

# Barriers to Accessing, Commencing and Completing Cancer Treatment Among Geriatric Patients in Rural Australia: A Qualitative Perspective

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**Purpose:** To explore patients', caregivers', and health professionals' perspectives on barriers and challenges to accessing, commencing and completing cancer therapy, with a focus on geriatric patients and the impacts of comorbidities and rurality.

**Patients and Methods:** A qualitative sub-study using focus group discussions was conducted in a regional cancer center and one of its outreach clinics in rural New South Wales, Australia. Five discussions with three distinct cohorts were undertaken, including: 1) geriatric cancer patients (two discussions); 2) caregivers (two discussions); and 3) health professionals (one discussion). Each focus group comprised eight to ten participants. A question guide was used to elicit participants' experiences of receiving/providing cancer care and support during cancer treatment in a rural setting. Iterative thematic analysis was undertaken, with transcripts coded using NVivo software.

**Results:** Participants identified travel to larger regional centers and/or metropolitan areas and related arrangements as primary challenges to accessing diagnostic tests, surgeries, some treatments, and follow-up tests. Financial stress, and a lack of knowledge regarding available support services and mechanisms, was also a key issue for most patients and caregivers. Differences in availability of specific testing equipment, such as PET-CT, further complicated patients' and caregivers' experience of seeking diagnosis and management of cancer. While all interview cohorts identified positive rapport between clinicians and patients as a key characteristic of their experience of cancer management in rural and regional areas, difficulty in retaining clinical staff and related staffing levels at some health services were understood to negatively impact patients' and caregivers' experiences.

**Conclusion:** Overall, the study highlights the effects of geographical, social, and informational isolation on patients' and caregivers' experience of cancer diagnosis and management, and suggests several implications for further research and practice improvement.

**Keywords:** cancer, elderly, regional, rural, geriatric oncology, patient experience

## Introduction

Cancer is the leading cause of death and disease burden in Australia. While cancer occurs across all age groups, it is estimated that 1 in 2 Australians will be diagnosed with cancer by the age of 85.<sup>1</sup> The incidence of cancer increases in the age group of 65 years and above, with about 58% of all new cancer diagnoses occurring in that cohort.<sup>2</sup> While overall cancer mortality has been decreasing, with a 5-year survival rate of 69%,<sup>1</sup> cancer nevertheless represents a huge social and economic burden with a direct health-care cost of approximately 4.5 billion dollars per year.<sup>3</sup>

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## Challenges: Ageing Populations & Comorbidities

There are several barriers for patients, caregivers, and health-care professionals that can complicate experiences and outcomes of cancer care. Older patients with cancer represent a specific care and management scenario. While the authors acknowledge the complexity and limitations of using chronological age as a basis for analysis of health care and outcomes, for methodological and definitional clarity this study nonetheless follows the established geriatric oncology literature and takes “geriatric” to mean those patients 65 years and older.<sup>6,36,37</sup> This cohort comprised of patients aged 65 years and older with a diagnosis of cancer represents 10% of all hospital admissions.<sup>4</sup>

Older patients are also more likely to have multiple health problems, with around 80% of the population  $\geq$  65 years in Australia having three or more chronic health conditions (eg, heart disease, stroke or cancer). Having multiple health problems is also shown to have a detrimental effect on cancer detection, treatment and outcomes.<sup>5</sup> From a sociodemographic perspective, over the last 20 years, the age group 65 years and over has increased from 12% to 15.3% of the population, and the 85 years and older age group has increased by 141.2% compared to a 32.4% total population growth in the same timeframe.<sup>6</sup> Ageing is related to an increase in physical health issues,<sup>7</sup> psychological and emotional problems,<sup>8</sup> and disability. As such, ageing adds to the cancer burden through an increased likelihood of comorbidities and consequent impacts on cancer treatment outcomes,<sup>6</sup> as well as contributing an element of complexity to the patient’s, caregiver’s, and health professional’s experience of cancer care and treatment.

## Barriers: Rurality & Access

Ageing in the rural setting is further complicated by accessibility and other factors, rendering cancer care management of older patients more demanding in that context.<sup>9</sup> The incidence-mortality ratio of cancer is lower in developed countries than in developing countries due to lesser availability and clinical effectiveness of geriatric oncology care programs.<sup>6</sup> Rural populations, even in the relatively wealthy country of Australia, are at a comparative disadvantage due to factors such as more limited access to specialised health services, and as a result experience poorer health status and outcomes compared to their metropolitan counterparts.<sup>19</sup> Meta-analysis conducted by

Carriere et al<sup>10</sup> concluded that rural cancer survival was 5% lower than in urban areas globally. This can be compounded by socioeconomic factors: In Australia, for example, higher mortality was observed in people living in lower socioeconomic areas between 2014 and 2016, and was seen to improve relative to an increase in socioeconomic advantages.<sup>1</sup>

Treatment is also often perceived to commence earlier in urban areas due to accessibility and availability of facilities and health-care professionals.<sup>11</sup> Lack of certain diagnostic and other equipment in non-metropolitan areas may also increase the financial burden for patients due to travel and accommodation, and these factors have been found to have a significant influence on treatment choice for some patients.<sup>12</sup> Distance to the closest treatment facilities is also significant, and may adversely affect treatment decisions and therefore result in discrepancies between rural and urban survival rates.<sup>11,13</sup> Despite significant investment by the Australian government in cancer research, and the establishment of regional cancer care centers in several centers, rural cancer care therefore remains challenging due to geographical remoteness.<sup>14</sup> Travel and related logistical considerations (such as accommodation, navigating metropolitan areas, and related costs) have been consistently observed as typical obstacles for rural patients.<sup>15</sup>

## Barriers: Communication & Information

Health-care professionals are the hub for dissemination of information, however some research notes that the complexity of information, communication barriers, and variable information provided to patients regarding cancer care facilities may be reasons for patients’ unfamiliarity with or difficulty accessing cancer care services, facilities and supports.<sup>9,16–18</sup>

Despite these consistent conclusions in the available research, there is little information on the interrelated effects of multiple health problems on diagnosis and management of cancer in rural settings specifically. There is inadequate population-level data in Australia to clearly identify the specific factors at work in this disparity, which can make it difficult to identify those areas requiring support.<sup>11</sup> It is therefore important to consider the effects of rurality on the experience of cancer care in older patients, and further, to comprehend the impacts of combined rurality and comorbidity for those supporting, or providing clinical care to, those patients.

The larger study of which this article focus forms a part is a prospective cohort study that aims to address this gap in the available research, by investigating possible associations between having more than one health condition, living in a rural area, and quality of life, treatment commencement and completion of cancer therapy of patients aged  $\geq 65$  years. The broader study includes two key elements: a quantitative component, and the qualitative sub-study reported in this paper. The qualitative component of the study has been designed to complement the quantitative data collection and analysis, by focusing on the self-reported experiences of patients, and the perspectives of their caregivers and of health-care professionals involved in cancer care. The qualitative sub-study has used focus group interviews to allow for findings that shed light on individuals' subjective experiences and the meanings ascribed to them.<sup>38,39</sup> In this way, the qualitative component is intended as a complement to quantitative and clinical data collected by the study, and to provide for thematic analysis of those factors impacting cancer management for older patients receiving treatment for cancer in a rural area. The focus group discussions in particular enable exploration of the qualitative, experiential dimensions of a possible relationship between having multiple health problems, living in a rural (or remote) location, and quality of life in older patients with cancer.

## Materials and Methods

### Study Design

To understand patient, caregiver and health professional experiences and perspectives on cancer diagnosis and treatment, comorbidities, and rurality, the qualitative component employed semi-structured interviews in a group setting. Data collection and analysis approaches drew on qualitative health research approaches involving the application of grounded theory and iterative thematic analysis to identify themes as these emerge in the data, rather than testing of existing hypotheses or application of statistical analysis.<sup>39,41</sup>

### Study Setting

The research was conducted at a regionally-located, dedicated cancer care facility and one of its outreach clinics in New South Wales, Australia, during 2018. The facility is a part of a wider health district encompassing numerous smaller centers and communities, and services a population situated over a geographical area of over

100,000km<sup>2</sup>. The main facility is situated over 400 km road or air travel from the closest capital city, and almost 300 km from the nearest large metropolitan center. The majority of patients from within the broader region who are diagnosed with cancer are referred to this center for ongoing management, and treatment if appropriate. The center provides outpatient cancer services, with specialists available in medical oncology, radiation oncology, and haematology, and coordinated linkages to allied health and supportive care, and palliative care services.

### Recruitment

Initial screening for prospective participants was undertaken of all patients attending the rurally-located cancer care facility and its outreach clinics located in several smaller rural townships within the same district. The project research assistant provided participant information sheets and consent forms to eligible patients, and to related caregivers, either directly or via staff at the oncology clinics in the two specified locations. Follow-up contact was made by phone and those individuals who consented to participate were invited to a focus group specific to their cohort. Health professionals were identified through a purposive snowball recruitment technique.

The participant sample overall consisted of two patient focus groups, two caregiver groups, and one health professional group. Each focus group included a minimum of eight participants and a maximum of ten participants. Inclusion criteria across all three groups included those who were: above 18 years of age; willing to participate; capable of and willing to provide informed consent; and proficient in the English language. Any individual with significant intellectual or cognitive impairment who would face difficulty in communication and/or in providing informed consent was to be excluded from the study. As well, any individual with significant mental health concerns that were considered to unduly heighten that person's risk of distress during the focus group discussion were ineligible. Should determination of eligibility have been required, such as in the case of intellectual or cognitive impairment or mental health concerns, the treating clinician and/or principal clinician-investigator for the study were vested with ultimate decision-making responsibility. This was not invoked at any stage during recruitment.

Inclusion criteria specific to the patient cohort included that the participant: was 65 years or older at the time of recruitment; had been diagnosed with a solid tumour/

haematological malignancy; and had received or was continuing to receive systemic treatment for cancer, at the cancer center where the study was located. Patients who were participating in clinical trials were excluded from the study.

Inclusion criteria specific to the caregiver cohort included that the participant: was a family member, relative or friend providing care on an established regular part-time or full-time basis to a geriatric cancer patient who was receiving treatment.

Inclusion criteria specific to the health professional cohort included that the participant: was providing a medical service to geriatric cancer patients (ie, patients aged  $\geq 65$  years and receiving treatment or management of cancer). "Medical services" included those provided by general practitioners, and specialist doctors working in the health service. Qualified professionals working in the area of allied health – such as physiotherapy and occupational therapy – or those in the area of alternative/complementary therapy were excluded from the study.

## Data Collection

Data collection entailed focus group discussions, conducted as semi-structured group interviews as per the qualitative health research described by Green.<sup>43</sup> Three participant cohorts were identified via a purposive sampling approach, with individuals invited to participate in a focus group specific to their cohort. These included: 1) patients,  $\geq 65$  years, of the medical oncology department at the main regional hospital (or its smaller rural outreach clinic); their caregivers (spouses/partners, family members, or friends); and health professionals providing care to cancer patients in the broader region.

A moderator facilitated discussions of between 60 and 90 minutes' duration with each group. The moderator was employed as a research officer for the project, and is an experienced qualitative health researcher with no existing personal, clinical, or research relationship with participants.

One patient and one caregiver focus group discussion was conducted at each of the two locations: one, the primary cancer care facility located in a major regional center; and two, the location of a regular outreach clinic and treatment facility operating as a satellite to the primary cancer care facility. The health professional focus group discussion was conducted at the primary cancer care facility, due to the majority of participants residing in that area.

Audio was recorded with the express consent of all participants. A semi-structured question guide ([Appendix 1](#)) was used to help focus the discussion on particular questions and topics, and to provide prompts to participants as required, and this guide also supported identification of themes and data saturation during the analysis phase.<sup>39,40,43</sup> The participants were informed of the planned duration of the discussion and general topic area ahead of time, and were made aware of their right to request access to the recording and transcriptions.

## Data Analysis

Transcripts of the group discussions and some additional notes taken by the facilitator during the discussions were coded by theme, with NVivo Plus version 12.0 qualitative data analysis software used to manage, analyze and code, and visualize data. Data was coded based on the broad research aims and objectives, with open coding used to identify themes and sub-themes through an inductive approach. Secondly, axial coding was undertaken to identify points of intersection (axes) between themes or sub-themes. The resultant codebook is included as [Appendix 2](#). As such, an iterative, inductive and abductive thematic analysis approach was utilized, involving identification of key themes drawn from the initial research questions and question guide used in each of the focus group discussions (refer [Appendix 1](#)). Data was coded to additional nodes (sub-themes) and additional themes were identified until such time as theoretical and thematic saturation was observed.<sup>39,41</sup> In addition, two coders (the project research officer, and a second researcher with experience in health service research of this type), analysed an initial sample of data to assess inter-rater reliability and rigour, with ongoing discussion between those two individuals and a third researcher enabling identification and resolution of points of disagreement.<sup>42</sup>

## Research Ethics

Ethical approval for this research was obtained from the Hunter New England Human Research Ethics Committee and University of New England Human Research Ethics Committee. Informed consent was obtained from participants before commencement of data collection, and included consideration of potential for participant distress and relevant risk mitigation. Participants' informed consent included use of data (anonymized focus group/interview responses) in future publications, presentations and other means of research dissemination. The research has

been conducted in adherence with the National Statement on Ethical Conduct in Human Research (Australia),<sup>45</sup> and with the Declaration of Helsinki.<sup>46</sup>

## Results

Five (5) focus group discussions were conducted in total, and each group included an average of eight (8) participants. A total sample size of 42 was reached, which aligns with Guetterman's work which found qualitative studies with sample sizes of between 10 and 147, and an average of 53, were capable of reaching data saturation point.<sup>41</sup> There was an approximately even distribution of male and female participants in the patient and caregiver focus groups, representing patients or caregivers of patients with diagnoses ranging across breast, bowel, lung, prostate and other, less common, cancers. The health professional group included a greater proportion of male participants (6 males, 1 female), with a mixture of senior specialists and general practitioners. Owing to the small sample size and risk of re-identification, individual participant attributes are not reported here.

In the following results and discussion sections, participants are labelled by group (P=Patient, C=Caregiver, H=Health professional) and speaker number (ie, P2). Owing to the highly specific nature of many participants' characteristics and cancer-related experiences, the authors have intentionally left out details that might lead to re-identification of participants.

Overall, a range of high-level themes were identified as significant in the context of the discussions themselves, and relative to the specific research questions posed (refer Question Guide including notes on related themes: [Appendix 1](#); Codebook: [Appendix 2](#)):

- Cancer care facilities (availability, proximity, quality)
- Factors impacting the caregiver's experience of diagnosis or treatment
- Factors influencing the patient's experience of treatment
- Factors influencing treatment access, commencement and completion
- Impact of comorbidities on experience of obtaining diagnosis and/or receiving treatment
- Perceptions of the diagnosis process
- Access to information (regarding treatment, and support options)
- Suggestions for improvement.

Additionally, two minor themes were identified:

- Age in relation to diagnosis or treatment
- Family situation (general comment or in relation to financial hardship/challenges).

The following section explores more fully several sub-themes identified as most significant, by virtue of their frequency and quality of mentions in the data. These themes include:

1. Factors influencing treatment access, commencement and completion, including particularly: difficulty of travel; cost of travel and accommodation; and impacts of living in a regional location
2. Perceptions of diagnosis, including particularly: delays or complications in diagnosis; and emotional aspects of diagnosis
3. Positive experiences of facilities including equipment and proximity
4. Positive experiences with staff and clinicians.

Together these dominant thematic results indicate that logistical (including financial) challenges involved in accessing diagnosis and treatment were some of the perceived "barrier" factors impeding more positive experiences of cancer care in a rural setting. This, along with counterbalancing positive experiences of cancer care, is detailed further in the following results and discussion sections.

## Factors Influencing Treatment Access, Commencement and Completion

A common thread throughout the patient and caregiver discussions related to factors influencing access to pre-treatment processes such as diagnostic tests and surgery prior to commencing chemotherapy or radiation. Most patients travelled at least 300km, and usually more, to access PET-CT scans and various surgical procedures otherwise unavailable to them in the major regional center:

It's just really hard if you go to [the city]. We always go on [about] the driving because the driving is a bit horrendous. You need to have at least two nights' accommodation down there. Sometimes my appointment with the specialist down there lasts 15 minutes and I feel at times I could possibly have the scan here, talk to him on a screen here, rather than do that. Because, I mean you're looking at train



fares [as an alternative]. We use our free ones up very quickly, plus two nights' accommodation, plus eating down there. It really adds up every time ... if this trial for me goes ahead ... [my husband] and I have got to go to [the city] every week for 12 months on the train. (P2-7)

Patients and caregivers located in outer-lying towns serviced by the major regional center also needed to travel to access treatment, and in some cases this required weekly trips or longer stays of several days' or weeks' duration. Patients spoke of their experiences of arranging scans and access to other procedures and appointments in the closest available metropolitan location, touching on financial challenges involved:

When you've got to travel to [a capital city] and [with] the distance to [metro areas] and back, you've still got to find the money to do that ... [so my] daughter got on the computer and found something for mum close by, bed and breakfast. Financially, I'm not going to get that money back. That \$3000 that it cost me that time, has gone. That's a lot on the pension. (P1-6)

Caregivers corroborated these difficulties in travelling to metropolitan areas for required scans and other procedures:

We couldn't get anywhere [at hospital accommodation] so we stayed in a motel ... Every time you left the hospital, it was another 12 bucks to get back into the car park. It cost us more for the car parking than it did for the motel. So, you're hopeless with a car down there, and we go down this time for 15 days. Where are we going to put the car at the hospital? (P2-9)

What I'm trying to say is a lot of us are going crook about having to go to [the metro centers for appointments]. I think that's a fairly common theme here. (P1-6)

Patients and caregivers residing in smaller surrounding towns also emphasized the challenges posed by travel to the regional cancer center for treatment, again noting financial hardship:

Well, when I went there the first time with breast cancer, we had to spend six weeks in [the regional center] and the only place we could get into was [a motel] which was \$140 a night. (P2-7)

Both patients and caregivers further identified difficulties in identifying appropriate and available financial supports where these were sought:

When we went to buy our [train] tickets the other day, they said it'll be close to \$200 return for both [of us]. We were just lucky. The travel agency said, "Why don't you find out about a [special] pass? All you've got to do is look on the internet". I said, "I'm too old to know anything about the internet". She said, "How about we just do it for you?". (P2-7)

Many referenced their age as having an impact on their informational and social isolation, and discussed their reliance (as above) on family members or others to uncover relevant information:

Having assets doesn't mean to say you can just draw \$9000 out of the bank. Through the years, people have been saying that you can get a carer's pension, so we've been into [social security agency] three or four times and they've said no, you've got to do all your tax returns and it's means tested. The other day, I was talking to somebody and they said that there is available a carer's allowance. (C2-6)

Overall, participants agreed that reducing social and informational isolation was key:

You're capable of dealing with it if you know what's in front of you, don't you? (C1-8)

This extended to health professional knowledge of relevant supports for patients and carers:

When I went to [my town] nobody knew anything about [the support groups]. I gave things to doctors, I gave things to everyone. The doctors put it in the drawer and that was it. They forgot about it. (C1-7)

Health professionals tended to focus less on the range of financial and logistical difficulties involved in seeking diagnosis and treatment, noting instead the particular health-related challenges inherent in not having specific diagnostic facilities and specialist follow-up care available locally:

Some of the surgeries, that is a barrier but also that's kind of like a one off thing. You go down and you have this big surgery, maybe that's all right, but it's things like those that are ongoing and your ongoing treatment, and if you're fit enough to have your pancreas taken out, maybe you're fit enough to get down there in the first place ... Surgical follow up seems to be one of the things as well that I was thinking of. On that kind of best care thing again, people going off on trips doesn't seem to be a problem too much but when they come back trying to get somebody to look

after their post-operative care [that] seems to be a fairly big issue. (H-1)

Of note, most participants, and in particular patients, tended to minimise or outright dismiss the impacts of comorbidities on their experience of obtaining diagnosis and commencing treatment. Nonetheless, other health conditions were mentioned in passing as factors that compounded the abovementioned challenges:

In regard to travel, I find that going down to the [metro hospital] there, is quite a long trip. Now, I consider myself a fairly fit person but I do have sciatica in the right leg and I have bursitis in both hips. So, sitting down for any period of time is very hard for me. (P2-9)

The experience of coming down from [a town an hour away] to the [regional center] for CT scans and that was horrific. I spewed all the way down. I spewed all the way back. I was pretty crook. (P1-6)

Many patients and caregivers also tended to downplay their own health and other circumstances:

They said that with all these trips to [the metro area], I can get Angel Flight, but how sick do you have to be to get an Angel Flight? I'd feel guilty getting one. ... Now, there must be people out there that are really worse off than myself. Mine's a minor detail and it's a long way to go, long way to travel for anybody, to go down for a PET scan. (P2-9)

Patients' and caregivers' tendency to minimize or set aside personal circumstances was further observed by health professionals:

I know you've got a coordinator and a social worker and they help them find respite and things like that but often the person doing the caring is too guilty to take it up. For instance, they won't go and have the [radiation] therapy because they know they have to be completely separated from everybody so they forego it to see what happens. (H-5)

## Perceptions of Diagnosis

As noted by Heathcote & Armstrong,<sup>19</sup> there is some disparity in length of time from presentation to diagnosis and commencement of treatment for rurally-located patients, compared to those in more metropolitan areas. That research indicates that this data may be skewed by the large Indigenous population in rural areas, and the worse health outcomes generally experienced by this group.

In contrast, the participants involved in this research in general noted that their diagnosis (or that of the patient in question) was relatively straightforward and timely, and complications were uncommon. Patients noted that, once appropriate referrals were in place, progress towards a diagnosis was quite speedy:

You were sent straight to the specialist and then once you got to the specialist, the specialist just took over (P2-2)

For some patients, however, the initial referral and diagnosis process took longer, and they indicated that this had delayed their treatment commencement:

[The GP] told me to organise my own CT scan and it was going to take three months. (P2-2)

Caregivers discussed feeling initially fearful of future outcomes, and then progressing to coordinating elements of care and support required as patients' diagnoses were confirmed and treatment commenced:

I was so frightened and scared because I thought I was going to lose him. It was the most horrible feeling, but now I'm coping ... I had to do all the online stuff to get him into hospital and all the dates and he didn't do anything. He just sat back. (C2-1)

Positive experiences of health-care facilities, including available equipment and proximity of cancer center/s, were touched on by participants. However, as one patient indicated:

It all comes back to, let's see what we can do to get [diagnostic and other procedures] all done in [the regional center] because you've got a great hospital here now, you know? (P1-8)

## Positive Experiences with Healthcare Staff and Clinicians

Overall patients and caregivers identified the proximity of and quality of care provided by health professionals as positive aspects of their experiences. Overall there did tend to be qualification of these observations – patients and caregivers acknowledged that the services provided to outer-lying areas were often lesser than those in the regional center, due to lesser resourcing:

I think you can get good treatment quickly because it's smaller and people know [you]. I think we're lucky at the moment, where we've got staff to do that. I think staffing

is a great, [but also] is probably our biggest bug bear, but they seem to be getting better. (C2-6)

The fact that we have a professional that actually comes up here [to the outreach clinic] makes it a heck of a lot easier ... we know it's a lot of time out of your time, but by gun, it helps us country people if we don't have to go to [the regional center]. (P2-4)

There was at times a marked contrast in the self-reported experiences of patients and caregivers located close to the regional center, and those who lived in more remote areas. For the latter, there were additional complexities identified in accessing clinical services when needed:

What we don't like is whenever we need somebody [locally], they're never here. You just get told to ring [the regional center]. We don't want [the regional center]. They're just not here [at the local hospital] and even when they're here, they [might not] answer the phone. So, I've rung [the regional center] just for something minor and apologised profusely because [the local hospital] won't answer the phone. It's quite frightening because if anything's going to happen to your husband, it's always on a weekend. (C2-6)

Most of the time when I have chemo on Thursdays, there's only the two [nursing staff] there and they're run ragged. (P2-6)

The health professional cohort noted that established relationships between specialists and general practitioners, both locally and in metropolitan areas, were key to ensuring good patient outcomes:

We [GPs] know the surgeons and they know us and the fact that we know them helps. (H-4)

## Discussion

### The Impacts of Rurality on the Experience of Cancer Care

The results of the focus group discussions suggest that living in a rural location impacts on patients' and caregivers' experiences of diagnosis and ongoing management of cancer. Patients and caregivers living in outer-lying areas within the health district travel distances ranging up to 300 km or more to access regular oncology clinics and treatment. These patients may also need to attend larger metropolitan facilities to access specific tests or procedures, and this entails additional travel with attendant accommodation and intra-metro transport costs.

Availability of equipment and specific diagnostic procedures was also identified as having a significant, often negative impact by patients, caregivers, and by health professionals working in those rural locations. Again, the inability to complete all required diagnostic, surgical and follow-up procedures and tests in the local region or indeed within the health district translates into additional travel and accommodation impacts for patients, and additional wait times for results that are used to inform clinicians' decision-making.

While noting that rurality has at times negatively impacted their experiences of accessing cancer care and treatment, patients (and their caregivers) also repeatedly emphasised their positive perceptions of experiences with rurally-based health-care staff and clinicians. Positive experiences of health care and interpersonal interactions have been shown by Moore et al and Jong et al<sup>17,20</sup> to enhance the overall perceptions of care by patients and their caregivers. Our research would support this finding, and also further highlights that these positive experiences with staff and clinicians tend to mediate the patients' and caregivers' perceptions of and responses to less-positive aspects of their experience, such as increased travel and accommodation requirements relating to diagnostic and treatment processes.

### The Impact of Physical Comorbidities on the Experience of Cancer and Cancer Care

While several participants did reference their own or others' existing health conditions, surprisingly only two (2) participants explicitly noted the effects of physical comorbidities on their experience of cancer and of cancer care. This was particularly in reference to delays in receiving diagnostic procedures or surgery to resect tumours, as a result of health conditions such as cardiac irregularities. This finding reflects a tendency among patients in particular that has been identified in research by Wiggins et al<sup>15</sup> whereby patients tend to minimise the severity of other health conditions when discussing their experience of cancer as a current health concern. This finding also reflects preliminary analysis of the quantitative data collected for this study, insofar as 1–4 comorbidities are prevalent among the patient cohort aged 65 years and over, however this is rarely mentioned by patients themselves during data collection. In a minority of cases, existing physical



comorbidities appear to significantly impact on diagnosis or treatment through delay or dose modification.

## General Observations on Findings: Intersecting Complexity and Enhancing Communication

Although there have been a range of qualitative studies focused on experiences of cancer, this is the first of its kind undertaken in Australia that explicitly explores key dimensions among the three key groups involved in geriatric cancer care – patients, caregivers, and professionals – within the same time frame. The study highlights the need for special attention to be given to the field of geriatric oncology and the services provided in rural areas to this cohort. The implications of this study are therefore multiple.

The current study reveals that travel and accommodation for treatment remains one of the greatest challenges for both patients as well as caregivers. Lesser hospital facilities or equipment in rural areas requires patients to travel for diagnostic imaging and other procedures, causing related financial strain as well as compounding additional workload challenges for caregivers accompanying patients.<sup>10</sup> Rural-urban disparities and geographical distance in accessing treatment facilities are considered as major hindrances in cancer treatment all over the world, and this was borne out in our study.<sup>21–23</sup> Some options for addressing these issues may include: improving telemedicine; identifying options for in-home support; and other means of reducing the discomfort, inconvenience and financial burden of travel.<sup>24–26</sup>

A further significant finding relates to availability and accessibility of specific equipment relating to diagnosis and staging. While patients and caregivers emphasized the positive aspects of local facilities and staffing, research indicates that patients living in remote areas in NSW may face a 35% increase in risk of dying compared to those who have greater access to close-by facilities.<sup>20</sup> Similarly rates of screening have also been comparatively less in rural than in urban areas among older patients.<sup>27</sup> A single cancer care center or access point with multidisciplinary facilities has been identified as one option for addressing this issue in rural Australia.<sup>18,24</sup> A meta-analysis which included two Australian studies on breast cancer has also indicated that better equipment in rural hospitals and initiatives to decentralize treatments may result in similar survival rates of rural and urban patients in Australia.<sup>10</sup>

Crawford-Williams et al's<sup>11</sup> study on colorectal cancer however showed geographical variations in delivery of treatment similar to our study. The findings of the present study also appear to confirm a recent qualitative study done in Bunbury, which noted that enhancement in facilities in rural areas enabled enhanced treatment response of patients, owing in part to the bridging of geographical gaps.<sup>12</sup> Haigh et al<sup>28</sup> also identified that many cancer patients were satisfied with the support services of regional centers while receiving radiotherapy in Western Australia. In our study, there have been positive responses of both patients and caregivers from within the regional center, and those residing in surrounding areas accessing outreach clinics, regarding the quality of facilities and staff in the regional cancer care center. Both cohorts, however, also commented on the challenges arising from the limited availability of certain facilities and the problems related to travel for diagnostic procedures and tests, and for cancer care-related visits.

In this study, caregivers in particular identified problems in sourcing and utilizing available supports, such as government health-care subsidies and cancer support organization assistance. Equipping patients and their caregivers with comprehensive information on and access to appropriate auxiliary supports, including subsidies and financial assistance, has the potential to ease the identified financial and logistical burden posed by cancer. A Western Australian study revealed that patients spent about AU \$2179 including both medical and non-medical expenses within the first 3 weeks following diagnosis, and 11% of the study participants spent more than 10% of their household expense with a relatively higher cost paid out by younger patients and those with private medical insurance.<sup>29</sup> This result is of particular interest to the current study as several participants were unaware of reimbursement and financial support options available via government agencies and through not-for-profit assistance organisations.

Strengthening of communication between health-care staff and family members is also flagged as essential. Although the present study indicates a good rapport built between patients and health-care professionals, fragmented or partial communication and information was also evident. Improvement in communication skills including counselling elements by health professionals has been identified in the research as one of the areas which holds potential for benefitting both patients and caregivers, lessening distress and improving communication outcomes.<sup>30</sup>

Although cancer care coordinators exist across Australia,<sup>31</sup> including in the study setting for this research, the research also indicates an ongoing need to increase these resources in all centers in order to facilitate and scaffold support for cancer patients and family members. Additional training of health professionals involved in cancer care may also be useful in this context.<sup>32</sup> Of particular note, Weiner & Schwartz's work indicates the usefulness of communication training that focuses on "listening to what matters" as an approach for health professionals to effectively explore contextual red flags during patient consultations.<sup>44</sup> This may help clinicians and other health-care professionals to better identify and address some of the barriers consistently noted by patients in this study, but which may go undetected in patient-clinician interactions. A 3 year intervention conducted in Japan, as well, also resulted in improved attitudes towards palliative care among the caregivers – a significant finding in terms of addressing informational and resource isolation experienced by many of the study participants and their caregivers.<sup>33</sup>

In addition to the above, relevant research has indicated that older patients with cancer can possess a range of presumptions and restrictions regarding diagnosis and treatments. They have been found to be less aware of diagnosis and early detection, and cancer treatment has been perceived more negatively by older patients with about one-third in some studies choosing not to receive any treatment for growing cancers.<sup>8</sup> Lack of awareness, inadequate information, and conservative perceptions of disease and treatment may also contribute to this reluctance on the part of patients and caregivers.<sup>18,34</sup> Active contribution of caregivers to a patient's cancer treatment experience is also shown to improve pain management in cancer patients.<sup>35</sup> In the present study, the role of family members – and their impacts both positive and negative – has been strongly acknowledged by the professionals; however there remains space to further support caregivers in relation to cancer management. It is thus important to empower both health-care recipients and their caregivers with sufficient information to enable them to make informed choices that consequently assist in lessening the burden of cancer treatment. The study suggests that more, and more effective, communication is needed with both treating team members and with nursing and allied health staff.

In addition, participants repeatedly confirmed the importance of financial assistance for supporting patient

travel to metropolitan cities and accommodation, to enable diagnostic procedures, further treatment and investigation. Taken together, the lived experience of older patients with cancer and their caregivers is one of financial, informational and geographical isolation and stress, with the above highlighting the critical need for mechanisms including: a health-care pathway for geriatric oncology patients as a distinct cohort; enhanced communication practices between clinicians and patients; and the use of dedicated geriatric oncology cancer care coordinators in rural cancer centers.

## Study Limitations

Results of the qualitative sub-study should be interpreted in light of study limitations, and take into account the situating of the qualitative sub-study relative to the broader study. All qualitative sub-study participants were from within a particular geographical area and health district, and the study sample was limited to a degree due to travel required for participation. This impacted the number of participants drawn from very remote parts of the health district, however the organization of data collection in the location of a rural outreach clinic helped to mitigate this limitation.

The sample size of 42 participants in total across 5 data collection events should also be considered when interpreting study results. However in the context of small-scale qualitative health research, and taking into account the application of grounded theory and iterative thematic analysis, theoretical saturation was understood to have been reached at this point.<sup>39–41</sup> Further research examining the perspectives and lived experiences of older patients with cancer, as well as their caregivers and involved health professionals, in other rural areas of Australia would nonetheless enable comparison and potential confirmation of results beyond the limits of a single-site study. Additionally, comparison of results with younger patients with cancer, living in rural areas, may be useful in providing a comparative perspective and further analytical strength to findings and conclusions.

## Conclusion

As one-third of the Australian population lives outside cities, it is imperative that researchers and clinicians comprehend the barriers and challenges faced by patients when seeking to access cancer care and treatment. In particular, consideration of the specific needs of older patients with cancer, both from the perspective of comorbidities and

treatment needs as well as support and informational requirements, is highlighted repeatedly in the available literature and largely confirmed by the participants in this study. While comorbidities were hardly spoken of, themes of social, geographical and informational isolation featured repeatedly in patients' and caregivers' articulation of their experiences; whereas health professionals tended to focus on availability of services and specialties. Following from this, we suggest that a range of strategies for understanding and addressing patients' isolation and financial hardship, combined with support for development of health professional communication approaches, will be critical in helping to narrow the rural-urban treatment outcome gap.

## Disclosure

The authors report no conflicts of interest in this work.

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