

# Support-seeking by cancer caregivers living in rural Australia

Elizabeth A. Johnston,<sup>1-3</sup> Belinda C. Goodwin,<sup>1,4</sup> Larry Myers,<sup>1,5</sup> Sonja March,<sup>4,5</sup> Joanne F. Aitken,<sup>1,4,6,7</sup> Suzanne K. Chambers,<sup>8-10</sup> Jeff Dunn<sup>1,4,8,10-12</sup>

Following a cancer diagnosis, family members and friends often become informal caregivers, helping with activities of daily living, medical care and follow-up, and providing emotional and social support.<sup>1,2</sup> While some studies have reported positive outcomes of caring for someone with cancer, including personal growth and dyadic resilience (i.e. relationship growth and mutual coping between caregiver and patient),<sup>3-5</sup> other studies report negative impacts of long-term caregiving on the caregiver's health and wellbeing. These include reduced diet quality and physical activity,<sup>6,7</sup> weight gain,<sup>6,7</sup> anxiety or depression,<sup>8,9</sup> stress<sup>10</sup> and delays in seeking medical help for themselves.<sup>11</sup>

Supporting the health and wellbeing of those caring for someone with cancer is a priority since poorer physical and psychological health has been associated with higher levels of caregiver burden.<sup>12</sup> Poor physical and psychological health may also affect a caregiver's capacity to provide support. In intervention studies, providing cancer caregivers with psychosocial support has been demonstrated to reduce caregiver distress and improve quality of life,<sup>13,14</sup> and there is some evidence that post-treatment lifestyle interventions can improve diet quality and physical activity of cancer survivors and their family members.<sup>15</sup>

## Abstract

**Objective:** Rural cancer caregivers report poor wellbeing and high unmet needs for support. This study investigates sources of support sought by cancer caregivers living in rural Australia, and factors associated with support-seeking.

**Methods:** Informal caregivers of people with cancer completed a questionnaire assessing sociodemographic characteristics, caregiver factors and support-seeking. Descriptive statistics, bivariate analyses and logistic regression were used to identify common sources of support and factors associated with support-seeking. Alluvial and radar plots were used to identify and describe support-seeking profiles.

**Findings:** Of 244 rural caregivers, 64% reported seeking support for themselves, 72% for the cancer patient, and 22% did not seek any support. The most common sources of support were general practitioners and online. Higher caregiver burden, higher income, caring for someone with anxiety/depression or caring for someone who has difficulty completing their usual activities were associated with seeking support from a greater number of sources. The 'No support-seekers' profile had the highest proportions of caregivers who were male, caring for someone <12 months post-diagnosis and lower income earners.

**Conclusions:** Many rural caregivers seek support for themselves and the cancer patient, commonly from medical and online sources.

**Implications for public health:** Further work may be needed to reduce caregiver burden and support caregivers who are male, caring for someone recently diagnosed, and those with lower incomes.

**Key words:** caregivers, oncology, regional and remote, rural, supportive care

As cancer prevalence increases due to increasing cancer incidence and survival, the role of caregivers in providing support to cancer survivors will become increasingly vital, particularly in geographically isolated areas. Currently, cancer caregivers living

in regional and remote (i.e. rural) Australia report poorer than average mental wellbeing compared to population norms.<sup>16</sup> They also report high unmet needs for practical support (e.g. transportation, lodging, finances), their own physical health and psychological

1. Viertel Cancer Research Centre, Cancer Council Queensland, Queensland

2. School of Exercise and Nutrition Sciences, Queensland University of Technology, Queensland

3. Population Health Program, QIMR Berghofer Medical Research Institute, Queensland

4. Centre for Health Research, University of Southern Queensland, Queensland

5. School of Psychology and Wellbeing, University of Southern Queensland, Queensland

6. School of Public Health and Social Work, Queensland University of Technology, Queensland

7. School of Public Health, The University of Queensland, Queensland

8. Faculty of Health Sciences, Australian Catholic University, Queensland

9. St Vincent's Health Network Sydney, New South Wales

10. Menzies Health Institute Queensland, Griffith University, Queensland

11. Exercise Medicine Research Institute, Edith Cowan University, Western Australia

12. Prostate Cancer Foundation of Australia, New South Wales

**Correspondence to:** Elizabeth A. Johnston, Viertel Cancer Research Centre, Cancer Council Queensland, 553 Gregory Terrace, Fortitude Valley, QLD, Australia 4006; e-mail: ElizabethJohnston@cancerqld.org.au

Submitted: April 2022; Revision requested: June 2022; Accepted: July 2022

The authors have stated they have no conflicts of interest.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

*Aust NZ J Public Health.* 2022; Online; doi: 10.1111/1753-6405.13304

wellbeing, and information to assist them in caring for someone with cancer.<sup>17</sup> Living outside of a major city presents several challenges to accessing cancer-related support, including greater travel distances, higher costs and fewer local healthcare services.<sup>18–20</sup> These findings suggest there is a need for improved support for rural cancer caregivers. However, little is known regarding the sources of support they currently access for themselves and for the person they care for and the factors associated with seeking such support.

Therefore, this study aims to: 1) identify the most common sources of support sought by cancer caregivers living in rural Australia, as well as the most common profiles of support-seeking behaviour; and 2) investigate the sociodemographic, caregiver and patient factors associated with seeking support. Research findings will provide further understanding of the support-seeking behaviours of cancer caregivers living in rural Australia and contribute to identifying areas of priority for future intervention to support the health and wellbeing of this population.

## Methods

### Participants and recruitment

Caregivers included in this study were nominated by people diagnosed with cancer who were taking part in a longitudinal study investigating the experiences of people living in rural Queensland who have travelled to a major centre for cancer treatment. Recruitment of people diagnosed with cancer and their caregivers has been described elsewhere.<sup>17,21</sup> Caregivers, including spouses/partners, family members or friends, were eligible to participate if they were aged 18 years or older and able to read and understand English. Of the 402 caregivers nominated, 259 consented to participate and completed a questionnaire (Supplementary Figure 1). After excluding caregivers living in a major city, determined using the Australian Statistical Geography Standard Remoteness Structure,<sup>22</sup> those who did not complete questionnaire items for support-seeking and those caring for someone without a cancer diagnosis, responses from 244 rural caregivers were included in this analysis (Supplementary Figure 1). Ethical approval was obtained from a recognised institutional Human Research Ethics Committee (H17REA152).

### Data collection

A self-administered questionnaire at recruitment collected information on support-seeking, socio-demographic and caregiver characteristics. When completing the baseline questionnaire, caregivers had been caring for someone diagnosed with cancer for a median of 9 months (IQR 5 to 23 months). Information relating to the person they were caring for was extracted from baseline patient questionnaires completed at study recruitment (median 6 months post-diagnosis, IQR 3 to 22 months).

**Support-seeking:** Caregivers were asked whether they had sought cancer-related support (yes/no) since becoming a cancer caregiver for: 1) themselves as a caregiver; and 2) the person they were caring for. Both questions listed five sources of support: 1) Cancer Council information and support service; 2) cancer support groups (for themselves as a caregiver, this included friends and family of someone with cancer); 3) general practitioner or other medical professional; 4) psychologist, social worker or counsellor; and 5) online.

#### Sociodemographic factors:

Sociodemographic information collected at recruitment included age, gender, relationship to patient, education, income and country of birth. Residential street address was geocoded and mapped to the 2011 Statistical Areal Level 2 (SA2) boundaries using MapMarker® Australia Version 15.16.0.21 and MapInfo Pro® Version 15.0. SA2 was used to classify caregivers by remoteness and relative socioeconomic advantage and disadvantage.<sup>22,23</sup>

**Caregiver comorbidity:** The number of comorbidities was identified using the items from the Charlson Comorbidities Index.<sup>24</sup> Caregivers were grouped according to whether they reported no chronic illnesses or at least one chronic condition (e.g. diabetes, cardiovascular disease, arthritis).

**Caregiver burden:** Perceived caregiver burden was assessed using the validated Caregiver Burden Scale developed by Elmstahl and colleagues.<sup>25</sup> The scale consists of 22 items across five domains (general strain, isolation, disappointment, emotional involvement, environment). Participants responded to items such as: “Do you worry about not taking care of the person with cancer in a proper way?” using a 5-point scale ranging from 1 = “not at all” to 4 = “often”.

A mean score was calculated for the total scale and each domain, with higher scores indicating a greater subjective burden. Internal consistency of this global scale in the current study was high at  $\alpha=0.93$ .

**Caregiver stress:** The challenge and threat subscales from the Carer Stress Appraisal Scale<sup>26</sup> were used to assess caregiver stress. Example items included: “I am eager to tackle this problem” (challenge subscale) and “This situation makes me feel anxious” (threat subscale) with response options ranging from 1 = “not at all” to 5 = “extremely”. A mean score was calculated for each subscale, with higher scores indicating greater challenge or threat appraisals. Internal consistency for each subscale was good (Challenge  $\alpha=0.84$ ; Threat  $\alpha=0.85$ ).

#### Caregiver attitudes to health-related help-seeking:

Two subscales from Mansfield and colleagues' Barriers to Help-Seeking Scale<sup>27</sup> were assessed; the need for control and self-reliance (NCS) and minimising problems and resignation (MPR). Example items included: “It would seem weak to ask for help” (NCS) and “I wouldn't want to overreact to symptoms that weren't serious” (MPR). Response items ranged from 1 = “not at all” to 5 = “very much”. The mean score of each subscale was calculated, with higher scores representing higher levels of NCS and MPR. Internal consistency for the subscales was good (NCS  $\alpha=0.88$ ; MPR  $\alpha=0.89$ ).

**Caregiver fatalistic beliefs:** Caregivers' beliefs regarding their health were assessed using the 10-item predetermination subscale of Shen and colleagues' Health Fatalism Scale.<sup>28</sup> Items include: “If someone is meant to have a serious disease, they will get that disease”. Response options ranged from 1 = “strongly disagree” to 5 = “strongly agree”, with higher scores indicating greater fatalistic beliefs. Internal consistency in the current sample was excellent ( $\alpha=0.90$ ).

**Patient factors:** Cancer patients reported their cancer type and date of diagnosis at recruitment to the longitudinal study.<sup>21</sup> These were verified in the population-based Queensland Cancer Register (QCR). Patient self-report data were solely used where diagnosis could not be verified by the QCR, or the patient's diagnosis was very recent and had not yet been notified to the QCR. Time since diagnosis was defined as the number of months from the patient's cancer diagnosis date to the caregiver's questionnaire completion date.

**Patient health status:** The EQ-5D-5L instrument was used to assess patient health status at recruitment. EQ-5D-5L descriptively evaluates the health-related quality of life across five dimensions (mobility, self-care, usual activities, pain or discomfort, anxiety or depression).<sup>29,30</sup> For each dimension, patients identified whether they had 'no problems', or 'slight', 'moderate', 'severe' or 'extreme' difficulty. Patients' responses for each dimension were categorised as 'Yes' and 'No', with 'Yes' including those who reported 'slight' to 'extreme' difficulty. A single utility score combining responses to the five dimensions was also calculated for each patient using the scoring algorithm based on a value set from the United Kingdom.<sup>31</sup>

### Data analysis

Descriptive statistics were used to characterise the sample of rural caregivers and the proportion of caregivers using each source of support for themselves and for the person they were caring for. Bivariate associations between sources of support sought and sociodemographic, caregiver and patient factors were assessed using chi-square tests for categorical variables and independent t-tests for continuous variables. Significance values were adjusted for family-wise error using the Benjamini-Hochberg Procedure.<sup>32</sup> Where sociodemographic, caregiver and patient factors shared a significant association with support-seeking in bivariate analyses, they were entered into binary logistic regression models to estimate odds ratios (OR) and 95% confidence intervals (CI) associated with the likelihood of support-seeking for themselves and for the person they were caring for. ORs were adjusted for age and education as these variables were strongly associated with the other sociodemographic, caregiver and patient factors in bivariate analyses.

We also sought to identify profiles of support-seeking behaviour for themselves as a caregiver and for the person they were caring for. The use of hierarchical clustering methods did not generate a parsimonious solution ( $\geq 15$  clusters). Thus, a descriptive approach was adopted using alluvial plots<sup>33</sup> to visually depict the profiles of support-seeking. In these alluvial plots, the horizontal bands show the types of support sought by caregivers from the five sources listed; each caregiver fits into one profile only, with a profile comprising of caregivers who sought support from the same source/s. The width of the horizontal

bands is proportional to the number of caregivers in that profile, whereas the height of the vertical bars is proportional to the number of people who reported seeking support from that particular source (yes/no). A support-seeking profile was retained (i.e. reported as a discrete profile) if its frequency of occurrence in the study population was greater than expected had responses for support-seeking been generated at random (based on 100 iterations); see Supplementary Figure 2. Alluvial plots were generated using the R statistical program (R Core Team) and 'alluvial' package.<sup>34</sup>

Radar plots were created in Excel to identify and describe the sociodemographic, caregiver and patient characteristics of the support-seeking profiles identified in the alluvial plots. For radar plots, continuous variables were categorised into two groups based on the sample median and categorical variables with more than two levels (relationship to patient, income, area-level disadvantage, remoteness) were collapsed into two groups. Chi-square tests were used to identify significant differences between support-seeking profiles based on the sociodemographic, caregiver and patient factors presented in the radar plots. All analyses were performed using SAS, version 9.4 (SAS Institute) with a  $p < 0.05$  (two-sided) cut-off for statistical significance.

## Results

### Rural caregiver characteristics

The characteristics of rural caregivers included in this study are presented in Supplementary Table 1. Most rural caregivers were female (62%), the spouse or partner of the person diagnosed with cancer (83%), born in Australia (69%) and living in a low socioeconomic area (83%). On average, rural caregivers were aged 62 years (standard deviation (SD) = 13, range 18–91) and were mostly caring for someone who was diagnosed with cancer of the breast (19%),

skin (14%), prostate (11%) or head and neck (10%). Most rural caregivers resided in inner (52%) and outer (42%) regional areas, with only 6% in remote or very remote areas.

### Sources of support sought for themselves and for the person they were caring for

Of the 244 rural caregivers, 141 (58%) sought support for both themselves and the person they were caring for, 15 (6%) for themselves only and 35 (14%) for the person they were caring for only. Fifty-three (22%) caregivers did not report seeking support from any of the listed sources for themselves or the person they were caring for.

Rural caregivers who reported seeking support for themselves ( $n=156$ ; 64%), most frequently sought support from a general practitioner (GP) or other medical professional (38%), online resources (30%) and cancer support groups or friends and family of someone with cancer (30%); see Table 1. Those who reported seeking support for the person they were caring for ( $n=176$ ; 72%), most frequently sought support from a GP or other medical professional (47%) and online resources (40%); see Table 1.

Rural caregivers who sought support for themselves from a particular source were more likely to also seek support from that source for the person they were caring for, including Cancer Council information and support ( $\chi^2(1)=126.75, p < 0.0001$ ), support groups ( $\chi^2(1)=58.30, p < 0.0001$ ), GP or other medical professional ( $\chi^2(1)=68.83, p < 0.0001$ ), psychologist, social worker or counsellor ( $\chi^2(1)=128.79, p < 0.0001$ ) and online resources ( $\chi^2(1)=118.61, p < 0.0001$ ). See Table 1 for percentages.

### Factors associated with seeking support for themselves as a caregiver

Of the 156 rural caregivers who reported seeking support for themselves, 31% sought support from one source only, 30% from two

**Table 1: Sources of support sought by rural cancer caregivers for themselves as a caregiver and for the person they were caring for ( $n=244$ ).**

Sources of support	For themselves as a caregiver		For the person they were caring for	
	N	(%)	N	(%)
Cancer Council information and support service	53	(22)	67	(28)
Cancer support groups	73	(30)	52	(21)
General practitioner or other medical professional	93	(38)	114	(47)
Psychologist, social worker, counsellor	63	(26)	58	(24)
Online resources	73	(30)	96	(40)
Any of the above	156	(64)	176	(72)

sources and 39% from three or more sources. Rural caregivers who reported a higher income (>\$100,000 per year;  $\chi^2(3)=9.28, p=0.026$ ), those with a caregiver burden score above the sample average (total score:  $\chi^2(3)=20.89, p=0.0001$ ) and those caring for someone with some level of anxiety or depression ( $\chi^2(3)=8.54, p=0.036$ ) were more likely to report accessing a greater number of sources of support.

Sociodemographic, caregiver and patient factors associated with seeking support for themselves as a caregiver are summarised in Figure 1. After adjusting for family-wise error, caregiver burden (total score and subscales for strain, disappointment and environment) was associated with seeking support for themselves from a psychologist, social worker or counsellor (Figure 1). Caregiver age, education, income, burden (disappointment subscale) and fatalistic beliefs regarding health were associated with seeking support for themselves online (Figure 1).

These significant factors were entered into separate binary logistic regression models; after adjusting for age and education, those who reported a higher score for caregiver

burden (total score: OR=2.41, 95%CI=1.36-4.26; strain subscale: OR=2.02, 95%CI=1.27-3.22; disappointment subscale: OR=1.83, 95%CI=1.16-2.89; environment subscale: OR=1.82, 95%CI=1.10-3.00) were more likely to report seeking support for themselves from a psychologist, social worker, or counsellor (Supplementary Table 2). Those who were older (OR=0.95, 95%CI=0.93-0.98) and those who reported a higher score for fatalism (OR=0.69, 95%CI=0.49-0.98) were less likely to report seeking support for themselves online (Supplementary Table 2).

Visual inspection of the scree plot suggested four profiles of support-seeking for themselves as a caregiver (Supplementary Figure 2). These four profiles are highlighted in Figure 2: 1) 'No support-seekers' (i.e., those who did not seek any form of support; 36%), 2) 'Medical support only' (i.e. GP or other medical professional; 6%), 3) 'Online only' (6%) and 4) 'Medical and psychological support only' (i.e. GP or other medical professional and psychologist, social worker, or counsellor; 5%). The remaining caregivers (47%) fell into a variety of 'Other support-seeking' profiles who sought support for themselves from at

least one but most often a combination of three sources.

The 'No support-seekers' group had the highest proportion of rural caregivers who were caring for someone less than 12 months post-diagnosis and the lowest proportion of higher income earners (Supplementary Figure 3). Compared to the 'No support-seekers', those who sought support 'Online only' were more likely to have completed tertiary education ( $\chi^2(1)=4.85, p=0.028$ ) and be higher income earners ( $\chi^2(1)=7.59, p=0.0059$ ). Those in the 'Other support seekers' group were less likely to be the spouse or partner of the person diagnosed with cancer ( $\chi^2(1)=4.92, p=0.027$ ), and more likely to be higher income earners ( $\chi^2(1)=4.92, p=0.027$ ) and report a caregiver burden score above the sample average (total:  $\chi^2(1)=8.67, p=0.0032$ ) than the 'No support-seekers' group.

### Factors associated with seeking support for the person they were caring for

Of the 176 rural caregivers who reported seeking support for the person they were caring for, 38% sought support from one

Figure 1: Summary of bivariate associations between sociodemographic, caregiver, and patient factors and support-seeking by rural cancer caregivers for themselves as a caregiver.

	Any support	Cancer Council	Support groups	GP or other medical	Psychologist, social worker, counsellor	Online resources
<b>Sociodemographic factors</b>	Income	○	○	○	○	●
	Gender	○	●	○	○	●
	Education	○	○	○	○	●
	Relationship to patient	○	○	○	○	●
	Age	○	○	○	○	●
	Country of birth	○	○	○	○	●
	Remoteness	○	○	○	○	○
	Area-level disadvantage	○	○	○	○	○
<b>Caregiver factors</b>	Patient support from same source	●	●	●	●	●
	Carer stress (challenge)	●	○	○	●	○
	Caregiver burden (total)	○	○	○	○	●
	Caregiver burden (isolation)	○	○	○	○	●
	Caregiver burden (disappointment)	○	○	○	○	●
	Caregiver burden (strain)	○	○	○	○	●
	Caregiver burden (environment)	○	○	○	○	●
	Carer stress (threat)	○	○	○	○	○
	Fatalism	○	○	○	○	○
	Comorbidity	○	○	○	○	○
	Caregiver burden (emotional involvement)	○	○	○	○	○
	Barriers to help-seeking (NCS)	○	○	○	○	○
Barriers to help-seeking (MPR)	○	○	○	○	○	
<b>Patient factors</b>	Cancer type	○	○	○	○	○
	Usual activities	○	○	○	○	○
	Anxiety or depression	○	○	○	○	○
	Pain or discomfort	○	○	○	○	○
	Time since diagnosis	○	○	○	○	○
	Utility score	○	○	○	○	○
	Mobility	○	○	○	○	○
	Self-care	○	○	○	○	○

NCS: Need for control and self-reliance  
MPR: Minimising problems and resignation

○ Significant association in bivariate comparisons  
● Significant association after adjusting for family wise error

source only, 24% from two sources and 38% from three or more sources. Rural caregivers who reported a caregiver burden score above the sample average (total score:  $\chi^2(3)=17.85$ ,  $p=0.0005$ ) and those caring for someone with some degree of difficulty completing their usual activities ( $\chi^2(3)=8.17$ ,  $p=0.043$ ) were more likely to report accessing a greater number of sources of support.

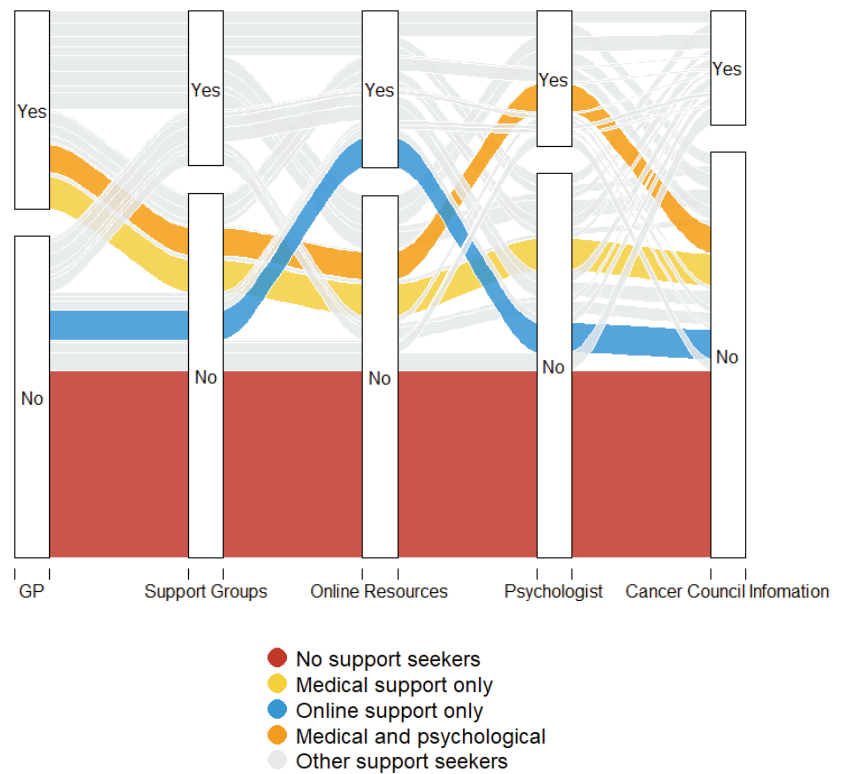
Sociodemographic, caregiver and patient factors associated with seeking support for the person they were caring for are summarised in Supplementary Figure 4. After adjusting for family-wise error, caregiver burden (total score and sub-scales for strain and environment) and the patient's ability to complete their usual activities were associated with seeking support for the cancer survivor from a psychologist, social worker or counsellor (Supplementary Figure 4). Caregiver age, education, income, burden (disappointment subscale), comorbidity, stress (threat subscale) and fatalistic beliefs regarding health were associated with seeking support for the cancer survivor online (Supplementary Figure 4).

These significant factors were entered into separate binary logistic regression models; after adjusting for age and education, those who reported a higher score for caregiver burden (total score: OR=2.04, 95%CI=1.17-3.56; strain subscale: OR=1.78, 95%CI=1.13-2.82; environment subscale: OR=1.84, 95%CI=1.12-3.03) and those caring for someone with some level of difficulty completing their usual activities (OR=3.26, 95%CI=1.48-7.19) were more likely to report seeking support for the cancer survivor from a psychologist, social worker or counsellor (Supplementary Table 2). Those who were older (OR=0.96, 95%CI=0.93-0.98) and reported a higher score for fatalism (OR=0.63, 95%CI=0.45-0.87) were less likely to report seeking support for the cancer survivor online (Supplementary Table 2).

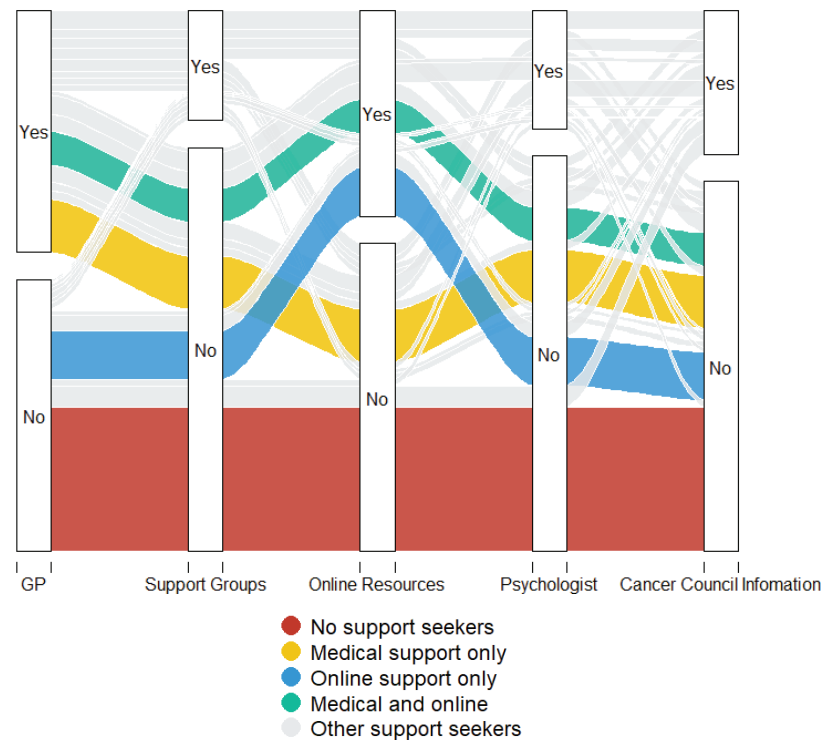
Visual inspection of the scree plot suggested four profiles of support-seeking for the person they were caring for (Supplementary Figure 2). These four profiles are shown in Figure 2: 1) 'No support-seekers' (i.e. those who did not seek any form of support) (28%); 2) 'Medical support only' (i.e. GP or other medical professional) (10%); 3) 'Online only' (9%); and 4) 'Medical and online only' (7%). The remaining caregivers (46%) fell into a variety of 'Other support-seeking' profiles who sought support for the cancer survivor from

Figure 2: Alluvial plots showing profiles of support-seeking by rural cancer caregivers for (1) themselves as a caregiver and (2) the person they were caring for.<sup>a</sup>

(1) Profiles of support-seeking for themselves as a caregiver.



(2) Profiles of support-seeking for the person they were caring for.



Note:

a: The height of the vertical bars in the alluvial plot is proportional to the number of caregivers who reported seeking support from each source (Yes/No). The width of the horizontal bands is proportional to the number of caregivers in each profile. Each caregiver fits into one support-seeking profile only in (1) and in (2).

at least one but most often a combination of three sources.

The 'No support-seekers' group had the highest proportion of male caregivers and those caring for someone less than 12 months post-diagnosis, and the lowest proportion of higher income earners (Supplementary Figure 5). Compared to the 'No support-seekers', those who sought support from 'Medical and online only' were more likely to have completed tertiary education ( $\chi^2(1)=4.22, p=0.04$ ) and be higher income earners ( $\chi^2(1)=6.89, p=0.0086$ ). Those in the 'Other support seekers' group were less likely to be male ( $\chi^2(1)=4.94, p=0.026$ ) and more likely to have completed tertiary education ( $\chi^2(1)=4.67, p=0.031$ ), report a caregiver burden score above the sample average (total:  $\chi^2(1)=9.57, p=0.002$ ; emotional involvement:  $\chi^2(1)=5.70, p=0.017$ ) and be caring for someone with some degree of difficulty completing their usual activities ( $\chi^2(1)=5.94, p=0.015$ ) compared to those who did not seek support for the cancer survivor.

## Discussion

This study provides novel insights regarding the support-seeking behaviours of cancer caregivers living in rural Australia; well over half report seeking at least one form of support for themselves and almost three-quarters seek support for the person they are caring for. This highlights that caring for someone with cancer while living in a rural area is a significant undertaking and many seek support. However, there is still a substantial proportion of rural caregivers who did not report seeking any form of support, particularly for themselves as a caregiver. This might reflect their actual need for support but may also suggest that some rural caregivers are under-supported or may require further support in the future as they become long-term caregivers.<sup>17</sup>

Similar to cancer survivors living in rural Australia,<sup>21</sup> the most common forms of support sought by rural caregivers in our study were general practitioners (GPs) or other medical professionals and online resources. GPs are well placed to support rural cancer caregivers; current hospital-based models for cancer care focus on the patient and there is limited guidance for addressing caregiver needs in that context.<sup>35</sup> GPs can also provide continuity of care to rural caregivers throughout the cancer care journey. In semi-structured interviews, rural cancer survivors

and their caregivers reported a preference for receiving support from the same person to avoid having to repeat information and to enable them to build rapport with their healthcare provider.<sup>36</sup> However, they also reported several difficulties accessing care from local GPs, including high staff turnover in rural practices and longer waiting times.<sup>36</sup> Considering GPs are one of the most common sources of support sought by rural caregivers in our study and rural caregivers value continuity of care, further work is needed to increase GP access and better integrate primary care into survivorship care.<sup>37</sup>

The use of online resources for support has also been reported in other caregiver populations; in a survey of cancer caregivers in Singapore, the Internet was the most sought source of information, followed by healthcare professionals.<sup>38</sup> The main reasons for using the Internet to obtain cancer-related information were convenience and accessibility.<sup>38</sup> These reasons may also be applicable to rural caregivers who report several challenges to accessing cancer-related support, including greater travel distances, higher costs and fewer local healthcare services.<sup>18–20</sup> However, in the study by Chua and colleagues,<sup>38</sup> almost half of the caregivers who used the Internet to obtain cancer-related information expressed concern about the quality of information. Similarly, cancer survivors report difficulty identifying credible sources of dietary information online,<sup>39</sup> and a review of websites providing physical activity information after cancer identified poor quality and depth of information online.<sup>40</sup>

Compared to GPs and online resources, other forms of support, including psychologist or social worker, cancer support groups and Cancer Council information and support services appeared to be less commonly sought by rural caregivers. The reasons for this in the current study are unknown. Potentially, it could reflect the level of need for these services in our sample. However, there is evidence to suggest that rural caregivers have high unmet needs for psychosocial support.<sup>17</sup> Previous studies in rural populations have identified that help-seeking for mental health issues may be hindered by perceived norms and expectations of being self-reliant and resilient, as well as the practical constraints of taking time off work to attend appointments and the costs involved.<sup>41,42</sup> From previous research, the use of psychosocial support services by rural caregivers may also be limited by a lack of local services or clear

post-treatment pathways to these services.<sup>36</sup> Future work could investigate how to best support rural caregivers' psychosocial needs, including facilitating access to support services that align with their needs and preferences.

We also identified that rural caregivers who reported seeking support often sought support from multiple sources. Higher caregiver burden, higher income, caring for someone with some level of anxiety or depression or caring for someone who has difficulty completing their usual activities, were associated with seeking support from a greater number of sources. Although it is unknown what type of support rural caregivers sought from each source, these findings support previous studies reporting on the multi-faceted nature of caregiver burden (e.g. physical, emotional, psychological, social, financial)<sup>12</sup> and suggest that rural caregivers' supportive care needs may not be met by one source alone. This highlights the complexity involved in supporting someone with cancer while living in a rural area and the enhanced capacity and literacy required of caregivers in seeking support. It is unknown whether, or how, the need to seek multiple sources of support affects caregiver burden.

Despite a high proportion of rural caregivers reporting they did seek support for themselves or for the person they were caring for, at least one in five had not accessed any form of support since becoming a caregiver. Compared to groups of rural caregivers who did seek support, the no support-seeking group had the highest proportions of caregivers who were male, caring for someone less than 12 months post-diagnosis and lower income earners. Previous studies provide some evidence that these factors may influence support-seeking. Rural male cancer caregivers report lower levels of unmet needs than females<sup>17</sup> and cancer caregivers often reported not accessing support for themselves due to prioritising the needs of the person diagnosed with cancer, feeling there was limited opportunity to express their need for support and difficulty allocating time to attend an appointment.<sup>19</sup> Finally, lower-income earners may experience financial barriers to accessing support services, as informal caregiving has been associated with significant direct and indirect costs, often estimated at more than \$1,000 per month.<sup>43</sup>

## Practical implications

Overall, this study indicates there is a need to ensure adequate support is available and accessible to rural cancer caregivers. This need is supported by previous research reporting poorer mental wellbeing among rural cancer caregivers,<sup>16</sup> as well as high unmet needs for supportive care<sup>17</sup> and challenges in accessing local support services.<sup>19,36</sup> Thus, system-wide changes are needed to address these challenges. For example, screening for rural caregivers' supportive care needs and providing referrals to community-based services could commence from diagnosis, alongside screening and referral for the cancer patient's needs. Health professionals should be aware that rural caregivers who are male, those caring for someone recently diagnosed and those who are lower income earners may be less likely to seek support.

## Study limitations

Rural caregivers in this study were nominated by people who had been diagnosed with cancer and had stayed at a subsidised accommodation service for people living outside of a major city. This may have introduced sampling bias because those who access this accommodation may be more likely to seek support or have received information about support services available. Even so, 22% of the study sample had not accessed any of the listed sources of support since becoming a cancer caregiver. The study sample also included a low proportion (6%) of caregivers living in remote or very remote areas, so we are less confident about the help-seeking behaviours of those living in these areas. The proportion of female caregivers in this sample was also lower than typically reported in rural caregiver samples in Australia. While we believe this was not low enough to invalidate any findings, it does suggest a possible sampling bias.

The cross-sectional study design means that causation cannot be inferred in the associations observed between sociodemographic, caregiver and patient factors and cancer-related support-seeking. Additionally, comparisons between some of the support-seeking profiles were insufficiently powered ( $n < 18$ ) to detect differences in these factors. It is also unknown how associations between sociodemographic, caregiver and patient factors and support-seeking change over time. For example, how changes in caregiver

burden influence subsequent support-seeking. While the use of online resources for support was commonly reported in our study, it is not known what type of resources caregivers accessed online (e.g. websites, forums, support groups). Further, the study questionnaire did not collect information regarding why rural caregivers did or did not access specific sources of support, the information they were seeking from each source, the mode of delivery (e.g. in-person, online, telephone), their preferences for support and their confidence and capacity to seek the support they need. Future work could address these gaps, contributing to a better understanding of how to support rural caregivers.

## Conclusions

Since becoming a caregiver for someone diagnosed with cancer, many rural caregivers report seeking support for both themselves and for the person they are caring for. The most common forms of support sought were general practitioners (or other medical professionals) and online resources. Higher caregiver burden, higher income, caring for someone with some level of anxiety or depression or caring for someone who has difficulty completing their usual activities were associated with seeking support from a greater number of sources. Further work may be needed to ensure rural caregivers who are male, those caring for someone diagnosed in the past 12 months and lower income earners have access to appropriate support. Future interventions could consider how to optimise the availability and accessibility of support for rural caregivers to strengthen their capacity to provide their vital support to cancer survivors.

## Acknowledgements

The authors would like to thank all the participants in this study. We would also like to acknowledge the invaluable support of our research volunteers, research assistants and Cancer Council lodge staff.

## Funding

This work was supported by funding from Cancer Council Queensland and University of Southern Queensland.

## Ethics approval

The questionnaire and methodology for this study were approved by the Human Research Ethics Committee of the University of Southern Queensland (Ethics approval number: ref. H17REA152).

## References

1. Yabroff KR, Kim Y. Time costs associated with informal caregiving for cancer survivors. *Cancer*. 2009;115(518):4362–73.
2. Girgis A, Lambert S. Caregivers of cancer survivors: The state of the field. *Cancer Forum*. 2009;33:167–71.
3. Cormio C, Romito F, Viscanti G, Turaccio M, Lorusso V, Mattioli V. Psychological well-being and posttraumatic growth in caregivers of cancer patients. *Front Psychol*. 2014;5:1342.
4. Gibbons SW, Ross A, Wehrlen L, Klagholz S, Bevans M. Enhancing the cancer caregiving experience: Building resilience through role adjustment and mutuality. *Eur J Oncol Nurs*. 2019;43:101663.
5. Mosher CE, Adams RN, Helft PR, O'Neil BH, Shahda S, Rattray NA, et al. Positive changes among patients with advanced colorectal cancer and their family caregivers: A qualitative analysis. *Psychol Health*. 2017;32(1):94–109.
6. Beesley VL, Price MA, Webb PM. Loss of lifestyle: Health behaviour and weight changes after becoming a caregiver of a family member diagnosed with ovarian cancer. *Support Care Cancer*. 2011;19(12):1949–56.
7. Ezendam NPM, Karlsen RV, Christensen J, Tjønneland A, van de Poll-Franse LV, von Heymann-Horan A, et al. Do people improve health behavior after their partner is diagnosed with cancer? A prospective study in the Danish diet, Cancer and Health Cohort. *Acta Oncol*. 2019;58(5):700–7.
8. Unsar S, Erol O, Ozdemir O. Caregiving burden, depression, and anxiety in family caregivers of patients with cancer. *Eur J Oncol Nurs*. 2021;50:101882.
9. Papastavrou E, Charalambous A, Tsangari H. Exploring the other side of cancer care: The informal caregiver. *Eur J Oncol Nurs*. 2009;13(2):128–36.
10. Lund L, Ross L, Petersen MA, Groenvold M. Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: A survey. *BMC Cancer*. 2014;14:541.
11. Mazanec SR, Daly BJ, Douglas SL, Lipson AR. Work productivity and health of informal caregivers of persons with advanced cancer. *Res Nurs Health*. 2011;34(6):483–95.
12. Thana K, Lehto R, Sikorskii A, Wyatt G. Informal caregiver burden for solid tumour cancer patients: A review and future directions. *Psychol Health*. 2021;36(12):1514–35.
13. Chambers SK, Girgis A, Occhipinti S, Hutchison S, Turner J, McDowell M, et al. A randomized trial comparing two low-intensity psychological interventions for distressed patients with cancer and their caregivers. *Oncol Nurs Forum*. 2014;41(4):e256–66.
14. Treanor CJ. Psychosocial support interventions for cancer caregivers: Reducing caregiver burden. *Curr Opin Support Palliat Care*. 2020;14(3):247–62.
15. Ellis KR, Raji D, Olaniran M, Alick C, Nichols D, Allicock M. A systematic scoping review of post-treatment lifestyle interventions for adult cancer survivors and family members. *J Cancer Surviv*. 2022;16(2):233–56.
16. Goodwin BC, Crawford-Williams F, Ireland M, March S, Chambers SK, Aitken JF, et al. The quality of life of regional and remote cancer caregivers in Australia. *Eur J Cancer Care (Engl)*. 2022;31(4):e13587.
17. Stiller A, Goodwin BC, Crawford-Williams F, March S, Ireland M, Aitken JF, et al. The supportive care needs of regional and remote cancer caregivers. *Curr Oncol*. 2021;28(4):3041–57.

18. Paul CL, Hall AE, Carey ML, Cameron EC, Clinton-McHarg T. Access to care and impacts of cancer on daily life: Do they differ for metropolitan versus regional hematological cancer survivors? *J Rural Health*. 2013;29 Suppl 1:s43-50.
19. Taylor J, Fradgley EA, Clinton-McHarg T, Byrnes E, Paul CL. Access to support for Australian cancer caregivers: In-depth qualitative interviews exploring barriers and preferences for support. *J Psychosoc Oncol Res Pract*. 2021;3(2):e047.
20. Barlow KH, van der PJC, Ekberg S, Johnston EA. Cancer survivors' perspectives of dietary information provision after cancer treatment: A scoping review of the Australian context. *Health Promot J Austr*. 2022;33(1):232-44.
21. Goodwin BC, Chambers S, Aitken J, Ralph N, March S, Ireland M, et al. Cancer-related help-seeking in cancer survivors living in regional and remote Australia. *Psychooncology*. 2021;30(7):1068-76.
22. Australian Bureau of Statistics. *Australian Statistical Geography Standard (ASGS)* [Internet]. Canberra (AUST): ABS; 2016 [cited 2021 Jul 23]. Available from: [https://www.abs.gov.au/websitedbs/D3310114.nsf/home/Australian+Statistical+Geography+Standard+\(ASGS\)](https://www.abs.gov.au/websitedbs/D3310114.nsf/home/Australian+Statistical+Geography+Standard+(ASGS))
23. Australian Bureau of Statistics. *SEIFA* [Internet]. Canberra (AUST): ABS; 2016 [cited 2021 Jul 23]. Available from: <https://www.abs.gov.au/websitedbs/censushome.nsf/home/seifa>
24. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *J Chronic Dis*. 1987;40(5):373-83.
25. Elmstahl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Arch Phys Med Rehabil*. 1996;77(2):177-82.
26. Roesch SC, Rowley AA. Evaluating and developing a multidimensional, dispositional measure of appraisal. *J Pers Assess*. 2005;85(2):188-96.
27. Mansfield AK, Addis ME, Courtenay W. Measurement of men's help seeking: development and evaluation of the barriers to help seeking scale. *Psychol Men Masc*. 2005;6(2):95.
28. Shen L, Condit CM, Wright L. The psychometric property and validation of a fatalism scale. *Psychol Health*. 2009;24(5):597-613.
29. Herdman M, Gudex C, Lloyd A, Janssen M, Kind P, Parkin D, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res*. 2011;20(10):1727-36.
30. Pickard AS, De Leon MC, Kohlmann T, Cella D, Rosenbloom S. Psychometric comparison of the standard EQ-5D to a 5 level version in cancer patients. *Med Care*. 2007;45(3):259-63.
31. EUROQOL. *EQ-5D User Guides - EQ-5D* [Internet]. Rotterdam (NLD): EUROQOL; 2022 [cited 2022 Jan 10]. Available from: <https://euroqol.org/publications/user-guides/>
32. Benjamini Y, Hochberg Y. Controlling the false discovery rate: A practical and powerful approach to multiple testing. *J R Stat Soc Series B Stat Methodol*. 1995;57(1):289-300.
33. Siegler AJ, Luisi N, Hall EW, Bradley H, Sanchez T, Lopman BA, et al. Trajectory of COVID-19 vaccine hesitancy over time and association of initial vaccine hesitancy with subsequent vaccination. *JAMA Netw Open*. 2021;4(9):e2126882.
34. Bojanowski M, Edwards R. *alluvial: R Package for Creating Alluvial Diagrams*. R package Version: 0.1-2 [Internet]. Warsaw (POL): Kozminski University; 2016 [cited 2022 Feb 28]. Available from: <https://CRAN.R-project.org/package=alluvial>
35. Ugalde A, Winter N, Sansom-Daly UM, Rhee J, Jongebloed H, Bergin RJ, et al. Effective integration of caregivers and families as part of the care team for people with cancer. *Aust J Gen Pract*. 2021;50(8):527-31.
36. Gunn KM, Olver I, Skrabal Ross X, Harrison N, Livingston PM, Wilson C. Improving survivors' quality of life post-treatment: The perspectives of rural Australian cancer survivors and their carers. *Cancers (Basel)*. 2021;13(7):1600.
37. Chan RJ, Crawford-Williams F, Crichton M, Joseph R, Hart NH, Milley K, et al. Effectiveness and implementation of models of cancer survivorship care: An overview of systematic reviews. *J Cancer Surviv*. 2021;1-25. doi: 10.1007/s11764-021-01128-1.
38. Chua GP, Ng QS, Tan HK, Ong WS. Caregivers of cancer patients: What are their information-seeking behaviours and resource preferences? *Ecancermedicalscience*. 2020;14:1068.
39. Johnston EA, van der Pols JC, Ekberg S. Needs, preferences, and experiences of adult cancer survivors in accessing dietary information post-treatment: A scoping review. *Eur J Cancer Care (Engl)*. 2021;30(2):e13381.
40. Goodwin BC, Crawford-Williams F, Castro O, Rowe A, De Cocker K. Online physical activity and sedentary behaviour information for cancer survivors. *J Cancer Surviv*. 2020;14(5):677-88.
41. Vayro C, Brownlow C, Ireland M, March S. 'Farming is not just an occupation [but] a whole lifestyle': A qualitative examination of lifestyle and cultural factors affecting mental health help-seeking in Australian farmers. *Sociol Ruralis*. 2020;60(1):151-73.
42. Vayro C, Brownlow C, Ireland M, March S. "Don't... break down on tuesday because the mental health services are only in town on Thursday": A qualitative study of service provision related barriers to, and facilitators of farmers' mental health help-seeking. *Adm Policy Ment Health*. 2021;48(3):514-27.
43. Coumoundouros C, Ould Brahim L, Lambert SD, McCusker J. The direct and indirect financial costs of informal care: A scoping review. *Health Soc Care Community*. 2019;27(5):e622-36.

## Supporting Information

Additional supporting information may be found in the online version of this article:

**Supplementary Table 1:** Characteristics of rural cancer caregivers (n=244).

**Supplementary Table 2:** Logistic regression for significant associations identified in bivariate analyses between sociodemographic, caregiver and patient factors and support-seeking by rural cancer caregivers.

**Supplementary Figure 1:** Flowchart showing recruitment of participants to a longitudinal study of cancer patients travelling for treatment and the cancer caregivers included in this analysis.

**Supplementary Figure 2:** Scree plots for profiles of support-seeking by rural cancer caregivers for (1) themselves as a caregiver and (2) the person they were caring for.

**Supplementary Figure 3:** Radar plots for profiles of support-seeking for themselves as a carer.

**Supplementary Figure 4:** Summary of bivariate associations between sociodemographic, caregiver and patient factors and support-seeking by rural cancer caregivers for the person they were caring for.

**Supplementary Figure 5:** Radar plots for profiles of support-seeking for the person they were caring for.