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Psychological morbidity among Australian rural and urban support persons of haematological cancer survivors: Results of a national study.

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Abstract

Objective: To compare the prevalence of anxiety, depression and stress among rural and urban support persons of haematological cancer survivors, and explore factors associated with having one of more of these outcomes.

Methods: Haematological cancer survivors were identified via one of 5 state-based cancer registries and invited to take part in a survey. Those who agreed were asked to pass on a questionnaire package to their support person. Measures included the Depression, Anxiety and Stress Scale, Support Persons' Unmet Need Survey and sociodemographic questions.

Results: Nine-hundred and eighty-nine (66%) of participating survivors had a participating support person**.** There were no significant differences in the proportion of urban versus rural support persons who reported elevated levels of depression (21% vs 23%), anxiety (16% vs 17%), or stress (16% vs 20%), p>0.05. Odds of reporting at least one indicator of psychological morbidity increased by 10-17% for each additional high or very high unmet need; by 2% for those who had relocated from their usual place of residence in order for the survivor to receive treatment; and was decreased by 5-54% for those support persons who reported that they had no chronic health conditions.

Conclusions: Psychological outcomes for rural and urban support persons are similar. Those who have poor health, have had to relocate, and who have multiple unmet needs are particularly vulnerable to poor psychological outcomes. These factors should be assessed to enable early intervention for those at risk of poor outcomes.

BACKGROUND

A support person has been defined as the person whom a patient identifies as their primary source of emotional and practical support (1). Support persons play various roles including the provision of emotional support, information seeking, help with day-to-day tasks, and (2) assisting with management of side effects (3). Supporting a person with haematological cancer poses particular challenges. Some haematological cancers have alternating periods of remission and active treatment (4) and may require intensive inpatient treatments(4). Long-term side effects and late effects such as second cancers and cardiopulmonary complications may occur (5).

An Australian population-based study involving 436 support persons of cancer survivors with mixed diagnoses, found that, next to lung cancer support persons, rates of anxiety (47%) and depression (21%) were highest among those providing support to someone with a haematological cancer (6). Psychological morbidity among support persons has been associated with greater unmet needs, poorer informational and emotional support, less positive social interaction, involvement in personal care (6) as well as survivor psychological wellbeing (7). One study of 93 partners of multiple myeloma patients indicated that half of the partners (49%) reported anxiety and 14% reported depressive symptoms (7).

Compared to those in urban areas, people with cancer in rural areas experience poorer access to cancer specialists (8), specialist treatments (9) and supportive care (10), poorer survival (11), and poorer health outcomes. Those living in rural areas often need to travel long distances or relocate to access treatment and follow-up (12). Social isolation, disruption of family life, and out of pocket expenses associated with relocation may profoundly impact on psychosocial wellbeing (13). These issues may be particularly pertinent to support persons in

Australia because up to 32% of the population resides in non-urban areas (14), and there are large geographic distances between remote areas and urban centres. Despite the potential inequalities in access to services facing support persons of haematological cancer patients, no prior research has examined whether there are disparities in psychological outcomes for rural versus urban support persons of people with haematological cancer.

Aims:

1) To compare the prevalence of anxiety, depression and stress among rural and urban support persons of haematological cancer survivors.

2) To assess the extent to which survivor characteristics, support person health, unmet needs and sociodemographic characteristics are associated with having one or more elevated psychological outcomes (anxiety, depression or stress).

METHODS

Design and setting

Cross sectional study in which haematological cancer survivors recruited from population-based cancer registries were asked to nominate a support person to participate in survey. In Australia, each state has its own population-based cancer registry. Approval was obtained from the University of Newcastle Human Research Ethics Committee (2009-032) and from each registry.

Survivor sampling and recruitment

Survivors diagnosed with a haematological cancer including, Non-Hodgkin lymphoma, leukaemia, myeloma, and other blood cancers were identified via five Australian population-based cancer registries. Postcodes classified as major cities and inner regional using the Accessibility and Remoteness Index of Australia (ARIA +) classification (15) were

considered to be "urban"; while those in outer regional, remote and very remote locations were classed as "rural". All eligible rural survivors, and where possible a random sample of eligible urban survivors were invited to take part.

Survivors were recruited using the standard registry procedures applicable in each registry. Registry A mailed the survey on behalf of the research team with a second survey and reminder letter sent after 3 weeks to non-responders. Registries B, C, and D wrote to clinicians and asked them to contact the registry within one month if the survivor should not be approached, while registry E required clinicians to provide written consent to contact the survivor. Registries B to E sought written permission from survivors to pass their contact details onto the research team. Those who agreed were mailed a questionnaire pack which included an information statement, survey, and reply-paid envelope. Non-responders were sent a second recruitment package at 3 weeks and a reminder telephone call at 6 weeks.

Eligibility and recruitment of support persons

A support person questionnaire package was enclosed within each of the questionnaire packages sent to survivors. Survivors were asked to pass the support person questionnaire package onto their nominated support person. Support persons were defined as ''someone who has helped you the most during your cancer journey'', and were required to be aged 18 or older and capable of providing informed consent.

Measures

Data were collected from registry A first, and then minor changes to the survey were made. This resulted in additional items on number of chronic medical conditions and whether the support person had had to relocate (temporarily or permanently) from their usual residence so

that the survivor could access treatment. These data were collected in the survey administered by the remaining registries.

Outcome variables: The Depression, Anxiety and Stress Scale - 21 item version (DASS-21) consists of depression (7 items), anxiety (7 items) and stress (7 items) sub scales. Respondents were asked to indicate the extent to which they have experienced each symptom over the past 7 days on a four point likert scale (16). Reliability, convergent and divergent validity have been demonstrated with non-clinical populations (17).

Explanatory variables: Sociodemographic variables. Support persons were asked to report their date of birth, gender, marital status, employment status, education, post code of residence, country of birth and whether they were of Aboriginal and/or Torres Strait Islander origin.

Health variables. Support persons (excluding Registry A) were asked whether they had: cancer, arthritis or joint problems, heart disease, diabetes, depression, asthma or sight or hearing problems.

Caregiver role variables. Information about the support person's relationship to the person with cancer (e.g. spouse/partner, child/grandchild etc), whether they lived with the person with cancer whom they supported, and whether they had had to relocate for the survivors' treatment was also sought. Respondents indicated whether any of the following financial impacts had occurred: had to resign or close business, had to take time off work, had less income, used up savings, had to sell an asset or had difficulty meeting day-to-day expenses.

Supportive care needs of support persons. The Support Person Unmet Needs Survey (SPUNS) (1) was used to assess unmet supportive care needs. This 78 item survey assessed needs across 6 domains: information and relationship needs, personal needs, worries about the future, work and financial needs, health care access and continuity, and emotional needs. Need for help for each item is indicated on a five point Likert scale: 0 "no unmet needs" to 4

"very high unmet need". Adequate internal reliability, test-retest reliability and construct validity has been demonstrated (1).

Survivors. Registry data was collected for: age at diagnosis, sex, date of diagnosis, haematological cancer type and postcode of residence. Survivor self-report data was obtained on marital status, employment, education level, and treatments received.

Statistical analysis

DASS-21 subscale scores were only calculated for those who completed at least 6 of the 7 items in each sub scale, with missing items imputed using the mean of the 6 completed items. Subscale scores were calculated by summing the scores for all non-missing items, dividing by the number of non-missing items and multiplying by 2 (16). Respondents were classified as reporting elevated levels of anxiety (≥ 8), depression (≥ 10) and stress (≥ 15), based on population norms outlined in the DASS scoring manual (16).

The number of health conditions and number of high/very high unmet needs (SPUNS) were summed for each participant. Frequencies and percentages were calculated for DASS-21 outcomes and for demographic variables of interest. Chi-square tests were used to examine the difference in the proportion of urban and rural support persons experiencing elevated anxiety, depression and stress.

The DASS-21 subscales were combined to identify patients who presented with at least 1 DASS-21 outcome. Chi-square or exact tests were used to test for the univariate associations between having at least 1 outcome and each demographic variable. Those with a chi-square or Fisher's exact p-value of less than 0.2 were entered as covariates into an adjusted logistic

regression model, along with rurality as the main associate of interest. Adjusted odds ratios (95% CIs) and Wald p-values are presented to examine the odds of having at least 1 DASS-21 outcome. Statistical analyses were programmed using SAS v9.4.

With a sample size of 800 urban and 200 rural support persons, we would have 80% power to detect a difference as small as 11% in the proportion of those experiencing elevated anxiety, depression or stress, assuming a two-sided test with alpha set at 0.05.

RESULTS

Survivor response rate and characteristics

Of the 4,299 eligible haematological cancer survivors who were contacted about this study, 1,511 (35%) returned a completed survey. Of those survivors with postcode data available, 1144 were from an urban location and 270 were from a rural location. A higher percentage of rural (42%) returned a completed survey compared to urban survivors (35%) (p=0.002). Please refer to Supplementary Table 1 for a comparison of characteristics of consenting and non-consenting survivors.

Nine-hundred and eighty-nine (66%) of participating survivors had a participating support person. Of these, 504 (55%) were diagnosed with NHL, 157 (17%) with myeloma, 147 (16%) with leukaemia, and 101 (11%) with other blood cancers. One hundred and eighty-five (19%) reported currently receiving treatment. Almost half of the survivors were aged 60 or older (n= 444; 49%); 59% (n= 536) were male; 66 (7%) were diagnosed 12 months ago or less, 114 (13%) 13-24 months ago, 197 (22%) 25-36 months ago and 513 (57%) 37 months ago or more.

Support person characteristics

The majority of support persons were female (n=656; 67%), Australian born (n=776; 79%) and lived with the person they supported (89%; n= 868), half were employed (n= 478; 49%); 84% (n= 807) were the spouse or partner of the person with cancer (n = 807; 84%); and 118 (12%) had been diagnosed with cancer. Other characteristics are shown in Table 1.

[TABLE 1 ABOUT HERE]

Psychological outcomes

Overall, 21% (n= 200) of the sample reported elevated depression scores, 16% (n=153) reported elevated anxiety scores, and 16% (n=159) reported elevated stress scores. There were no differences in the proportion of urban support persons and rural support persons who reported elevated levels of depression (21%, n= 158 versus 23%, n = 43; p = .48), anxiety (16%, n=121 versus 17%, n= 31, p = .62) or stress (16%, n= 122 versus 20%, n= 36, p=.16).

Factors associated with having one or more DASS outcome

One hundred and ninety-nine urban (25%) and 53 (28%) rural support persons were identified as having one or more DASS indictors of psychological morbidity (DASS-D >=8, DASS-A >=10 or DASS-S >=15). (Twenty support persons had missing values for the ≥1 DASS outcome). There was some evidence (p < 0.2) that age, marital status, number of people in household, previous diagnosis of cancer for the support person, time since the survivor's diagnosis, number of financial impacts and unmet needs were associated with at least 1 DASS outcome. These were added into an adjusted logistic regression model along with rurality as the main predictor of interest. Number of health conditions and having to relocate were also associated with the outcome however these variables included no participants from Registry A. Because these two variables were not completed by the entire sample, three regression models were run (see Table 2): 1) Complete cohort - regression of ≥1 DASS outcome on variables common to all sites. 2) Excluding Registry A respondents -

regression of ≥1 DASS outcome on variables common to all sites. 3) Excluding Registry A respondents - regression of ≥1 DASS outcome on variables common to all sites with the addition of two variables not surveyed in the Registry A population.

In the complete cohort, there was no evidence of an association between having at least 1 DASS outcome and rurality (p=0. 5006). The odds of having at least 1 DASS outcome increased between 12 to 18% for each additional high or very high unmet need (p<0.0001).

Excluding Registry A respondents from the regression of ≥1 DASS outcome on variables common to all states, rurality remained un-associated with the outcome (p=0.56) and similarly, the odds increased between 10 to 16% for each additional high or very high unmet need (p<0.0001).

Excluding Registry A respondents from the regression in order to assess the effect of two further variables on the outcome did not substantially change the estimates of the variable common to all states. The odds of ≥1 DASS increased between 10 to 17% for each additional high or very high unmet need (p<0.0001). The odds of ≥1 DASS were lower for those with fewer health conditions compared with having ≥4 (P<0.0001). Support persons who had to relocate had 2.06 higher odds of having DASS ≥1 (95%CI 1.15 to 3.70, p=0.015).

[TABLE 2 ABOUT HERE]

DISCUSSION

Just over a quarter of support persons (28%) reported one or more indicators of psychological morbidity. In contrast to previous studies of caregiver populations (6), we found that the

prevalence of depression (21%) was higher than the prevalence of anxiety (16%) in our sample. This may reflect that the majority of support persons in our sample were caring for a person who was more than 2 years' post diagnosis. In this context, lower prevalence of anxiety may reflect greater familiarity with cancer care processes; while the higher prevalence of depression may reflect the chronic nature of the caregiver role for many of those in our sample.

Contrary to expectations, no differences were found in psychological outcomes of urban and rural support persons. Given that other studies have reported a range of disparities in access to care for rural survivors (13), our findings may suggest that access factors (in so far as we assessed them) do not have any great influence on support person psychosocial outcomes. One exception to this may be having to relocate from one's usual residence so that the survivor could receive treatment, which is more common in rural areas (36% vs 12%). Those who had had to relocate were twice as likely to report one or more indicator of psychological morbidity.

The odds of having one or more elevated indicator of psychological morbidity was increased for each additional unmet need reported by support persons. This aligns with other research which has shown that unmet supportive care needs are associated with poorer psychological outcomes (7, 18). While causality cannot be determined, it is plausible that the relationship between unmet needs and psychological outcomes is bi-directional. For example, having many unmet needs may increase the likelihood of subsequent psychosocial distress; while psychosocial distress results in one being less able to access the help needed to address supportive care needs.

Support persons who had fewer chronic health conditions were less likely to report indicators of psychological morbidity. Similarly, other studies that have found a 'dose-response' relationship between the number of chronic conditions and the likelihood of depression (19, 20).

Clinical Implications

Our findings suggest need to consider a range of physical, social and psychological determinants of psychological wellbeing among support persons, rather than just those factors related directly to the caregiver role. Relocation in order to support a person with haematological cancer should serve as "red flag" to health care providers to assess for and proactively offer support services. The physical wellbeing of the support person and the complexity of self-management demands of their own chronic health conditions should also be considered when evaluating a support person's need for help.

Study Limitations

The poor consent rates of survivors (35%) affected the extent to which a representative sample of carers could be recruited to this study. Multi-step recruitment processes such those required by cancer registries have been shown to have an adverse impact on research consent rates (21). Encouragingly, however, response rates of support persons (66%) were significantly higher than other studies using a similar methodology (1, 6).

CONCLUSIONS

Rural and urban support persons of haematological cancer survivors report similar psychological outcomes, with an overall prevalence of 16% for anxiety, 16% for stress and 21% for depression. Those with more unmet supportive care needs, more chronic health

conditions and who had had to relocate so the survivor could receive treatment were more

likely to report poor outcomes.

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Table 1. Characteristics of rural and urban support persons

Variable	Category	Urban (n=783)	Rural (n=187)	Total (N=970)[1]	p-val
	15 to 39	59 (8.2%)	19 (10%)	80 (8.8%)	0.71
	40 to 49	75 (10%)	22 (12%)	97 (11%)	
	50 to 59	179 (25%)	40 (22%)	226 (25%)	
	60+	407 (57%)	100 (55%)	515 (56%)	
Marital status	Single	30 (3.8%)	6 (3.2%)	37 (3.8%)	0.02[2]
	Married or defacto	712 (91%)	178 (96%)	905 (92%)	
	Widowed	10 (1.3%)	2 (1.1%)	13 (1.3%)	
Education	High School or below	316 (41%)	100 (54%)	426 (43%)	<0.00
	Vocational or other	234 (30%)	46 (25%)	285 (29%)	
	University	226 (29%)	39 (21%)	269 (27%)	
Number of health conditions[3]	0	408 (52%)	92 (49%)	509 (51%)	0.55
	1	220 (28%)	52 (28%)	278 (28%)	
	2	101 (13%)	26 (14%)	130 (13%)	
	3	40 (5.1%)	10 (5.3%)	51 (5.2%)	
	>=4	14 (1.8%)	7 (3.7%)	21 (2.1%)	
Number of people in household	1	32 (4.1%)	4 (2.2%)	38 (3.9%)	0.03[2]
	2	569 (73%)	155 (83%)	736 (75%)	
	3	100 (13%)	15 (8.1%)	118 (12%)	
	>=4	80 (10%)	12 (6.5%)	93 (9.4%)	
Number of close confidants	1-2	315 (41%)	77 (43%)	400 (41%)	0.27
	3-4	216 (28%)	37 (21%)	259 (27%)	
	>=4	183 (24%)	49 (28%)	235 (24%)	
	None	60 (7.8%)	15 (8.4%)	76 (7.8%)	
Relocated for treatment[3]	Yes	74 (12%)	53 (36%)	133 (17%)	<0.00
Number of financial impacts	0	376 (48%)	65 (35%)	447 (45%)	0.01
	1	184 (23%)	52 (28%)	245 (25%)	
	2	110 (14%)	29 (16%)	140 (14%)	
	3	47 (6.0%)	13 (7.0%)	61 (6.2%)	
	4	29 (3.7%)	13 (7.0%)	44 (4.4%)	
	5	26 (3.3%)	7 (3.7%)	33 (3.3%)	
	6	8 (1.0%)	6 (3.2%)	14 (1.4%)	
	>=7	3 (0.4%)	2 (1.1%)	5 (0.5%)	
Number of high/ very high unmet needs	0	452 (58%)	90 (48%)	556 (56%)	0.31
	1	50 (6.4%)	15 (8.0%)	66 (6.7%)	
	2	30 (3.8%)	10 (5.3%)	40 (4.0%)	
	3	28 (3.6%)	9 (4.8%)	38 (3.8%)	
	4	14 (1.8%)	6 (3.2%)	20 (2.0%)	
	5	12 (1.5%)	2 (1.1%)	14 (1.4%)	
	6	11 (1.4%)	5 (2.7%)	16 (1.6%)	
	>=7	186 (24%)	50 (27%)	239 (24%)	

1. 970/989 had data on rural/urban status. **Total numbers may be less than 970 for some variables due to missing data.**
2. Exact tests used due to low/zero counts in some categories
3. Excluding registry A

Table 2. Adjusted odds ratios for support persons with at least 1 DASS outcome

Variable	Category	Common variables				With additional (Non-Registry A) variables	
		All States (n=784)		Excluding Registry A (n=632)		Excluding Registry A (n=626)	
		Odds of at least 1 DASS outcome (95% CI)	pval	Odds of at least 1 DASS outcome (95% CI)	pval	Odds of at least 1 DASS outcome (95% CI)	pval
Survivor time since diagnosis	<=12m	1.73 (0.72, 4.18)	0.1478	0.83 (0.03, 24.07)	0.3551	0.78 (0.02, 27.13)	0.41
	13 to 24m	1.60 (0.74, 3.49)		1.45 (0.57, 3.64)		1.86 (0.70, 4.93)	
	25-36m	0.88 (0.41, 1.86)		1.01 (0.47, 2.16)		1.11 (0.51, 2.40)	
	37-48m	1.54 (0.74, 3.19)		1.58 (0.77, 3.24)		1.63 (0.78, 3.42)	
	49-60m	1.84 (0.93, 3.65)		1.82 (0.93, 3.55)		1.86 (0.93, 3.72)	
	61+	ref		ref		ref	
Rurality	Urban	1.19 (0.72, 1.97)	0.5006	1.18 (0.68, 2.03)	0.5616	1.62 (0.89, 2.94)	0.11
	Rural	ref	.	ref		ref	
Age	15 to 39	1.17 (0.55, 2.49)	0.9180	1.37 (0.62, 3.04)	0.7891	2.40 (1.00, 5.76)	0.10
	40 to 49	0.93 (0.47, 1.85)		1.16 (0.56, 2.38)		1.90 (0.88, 4.12)	
	50 to 59	1.13 (0.70, 1.83)		1.26 (0.74, 2.12)		1.72 (0.98, 3.00)	
	60+	ref		ref		ref	
Marital status	Married or defacto	0.32 (0.06, 1.63)	0.3794	0.21 (0.04, 1.27)	0.2671	0.23 (0.04, 1.35)	0.41
	Separated or divorced	0.48 (0.06, 3.66)		0.24 (0.02, 2.36)		0.23 (0.02, 2.24)	
	Single	0.59 (0.09, 3.81)		0.46 (0.06, 3.27)		0.37 (0.05, 2.75)	
	Widowed	ref		ref		ref	
Previous diagnosis of cancer	Yes	0.66 (0.34, 1.26)	0.2088	0.72 (0.36, 1.44)	0.3517	0.65 (0.32, 1.32)	0.23
	No	ref		ref		ref	
Number of people in household	1	0.57 (0.15, 2.10)	0.5304	0.55 (0.14, 2.21)	0.5217	0.42 (0.10, 1.83)	0.59
	2	0.80 (0.41, 1.55)		0.88 (0.40, 1.95)		0.77 (0.34, 1.73)	
	3	1.15 (0.52, 2.56)		1.30 (0.51, 3.33)		1.01 (0.38, 2.64)	
	>=4	ref		ref		ref	
Number of financial impacts	Unit increase	1.13 (0.99, 1.29)	0.0791	1.12 (0.97, 1.30)	0.1095	1.02 (0.87, 1.20)	0.78
Number of high or very high unmet needs	Unit increase	1.15 (1.12, 1.18)	<.0001	1.13 (1.10, 1.16)	<.0001	1.13 (1.10, 1.17)	<0.00
Number of health conditions*	0		.		.	0.16 (0.05, 0.54)	<0.00
	1					0.36 (0.11, 1.22)	
	2					0.75 (0.21, 2.62)	
	3					0.57 (0.14, 2.28)	
	>=4					ref	
Relocated for treatment *	Yes		.		.	2.06 (1.15, 3.70)	0.02
	No					ref	

*Excludes Registry A

Supplementary data

Table 3. Comparison of characteristics of consenting and non-consenting survivors.

Characteristic	Participant N (%)	Non-participant N (%)	Chi squared results
Age at diagnosis			87.80(4), p <0.001
15-39	143 (23%)	478 (77%)	
40-49	166 (31%)	365 (69%)	
50-59	419 (44%)	537 (56%)	
60-69	491 (41%)	721 (59%)	
70+	247 (34%)	882 (66%)	
location			9.89(1), p=0.002
Rural	281 (42%)	396 (58%)	
Urban	1,185 (35%)	2,187 (65%)	
Sex			2.79(1), p=0.095
Male	822 (35%)	1,518 (65%)	
Female	644 (38%)	1,065 (62%)	
Cancer type			16.53(3), p=0.001
NHL	811 (35%)	1,483 (65%)	
Leukaemia	246 (36%)	430 (64%)	
Myeloma	229 (44%)	296 (56%)	
Other	180 (32%)	374 (68%)	