



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

Marita C. Lynagh^{1,2}  · A. Williamson³ · K. Bradstock^{4,5} · S. Campbell⁶ · M. Carey^{1,2} · C. Paul^{1,2} · F. Tzelepis^{1,2,7} · R. Sanson-Fisher^{1,2}

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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

✉ Marita C. Lynagh
Marita.Lynagh@newcastle.edu.au

¹ School of Medicine and Public Health, University of Newcastle, Level 4, West, HMRI Building, Callaghan, NSW 2308, Australia
² Hunter Medical Research Institute (HMRI), Newcastle, NSW, Australia
³ The Leukaemia Foundation, Windsor, QLD, Australia
⁴ Haematology Department, Westmead Hospital Clinical School, Westmead, NSW, Australia
⁵ Sydney Medical School, University of Sydney, Sydney, NSW, Australia
⁶ Propel Centre for Population Health Impact, University of Waterloo, Waterloo, Ontario, Canada
⁷ Hunter New England Population Health, Hunter New England Area Health District, New Lambton, NSW, Australia

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 as the difference between services or support necessary to deal 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.

The Institute of Medicine (IOM) and other international cancer organisations advocate that formal health care providers have a responsibility to prepare support persons for their role and help them to manage their own well-being [24, 25]. It is imperative then that the specific unmet needs of support persons of all types of haematological cancer survivors are identified and understood, including those who are most vulnerable, so that appropriate and targeted interventions are provided for support persons to address their needs. This exploratory study thus 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 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 a ‘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% ($n = 487$)

Table 1 Demographic characteristics of rural and urban support persons of haematological cancer survivors

Variable	Category	Urban (<i>n</i> = 792)	Rural (<i>n</i> = 193)	Total (<i>N</i> = 1004)	<i>p</i>	
Gender	Male	263 (33%)	58 (30%)	328 (33%)	0.3896	
	Female	523 (67%)	134 (70%)	669 (67%)		
Age	Median (min, max)	62 (14, 89)	61 (22, 87)	61 (14, 89)	0.1965	
	Median (Q1, Q3)	62 (52, 68)	61 (51, 67)	61 (52, 68)		
	Mean (SD)	59 (12)	58 (13)	59 (13)		0.2073
	14 to 39	59 (8.1%)	19 (10%)	81 (8.7%)		0.6438
	40 to 59	260 (36%)	67 (36%)	334 (36%)		
Relationship to person with cancer	60 to 80	410 (56%)	101 (54%)	519 (56%)	0.5737*	
	Spouse/partner	641 (83%)	167 (89%)	819 (84%)		
	Child/grandchild	35 (4.5%)	7 (3.7%)	43 (4.4%)		
	Parent	49 (6.3%)	10 (5.3%)	61 (6.2%)		
	Sibling	20 (2.6%)	3 (1.6%)	23 (2.4%)		
	Other relative	5 (0.6%)	0	5 (0.5%)		
	Friend	15 (1.9%)	1 (0.5%)	18 (1.8%)		
Education	Other	7 (0.9%)	0	8 (0.8%)	0.0062	
	Primary	24 (3.1%)	10 (5.2%)	37 (3.7%)		
	Secondary	296 (38%)	94 (49%)	397 (40%)		
	Vocational or other	236 (30%)	46 (24%)	287 (29%)		
	University	229 (29%)	41 (21%)	274 (28%)		
Employment	Employed	382 (49%)	96 (50%)	488 (49%)	0.8428	
	Unemployed	392 (50%)	93 (48%)	493 (50%)		
	Other	9 (1.1%)	3 (1.6%)	12 (1.2%)		
	Lives with person with cancer	Yes	693 (89%)	177 (93%)		882 (89%)
Aboriginal	Yes	7 (0.9%)	1 (0.5%)	8 (0.8%)	1.0000*	
Country of birth	Australia	607 (77%)	168 (88%)	789 (79%)	0.0012	
	Other	183 (23%)	24 (13%)	211 (21%)		
Non-cancer-related health problems ^a	Yes	378 (48%)	99 (51%)	487 (49%)	0.3738	
Previous diagnosis of cancer	Yes	94 (12%)	22 (12%)	118 (12%)	0.8206	

^a Excludes one state registry

*Exact test

indicated they experienced other non-cancer health-related problems including arthritis (74%) and vision or hearing difficulties (545). 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,

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

SPUNS domain	Urban (<i>n</i> = 193) mean (SD)	Rural (<i>n</i> = 792) mean (SD)	<i>t</i>	<i>p</i>
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

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 ≥ 10 on

the DASS-21 depression subscale (AOR = 5.91, 95%CI 3.37:10.36, $p < 0.0001$) and scored ≥ 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 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 (<i>n</i> = 1004) <i>n</i> (%)	Urban (<i>n</i> = 792) <i>n</i> (%)	Urban rank	Rural (<i>n</i> = 193) <i>n</i> (%)	Rural rank	Chi-square	<i>p</i>
1	Dealing with the worrying about the future of the person I support	Needs relating to the future	186 (19%)	140 (18%)	2	43 (23%)	1	2.65	0.104
2	Dealing with not knowing what lies in the future	Needs relating to the future	184 (19%)	144 (18%)	1	38 (21%)	2	0.61	0.433
= 3	Dealing with worry about the cancer getting worse	Needs relating to the future	138 (14%)	105 (14%)	= 5	31 (17%)	4	1.50	0.221
= 3	Dealing with worries about the emotional well-being of my family	Personal needs	138 (14%)	106 (14%)	4	29 (16%)	5	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%)	7	37 (20%)	3	7.00	0.008
6	Telling my family friends how I am feeling emotionally	Personal needs	136 (14%)	112 (14%)	3	23 (12%)	12	0.53	0.466
7	Dealing with worry about the cancer coming back	Needs relating to the future	130 (13%)	105 (13%)	= 5	23 (13%)	11	0.09	0.764
8	Dealing with feeling stressed	Personal needs	125 (13%)	97 (13%)	8	26 (14%)	= 7	0.22	0.637
9	Not sleeping well	Personal needs	122 (12%)	91 (12%)	10	28 (15%)	6	1.73	0.188
10	Feeling tired or lacking energy	Personal needs	121 (12%)	95 (12%)	9	24 (13%)	= 9	0.05	0.819

Table 4 Multiple logistic regression analysis of variables associated with support persons reporting multiple 'high or very high' unmet needs

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)	0.0098	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)	
Rurality	14 to 39	51 (9.0%)	19 (10%)	70 (9.3%)	Ref	0.8058	Ref	
	Urban	458 (80%)	148 (81%)	606 (81%)	1.05 (0.69, 1.62)			
Relationship to person with cancer	Rural	111 (20%)	34 (19%)	145 (19%)	Ref	0.0586	1.05 (0.10, 10.81)	0.0685
	Other relative	3 (0.5%)	2 (1.1%)	5 (0.7%)	0.84 (0.12, 5.72)		0.86 (0.20, 3.73)	
Siblings	Sibling	10 (1.8%)	6 (3.3%)	16 (2.1%)	0.76 (0.22, 2.57)		0.40 (0.12, 1.32)	
	Parent	34 (6.0%)	16 (8.8%)	50 (6.7%)	0.60 (0.24, 1.47)		0.27 (0.11, 0.67)	
Spouse/partner	Spouse/partner	491 (86%)	140 (77%)	631 (84%)	0.36 (0.18, 0.73)		0.21 (0.02, 1.95)	
	Friend	8 (1.4%)	2 (1.1%)	10 (1.3%)	0.32 (0.06, 1.72)		0.05 (0.00, 1.43)	
Other	Other	4 (0.7%)	1 (0.5%)	5 (0.7%)	0.32 (0.03, 3.14)		Ref	
	Child/grandchild	19 (3.3%)	15 (8.2%)	34 (4.5%)	Ref	0.8717	Ref	
Education	Vocational or other	163 (29%)	58 (32%)	221 (29%)	1.13 (0.43, 2.96)			
	Secondary	224 (39%)	69 (38%)	293 (39%)	0.98 (0.37, 2.54)			
University	University	163 (29%)	49 (27%)	212 (28%)	0.95 (0.36, 2.52)			
	Primary	19 (3.3%)	6 (3.3%)	25 (3.3%)	Ref	0.2841		
Other	Other	3 (0.5%)	3 (1.6%)	6 (0.8%)	2.98 (0.59, 15.00)			
	Unemployed	271 (48%)	80 (44%)	351 (47%)	0.88 (0.63, 1.23)			
Employment	Employed	295 (52%)	99 (54%)	394 (52%)	Ref	0.0999	0.65 (0.25, 1.69)	0.3781
	Yes	518 (91%)	158 (87%)	676 (90%)	0.65 (0.39, 1.09)		Ref	
Lives with person with cancer	No	51 (9.0%)	24 (13%)	75 (10%)	Ref	0.3280		
	Other	121 (21%)	45 (25%)	166 (22%)	1.22 (0.82, 1.80)			
Country of birth	Australia	448 (79%)	137 (75%)	585 (78%)	ref	0.9153		
	Yes	61 (11%)	19 (10%)	80 (11%)	0.97 (0.56, 1.67)			
Previous diagnosis of cancer	No	508 (89%)	163 (90%)	671 (89%)	Ref	0.0066	0.87 (0.49, 1.55)	0.6467
	Yes	82 (14%)	42 (23%)	124 (17%)	1.78 (1.17, 2.70)		Ref	
Forced to relocate	No	487 (86%)	140 (77%)	627 (83%)	Ref	0.6486		
	More than 2 h	86 (15%)	25 (14%)	111 (15%)	0.89 (0.55, 1.45)			
Travel time	Less than 2 h	483 (85%)	157 (86%)	640 (85%)	Ref	0.0763	0.97 (0.58, 1.62)	0.9144
	Take time off work	251 (44%)	94 (52%)	345 (46%)	1.35 (0.97, 1.89)		Ref	
Other impacts	No	318 (56%)	88 (48%)	406 (54%)	Ref	0.0005	0.99 (0.55, 1.75)	0.9617
	Less income	151 (27%)	73 (40%)	224 (30%)	1.85 (1.31, 2.63)			

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	No	418 (73%)	109 (60%)	527 (70%)	Ref		Ref	
	Resign or close my business	32 (5.6%)	23 (13%)	55 (7.3%)	2.43 (1.38, 4.27)	0.0021	2.08 (0.94, 4.61)	0.0721
Other impacts	No	537 (94%)	159 (87%)	696 (93%)	Ref		Ref	
	Difficulty paying bills	50 (8.8%)	61 (34%)	111 (15%)	5.23 (3.43, 7.99)	<0.0001	3.02 (1.42, 6.45)	0.0042
Other impacts	No	519 (91%)	121 (66%)	640 (85%)	ref		ref	
	Used up savings	78 (14%)	62 (34%)	140 (19%)	3.25 (2.21, 4.80)	<0.0001	1.10 (0.58, 2.11)	0.7706
Other impacts	No	491 (86%)	120 (66%)	611 (81%)	Ref		Ref	
	Trouble meeting daily expenses	27 (4.7%)	42 (23%)	69 (9.2%)	6.02 (3.59, 10.11)	<0.0001	1.58 (0.66, 3.83)	0.3070
Participated in support group in last month	No	542 (95%)	140 (77%)	682 (91%)	Ref		Ref	
	Yes	15 (2.6%)	4 (2.2%)	19 (2.5%)	0.83 (0.27, 2.53)	0.7434		
DASS depression	No	554 (97%)	178 (98%)	732 (97%)	Ref		Ref	
	≥ 10	49 (8.6%)	109 (60%)	158 (21%)	15.85 (10.45, 24.04)	<0.0001	5.91 (3.37, 10.36)	<0.0001
DASS anxiety	< 10	520 (91%)	73 (40%)	593 (79%)	Ref		Ref	
	≥ 8	37 (6.5%)	77 (42%)	114 (15%)	10.54 (6.76, 16.44)	<0.0001	1.22 (0.63, 2.39)	0.5552
DASS stress	< 8	532 (93%)	105 (58%)	637 (85%)	Ref		Ref	
	≥ 14	58 (10%)	107 (59%)	165 (22%)	12.57 (8.42, 18.77)	<0.0001	4.71 (2.64, 8.40)	<0.0001
	< 14	511 (90%)	75 (41%)	586 (78%)	Ref		Ref	

Table 5 Additional adverse impacts associated with being a support person for a haematological cancer survivor in rural and urban areas

Adverse impact	Urban (<i>n</i> = 792) <i>n</i> (%)	Rural (<i>n</i> = 193) <i>n</i> (%)	Total (<i>N</i> = 1004) <i>n</i> (%)	<i>p</i>
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

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 6 Services identified as being helpful in reducing financial impact of supporting a person with haematological cancer

Adverse impact	Urban (<i>n</i> = 792) <i>n</i> (%)	Rural (<i>n</i> = 193) <i>n</i> (%)	Total (<i>N</i> = 1004) <i>n</i> (%)	<i>p</i>
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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