BMJ Open

# Understanding rural caregivers' experiences of cancer care when accessing metropolitan cancer services: a qualitative study

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**To cite:** Ugalde A, Blaschke S, Boltong A, *et al*. Understanding rural caregivers' experiences of cancer care when accessing metropolitan cancer services: a qualitative study. *BMJ Open* 2019;**9**:e028315. doi:10.1136/bmjopen-2018-028315

► Prepublication history for this paper is available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2018-028315).

Received 2 December 2018
Revised 5 May 2019
Accepted 29 May 2019



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## ABSTRACT

**Objective** To explore the experiences of cancer caregivers who live in rural Australia and travel to a metropolitan cancer health service to access cancer treatment.

**Design** A qualitative study using semistructured, audio-recorded interviews conducted between December 2017 and July 2018 with caregivers and social workers. Thematic analysis using interpretative descriptive techniques performed on textual interview data within a critical realist paradigm to develop understanding of rural caregivers' lived experiences.

**Setting** Participants were from rural areas attending a metropolitan cancer centre in Australia and social workers.

**Participants** 21 caregivers (16 female) of people with cancer living in rural Australia within a minimum distance of 100 km from the metropolitan cancer centre where they access treatment, and five social workers employed at a metropolitan cancer service with experience of working with rural patients and caregivers.

**Results** Thematic analysis developed two overarching themes: theme 1: *caregiving in the rural setting* describes the unique circumstance in which caregiving for a person with cancer takes place in the rural setting at considerable distance from the cancer service where the person receives treatment. This is explored in three categories: 'Rural community and culture', 'Life adjustments' and 'Available supports'. Theme 2: *accessing metropolitan cancer services* captures the multiplicity of tasks and challenges involved in organising and coordinating the journey to access cancer treatment in a metropolitan hospital, which is presented in the following categories: 'Travel', 'Accommodation' and 'Health system navigation'.

**Conclusions** Caregivers who live in rural areas face significant challenges when confronting geographic isolation between their rural home environment and the metropolitan setting, where the patient accessed cancer treatment. There is a need for healthcare services to identify this group to develop feasible and sustainable ways to provide interventions that have the best chance of assisting rural caregivers in supporting the patient while maintaining their own health and well-being.

## Strengths and limitations of this study

- This study collected two separate datasets using interviews with cancer caregivers and social workers in order to explore an under-researched topic from the caregiver perspective within a healthcare context.
- The methodology generated two themes that provide a rich understanding of the experience of cancer caregivers, with data collected from both caregivers and social workers.
- The study was informed by previous studies with rural and regional cancer patients, which provided insight into successful study procedures for this specific cohort including, for example, effective recruitment strategies and interview schedules.

## INTRODUCTION

Informal caregivers represent a large and growing group who assume a pivotal role in providing care to people in need.[1 2] In Australia, approximately one-third of caregivers are estimated to spend up to 40 hours or more per week in their caregiving role, accounting for an estimated 1.9 billion hours of unpaid care.[1] Most people with cancer may have a partner, family member or close friend who, out of preference or necessity, assists them in meeting their care needs.[3 4] While such a caregiving role can be rewarding and gratifying,[5] supporting a person with cancer can present multiple challenges and result in the caregiver feeling burdened.[6] Consequently, several negative impacts have been associated with taking on a caregiving role: reduced health-related quality of life, greater psychological distress, work productivity impairment, increased healthcare usage and stress-related comorbidities such as depression, anxiety and insomnia,[7 8] and caregivers can

suffer greater levels of distress and anxiety as compared with the patients they care for.[9] Furthermore, caregivers report having various supportive care needs, particularly relating to disease-specific and health services information, and psychological and emotional support.[9] It is known that their needs can persist over long periods of time and remain unmet even after the patient completes treatment.[10] Thus, the prevailing perception that caregivers are more often persons providing support rather than needing support must be questioned,[11 12] and the task of adequately supporting caregivers must be addressed as a part of routine service provision.

Several factors can present additional complexity and challenge to caring for a person with cancer. It is well established that cancer outcomes in rural areas are poor relative to urban populations.[13–15] Geographic isolation, greater distance to healthcare services, limited transportation options and variations in socioeconomic status and employment options all contribute to poorer rural cancer outcomes.[13–16] Lack of information about available emotional, practical and financial support services and travel and accommodation assistance while away from home further contribute to the challenges facing rural people with cancer.[17] Additionally, it is known that rural populations are more likely to experience socioeconomic disadvantage including lower levels of education and employment opportunities and reliance on government support.[1] Access to radiation and chemotherapy services in rural Australia is improving; nevertheless, rural patients are often required to travel to metropolitan health services to access specific treatment.[18] Given that timely and appropriate cancer treatment is associated with improved cancer outcomes,[19 20] and the fact that distance between home and cancer treatment services has been associated with lower rates of treatment[21 22] and poorer cancer outcomes,[23 24] it is important to understand how rural people deal with the specific barriers presented by their unique circumstance and how these may be overcome.

Studies have examined the experience and needs of people with cancer who live in rural areas,[25] finding that they experience complex decision making,[19] and they are required to consider socioeconomic factors related to travel and being away from home in order to access treatment.[26] To date, however, the experience of rural caregivers who assist patients in accessing metropolitan cancer services has not been investigated, leaving a gap in understanding about their role in supporting and caring for rural people with cancer. Given the significance of caregiver contributions to patient care,[2 27] and the possible negative impacts on their own health and well-being,[1 28–32] it is important to ensure mechanisms are in place to support caregivers. In the clinical setting, social workers provide various types of support such as psychosocial assessment, emotional support counselling, information provision and education, community referrals and assisting patients and families in navigating the health service and system.[33] Their diverse clinical role enables them to address a broad array of issues encountered by patients and families.

The aim of this study was to understand rural caregivers' experiences of supporting patients in accessing cancer treatment in metropolitan settings from the perspectives of both cancer caregivers and oncology social workers.

## METHOD

### Study design

This research adopted a qualitative design using semi-structured interviews to elicit lived experiences of rural Australians caring for a person with cancer who is required to access a metropolitan cancer service. A critical realist[34] approach was adopted, which aligns with the study's phenomenological aim to investigate subjective first-person experience, and the pragmatic aim to inform health services development based on a better understanding of the challenges facing cancer caregivers who live in rural settings. Research procedures and reporting followed the Consolidated Criteria for Reporting Qualitative Research guidelines.[35]

### Participants and recruitment

Two participant groups were recruited from a major Australian metropolitan health service. These included caregivers of patients with cancer who resided in an area requiring long-distance travel of more than 100 km to access cancer treatment or care at the metropolitan service. Social workers who were employed at the cancer service with experience working with rural caregivers were eligible to participate. Recruitment took place between December 2017 and July 2018, an 8-month period due to research assistant availability and pragmatic considerations. A purposive sampling strategy was applied to achieve a broad representation of experiences.[36] Social workers with relevant work experience were identified by the head of department who has knowledge of team members' case loads including regular contact with patients and caregivers from rural areas. All social workers saw a minimum of 10 rural patients a month. Identified social workers were emailed study information and were invited to participate. Rural patients were identified through the in-hospital accommodation booking system and were emailed a study description and participation information sheet and invited to forward these to the person they identified as their caregiver.

### Public and patient involvement

This research included participation by cancer caregivers who are the population under investigation. We did not directly involve patients, the public or caregivers in the development of this study.

### Data collection

Face-to-face (in the hospital setting) or telephone one-off interviews were conducted by researchers trained in qualitative interviewing who did not have an clinical or

**Box 1 Semistructured interview questions**

**Caregiver interview questions**

- How would you describe your role in assisting (patient name) with their cancer diagnosis or other health condition?
- Can you tell me about the travelling you need to do in the care for (patient name)?
- How were you involved in (patient name) decision to come to (name of metropolitan service) for treatment, if at all?
- In what ways do you feel travelling to (name of metropolitan service) has impacted you?
- How much information and support did you receive regarding your trip to (name of metropolitan service) for your treatment?

**Social worker interview questions**

- Based on your experiences, what are the different needs experienced by families and caregivers who travel to Peter Mac, compared with those who reside in metropolitan settings?
- What are the impacts of travelling from rural communities on caregivers?
- Do you feel rural and regional patients and caregivers receive enough information and support to come to Peter Mac for treatment?

otherwise established relationship with any of the participants (SB and a trained research assistant). Two separate datasets were generated: one using caregiver data and one using social worker data. A semistructured interview guide was designed based on successful examples from previous research with caregivers of cancer patients[31] and caregivers of patients with motor neuron disease[37] (see box 1). Interviews with social workers were guided by a set of questions developed to retrieve specific information related to their experience working with rural caregivers (see box 1). At the start of each interview, the researchers introduced themselves as affiliated with the institution facilitating the research and explained their role in assisting with the research project. Sociodemographic questionnaires were administered. The mean duration of interviews was 32 min (range 11–69 min). All interviews were audio-recorded and transcribed verbatim; field notes were not made. Participants were not provided a copy of the transcript for comment or correction. All researchers have relevant PhD degrees and were working in research or health service roles.

### Data analysis

First, all data were sorted into predefined subject headings within each dataset (caregiver and social worker) as determined by the aim of the study, which was to explore the rural caregiver experience when travelling to a metropolitan cancer centre to access cancer treatment. Subject headings included, for example, 'Information and financial assistance', 'Easing the burden on rural people' and 'Navigating metropolitan services'. Next, thematic analysis[38] using interpretive descriptive techniques[39] was performed by SB to explore emerging and recurring concepts within participants' responses. Textual data were inductively coded and interpreted in a constant comparative manner whereby salient concepts were labelled as codes. Codes were then logically grouped into larger categories. Interpretive analysis sought meaningful connections between categories within each dataset with the aim to understand and describe shared experiences of each participant group. Thematic description was further developed to fully capture the salience of participants' reported experiences. Initial analyses were conducted separately on each dataset with caregiver experience data being of primary interest. Social worker data were used to glean contextual understanding of caregivers' experiences in the metropolitan healthcare setting. Relevant connections were identified in the last step when overlaps and statements were identified to finalise the overarching themes. An inter-rater reliability process was undertaken to check interpretative congruity as is recommended to ensure rigour in qualitative analysis procedures and trustworthiness of findings.[40] This included a second member of the research team (AU) reading the raw textual data and the developed coding structure. Incongruences in interpretations were discussed until agreement was reached. Descriptive statistics were used to summarise participants' sociodemographic information. Computing software was used to manage the data including NVivo version 10[41] and Microsoft Excel.

## RESULTS

One hundred and sixty-four emails were sent to patient email addresses to result in 21 caregivers (n=16 female; 76%) providing signed, informed consent and participating in an interview. The number of emails received, read and opened are not known. Caregivers resided in three different states in Australia, and most (90.5%) lived with the patient at the time of study recruitment. The study cohort included caregivers with varied types of relationship to the patient. Sociodemographic information for each participant is provided in table 1. Five female social workers with experience of working with rural patients and caregivers at a metropolitan cancer service participated. Their demographic and professional information are also presented in table 1.

Analysis generated two overarching themes: '*Caregiving in the rural setting*' and '*Accessing metropolitan cancer services*'. The first overarching theme describes the unique circumstance in which a person assumes a caregiving role for a family member who is diagnosed with cancer and who wishes to access treatment in a metropolitan hospital. The second overarching theme captures the multiplicity of tasks and challenges involved in organising and coordinating the journey to access cancer treatment in a metropolitan hospital. Table 2 shows the supporting categories for each theme and provides illustrative quotes, with accompanying participant numbers. C01–C21 represent caregiver quotes and SW01-05 represent social worker quotes.

### Theme 1: caregiving in the rural setting

Rural participants described their caregiving experiences against the context of their particular rural community.

Table 1 Participant characteristics

| Caregiver characteristics (n=21) | n (%) |
|---|---|
| Sex | |
| Female | 16 (76) |
| Male | 5 (24) |
| Relationship to patient | |
| Spouse/partner | 16 (76) |
| Son or daughter | 4 (19) |
| Parent | 1 (5) |
| Living situation | |
| With the patient | 19 (90) |
| Not with the patient | 2 (10) |
| Tumour stream | |
| Haematology | 6 (29) |
| Gastrointestinal | 5 (24) |
| Bone/soft tissue | 3 (14) |
| Melanoma/skin | 2 (10) |
| Other (breast, lung and gynaecological) | 3 (14) |
| Time spent as a caregiver | |
| Less than a year | 5 (24) |
| 1–2 years | 7 (33) |
| 3–5 years | 4 (19) |
| 6–10 years | 3 (14) |
| 10+years | 2 (10) |
| | **Mean (range)** |
| Caregiver age (years) | 59.95 (32–83) |
| **Social worker characteristics (n=5)** | **n (%)** |
| Sex | |
| Female | 5 (100%) |
| | **Mean (range)** |
| Age | 45.80 (30–60) |
| Years worked as a social worker | 13.60 (6–21) |
| Years employed at health service | 5.45 (2–16) |

They discussed making several life adjustments as a consequence of a cancer diagnosis in the family and they reported on the support resources available to them to assist with their life situation. This overarching theme is represented by three categories: rural culture and community, life adjustments, and available supports.

### Rural culture and community

Caregivers described mixed experiences regarding their local community and its role in caring for a family member with cancer, which diverged based on the level of perceived social support they were able to draw from their community. The majority of caregivers reported feeling embedded within a supportive community consisting of nearby family, friends or neighbours who were able to provide practical and emotional support. These participants discussed feeling a loss of community when having to spend time away from home to receive cancer treatment. Other caregivers, however, reported a lack of support due to social estrangement caused by geographic isolation, neighbours being of older age and therefore unable to provide support or an attitude of stoicism and self-sufficiency preventing either party from engaging in helping or help-seeking behaviour. Social workers reflected on their clinical encounters with rural families and described instances of struggle when families felt separated from their community support due to distance. One social worker discussed her observation of rural patients whose 'stoic' attitude created additional barriers for their caregiver to seek social support, and based thereon, noted that patient and caregiver social needs may differ.

### Life adjustments

Caregivers discussed a range of life adjustments following a cancer diagnosis, which could impact on the entire family unit. Three caregivers reported making major life changes by relocating their home in order to gain better access to the metropolitan cancer service, reduce travel time, mitigate cost and gain closer proximity to family support.

The necessity for caregiver and patient to spend time away from home impacted on other family members too. Young and adolescent children were at the forefront of caregivers' concern when feeling responsible for the well-being of the family unit. Leaving children unattended and alone at home or requesting of them to take alternative transport to school caused additional worry. Caregivers and social workers discussed particularly challenging scenarios caused by unanticipated and abrupt changes to treatment plans, which demanded a fast decision to either leave the patient without caregiver support or for the caregiver not to return home as planned to care for the children.

Lack of practical home assistance was discussed in the context of neglecting ongoing domestic duties and farm work. Some caregivers had to accept a decline in living standard due to their extended absence and limited capacity to maintain the home and farm. Some caregivers discussed reluctance to hand over farm responsibilities to avoid imposing on others or simply because self-sufficiency and independence were preferred. To this end, one caregiver described the purchase of new work equipment to accommodate her husband's declining health condition and limited mobility. Other female caregivers reported having to take on new and physically vigorous farm tasks while their partner travelled unaccompanied to the city for cancer treatment. Of particular note was an observation made by C16 regarding the worry experienced by rural farmers during the bushfire season. In her view, some rural patients may need to decline treatment in a metropolitan hospital during this time.

**Table 2** Overarching themes and supporting categories

| Supporting Categories | Exemplar quotes |
|---|---|
| **Caregiving in the rural setting** | |
| Rural community and culture | **Carer data:** 'all of a sudden thrown out of a community, to get the best medical care, because without question that's where you're gonna get the best medical care, is in Melbourne, with specialist doctors' (C11). 'I mean, it was really awful [cancer treatment], but some really good things came out of it. And you know, especially living in a country town, but the support you get is amazing, it really is' (C01). 'I know we're aliens to them. Very alien. Um, you know, nice people but wouldn't have a clue of the demands of a rural setting and rural life' (C03). '[T]hat's just our, the burden that you shoulder when you live in the country, it has advantages and it has disadvantages and that's not a problem that we would expect them to deal with' (C16).<br>**Social worker data:** 'such a different experience for rural and regional patients and I think it is a difficult thing for some of the staff who are used to just working in [metropolitan city] and dealing with people who are from [metropolitan city]. … saying 'this is, it's really hard to be in [metropolitan city], people don't understand'. But as soon as I say 'Well I'm from the country too' they'll actually, all of a sudden, be fine' (SW01). 'It's almost that continuation of community. … the patient who's very stoic and doesn't want anything from anyone and doesn't want to know anyone or talk to the neighbours, you know that might be the patient's wish, but the carer might be going, "yeah, but I just really want to talk to someone else, is there anyone else who also has a relative who's like this and doesn't get that this is really hard"' (SW04). |
| Life adjustments | **Carer data:** 'move closer to the airport so we're only about an hour away from the airport now. … So we've really reduced the strain on our family and on our finances by, yeah, basically picking everything that we do up and moving it a couple of hours closer to the airport' (C19). '[P]urchasing equipment and things you know, on the farm, that accommodate his degenerating position' (C03). 'essentially using carer's leave to take those days off. So it's essentially eating into my own personal leave. I've not long been in this job so it's a bit of a challenge at times' (C05). 'So whatever I have planned for that day you have to swap around, or wanted to have planned, swap around and that. So I guess that's, to me, one of the most annoying things, is that you just can't live a regular life. You sort of have to work around all these things' (C07). ' Um, and we've got a bed and breakfast, on the property, and that's been difficult to run. We've virtually closed the bed and breakfast. …. Because you think you're going to get time off but you don't really, because there's other appointment' (C12).<br>**Social worker data:** '… so there is a lot of carers who actually also need care and support themselves. And that can be quite difficult to manage as well if they're mobility's not great then, often a lot of people are able to provide emotional kind of caring role but may not be able to provide the physical aspects of some of the carer's role. … difficult in terms of role reversal when you have kids coming down who are caring for their parents, and adult children who are looking after parents' (SW01). '[I]f they have children and commitments back in their home town then it would be hard for them to juggle that because they're travelling distances. … if they're running their own businesses, and a lot of them are, have farms, and they're doing farming, and they take days of work just to be with their, um, patient or spouse or loved ones' (SW02). |
| Available supports | **Carer data:** 'They wanted staff that would be able to go and volunteer with the needs of people who were um, living in rural situations. I thought, well I know their situation very, very well' (C03). '[A]ccess to a lot more stuff … ended up with a bed um, chair, um, a yeah, all those things that we sort of needed for you know, just the physical day to day stuff … they were coming, oh, every few weeks, just to make sure that everything was okay' (C01). 'But I'd don't think I'd have the same support friendship wise. Because there's probably not so much, if you've just got friends in Melbourne, they might ring up and say, "do you want a coffee" but there's not the physical things that you need when you're in the country. So, 'cause [Husband]'s not allowed to lift anything, so just clearing the house you know, I mean, he really couldn't do. He'd leave with me a pile of things on the table for me to pack' (C01). 'Well, my daughter, we just sort of, my two daughters live at home so they've been, and [Daughter 1] and her partner let their house Air BnB so they come back and stay at home and you know, doing that and if there's anything needs doing or the lawns need doing the girls with deal with that' (C08).<br>**Social worker data:** '[S]he was admitted for a long time and she really wanted to see her kids and nobody could bring them over. So we actually facilitated that, we, there is an organization called Mummy's Wish, and we managed to get, get someone to pay for a carer to bring the children over to see their mother' (SW02). 'Some of them are extremely well supported, but some of them are sort of not quite as savvy at finding supports or don't really feel like they should or need to, maybe' (SW04). '[E]ven the resources for cares in the rural areas are less than the resources for cares in [metropolitan city]. … when the nearest you know, um, carers group of whatever support is almost a drive away' (SW02). |
| **Accessing metropolitan cancer services** | |
| Accommodation | **Carer data:** '[S]taying within the apartments, um, within [metropolitan hospital] would be really helpful for us… Everyone's so sick in there, how can you prioritise yourself over um, you know, a mother with a little kid who's having chemo' (C13). 'I generally just look on booking sites for places close by … The cancer in the lung reduces his capacity to breathe and exercise so it just depends on the time and um, how everybody's feeling as to how close we stay. But I'm not too bad at that, I'll do a lot of research. Because it's at our cost I sort of find the best place but possibility the cheapest, so yeah' (C19). '[V]ery grateful and appreciative of the VPTAS, um, reimbursement scheme, um, and it does keep the cost down' (C06). '[W]e got some information that we could park on site … the information as clear, um, there wasn't a problem with that, um, and I don't know if anyone can prepare you for the practicalities of coming in everyday' (C14). '[G]ood thing about this place is you can just drive into the parking lot and you're here. You don't have to go out of the building again 'til you leave. So everything's here and you just hop on elevators all day, where ever you have to be. So that's good, that takes a lot of pressure off having to find somewhere else to be in Melbourne' (C07).<br>**Social worker data:** '[A]ccommodation and being able to access the hospital are really big things for caregivers and families where there's probably more options locally for metropolitan patients … things like the costs associated with transport, or parking, and just general access to the hospital, are things that probably that rural and regional patients struggle more with, because they're not used to the costs and they're not used to having to work out how around in a busy metropolitan area' (SW04). '[T]hey can't afford to stay in accommodation overnight, so they have to get up at 4 o'clock in the morning to be able to leave at 5 to be here by 9' (SW03). 'Especially if, as I said, if they're not used to the metropolitan environment and don't want to navigate the city and would rather be within the hospital' (SW02). |

Continued

**Table 2** Continued

| Supporting Categories | Exemplar quotes |
|---|---|
| Travel | **Carer data:** 'That's really hard because you know he's, he don't look to good and sometimes he don't feel up to it. As I said to him, you know, 'you've got to go, it's saving your life.' You know? If you're going, you've got to go. But once he starts, you know, travelling and gets there he's ok' (C18). 'Cause he couldn't, he um, was unable to travel. So we, a couple of times, before the radiation treatment started, we would get into the car and get half way there and he was dizzy and vomiting and just couldn't persist' (C13). 'I have a friend on [metropolitan address], but sort of, you don't want to impose, or intrude, and they say, "look its fine" and they're really understanding but it's, you know, you make do, of course. And I've got my sister, step sister [metropolitan address] so that's okay, but you've still got to travel' (C06). '[H]our and a half into the city from there and the time of the day, because the appointments were often around sort of early morning, you're caught in the peak hour traffic so that was a bit of a challenge not that, I – I've lived in [metropolitan address] so I'm used to the traffic but I guess it was just an added you know, sort of layer of stress that I probably didn't need' (C05). 'It was, the first time was really scary. … I don't drive in Melbourne as a general rule, and trying to find where to park and where to get into the car park in the old building, I got myself really confused … I kind of look back and go, 'Oh, yuck I wouldn't want to do that again' (C09).<br>**Social worker data:** 'Even outlining some of the challenges you may come across, the transport, the cost of treatment, sorry not treatment, the cost of travelling to [metropolitan hospital], the cost of accommodation, isolation from your normal supports' (SW03). '[T]he stress of traveling for some patients. They're unwell, and it's a lot of travel for some, when they're traveling long distances' (SW03). 'You know, they're in the city which they're not used, they're very fearful sometimes of navigating the city, how to use public transport' (SW02). |
| Health system navigation | **Carer data:** 'I had to intervene yesterday because [Wife] got quite emotional. had to go and talk to radiology and they didn't know what was going on and she said, "I can't talk to the oncologist." Well that's crazy. So eventually, that's the really the only time we've had a real problem. We've to better contact now with the doctor. We've got contact with a nurse. … now we seem to have a more consistent point of contact' (C12). '[W]e would do all the communication regarding appointments … We supported her to get to every appointment and we'd sit with her and try and make sense of it for her. … So that was probably the most challenging part of that journey' (C11). 'So you have to be a case manager. You can't assume anything' (C04).<br>'They then said they'd try to get us in for like the slot straight after lunch so then you're sort of first in and not waiting on all the prior appointments. Or, so we either got like a 10 o'clock appointment or something like that so we could get in, sort of get in and out and still be home at a reasonable sort of time, or we got in just after lunch. So they were pretty good like that, if, they knew we had to travel so they were happy to try and put us in at the times that they knew wouldn't have as much backlog' (C20). '[rural cancer service provider] oncology section that is pretty well organised, um, that um, we could ask questions where there were a few gaps, but fundamentally all the information about the accommodation and all the rest of it came through the web and looking at homepage' (C04). '[Y]ou need to find a place that's familiar to you that you can go when things get a bit tough, and find that early, you know, make use of the kitchens on the ward or on the day therapy um, they're great escapes … you're still in the space and you can sit down and grab 5 min, take a breath and then sort of go back. Make use of those spaces, they're there for everyone' (C06). '[A]lways on the look out for social workers, because I know that they're going to be super helpful. … they made phone calls and all of a sudden, um, whilst I was still in the emergency ward, I had accommodation sorted' (C11).<br>**Social worker data:** 'You know, I'm sure if you spoke to someone around health literary and literacy that rural areas would have some differences to metropolitan areas, … work through the information that they do receive might be a bit tricky as well. … from a hospital point of view, I think sometimes we don't provide people with enough information about what might happen' (SW04). '[T]hey don't want to make a fuss and they're just happy there's an appointment … empower them a bit … especially the older ones, they don't make a fuss. Um, they just say, "yeah it's okay" and then they will be up at 3 o'clock in the morning to make sure they're here by 8.30 or whatever time, you know' (SW03). |

Loss of family income was discussed as a challenge and was attributed to patients' absence from work as well as caregivers' need to take leave from work to care for the patient. Similar adjustments and loss were faced by a student-aged caregiver who deferred her university education until both her parents had completed cancer treatment and she was relieved from frequently taking time away to drive and accompany her parents to the metropolitan hospital. While aware of the detriment caused by some life adjustments, the opportunity to access high-quality cancer treatment was described, on the whole, to outweigh the burdens. Several caregivers accepted these burdens while dealing with cancer when living in a rural setting.

### Available supports

Caregivers discussed the availability of resources to assist them in providing patient care at home. Among these were visits from the district nurse and assistance with acquiring and fitting amenities such as raised handrails and raised beds. Some caregivers discussed negative experiences related to assistance in the home, which was mainly caused by healthcare workers being perceived as intrusive. While personal questions asked by healthcare workers were accepted as being of clinical nature, rural caregivers, nonetheless, experienced a breach of privacy. One person reported that 'city people' are not able to fully understand and appreciate the needs and attitudes of rural people. In this regard, caregivers described their preference for privacy in social interactions and their appreciation of more secluded lifestyles. This was also reported by social workers who similarly felt that healthcare workers with rural backgrounds were better placed to support rural families dealing with cancer. Thus, caregivers as well as social workers identified the need for culturally sensitive support, with both groups indicating that support services for rural people require attention to the cultural aspects of their care needs.

## Theme 2: accessing metropolitan cancer services

Rural caregivers assumed several essential tasks in regards to preparing and undertaking the journey from the rural setting to the city in order to access cancer treatment. They discussed their role in planning and coordinating three major components of the journey, which are presented below as the following three categories: travel, accommodation and health system navigation.

### Travel

All caregivers discussed their decision-making process when considering travel to access treatment providers, and several factors contributed to choosing a metropolitan service over a local one. These included word of mouth or personal past experience or personal preference for a specific service provider or individual specialist, the perception that quality of treatment and care was higher in a specialised cancer facility, the convenience of gaining easy access to a range of specialist services within one location and preference for an integrated care approach focused on cancer treatment specifically. Finally, some caregivers perceived not having a choice and felt that treatment decisions were made by their doctor. Long-distance travel presented a complex planning process requiring the caregiver to carefully balance several factors. The patient's state of health and level of fitness was a major factor when considering the most appropriate mode of transport that would allow the patient to endure long-distance travel. Depending on the patient's physical condition, caregivers were required to organise multiple forms of private or public transport and assistance.

Early morning appointments were discussed by caregivers as particularly inconvenient, requiring an early start to avoid high-traffic times to arrive on time. Social workers recounted instances of elderly rural patients and caregivers travelling during the night in order to keep early morning appointments.

A further consideration was given to caregivers' own level of confidence with driving in the city. Participant C14, for example, described how her husband took on driving immediately after treatment and against doctor's advice due to her low level of confidence with driving in the city. Caregivers discussed their strategies for overcoming their fear of city driving. They described practising their driving skills during 'test drives' to the health service, which also provided familiarity with the route to the hospital and the parking amenities, though this was considerably time intensive. Some caregivers resorted to seeking travel assistance from family and friends or from health organisations offering patient transport. Caregivers with previous exposure to city driving noted great relief for having gained familiarity with the city environment before having to travel in this high stress situation.

### Accommodation

Caregivers found it challenging to organise accommodation that was affordable yet in close proximity to the hospital. Social workers attested to this challenge and noted accommodation as being one of the most challenging aspects for rural families when attending the metropolitan cancer service. Caregivers and social workers held similar views about the importance of early provision of information about travel and accommodation options, which helped to reduce worry and uncertainty. Knowledgeable caregivers reported several avenues through which they accessed information about available supports and accommodation options. Some conducted their own internet research to retrieve information relevant to their circumstance. Other caregivers reported receiving information through their social networks and word of mouth or through a central contact person in the metropolitan service such as a nurse coordinator or social worker. In-hospital accommodation was preferred for convenience and for cost saving given the availability of government subsidies for this type of accommodation. However, in-hospital facilities were not always available

to caregivers due to insufficient supply, or other hospital requirements under which caregivers were required to seek external and self-funded accommodation.

Accommodation cost presented a significant financial dilemma for some rural families who had to cover out-of-pocket expenses with their own life savings. Social workers reported working with rural families who struggled to meet these financial demands. Specific challenges were mentioned regarding the availability of information about financial supports such as government reimbursement. Some caregivers found out about financial aid options later on and sometimes too late to reclaim costs that were incurred in previous years. Other caregivers discussed their difficulty as relating to the demanding and lengthy administrative processes involved in making reimbursement claims. Once claims were lodged, several rural families struggled to self-finance costs until the reimbursement was received, which were reported to take up to several months.

In this context, social workers advised of the usefulness of screening rural patients for unmet needs and advocated for mechanisms that could allow early detection of support needs to prevent later escalation of issues and reduce the resources needed to manage these.

### Health system navigation

Caregivers assumed several responsibilities once they arrived at the metropolitan cancer service. They provided various forms of personal assistance to the patient and assisted in navigating the health service and the physical hospital environment. Social workers were frequently accessed for assistance with these navigation tasks. In-hospital volunteer services were mentioned by caregivers and social workers as helpful. Caregivers' positive experiences of the volunteer service were underpinned by feeling recognised as 'country' people who may require additional practical and navigation assistance in the hospital setting. This caring attitude caused rural families to perceive volunteers as particularly personable and attentive towards their needs.

When presenting for multiple appointments during a single visit, caregivers described their tasks in navigating and locating different services in the hospital, checking in for appointments and assisting the patient during appointments. Their role included conveying information and supporting patients in comprehending and retaining clinical communication. When unable to attend and assist the patient themselves, efforts were made to organise another person to assist the patient during appointments. For some this presented discomfort when having to recruit support from their city networks or request a member of their local community to travel to the city.

Caregivers assumed varying levels of responsibility for future appointment booking and care coordination. Some caregivers discussed positive experiences and described the service as considerate of their specific needs and flexible in regards to appointment booking to meet their travel requirements. However, caregivers and social workers described mixed approaches and differing levels of self-advocacy about families' care needs. Caregivers who felt that they could not rely on service staff to communicate clinical information across different services assumed a more proactive role in following up with hospital administration. They took it on themselves to ensure that appointment times aligned with their travel and accommodation needs. In contrast, social workers described rural families, particularly older age patients and caregivers, as people who avoided 'making a fuss'. As a consequence, they were noted to accept unnecessary inconveniences.

Social workers also discussed the importance of empowering rural families to speak up about their needs and the necessity to implement support systems that ensure visibility and advocacy of rural families and their unique needs.

## DISCUSSION

The present study provides new insights into the specific scenarios encountered by rural caregivers who assist patients in travelling to a metropolitan hospital in order to access cancer treatment. The findings extend previous research on the experiences and challenges facing rural people who deal with cancer[19 26] and address an area of supportive care need that, to date, has received little attention.

There are several key findings from this study. The results demonstrate that there is extensive planning, impact and burden associated with travel for family caregivers. As per similar studies that focus on the patient, results suggest that decision making in regards to travel, and the actions required to execute this decision, are complex and need to balance multiple factors.[19] Several socioeconomic impacts were associated with accessing cancer treatment away from home. Notably, the burden of travelling and related financial cost emerged as particularly challenging for many rural families, which reflects findings from previous research with rural people who deal with cancer.[26]

We propose that interventions, supports or programmes to assist families and caregivers who travel for cancer treatment need to be appropriate and delivered within the context of rural community. The results support implementation of mechanisms in the oncology setting that increase the visibility of rural families, and identification of this group is likely to be an important first step. As advocated by social work participants in this study, early screening of support needs, ideally when first presenting at the metropolitan service, could prevent later escalation of issues, which may require more resource-intensive responses.

It is noteworthy that not all rural caregivers welcomed assistance and some described having very particular preferences for the type of support that they were willing to accept. This is consistent with previous research that identified people from rural and regional areas as preferring

a self-sufficient lifestyle, having stoic attitudes and being less likely to ask for help.[42] In our study, limited understanding and low sensitivity towards cultural differences between rural and urban populations were associated with negative experience. High importance was given to information and support resources that are specific and relevant to the needs of rural people. Both caregivers and social workers considered the relevance of support workers' own backgrounds and life experience with preference for health workers who come from rural background themselves. Similar to previous research focused on people with cancer, there may be specific groups of rural caregivers who most benefit from support, such as those experiencing financial burden[26 43] and those who have young children at home.[44] Support for these groups, including understanding and linking in with available community resources, could be a focus of future research. Development of policies to ensure mechanisms for isolated patient travel reimbursement is also warranted.

Limitations of this study include generalisability of findings. The study was solely conducted at one metropolitan cancer service. It cannot be concluded that the range of experiences is exhaustive when considering cancer experiences in other rural settings to attend other metropolitan hospitals for treatment. Additionally, there are known caregiver–patient relationships not represented in our study cohort. For example, non-kin rural caregivers did not participate in this study who may face different or additional challenges. Given these limitations, we concur with other researchers who suggest the need for prospective studies on people from rural settings affected by cancer.[42] Finally, differences between caregivers who choose to participate in research and those who choose not to participate need to be considered. Our recruitment strategy did not allow for reasons for non-participation to be well understood. It is therefore likely that a host of issues encountered by rural caregivers remain unreported and notably absent from the research literature.

In conclusion, our study identified the existence of a range of distinct challenges facing rural caregivers who assist patients in accessing metropolitan cancer services. These related to geographical distance as well as practical and, in particular, financial factors associated with travel and time spent away from home. While participants reflected on their circumstance with humility and great willingness to assume additional burdens, they were clear about the challenging nature of their responsibilities as a rural person caring for a family member with cancer.

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**Acknowledgements** We would like to thank Erin Tutty for research assistant support for this study.

**Contributors** All authors conceived the study and were responsible for design of the study; AU and SB drafted the protocol with input from the team. The draft was reviewed and commented on by AB, PS, SA, JP-N, SKC, MK and PL. SB assisted with data acquisition with support from AU and JP-N, and SB and AU conducted data analyses. All authors assisted with interpretation and contributed to drafting and critically revising the manuscript and related study materials. Correspondence across the team discussed any study issues, findings and interpretation of results. All authors read and approved the final manuscript.

**Funding** Anna Ugalde was the recipient of a Victorian Cancer Agency Early Career Seed Grant.

**Competing interests** None declared.

**Patient consent for publication** Not required.

**Ethics approval** Ethical approval was obtained from the Peter MacCallum Cancer Centre Human Research Ethics Committee (Reference number LNR/17/PMCC/189) and Deakin University (2017-368).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** Please contact the corresponding author in regards to any data sharing requests. Please note there are ethical restrictions on sharing of data.



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