A national study of the unmet needs of support persons of haematological cancer survivors in rural and urban areas of Australia

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Abstract

Purpose

This study aimed to compare support persons of haematological cancer survivors living in rural and urban areas in regard to the type, prevalence and factors associated with reporting unmet needs.

Methods

One thousand and four (792 urban and 193 rural) support persons of adults diagnosed with haematological cancer were recruited from five Australian state population-based cancer registries. Participants completed the Support Person Unmet Needs Survey (SPUNS) that assessed the level of unmet needs experienced over the past month across six domains.

Results

Overall, 66% of support persons had at least one ‘moderate, high or very high’ unmet need and 24% (n = 182) reported having multiple (i.e. 6 or more) ‘high/very high’ unmet needs in the past month. There were no significant differences between rural and urban support persons in the prevalence of multiple unmet needs or mean total unmet needs scores. There were however significant differences in the types of ‘high/very high’ unmet needs with support persons living in rural areas more likely to report finance-related unmet needs. Support persons who indicated they had difficulty paying bills had significantly higher odds of reporting multiple ‘high/very high’ unmet needs.

Conclusions

This is the first large, population-based study to compare the unmet needs of support persons of haematological cancer survivors living in rural and urban areas. Findings confirm previous evidence that supporting a person diagnosed with haematological cancer correlates with a high level of unmet needs and highlight the importance of developing systemic strategies for assisting support persons, especially in regard to making financial assistance and travel subsidies known and readily accessible to those living in rural areas.

Keywords

Supportive care · Informal care givers · Unmet needs · Haematological

Introduction

Currently, over 32 million people globally live with cancer [1] with incidence predicted to increase by 70% over the next two decades [2]. As health care systems struggle to cope with the mounting cancer burden and treatments have shifted from inpatient to outpatient modalities [3], care for cancer survivors is increasingly dependent upon relatives, friends and partners as informal caregivers (here on referred to as support persons) [4]. Support persons serve a crucial role in assisting patients during treatment, managing both disease and treatment-related side-effects, providing emotional and financial support, helping with activities of daily living and taking on additional family responsibilities [5, 6]. National survey data from the USA indicates that on average, support persons provide care for 8.3 h a day [6] addressing more than 50% of the care needs of cancer survivors [7]. In 2009, over 65 million
people in the USA served as support persons for ill relatives [8], while in Australia, the number is estimated to be 2.7 million and rising [9].

Caring for a person with cancer places enormous financial, physical and emotional burden on those taking on the role [10–14]. Cancer support persons report conflict and strain in their relationships [12], sleep deprivation and fatigue [15], diminished physical health [11, 12], heightened responsibility and fear [3], sexual dysfunction [16], and legal and financial hardship [17]. Estimations of the direct costs to support persons including hours spent having to take sick leave, holiday and unpaid leave as well as direct expenses, suggest an economic burden of $14,060US per year per cancer diagnosis [18]. An increasing worldwide incidence [19], lower survival rates [19] and aggressive treatment regimes that are often ongoing [20] mean that survivors of haematological cancer are a unique and vulnerable population. The role of support persons for this population may be especially critical.

To enable health care providers to address the needs of support persons, it is important to understand and assess their unmet supportive care needs. Unmet needs have been defined with particular issues and the services or support actually received [21]. They include informational, physical, social, emotional, spiritual and practical needs [22]. Limited research has explored the supportive care needs of support persons of haematological cancer survivors [3], with some evidence suggesting that they may have greater or specific needs that differ from support persons for other cancer patient populations. For example, a recent Australian study of newly diagnosed cancer patients and their support persons found that carers of haematological cancer patients reported significantly greater unmet needs compared with support persons of people diagnosed with solid tumours [14].

For cancer survivors (and their support persons) living in rural areas, there are additional burdens of greater distances to treatment centres, less access to health care providers and support groups, the need for relocation and associated financial costs [23]. To our knowledge, no studies have compared the unmet needs of support persons living in rural areas with those in urban areas. Further, no studies have investigated the unmet needs of support persons of haematological cancer survivors living in rural areas in regard to the type, prevalence and factors associated with reporting unmet needs and identify services perceived as helpful in reducing impact of unmet needs.

Methods

Study design

A cross-sectional, population-based sample of adult support persons were recruited as part of a larger, national study on unmet needs and psychological well-being of haematological cancer survivors and their support persons in Australia.

Participants

Study participants were adult support persons nominated by each haematological cancer survivor and defined as ‘someone who has helped you the most during your cancer journey.’ Cancer survivors were adults aged between 18 and 80 years and diagnosed with an ICD-10 or ICD-0-3 (M) defined haematological cancer (including leukaemia, non-Hodgkin lymphoma, myeloma and other blood cancers) recruited from five Australian state population-based cancer registries. There are eight state and territory cancer registries across Australia that serve a vital role in monitoring cancer incidence, mortality and linkage with patterns of care [26].

Procedure

Eligible cancer survivors were identified and recruited from each registry according to their specified registry recruitment procedures as described elsewhere [27]. All recruited cancer survivors were mailed a study package containing an invitation letter from the registry, a pamphlet explaining the purpose of the cancer registry, a study information statement, survey and reply-paid envelope. A second survey and reply-paid envelope were also included for survivors to pass on to their nominated support person. Non-responding survivors were sent a reminder letter and second study package after 3 weeks, with a follow-up telephone reminder at 6 weeks.

Measures

Socio-demographic-related items

The following demographic data were collected from support persons: gender, age, residential postcode, marital status, nationality, indigenous status, education, employment status, relationship to survivor and if living with the cancer survivor. Support persons were also asked about their own, if any, cancer history and non-cancer-related health problems.
Residential postcodes were used to classify support persons as ‘rural’ or ‘urban’ based on the Accessibility and Remoteness Index of Australia (ARIA+) [28].

Support Person Unmet Needs Survey

The 78-item Support Person Unmet Needs Survey (SPUNS) assesses the level of unmet need experienced by support persons over the past month across six domains: Information and Relationship Needs (27 items), Work and Financial Needs (8 items), Needs for Access and Continuity of Care (9 items), Personal Needs (14 items), Emotional Needs (16 items) and Needs relating to the Future (4 items). Each item is scored from zero to four, with zero representing ‘no unmet need’ and four representing a ‘very high unmet need’. A total unmet needs score was calculated by summing responses to the 78-item SPUNS. A total SPUNS score of zero corresponded with reporting no unmet needs. Six domain scores were calculated by summing responses for domain-specific items and dividing by the number of non-missing responses for that domain. The SPUNS has demonstrated satisfactory levels of reliability and construct validity among cancer survivor support persons [29].

Psychological well-being

The 21-item Depression, Anxiety and Stress Scale (DASS 21) was used to measure self-reported anxiety (e.g. I found it hard to wind down), depression (e.g. I felt I had nothing to look forward to) and stress (e.g. I experienced breathing difficulty) over the past week. Participants responded to each item on a 4-point scale from zero to three, with ‘zero’ representing ‘did not apply to me at all’ and ‘three’ representing ‘applied to me very much, or most of the time’. Three (3) sub-scales are assessed with seven items and domain scores are calculated by summing all subscale items and multiplying by two. DASS-21 cut-off scores of ‘10 or higher’ for depression, ‘8 or higher’ for anxiety and ‘15 or higher’ for stress were used to indicate clinical levels of symptoms [30]. Scores were only calculated for participants who responded to six or more items in each DASS-21 sub-scale. The DASS 21 has demonstrated acceptable levels of reliability and validity [31].

Additional adverse impacts

Seven items relating to other adverse impacts associated with providing care for a cancer survivor were asked of participants. These included Have you had to relocate as a result of the person you support having blood cancer? (Yes, temporarily; Yes, permanently; No). Those who responded ‘Yes, temporarily’ were asked to indicate how much time they spent in temporary accommodation. Those who responded ‘Yes, permanently’ were asked: Where did you relocate to? (Different place in the same town or city; Another town or city; Inter-state; Over-seas). All participants were asked about time spent travelling to access treatment services (5 response options); whether they had experienced any of seven different financial impacts (e.g. ‘Had less income’, ‘Had difficulty paying bills’); and preferred services perceived as helpful in reducing financial impacts.

Data analysis

Each categorical variable was summarised using frequencies and percentages with comparisons between urban and rural groups using chi-square/Fisher’s exact tests. Continuous variables were summarised using means, standard deviations, medians, min/max and interquartile ranges. Comparisons between urban and rural were conducted using t tests or Kruskal-Wallis tests. The mean, standard deviation, median and first and third quartile for each of the six SPUNS domains and total SPUNS scores were calculated. A conservative method of only utilising data from participants who completed more than 70% of items was adopted [32]. The percentage of support persons who reported a ‘high/very high’ level of unmet need was calculated for each of the 78 SPUNS items. Multiple unmet needs were defined as six or more ‘high/very high’ unmet needs, a similar cut-point used in previous research [16]. Multiple logistic regression analyses were conducted to identify factors associated with reporting multiple ‘high/very high’ unmet needs. All sociodemographic variables, the three DASS subscales and all additional adverse impact variables were included in logistic regression analyses. Variables with a p value of ≤0.2 on univariate analyses were included in the final multiple regression analyses. Complete case analysis was conducted. Statistical analyses were performed using SAS v9.4.

Results

Study sample

Of 4299 eligible haematological cancer survivors invited to participate in the larger national study, 1511 (35%) returned a completed survey. Of these, 1058 (92%) indicated they had planned to pass a survey on to their support person with 1004 (95%) support persons (792 urban and 193 rural) returning a completed survey. The majority of support persons were female (67%), aged over 60 years (56%) and the spouse or partner (84%) of a haematological cancer survivor. Rural support persons were less likely to have post-secondary school education (p = 0.006) and more likely to be have been born in Australia (p = 0.001) compared to urban participants (see Table 1). Twelve percent of support persons (n = 118) reported having a previous diagnosis of cancer themselves with the most common being breast (26%) and 49% (n = 487)
indicated they experienced other non-cancer health-related problems including arthritis (74%) and vision or hearing difficulties (54%). Rates of reported health problems did not differ significantly between urban and rural support persons.

### Prevalence of unmet needs

Overall 18% \((n = 172)\) of support persons expressed no unmet needs with 82% \((n = 802)\) reported having at least one unmet need. Two-thirds (66%) of support persons had at least one ‘moderate, high or very high’ unmet supportive care need with a median number of 5. Twenty-four percent \((n = 182)\) of participants identified having 6 or more ‘high/very high’ unmet needs. Of 1004 participants, 996 (99%) completed more than 70% of SPUNS items with the mean total unmet needs score for participants \((n = 996)\) found to be 47 (SD = 56) with a median of 26.0 (Q1 = 4.0; Q3 = 72). There were no significant differences between rural and urban support persons in regard to the prevalence of multiple unmet needs, median number of moderate/high/very high needs, mean total unmet needs scores and each of the six mean domain scores (as shown in Table 2). However, a significantly higher proportion of rural support persons (76%) had at least one ‘moderate/high/very high’ unmet need compared with urban support persons (64%, \(\chi^2 = 8.72, p = 0.003\)).

### Top ten ‘high/very high’ unmet needs

All four items in Needs relating to the Future were ranked in the top ten most frequently reported ‘high/very high’ unmet needs (see Table 3) with three of these—‘Dealing with worrying about the future of the person I support’ (19%), ‘Dealing with not knowing what lies in the future’ (19%) and ‘Dealing with worry about the cancer getting worse’ (14%) ranked one,
two and three, respectively. Five items from the Personal Needs domain were also listed in the top ten unmet needs. Rural and urban participants differed in regard to only one of the top ten needs—‘Finding information about what type of financial help is available and how to obtain it’ with significantly more rural support persons (20%) reporting this as a concern compared to their urban (13%, \( p = 0.008 \)) counterparts.

Factors associated with multiple ‘high/very high’ unmet needs

All of the variables tested in univariate analyses were found to have \( p \) values of 0.2 or less and hence were subsequently included in the multivariate analysis with the exception of two variables—‘number of health conditions’ and ‘had to sell an asset’. Results of multiple logistic regression analysis found that support persons who had ‘Difficulty paying bills’ (AOR = 3.02, 95%CI 1.42:6.45, \( p = 0.0042 \)), scored \( \geq 10 \) on the DASS-21 depression subscale (AOR = 5.91, 95%CI 3.37:10.36, \( p < 0.0001 \)) and scored \( \geq 14 \) on the DASS-21 stress subscale (AOR = 4.71, 95%CI 2.64:8.40, \( p < 0.0001 \)) had higher odds of reporting multiple ‘high/very high’ unmet needs. Living in a rural area and other sociodemographic variables were not significant predictors of multiple high unmet needs (see Table 4).

Additional adverse impacts

A significantly higher proportion of participants living in rural areas were forced to relocate temporarily in comparison with those living in urban areas (35 vs 8%, \( p < 0.0001 \)). For the majority of these (89%), relocation was to a different town or city. In contrast, 25% of urban participants forced to relocate did so within the same city versus only 1.5% of rural support persons (\( p < 0.0001 \)). The mean and median length of time spent in temporary accommodation for urban support persons was 125 and 77 days, respectively, with no significant

Table 2  Total and mean domain unmet needs scores of urban and rural support persons

| SPUNS domain                        | Urban \( (n = 193) \) mean (SD) | Rural \( (n = 792) \) mean (SD) | \( t \) | \( p \) |
|-------------------------------------|----------------------------------|---------------------------------|--------|-------|
| Information and relationship needs | 0.6 (0.8)                        | 0.7 (0.8)                       | 0.65   | 0.369 |
| Needs relating to the future       | 0.9 (1.0)                        | 1.1 (1.1)                       | 9.24   | 0.082 |
| Work and financial needs           | 0.3 (0.7)                        | 0.4 (0.7)                       | 7.34   | 0.099 |
| Needs for access and continuity of care | 0.4 (0.7)                         | 0.4 (0.7)                       | 1.74   | 0.250 |
| Personal needs                     | 0.8 (1.0)                        | 0.8 (0.9)                       | 0.004  | 0.812 |
| Emotional needs                    | 0.6 (0.9)                        | 0.7 (0.9)                       | 2.34   | 0.217 |
| Total unmet needs                  | 46.3 (56.7)                      | 51.0 (52.8)                     | 1.19   | 0.296 |

Table 3  Top ten most frequently reported ‘high or very high’ unmet needs in urban and rural support persons

| Overall rank | Unmet need item                                                                 | Domain                          | Total sample \( (n = 1004) \) n (%) | Urban \( (n = 792) \) n (%) | Rural \( (n = 193) \) n (%) | Chi-square | \( p \) |
|--------------|---------------------------------------------------------------------------------|---------------------------------|------------------------------------|-----------------------------|-----------------------------|------------|-------|
| 1            | Dealing with the worrying about the future of the person I support              | Needs relating to the future   | 186 (19%)                         | 140 (18%)                   | 43 (23%)                    | 2.65       | 0.104 |
| 2            | Dealing with not knowing what lies in the future                               | Needs relating to the future   | 184 (19%)                         | 144 (18%)                   | 38 (21%)                    | 0.61       | 0.433 |
| = 3          | Dealing with worry about the cancer getting worse                               | Needs relating to the future   | 138 (14%)                         | 105 (14%)                   | 31 (17%)                    | 1.50       | 0.221 |
| = 3          | Dealing with worries about the emotional well-being of my family               | Personal needs                 | 138 (14%)                         | 106 (14%)                   | 29 (16%)                    | 0.48       | 0.488 |
| 5            | Finding information about what type of financial help is available and how to obtain it | Information and relationship needs | 137 (14%)                         | 99 (13%)                    | 37 (20%)                    | 7.00       | 0.008 |
| 6            | Telling my family friends how I am feeling emotionally                          | Personal needs                 | 136 (14%)                         | 112 (14%)                   | 23 (12%)                    | 0.53       | 0.466 |
| 7            | Dealing with worry about the cancer coming back                                 | Needs relating to the future   | 130 (13%)                         | 105 (13%)                   | 23 (13%)                    | 0.09       | 0.764 |
| 8            | Dealing with feeling stressed                                                   | Personal needs                 | 125 (13%)                         | 97 (13%)                    | 26 (14%)                    | 0.22       | 0.637 |
| 9            | Not sleeping well                                                                | Personal needs                 | 122 (12%)                         | 91 (12%)                    | 28 (15%)                    | 1.73       | 0.188 |
| 10           | Feeling tired or lacking energy                                                 | Personal needs                 | 121 (12%)                         | 95 (12%)                    | 24 (13%)                    | 0.05       | 0.819 |
| Variable                     | Category                  | < 6 high/very high unmet needs (N = 569) | ≥ 6 high/very high unmet needs (N = 182) | Total (N = 751) | Crude OR (95%CI) | Crude p             | Adjusted OR (95%CI) | Adjusted p |
|------------------------------|---------------------------|-----------------------------------------|------------------------------------------|----------------|-----------------|---------------------|---------------------|------------|
| Gender                       | Male                      | 198 (35%)                               | 54 (30%)                                 | 252 (34%)      | 0.79 (0.55, 1.14) | 0.2028              | .                    | .          |
|                              | Female                    | 371 (65%)                               | 128 (70%)                                | 499 (66%)      | Ref             | .                   | .                    | .          |
| Age                          | 40 to 59                  | 201 (35%)                               | 85 (47%)                                 | 286 (38%)      | 1.14 (0.63, 2.04) | .0098               | 1.65 (0.71, 3.82) | 0.4563     |
|                              | 60–80                     | 317 (56%)                               | 78 (43%)                                 | 395 (53%)      | 0.66 (0.37, 1.18) | .        | 1.39 (0.57, 3.38) | .          |
|                              | 14 to 39                  | 51 (9.0%)                               | 19 (10%)                                 | 70 (9.3%)      | Ref             | .                   | .                    | .          |
| Rurality                     | Urban                     | 458 (80%)                               | 148 (81%)                                | 606 (81%)      | 1.05 (0.69, 1.62) | .        | 0.8058              | .          |
|                              | Rural                     | 111 (20%)                               | 34 (19%)                                 | 145 (19%)      | Ref             | .                   | .                    | .          |
| Relationship to person with cancer | Other relative           | 3 (0.5%)                               | 2 (1.1%)                                 | 5 (0.7%)       | 0.84 (0.12, 5.72) | .0586               | 1.05 (0.10, 10.81) | 0.0685     |
|                              | Sibling                   | 10 (1.8%)                               | 6 (3.3%)                                 | 16 (2.1%)      | 0.76 (0.22, 2.57) | .        | 0.86 (0.20, 3.73) | .          |
|                              | Parent                    | 34 (6.0%)                               | 16 (8.8%)                                | 50 (6.7%)      | 0.60 (0.24, 1.47) | .        | 0.40 (0.12, 1.32) | .          |
|                              | Spouse/partner            | 491 (86%)                               | 140 (77%)                                | 631 (84%)      | 0.36 (0.18, 0.73) | .        | 0.27 (0.11, 0.67) | .          |
|                              | Friend                    | 8 (1.4%)                                | 2 (1.1%)                                 | 10 (1.3%)      | 0.32 (0.06, 1.72) | .        | 0.21 (0.02, 1.95) | .          |
|                              | Other                     | 4 (0.7%)                                | 1 (0.5%)                                 | 5 (0.7%)       | 0.32 (0.03, 3.14) | .        | 0.05 (0.00, 1.43) | .          |
|                              | Child/grandchild          | 19 (3.3%)                               | 15 (8.2%)                                | 34 (4.5%)      | Ref             | .                   | .                    | .          |
| Education                    | Vocational or other       | 163 (29%)                               | 58 (32%)                                 | 221 (29%)      | 1.13 (0.43, 2.96) | .        | 0.8717              | .          |
|                              | Secondary                 | 224 (39%)                               | 69 (38%)                                 | 293 (39%)      | 0.98 (0.37, 2.54) | .        | .                    | .          |
|                              | University                | 163 (29%)                               | 49 (27%)                                 | 212 (28%)      | 0.95 (0.36, 2.52) | .        | .                    | .          |
|                              | Primary                   | 19 (3.3%)                               | 6 (3.3%)                                 | 25 (3.3%)      | Ref             | .                   | .                    | .          |
| Employment                   | Other                     | 3 (0.5%)                                | 6 (1.6%)                                 | 9 (0.8%)       | 2.98 (0.59, 15.00) | .        | 0.2841              | .          |
|                              | Unemployed                | 271 (48%)                               | 80 (44%)                                 | 351 (47%)      | 0.88 (0.63, 1.23) | .        | .                    | .          |
|                              | Employed                  | 295 (52%)                               | 99 (54%)                                 | 394 (52%)      | Ref             | .                   | .                    | .          |
| Lives with person with cancer | Yes                      | 518 (91%)                               | 158 (87%)                                | 676 (90%)      | 0.65 (0.39, 1.09) | .0999               | 0.65 (0.25, 1.69) | 0.3781     |
|                              | No                        | 51 (9.0%)                               | 24 (13%)                                 | 75 (10%)       | Ref             | .                   | .                    | .          |
| Country of birth             | Other                     | 121 (21%)                               | 45 (25%)                                 | 166 (22%)      | 1.22 (0.82, 1.80) | .4280              | .                    | .          |
|                              | Australia                 | 448 (79%)                               | 137 (75%)                                | 585 (78%)      | ref             | .                   | .                    | .          |
| Previous diagnosis of cancer | Yes                      | 61 (11%)                                | 19 (10%)                                 | 80 (11%)       | 0.97 (0.56, 1.67) | .4953              | .                    | .          |
|                              | No                        | 508 (89%)                               | 163 (90%)                                | 671 (89%)      | Ref             | .                   | .                    | .          |
| Forced to relocate           | Yes                      | 82 (14%)                                | 42 (23%)                                 | 124 (17%)      | 1.78 (1.17, 2.70) | .0066               | 0.87 (0.49, 1.55) | 0.6467     |
|                              | No                        | 487 (86%)                               | 140 (77%)                                | 627 (83%)      | Ref             | .                   | .                    | .          |
| Travel time                  | More than 2 h             | 86 (15%)                                | 25 (14%)                                 | 111 (15%)      | 0.89 (0.55, 1.45) | .4868              | .                    | .          |
|                              | Less than 2 h             | 483 (85%)                               | 157 (86%)                                | 640 (85%)      | Ref             | .                   | .                    | .          |
| Other impacts                | Take time off work        | 251 (44%)                               | 94 (52%)                                 | 345 (46%)      | 1.35 (0.97, 1.89) | .0763               | 0.97 (0.58, 1.62) | 0.9144     |
|                              | No                        | 318 (56%)                               | 88 (48%)                                 | 406 (54%)      | Ref             | .                   | .                    | .          |
| Other impacts                | Less income               | 151 (27%)                               | 73 (40%)                                 | 224 (30%)      | 1.85 (1.31, 2.63) | .0005               | 0.99 (0.55, 1.75) | 0.9617     |
Table 4 (continued)

| Variable                          | Category                      | <6 high/very high unmet needs (N=569) | ≥6 high/very high unmet needs (N=182) | Total (N=751) | Crude OR (95% CI) | Crude p       | Adjusted OR (95% CI) | Adjusted p       |
|----------------------------------|-------------------------------|----------------------------------------|---------------------------------------|---------------|--------------------|---------------|---------------------|-------------------|
| Other impacts                    | Resign or close my business  |                                        |                                       |               |                    |               |                     |                   |
| No                               |                               | 418 (73%)                              | 109 (60%)                             | 527 (70%)     | Ref                |               | 2.43 (1.38, 4.27)  | 0.0021            |
| No                               |                               | 32 (5.6%)                              | 23 (13%)                              | 55 (7.3%)     | Ref                |               | 2.08 (0.94, 4.61)  | 0.0721            |
| Other impacts                    | Difficulty paying bills      |                                        |                                       |               |                    |               |                     |                   |
| No                               |                               | 537 (94%)                              | 159 (87%)                             | 696 (93%)     | Ref                |               | <0.0001            | 3.02 (1.42, 6.45)  | 0.0042            |
| No                               |                               | 519 (91%)                              | 121 (66%)                             | 640 (85%)     | ref                |               |                     |                   |
| Other impacts                    | Used up savings              |                                        |                                       |               |                    |               |                     |                   |
| No                               |                               | 519 (91%)                              | 121 (66%)                             | 640 (85%)     | ref                |               |                     |                   |
| No                               |                               | 50 (8.8%)                              | 61 (34%)                              | 111 (15%)     | Ref                |               | 3.25 (2.21, 4.80)  | <0.0001           |
| No                               |                               | 491 (86%)                              | 120 (66%)                             | 611 (81%)     | ref                |               |                     |                   |
| Other impacts                    | Trouble meeting daily expenses |                                        |                                       |               |                    |               |                     |                   |
| No                               |                               | 542 (95%)                              | 140 (77%)                             | 682 (91%)     | Ref                |               | 6.02 (3.59, 10.11) | <0.0001           |
| No                               |                               | 491 (86%)                              | 120 (66%)                             | 611 (81%)     | ref                |               |                     |                   |
| Participated in support group in last month |                       |                                        |                                       |               |                    |               |                     |                   |
| Yes                              |                               | 15 (2.6%)                              | 4 (2.2%)                              | 19 (2.5%)     | 0.83 (0.27, 2.53)  | 0.7434        |                     |                   |
| No                               |                               | 554 (97%)                              | 178 (98%)                             | 732 (97%)     | Ref                |               |                     |                   |
| DASS depression                  | ≥10                           |                                        |                                       |               |                    |               |                     |                   |
| No                               |                               | 49 (8.6%)                              | 109 (60%)                             | 158 (21%)     | 15.85 (10.45, 24.04) | <0.0001 | 5.91 (3.37, 10.36) | <0.0001           |
| No                               |                               | 520 (91%)                              | 73 (40%)                              | 593 (79%)     | Ref                |               |                     |                   |
| DASS anxiety                     | ≥8                            |                                        |                                       |               |                    |               |                     |                   |
| No                               |                               | 37 (6.5%)                              | 77 (42%)                              | 114 (15%)     | 10.54 (6.76, 16.44) | <0.0001 | 1.22 (0.63, 2.39)  | 0.5552            |
| No                               |                               | 532 (93%)                              | 105 (58%)                             | 637 (85%)     | ref                |               |                     |                   |
| DASS stress                      | ≥14                           |                                        |                                       |               |                    |               |                     |                   |
| No                               |                               | 511 (90%)                              | 75 (41%)                              | 586 (78%)     | Ref                |               |                     |                   |
| No                               |                               | 58 (10%)                               | 107 (59%)                             | 165 (22%)     | 12.57 (8.42, 18.77) | <0.0001 | 4.71 (2.64, 8.40)  | <0.0001           |
| No                               |                               | 511 (90%)                              | 75 (41%)                              | 586 (78%)     | Ref                |               |                     |                   |
differences between rural and urban. Results indicated large differences in travel time from place of living to cancer treatment centres. Forty percent of rural participants had to travel between 2 and 5 h compared with only 5% of urban support persons, while travel time for the majority of those in urban areas (81%) was less than 1 h compared with 35% in rural areas (p < 0.0001).

When asked about financial impacts that occurred as a result of supporting the person with haematological cancer, significantly more participants from rural areas reported that they had to take time off work (52 vs 43%, p = 0.023), had less income (37 vs 27%, p = 0.009), had difficulty paying bills (22 vs 13%, p = 0.002), had trouble meeting day-to-day expenses (15 vs 8%, p = 0.011) and were forced to use up their savings (28 vs 16%, p = 0.0003) (see Table 5).

A higher proportion of rural support persons (54%) compared with urban (20%), indicated that getting treatment close to home would have been helpful in reducing the financial impact they experienced (p < 0.0001). Similarly, significantly more rural participants (26%) compared with urban (16%, p = 0.0013) indicated that access to free transport and financial assistance (31 vs 18%, p < 0.0001) would have been helpful (see Table 6).

Discussion

This study importantly builds onto the sparse literature on the unmet needs of support persons of haematological cancer survivors and is the first nation-wide study to measure unmet needs in this population. Further, it is the first study to directly compare the unmet needs of support persons in rural and urban areas in Australia. Findings indicate that 66% reported at least one ‘moderate to very high’ unmet supportive care need. A quarter of the sample (24%) reported six or more ‘high/very high’ unmet needs. These figures are similar to those reported in previous studies [16, 33, 34] but higher compared to rates of 15 and 14% reported by Heckel et al. [14] and Soothill et al. [35], respectively. The disparity is likely due to a higher cut-point (i.e. 10 or more) used to define multiple unmet needs and differing study populations. Our results appear to give weight to previous findings [14, 34] that supporting a person diagnosed with haematological cancer correlates with a high level of unmet needs. Given the importance of support persons for the functioning and well-being of survivors, failure to address these needs is likely to have implications for health care costs and productivity.

The most commonly reported unmet needs in the present study were in the domains of information, personal and emotional, and needs relating to the future. With regard to the later, concerns about what the future holds for the cancer survivor and managing those concerns were the most frequently reported needs by all support persons. This finding is consistent with previous research that has identified managing worries about the future and the possibility of cancer returning as overriding concerns for support persons [16, 33, 34]. A number of other unmet needs found to be frequently reported by participants in past studies, including accessibility of car parking [33], the

| Table 5 | Additional adverse impacts associated with being a support person for a haematological cancer survivor in rural and urban areas |
|---------|------------------------------------------------------------------------------------------------|
| Adverse impact | Urban (n = 792) | Rural (n = 193) | Total (N = 1004) | p |
|------------|---------------|----------------|----------------|----|
| Used up my savings | 117 (16%) | 49 (28%) | 169 (18%) | 0.0003 |
| Had difficulty paying bills | 96 (13%) | 39 (22%) | 138 (15%) | 0.0025 |
| Had less income | 202 (27%) | 66 (37%) | 271 (29%) | 0.0098 |
| Had trouble meeting daily expenses | 62 (8.4%) | 26 (15%) | 89 (9.6%) | 0.0112 |
| Had to take time off work | 313 (43%) | 92 (52%) | 415 (45%) | 0.0231 |
| Had to sell an asset to get extra cash | 37 (6.2%) | 13 (9.2%) | 50 (6.6%) | 0.2034 |
| Had to resign or close my business | 51 (6.9%) | 11 (6.2%) | 64 (6.9%) | 0.7344 |

| Table 6 | Services identified as being helpful in reducing financial impact of supporting a person with haematological cancer |
|---------|------------------------------------------------------------------------------------------------|
| Adverse impact | Urban (n = 792) | Rural (n = 193) | Total (N = 1004) | p |
|------------|---------------|----------------|----------------|----|
| Access to free parking | 333 (45%) | 55 (31%) | 396 (42%) | 0.0008 |
| Access to free transport | 116 (16%) | 46 (26%) | 166 (18%) | 0.0013 |
| Appointments on weekends | 66 (9%) | 22 (12%) | 88 (9%) | 0.1552 |
| Free medications or treatment | 218 (29%) | 61 (34%) | 283 (30%) | 0.1961 |
| Appointments outside of 9 am–5 pm | 70 (9%) | 16 (9%) | 86 (9%) | 0.8620 |
| Treatment close to home | 146 (20%) | 97 (54%) | 248 (26%) | < 0.0001 |
| Access to financial assistance | 132 (18%) | 55 (31%) | 190 (20%) | < 0.0001 |
impact of caring on the support person’s life [16] and reducing stress in the cancer survivor’s life [16, 34] were supported by the findings here also. Understanding the specific needs experienced by support persons of haematological cancer survivors can assist with offering specific services to address these needs, such as counselling around concerns for the future.

No differences were found between rural and urban support persons in regard to the proportions who had some and/or multiple high unmet needs though a significantly higher proportion of rural (76%) compared with urban (64%) had at least one moderate or higher level of unmet need. There were some significant differences between rural and urban participants in regard to specific unmet needs, particularly with regard to financial needs. Support persons from rural areas were more likely to report trouble with finding information about financial assistance, obtaining such support and being able to meet costs. As this is the first study to investigate the unmet needs of rural and urban support persons, there are no previous findings with which to compare our results. Not surprising though, our results appear to mirror the findings of Paul et al.’s study [36] on haematological cancer survivors in non-metropolitan areas in one Australian state who were also found to be more likely to report financial problems in comparison to their urban counterparts.

While living in a rural area was found to not be significantly associated with having multiple unmet needs in the present study, having financial impacts was. This suggests that differences in unmet needs of support persons are not necessarily based on the ‘rurality’ of where support persons reside, but rather related to financial stability. This is likely linked with the greater financial burden imposed by further distances to travel for treatment and relocation costs. One in three support persons from rural areas were forced to relocate temporarily to a different town while the cancer survivor underwent treatment and 40% reported extensive travel times (between 2 and 5 h). Significantly higher proportions of rural support persons also reported financial impacts including having to take time off work, having less income and using up savings. These findings again appear to mirror the problems experienced by cancer survivors living in rural areas as found by Paul et al. [36]. They suggest that cancer treatment and support services should target rural cancer survivors by proactively providing information about available travel subsidies and financial assistance [36]. We recommend this be extended to support persons in rural areas also with rural participants in this study indicating that financial assistance, free transport and treatment services closer to home would be beneficial in relieving the financial burden.

There are some limitations to the present study. First, the low response rate by cancer survivors (35%) may limit generalisability of our findings though this rate is comparable with other studies on haematological cancer survivors [14]. Additionally, the sociodemographic characteristics of our national sample of support persons closely correspond with participants in previous studies [14]. Second, due to the cross-sectional study design, it was not possible to explore causality nor how unmet needs may change over time.

Despite these limitations, the present study advances previous literature in this field. While past studies have used small samples of one or more haematological cancer subtypes, we have utilised a large, population-based sample inclusive of several sub-types of haematological cancers. Measurement of unmet needs was via a standardised, validated tool (the SPUNS) that addressed unmet needs across six domains. This was the first study to compare the unmet needs of rural and urban support persons in Australia and makes a substantial contribution to the paucity of research on the unmet needs of support persons of haematological cancer survivors.

**Conclusion**

Support persons of haematological cancer survivors appear to be greatly impacted by their role, reporting multiple unmet needs. Support persons living in rural areas are particularly vulnerable to financial-related unmet needs. Findings highlight the importance of greater efforts to ensure that health care providers and our models of health care service adequately address their needs. Future translational research should investigate the efficacy and adoption of strategies for addressing unmet needs of those people who are supporting survivors of haematological cancer with particular regard for strategies that address concerns about the future, and alleviate the financial burden imposed on those living in rural areas. Such strategies may include prioritising rural patients’ preferences regarding the timing of treatment and their access to financial support.

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Compliance with ethical standards

Ethics approval Ethics approval was obtained from the University of Newcastle Human Research Ethics Committee (2009-032) and from each of the state population-based cancer registries.

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

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References

1. International Agency for Research on Cancer. Cancer Today: Cancer Fact Sheets: All Cancers Excluding Non-Melanoma Skin. 2012 [cited 2017 6 December 2017]; Available from: https://gco.iarc.fr/today/fact-sheets-cancers?cancer=29&type=0&sex=0
2. World Health Organisation. Cancer: fact sheet. 2017; Available from: http://www.who.int/mediacentre/factsheets/fs297/en/
3. Ream E, Pedersen VH, Oakley C, Richardson A, Taylor C, Verity R (2013) Informal carers’ experiences and needs when supporting patients through chemotherapy: a mixed method study. Eur J Cancer Care 22(6):797–806. https://doi.org/10.1111/ecc.12083
4. Tamayo GJ, Broxson A, Munsell M, Cohen MZ (2010) Caring for the caregiver. Oncol Nurs Forum 37(1):E50–E57. https://doi.org/10.1188/10.ONF.E50-E57
5. Girgis A, Lambert SD (2009) Caregivers of cancer survivors: the state of the field. Cancer Forum 33(3):167–171
6. Yarkoff KR, Kim Y (2009) Time costs associated with informal caregiving for cancer survivors. Cancer 15:4362–4373
7. Applebaum AJ, Breitbart W (2013) Care for the cancer caregiver: a systematic review. Palliat Support Care 11(03):231–252. https://doi.org/10.1017/S1478951512000594
8. National Alliance for Caregiving in collaboration with AARP, Caregiving in the US 2009. 2009
9. Carers Australia, The economic value of informal care in Australia in 2015, 2015, Deloitte Access Economics
10. Girgis A, Lambert S (2017) Cost of informal caregiving in cancer care. Cancer Forum 41(2)
11. Given BA, Given CW, Kozachik S (2001) Family support in advanced cancer. CA Cancer J Clin 51(4):213–231. https://doi.org/10.1002/cncr.21349
12. Kim Y, Given BA (2008) Quality of life family caregivers of cancer survivors. Cancer 112(suppl):2556–2568. https://doi.org/10.1002/cncr.23449
13. Deniz H, Inci F (2015) The burden of care and quality of life of caregivers of leukemia and lymphoma patients following peripheric stem cell transplantation. J Psychosoc Oncol 33(3):250–262. https://doi.org/10.1080/07347332.2015.1019660
14. Heckel L, Fennell KM, Reynolds J, Osborne RH, Chirgwin J, Botti M, Ashley DM, Livingston PM (2015) Unmet needs and depression among caregivers of people newly diagnosed with cancer. Eur J Cancer 51(14):2049–2057. https://doi.org/10.1016/j.ejca.2015.06.129
15. Carter PA (2003) Family caregivers’ sleep loss and depression over time. Cancer Nurs 26(4):253–259. https://doi.org/10.1097/00002820-200308000-00001
16. Armoogum J, Richardson A, Armes J (2013) A survey of supportive care needs of informal caregivers of adult bone marrow transplant patients. Support Care Cancer 21(4):977–986. https://doi.org/10.1007/s00520-012-1615-4
17. Hassett MJ (2010) The full burden of cancer. Oncologist 15(8):793–795. https://doi.org/10.1634/theoncologist.2010-0211
18. Van Houtven CH, Ramsey SD, Hombrock MC, Atienza AA, van Ryn M (2010) Economic burden for informal caregivers of lung and colorectal cancer patients. Oncologist 15(8):883–893. https://doi.org/10.1634/theoncologist.2010-0005
19. Cartwright RA, Gilman EA, Gurney KA (1999) Time trends in incidence of haematological malignancies and related conditions. Br J Haem 106(2):281–295. https://doi.org/10.1046/j.1365-2141.1999.01480.x
20. Greipp PR, Miguel JS, Durie BGM, Crowley JJ, Barlogie B, Bladé J, Boccadoro M, Child JA, Avet-Loiseau H, Kyle RA, Lahuerta JJ, Ludwig H, Morgan G, Powles R, Shimizu K, Shustik C, Sonneveld P, Tosi P, Turesson I, Westin J (2005) International staging system for multiple myeloma. J Clin Oncol 23(15):3412–3420. https://doi.org/10.1200/JCO.2005.04.242
21. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P, Supportive Care Review Group (2000) The unmet supportive care needs of patients with cancer. Cancer 88(1):226–237.
22. Lambert SD et al (2012) The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. BMJ Support Palliat Care
23. Monroe AC, Ricketts TC, Savitz LA (1992) Cancer in rural versus urban populations: a review. J Rural Health 8(3):212–220. https://doi.org/10.1111/j.1748-0361.1992.tb00354.x
24. Adams E, Boulton M, Watson E (2009) The information needs of partners and family members of cancer patients: a systematic literature review. Patient Educ Couns 77(2):179–186. https://doi.org/10.1016/j.pec.2009.03.027
25. Institute of Medicine (2008) Retooling of an Ageing America: Building the Health Care Workforce. The National Academies Press, Washington, DC
26. Roder D, Creighton N, Baker D, Walton R, Aranda S, Currrow D (2015) Changing roles of population-based cancer registries in Australia. Aust Health Rev 39(4):425–428. https://doi.org/10.1071/AH14250
27. Carey M, Sanson-Fisher R, Paul C, Bradstock K, Williamson A, Campbell HS (2017) Psychological morbidity among Australian rural and urban support persons of haematological cancer survivors: results of a national study. Psycho-Oncology 26(11):1952–1958. https://doi.org/10.1002/pon.4411
28. Australian Bureau of Statistics (2003) Australian Standard Geographical Classification: purpose and use. Australian Bureau of Statistics, Canberra
29. Campbell HS, Sanson-Fisher R, Taylor-Brown J, Hayward L, Wang XS, Turner D (2009) The cancer support person’s unmet needs study: psychometric properties. Cancer 115(14):3351–3359. https://doi.org/10.1002/cncr.24366
30. Lovibond SH, Lovibond PF (1995) Manual for the depression anxiety stress scales, 2nd edn. Psychology Foundation Monograph, Sydney
31. Antony MM, Bieling PJ, Cox BJ, Enns MW, Swinson RP (1998) The depression anxiety stress scales in clinical groups and a community

Antony MM, Bieding PJ, Cox BJ, Enns MW, 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(2):176–181. https://doi.org/10.1037/1040-3590.10.2.176

32. 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(9):2032–2038. https://doi.org/10.1002/pon.3247

33. Molassiotis A et al (2010) Unmet supportive care needs, psychological well-being and quality of life in patients living with multiple myeloma and their partners. Psycho-Oncology

34. Girgis A et al (2010) Some things change, some things stay the same: a longitudinal analysis of cancer caregivers’ unmet supportive care needs. Psycho-Oncology

35. Soothill K, Morris SM, Harman JC, Francis B, Thomas C, McIllmurray MB (2001) Informal carers of cancer patients: what are their unmet psychological needs? Health Soc Care in the Community 9(6):464–475. https://doi.org/10.1046/j.0966-0410.2001.00326.x

36. Paul CL, Hall AE, Carey ML, Cameron EC, Clinton-McHarg T (2013) Access to care and impacts of cancer on daily life: do they differ for metropolitan versus regional haematological cancer survivors? J Rural Health 29(s1):S43–S50. https://doi.org/10.1111/jrh.12020