 0.40       | 0, 1.3                    | 164             | 0.17   | 0, 0.9                    | 2.27    | 0.024*      |
| Emotional Health                 | 258 | 0.50       | 0.1, 1.4                  | 164             | 0.30   | 0, 1.1                    | 1.89    | 0.059       |

| Table 2: Australian | and Canadian median | domain scores |
|---------------------|---------------------|---------------|
|                     |                     |               |

\*Significant at p<0.05

|                                | Information        | Financial Concerns | Access and Continuity | Relationships     | <b>Emotional Health</b> |
|--------------------------------|--------------------|--------------------|-----------------------|-------------------|-------------------------|
|                                | needs              |                    | of care               | _                 |                         |
|                                |                    | p-value            | p-value               | p-value           | p-value                 |
|                                | <i>p-value</i>     | Coef. (95%CI)      | Coef. (95%CI)         | Coef. (95%CI)     | Coef. (95%CI)           |
|                                | Coef. (95%CI)      |                    |                       |                   |                         |
| Variable                       |                    |                    |                       |                   |                         |
| Country                        |                    |                    |                       |                   |                         |
| Canada                         | 1                  | 1                  | 1                     | 1                 | 1                       |
| Australia                      | 0.828              | 0.149              | 0.735                 | 0.202             | 0.245                   |
|                                | 0.02 (-0.17, 0.21) | 0.12(-0.04, 0.29)  | 0.03(-0.13, 0.19)     | 0.12(-0.06, 0.30) | 0.11(-0.08, 0.31)       |
| Sex                            |                    |                    |                       |                   |                         |
| Male                           | 1                  |                    | 1                     | 1                 | 1                       |
| Female                         | 0.043*             |                    | 0.068                 | 0.002*            | 0.004*                  |
|                                | 0.19 (0.01, 0.38)  |                    | 0.14(-0.01, 0.30)     | 0.29(0.11, 0.47)  | 0.28(0.09, 0.47)        |
| Age group (years)              |                    |                    |                       |                   |                         |
| 15-49                          | 0.011*             | 0.001*             | 0.155                 | <0.001*           | 0.003*                  |
|                                | 0.31 (0.07, 0.55)  | 0.35(0.15, 0.56)   | 0.14(-0.05, 0.34)     | 0.57(0.34, 0.80)  | 0.37(0.12, 0.61)        |
| 50-59                          | 0.025*             | <0.001*            | 0.069                 | 0.002*            | 0.013*                  |
|                                | 0.25(0.03, 0.48)   | 0.44(0.25, 0.64)   | 0.17(-0.01, 0.35)     | 0.33(0.12, 0.54)  | 0.28(0.06, 0.50)        |
| 60+                            |                    | 1                  | 1                     | 1                 |                         |
| Education                      |                    |                    |                       |                   |                         |
| High school or lower           |                    | 1                  | 1                     | 1                 |                         |
| Vocational or other            |                    | 0.354              | 0.030*                | 0.011*            |                         |
|                                |                    | 0.09(-0.10, 0.27)  | 0.19(0.02, 0.37)      | 0.26(0.06, 0.46)  |                         |
| University or higher           |                    | 0.085              | 0.711                 | 0.463             |                         |
|                                |                    | -0.19(-0.40, 0.03) | -0.04(-0.24, 0.17)    | 0.09(-0.15, 0.32) |                         |
| Personal expense in last month |                    | , (,)              |                       |                   |                         |
| as a result of having cancer   |                    |                    |                       |                   |                         |
| No                             | 1                  | 1                  | 1                     | 1                 | 1                       |
| Yes                            | <0.001*            | <0.001*            | <0.001*               | 0.026*            | 0.006*                  |

# Table 3: Patient characteristics associated with mean domain scores

|                               | 0.48 (0.29, 0.66) | 0.50(0.33, 0.66) | 0.31(0.16, 0.47) | 0.23(0.03, 0.43) | 0.30(0.09, 0.51) |
|-------------------------------|-------------------|------------------|------------------|------------------|------------------|
| Consulted a health care       |                   |                  |                  |                  |                  |
| professional about cancer     |                   |                  |                  |                  |                  |
| treatment or concerns in last |                   |                  |                  |                  |                  |
| month                         |                   |                  |                  |                  |                  |
| No                            |                   |                  |                  | 1                | 1                |
| Yes                           |                   |                  |                  | 0.018*           | 0.024*           |
|                               |                   |                  |                  | 0.24(0.04, 0.44) | 0.24(0.03, 0.45) |

\*Significant at p<0.05

# Table 4: Australian and Canadian top 'high/very high' unmet needs

|      | Australian survivors   |           |                    |                               |  |  |  |
|------|--|-----------|--------------------|-------------------------------|--|--|--|
| Rank | Item   | n (%)     | Domain             | Rank for Canadian survivors   |  |  |  |
| 1    | Dealing with feeling tired   | 46 (17.9) | Emotional Health   | 1                             |  |  |  |
| 2    | Finding someone to talk to who understands and has been through a similar experience | 44 (16.9) | Relationships      | 36*                           |  |  |  |
| 3    | Finding car parking that I can afford at the hospital or clinic                      | 43 (16.7) | Work and Financial | 29                            |  |  |  |
| 4    | Coping with having a bad memory or lack of focus                                     | 42 (16.3) | Emotional Health   | 10                            |  |  |  |
| 5    | Dealing with worry about the emotional well-being of my family                       | 40 (15.6) | Emotional Health   | 26                            |  |  |  |
| 6    | Dealing with not feeling able to set future goals or make long-term plans            | 40 (15.5) | Emotional Health   | 6                             |  |  |  |
| 7    | Worry about earning money  | 39 (15.4) | Work and Financial | 60*                           |  |  |  |
| 8    | Dealing with being told I had cancer   | 39 (15.2) | Emotional Health   | 2                             |  |  |  |
| 9    | Dealing with changes in my physical ability  | 39 (15.2) | Emotional Health   | 20                            |  |  |  |
| 10   | Dealing with fears about cancer spreading  | 39 (15.1) | Information needs  | 7                             |  |  |  |
|      | Canadian Surviv  | ors       |                    |                               |  |  |  |
| Rank | Item   | n (%)     | Domain             | Rank for Australian survivors |  |  |  |
| 1    | Dealing with feeling tired   | 30 (18.3) | Emotional Health   | 1                             |  |  |  |
| 2    | Being told I had cancer  | 30 (18.3) | Emotional Health   | 8                             |  |  |  |
| 3    | Dealing with not feeling sure that the cancer has gone                               | 25 (15.2) | Information needs  | 13                            |  |  |  |
| 4    | Dealing with feeling stressed  | 25 (15.2) | Emotional Health   | 17                            |  |  |  |
| 5    | Dealing with feeling vulnerable  | 24 (14.6) | Emotional Health   | 25                            |  |  |  |
| 6    | Dealing with not feeling able to set future goals or make long-term plans            | 23 (14.0) | Emotional Health   | 6                             |  |  |  |
| 7    | Dealing with fears about cancer spreading  | 23 (13.9) | Information Needs  | 10                            |  |  |  |
| 8    | Dealing with feeling worried (anxious)   | 22 (13.3) | Emotional Health   | 14                            |  |  |  |
| 9    | Dealing with feelings about death and dying  | 20 (12.3) | Emotional Health   | 38                            |  |  |  |
| 10   | Coping with having a bad memory or lack of focus                                     | 20 (12.3) | Emotional Health   | 4                             |  |  |  |

\*Significant difference (p<0.05) between percentage of Australian and Canadian survivors reporting a 'high/very high' unmet need on that item