

# Psychosocial Experiences in a Rural Australian Cancer Service: Mixed method insights into patient and carer psychological distress and psychosocial service barriers

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## Research Article

**Keywords:** Psycho-oncology, cancer, rural, distress, barriers

**Posted Date:** March 2nd, 2023

**DOI:** <https://doi.org/10.21203/rs.3.rs-2584105/v1>

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# Abstract

**Purpose:** An increasing body of evidence indicates that people with cancer experience psychosocial concerns across the entirety of their cancer experience from pre-diagnosis to survivorship. These concerns have not just a deleterious effect on their medical journey, but impact more broadly across well-being and, importantly, the well-being of the people that love and care for them. Whilst most oncology research focuses on patients, the role and experiences of families and carers is increasingly recognised as a core component of health service delivery.

**Methods:** This paper outlines an evaluation of the psychosocial experiences of 125 rural people accessing cancer services through three health services in rural NSW.

**Results:** Despite an increasing and improved focus on rural health equity, and the funding of high-quality rural cancer services over the past decade, the findings of this study suggest that cancer patient and carer populations in rural NSW experience concerning levels of psychological distress and barriers to accessing quality healthcare.

**Conclusions:** The combination of high psychological need for patients and carers with insufficiency and inaccessibility of psychosocial support services have substantial implications for service provision and the psychological wellbeing of those they service. Under-detection of psychosocial need and a lack of support services poses a significant challenge for rural people with cancer and for those that care for them; this must be an urgent priority for quality improvement and equitable health care provision.

## Introduction

Cancer is a significant health concern in Australia, giving rise to a significant economic cost for society and a psychological cost for patients and their families [1]. Distress in cancer patients and their carers is not unexpected given the health and social changes cancer brings, and the cancer journey is known to seriously impact patient and carer wellbeing and increase psychological distress [e.g., 2]. Psychological distress for people with cancer and their carers can be experienced anywhere along the cancer journey from pre-diagnosis to survivorship, and involves emotional, behavioural and cognitive factors that impact the ability to effectively cope with any or all aspects of the cancer experience [3]. Psychological distress is essentially a generic term that refers to the multifactorial, unpleasant emotional experience of people with cancer [4]. It can include elevations in depression, stress and anxiety as well as social and/or spiritual factors [5], which may impact an individual's overall sense of well-being and their ability to cope with a cancer diagnosis, symptoms, treatment and survivorship. The psychological cost of the cancer experience is significant and has been shown to easily attenuate as a positive relationship between psychological well-being and treatment outcomes [6].

## Prevalence of Psychological Distress in Cancer Cohorts

As the concept of psychological distress can be broad and defined in various ways as a multifactorial or a single dimension, it can be difficult to estimate exact prevalence in patients and carers. However, two recent Australian studies suggested that 23% of people with cancer evidence moderate to high levels of distress [7], and almost all carers of people with cancer (96%) report clinically significant levels of distress, with 66% identifying as severely distressed [8]. Other research has indicated that the mean prevalence of psychological distress varies from approximately 4 to 50% depending on a range of factors including geographical location, treatment settings, cancer type and screening assessment tools used [9-11].

There is growing recognition that psychosocial care is a universal human right, and that understanding the level of psychological distress should be viewed as equally important and necessary in high-quality cancer care as understanding the standard Five Vital Signs like temperature and pulse [12]. Whilst the prevalence of clinically significant psychological distress is higher amongst people with cancer than the general population, identification, treatment and provision of psychological support is inconsistent across services and geographical areas, and notably lacking in rural areas [e.g. 13]. This remains the case, despite the fact that systematic application of screening, appropriate referral, and intervention can improve quality of life and reduce healthcare costs associated with inpatient and outpatient cancer care [e.g. 14]. Despite the importance of psychological well-being, about 20% of cancer patients in Australia are never screened for psychological distress during their cancer care [15]. Where psychological distress is identified, only 50% of patients are offered help for psychological distress [16]. Unfortunately, psychological well-being may often be an afterthought, taking a backseat to medical requirements and treatments [e.g., 15], which is a critical missed opportunity to improve outcomes for a significant number of people.

Similarly, there is increasing recognition that social support is a key protective factor for people facing cancer. Psycho-oncology services have an obligation in “caring for the carers” [17]. The caring role has evolved as cancer treatment has evolved from largely inpatient to largely outpatient models. The caring role has broadened in scope and is increasingly recognised as an essential component of quality oncology healthcare [18].

Findings suggest that carers are also experiencing significant psychological distress [8, 19], with caregivers often prioritising the needs of the patient over their own physical, spiritual and emotional needs. Importantly, some previous studies have identified that carer distress levels can actually *exceed* that of patients [8, 20]. When services do not systematically screen for carer wellbeing there is a further significant missed opportunity for intervention. There is strong evidence to suggest that targeted cancer caregiver interventions are beneficial in reducing caregiver burden and distress [21]. Notwithstanding, the psychosocial needs of carers have similarly remained largely underidentified and underserved [21]. Arguably, carer needs should be assessed and attended to as an equal priority to that of patients.

## **Barriers to Accessing Psychosocial Support Services**

Australian research suggests that significant barriers impact the accessibility and acceptability of psychosocial support services. These include underdetection by health care providers [15], under-offering of services or lack of service availability [13], under-utilisation of offered services as a result of both practical barriers (e.g., distance, expense, time) and intrapersonal barriers such as the impacts of stoicism [22] which minimises self-assessment of needs [23]. Rural people with cancer, and those who care for them, experience different health care services by the very nature of rurality as compared with people from urban areas. Populations from rural areas tend to experience additional psychosocial stressors relative to their urban counterparts, for example financial burden (e.g. travel, accommodation, loss of income, cost of taking leave) due to the distance from specialist health services. Psychosocial stressors have been shown to contribute to consistently poorer cancer outcomes for rural people (see for example Fox and Boyce [24]). Rurality, therefore, is an intersectional disadvantage, bringing additional psychosocial stressors for cancer patients and their carers. There are a growing number of rural cancer treatment centres being developed across Australia [25] giving patients the opportunity to receive treatment closer to home and consequently mitigating some of the psychosocial stressors related to the need to travel for specialised services. However, the vast geography of the country means that it is not possible to reduce distances to treatment for all Australians - many rural and remote people will continue to need to travel to access the specialised cancer services. It is therefore appropriate to investigate alternate approaches to identifying and addressing the impact of psychosocial stressors on the well-being of rural people who have experienced cancer and those that care for them.

Caregiving for people with cancer is a psychosocial stressor that is challenging physically and emotionally and can be a significant life role for an extended period of time (Jones, Whitford, & Bond, 2015). The uncertain nature of the disease and confrontation of a family member's mortality can also provoke one's own existential questions, distress and growth (Adams, Mosher, Cannady, Lucette, & Kim, 2014; Selman et al., 2018). Given the multiple psychosocial stressors experienced by carers, and the heightened physical and emotional needs of cancer patients, it is understandable that interpersonal and relationship functioning can become strained. The cumulative impact of stressors for both patients and carers can place both groups at increased risk of developing clinically significant levels of psychological distress and in turn psychological disorders, which previous Australian research has clearly recognised [see for example 26]. Therefore, the inclusion of formal and informal carers and family members forms a key component to understanding psychological experiences and service access barriers for people in rural areas.

The specific needs of *rural* patients and their carers are a further important consideration in providing quality psychosocial oncology care. There is a significant amount of research conducted in urban areas examining psychological well-being in those with cancer and their carers. Fradgley et al. (2019), identified that there are critical gaps in the delivery of distress management as outlined in Australian evidence-based guidelines. However, research data has not been consistently disaggregated for rurality to examine the differences in rural patients presenting to urban areas for treatment. This indicates issues of equity, and it is therefore important to take a systemic view of patient psychological wellbeing, and to consider the psychological wellbeing of their carers in tandem. Therefore the present study was designed to

examine the unique patient and carer experiences of rural people in the rural cancer treatment centres in NSW, and to examine the practical and perceived barriers to rural populations accessing psycho-oncological support in NSW.

Whilst accessing mental health and well-being services has come a long way from historical access challenges associated with mental health stigma [27], a range of barriers remain that impact access and engagement for rural populations accessing psychosocial supports [28]. Many patients who identify their distress, and who indicate awareness of supports that may assist them, often do not access these services [23]. There is, however, a difference between declining help and wanting help but being unable to access it. Service and professional barriers, such as ongoing physician beliefs about the benefit (or not) or psycho-oncology efficacy [29], and a lack of systematic integration of psycho-oncology support services into routine standard cancer care [30], can have lasting negative effects on patients. Carers have similarly reported feeling poorly supported by the health system [20].

Previous research has identified barriers to accessing general cancer care, such as finances and family or work commitments [e.g. 31], alongside other barriers such as not receiving information about different sources of support [32]. These barriers continue to impact the ability and ease with which people with cancer, and those that care for them, can access supports. Many patients and carers 'self-assess' and evaluate their symptoms as not 'bad enough' to warrant services [e.g. 23]. Some report feeling as though they need to 'suffer in silence' to reduce the burden on their loved ones [e.g. 20].

Therefore the present study sought to estimate the proportion of rural patients and carers living with clinically significant symptoms of psychological distress, and to explore the most salient barriers to accessing psychosocial support to improve overall outcomes. These salient barriers were explored by asking participants to endorse a list of known barriers and to respond to open ended questions to provide information about additional barriers particular to their experience or region.

This study aimed to examine:

- 1) the proportion of rural cancer patients who are experiencing moderate to severe symptoms of psychological distress, compared to normative data
- 2) the proportion of rural carers of a person with cancer who are experiencing moderate to severe symptoms of psychological distress, compared to normative data
- 3) barriers to accessing psychosocial oncology support in rural NSW for people with cancer
- 4) barriers to accessing psychosocial support in rural NSW for carers of people with cancer

## **Methodology**

## **Participants and setting**

Data is reported from 125 respondents, of which 91 identified as patients and 34 identified as carers. The online survey was distributed to patients and carers across the rural sectors of Hunter New England Local Health District (HNELHD). Participants also had the option to use their personal devices to complete the survey at home in their own time.

The sample was unevenly distributed across a range of 25-110 years of age, with a mean of 60 years. Seventy-five percent of the sample were aged 50 years or over, and fifty percent of the sample were aged 60 years and over. This older age distribution of the sample was expected given advancing age is the most important risk factor for cancer diagnoses [33]. Females were over-represented in our sample, with 19% identifying as male, 81% as female. More than half the sample ( $n = 85$ , 68%) reported a postcode in the Tablelands Sector of HNELHD, which encompasses the Armidale Cancer Centre. Twenty per cent of participants were from the Peel Sector ( $n = 25$ ), which encompasses the North West Cancer Centre in Tamworth. Whilst 6.5% of the sample were from the Moree hospital's Mehi Sector ( $n = 8$ ) and 5.6% were from another geographical area outside of HNELHD (e.g., travelling from the Murrumbidgee Local Health District).

The majority (80.8%) of the sample identified as having an 'Australian' cultural background, and 5 respondents (4%) identified as Aboriginal and Torres Strait Islander. This is similar to Australian census data for Aboriginal and Torres Strait Islander populations in Australia, but is below the proportion of Aboriginal people who live in HNELHD, which ranges from approximately 9% in the Tablelands Sector up to almost 19% in the Mehi Sector [34]. The remaining 19 respondents identified different backgrounds, including English ( $n = 7$ , 5.6%), New Zealand ( $n = 4$ , 3.2%), and Other (e.g., Germany) ( $n = 8$ , 6.4%).

## Measures

### Psychological Distress

Participants completed the 21-item Depression, Anxiety and Stress Scale [DASS-21; 35]. To explore the level of endorsement of symptoms of depression, anxiety and stress, Lovibond and Lovibond [35] cut-off scores yielded from their normative Australian sample of 717 participants were utilised. The patient and carer samples of depression, anxiety, stress were compared to normative data [35, 36]. This study utilised the total DASS-21 score as a measure of psychological distress, the utility of which is supported by previous studies [37-39]. Total scores were computed by averaging Z-scores and comparing to normative severity labels [40]. Proportion of responses in the lower ranges (normal and mild categories), and the higher ranges (moderate, severe, or extremely severe) were analysed against the DASS normative data of 13% in these ranges for each DASS subscale.

The DASS-21 has good internal consistency with Cronbach's alpha  $\alpha$  ranging from 0.88-0.94 for depression, 0.82-0.87 for anxiety, 0.9-0.91 for stress, and 0.93 for the Total score [36, 41]. The scale has demonstrated adequate validity in a variety of populations [41], and participants respond to questions

such as “I felt that life was meaningless” on a 4-point Likert scale ranging from 0 (*Did not apply to me*) to 3 (*Applied to me very much, or most of the time*). In the present study Cronbach’s alphas ranged from good to excellent (depression subscale  $\alpha = .89$ , anxiety subscale  $\alpha = .81$ , stress subscale  $\alpha = .89$ , and total score  $\alpha = .94$ ).

## Barriers to accessing support

Patient and carer samples were also asked to identify barriers to accessing psychosocial cancer supports. This data was collected via two methods. Firstly, quantitative data collection involved asking participants to endorse as many of a predefined list of barriers as were relevant to their experience. The list was based on the common barriers to accessing support reported at a regional cancer service, and similar research [e.g., 23]. Secondly, qualitative data collection involved asking participants, via open-ended questions (with no space or time limits), to describe any additional barriers or difficulties experienced when trying to access support services. They were further asked to nominate in an open text field any other ideas that may make it easier to access psychosocial support if they were to seek it.

## Procedure

The study surveyed cancer patients attending one of the three participating regional/rural treatment centres and the people that care for them formally or informally, referred to in the study as ‘carers’. Participants were invited to complete an online survey either via iPads located in the waiting and treatment spaces in the three participating sites, or by using a QR code link on a flyer to complete the survey on their own devices at anytime. This recruitment resulted in participation of 125 rural people (91 patients, 34 carers) accessing cancer care through Hunter New England Local Health District (HNELHD) rural services. The study was authorised by HNELHD, and approvals from both the HNE Human Research Ethics Committee and the University Human Research Ethics Committee were obtained.

## Statistical Analysis

This sample size of 125, with 91 patients and 34 carers, is sufficient for reliable analyses, which included single sample t-tests comparing participant data with normative data from an Australian sample. The results of an *a-priori* power analysis suggested a total sample size of 98 to achieve a power of 80% and a significance level of .05 [42]. Age was not skewed ( $z = 1.37$ ), but the older age distribution of the sample is representative of advancing age as the most important risk factor for cancer diagnosis [33]. The study used a convergent parallel mixed-method study design that integrated a cross-sectional quantitative survey and a qualitative analysis [43]. The collection and analysis of quantitative and qualitative data were implemented simultaneously and in parallel, and were addressed with equal priority. The independent quantitative and qualitative results were subsequently integrated and compared. This design recognised the strengths that quantitative and qualitative methods offer utilising a complementarity mixed

methods approach [44]. IBM SPSS Statistics Version 28.0 [45] was utilised to analyse the quantitative data and QSR International's NVivo 12 [46] software was used to store qualitative responses and manage codes. The Elo and Kyngäs (2008) process for content analysis was utilised to process, organise and report the data.

## Results

### Distress

As presented in Fig. 1, the level of depression, anxiety and stress symptoms, and the total score, were significantly higher in the combined sample and also in both the patient sample and the carer samples, compared to normative proportions for each DASS subscale [35] and Total score [47].

A third (33.1%) of the combined sample (patients and carers) population evidenced a much higher depression level, in the moderate/severe/extremely severe range, compared to 13% in the Lovibond and Lovibond [35] normative data. This rose to just under half (45.8%) when considering all patients and carers who rated their depression level outside the "normal" range. For patients only, 31% endorsed moderate-to-extremely severe levels of depression. For the carers, 38.7% endorsed moderate, severe, or extremely severe levels of depression, rising to 48.4% for all levels above the "normal range".

Similar results were found for anxiety levels, with 45.8% of the combined patient and carer sample evidencing anxiety in the upper ranges (moderate/severe/extremely severe) of concern, and over half (53.4%) endorsing anxiety levels above the "normal" range. For patients only, almost half (49.4%) identified anxiety in the moderate/severe/extremely severe range. The carer sample found 35.5% of participants in the moderate/severe/extremely severe ranges for anxiety.

The combined patient and carer sample evidenced similar levels of stress to the normative population, with 14.4% endorsing levels of stress above the moderate range, but again this increases to higher levels (30.8%) much greater than predicted when considering all levels outside the normal range. For patients this was 12.6% (up to 27.5% for all levels outside the normal range), and for carers this was 19.4% (up to 38.7% for all levels outside the normal range).

The total level of psychological distress in the sample found 33.9% of patients and carers identifying scores in the moderate-to-extremely severe range. This rose to just under half (48.3%) identifying total scores outside the "normal" range. The patient sample identified approximately a third of patients (32.1%) endorsing moderate, severe, or extremely severe levels of distress. Similarly, 38.7% of carers endorsed a total score in the moderate, severe, or extremely severe range.

A single-sample *t* test was conducted to compare the overall level of distress to Crawford and Henry [47] normative data. The mean level of the total score of psychological distress ( $M = 29.20$ ,  $SD = 20.949$ ) was significantly higher than Total DASS scores reported by Crawford and Henry [47] ( $M = 18.38$ ,  $SD = 18.82$ ), with a mean difference of 10.817,  $t(121) = 5.703$ ,  $p < .001$ . The patient and carer combined sample



endorsed significantly higher levels of psychological distress than predicted by normative data. The patient sample was also found to be significantly higher than the normative sample ( $M = 29.25$ ,  $SD = 20.321$ ), with a mean difference of 10.873,  $t(90) = 5.104$ ,  $p < .001$ . Similarly, the carer sample was significantly higher than the normative sample ( $M = 29.03$ ,  $SD = 23.047$ ), with a mean difference of 10.652,  $t(30) = 2.573$ ,  $p < .01$ .

A chi-squared test of independence was run to analyse the patient and carer participant groups. No association was found between patient and carer samples and depression, anxiety, stress, or total distress levels ( $\chi^2(4) > = 8.882$ ,  $p = 0.064$ ), suggesting that both groups endorsed similar levels of symptomology.

## Barriers for patients

For patients (Fig. 2) the most commonly endorsed barrier was the distance required for them to travel to access support services (50.5%). However patients also identified that a lack of support services in their area was a common access barrier (38.5%), with finances (34%) being the third most highly endorsed barrier. The least common barriers for patients was not knowing who to see for support (10%), self-assessing their support needs as not being “bad enough” (10%), and not knowing of cancer-specific support services to access (15%). Only 18.7% of patients reported having no barriers in accessing psychosocial support services.

## Barriers for carers

Quantitative barrier data indicated that about 26% of carers did not believe they had experienced any barriers in accessing psychosocial support services for themselves. Of those carers that did report experiencing barriers, carers identified with all 11 predetermined barriers as hindering their access to psychosocial supports (Fig. 2). The most commonly identified barrier was a lack of services in their area (48%), followed by not knowing what services might be available for carers (34%), and then not having enough time to access supports for themselves (29%). The least common barrier in accessing supports was transport (3%), followed by not seeing the benefit of accessing support services (11%), and financial barriers (11%).

Qualitative responses were analysed as to whether their content referred to an existing quantitative category, or whether the response spoke to a new, unspecified category not previously defined. The categories were identified inductively from the data, and following initial analysis, coding was undertaken. Initial coding was conducted by one researcher, and then two researchers collaboratively reviewed the codes until the coding was finalised and consensus reached.

Qualitative analysis revealed the following additional categories of barriers to accessing psychosocial supports (Fig. 3):

## Systemic Barriers

Systematic barriers were the largest category identified by the qualitative respondents. Both patients and carers endorsed a range of health system issues in accessing psychosocial supports. The most common issues related to their areas simply not having the services available, or insufficient capacity within existing services, leading to long waiting times. Patients referred to not having specific specialists available in their area, such as health psychologists, as well as issues of waiting lists and services being fully booked in instances when those support services are available. Such as this patient: *“By the time I was finished my [treatment] I still had no appointment to see the Psych. I went home without”*. And this carer: *“You have to wait too many weeks between appointments and time is something the patient doesn't have, in our case.... now it's too late”*.

Further systematic barriers included the restrictive limits that are imposed when accessing private services outside of public hospital systems, such as Medicare rebates under Mental Health Care Treatment Plans, that do not meet the needs of those with long-term health conditions or ongoing carer needs. Carers spoke of services and information catering for patients only, with carers not being a priority or not eligible. There was a recognition that existing support services and groups are targeted for common cancers (e.g., breast and prostate), with participants feeling as if others are “not welcome”. Along with the identification that there is no availability of general carers supports, carers also identified that any services that do exist are “overwhelmed with large caseloads”.

## **Interpersonal Barriers**

In the context of discussing systematic barriers, participants referred to health professional attributes, attitudes, and actions that impacted their ongoing access to supports. Particularly relevant to the rural context of the study sites, participants from smaller communities identified specific local barriers around confidentiality concerns, where patients and carers may have additional personal connections with professionals with no alternative service options available. The impact of these types of barriers mean patients and carers identified that they would ‘go without’ services, or have to access services via other means (e.g., telehealth). They identified that telehealth services impacted the ability to build a therapeutic relationship with their support provider.

Further barriers in accessing psychosocial supports related to negative interpersonal experiences between those seeking supports and those providing it. Concerns around poor communication, lack of empathy, poor follow-up, and poor service coordination were all cited. Moreover, participants also referred to a sense of disconnect with their providers, such as feeling “caught” between metropolitan and rural services, and feeling metropolitan providers exhibited a lack awareness of the rural-specific psychosocial stressors faced and the resulting impacts. This concept is encapsulated by a participant who commented “It would help if people in Sydney, say, were more aware of difficulties with availability of transport etc and the stress involved in organising travel and accommodation as well as having to stay in an unfamiliar area”.

## **Pandemic Barriers**

Much of this research occurred at the height of the COVID-19 pandemic, at which time health services underwent significant changes in configuration and delivery. Participants referred to the significant adjustments required to access services remotely and the impacts this had for them in accessing services due to provider priority adjustments and the implementation of public health protective measures such as stay-at-home orders. Additional concerns about the barriers imposed by the pandemic included impacts on building effective therapeutic relationships, and impacts on the speed and efficiency of communication with service providers. The changes the pandemic necessitated in service delivery were recognised, particularly by some carers, as necessary whilst equally recognising that there are time-constraints in cancer care with some carers identifying that delays resulted in services coming “too late” to be of benefit, with the person they cared for having died in the interim or having become too weak to access services. A patient further reported that “*It has been difficult during this period (COVID) to get responses from communication sent regarding my health issues... [and] trauma*”.

## **Intrapersonal Barriers**

Analysis revealed a final barrier category that was not clearly articulated by the predefined categories, that of interpersonal barriers. In particular physical “*exhaustion*” was a common code within this category. Participants referred to personal challenges that limited their ability to access support services, such as not having the energy to pursue support services, and feeling alienated and overwhelmed by their experience. Carers in particular referred to their demanding carer responsibilities necessitating that they put themselves second to the patient, delaying their own care needs. Carers reported feeling lonely in their care experiences. There was recognition by carers that putting themselves second meant not proactively seeking out supports. However, if services had approached them directly and systematically then they would have utilised them, as articulated by this carer:

The ideal thing would be to have a social worker or such come and get the support person or carer whilst the treatment is happening and ask them if they are okay “are you coping?” this would definitely help. Not today but when we arrived to Armidale last treatment, having not slept all night, getting up grumpy .... We then travelled the 90 minutes and I really felt blue. If someone had asked me how I was that morning I think I would have cried. I certainly would have said that I wasn’t coping so well.

## **Discussion**

This study examined levels of distress in patients and carers across three rural cancer services in Hunter New England Local Health District. The recognition of distress as a key component of quality oncology care is widely identified [12], with the importance of ‘caring for the carers’ also increasingly recognised [48]. However, this study suggests that there are still significant service improvements needed for rural people with cancer in this rural Australian area, and for those people that care for them.

In relation to the first two aims of this study, the proportion of patients and carers in this rural area who experienced levels of psychosocial distress within the moderate to severe range as measured by the DASS total score (32.1% and 38.1%) were significantly higher than the normative reference group (18%).

The rates of moderate to severe symptoms of depression, anxiety and stress for patients and their carers identified in this study warrant an increased emphasis on screening, referral and intervention practices within oncology services for both patients and carers. These results lend support to the internationally recognised concern that psychological distress in people with cancer often goes undetected and unmitigated [e.g. 16]. Moreover, carers are equally at risk of experiencing distress as patients with arguably even fewer formal structures and services in place to detect and intervene in their distress. Despite being a world leader in the development of comprehensive psychosocial care guidelines for people with cancer and recognition of the necessity of considering distress as the 'sixth vital sign' [12], the psychological distress of patients and carers in this rural area remains high and underserved.

Work has been undertaken in other countries to support decision-making around recruitment and staffing levels for adequate psycho-oncology health professionals, including minimum benchmark hiring, resourcing and staffing formulas, to ensure cancer patients and carers receive appropriate services to meet their needs and achieve positive health and well-being outcomes [e.g. 49]. Some countries have established benchmarks for the numbers of new cancer patients that should be referred for psychosocial support, counselling or psychotherapy. For example, the recommendations of the Canadian Association of Psychosocial Oncology [CAPO; 50] may be usefully applied, given Canada's approximately comparable socialised health care system including similar rural travel distances and their colonised indigenous population experiencing inequitable health outcomes. CAPO [50] recommends that if an oncology service has anything less than 35% of new patients being referred to psychosocial support services, then the service should undertake an assessment of their screening practices, referral practices by the other professionals in their organisation, and/or promotion of services to cancer patients and families [CAPO, 50]. This percentage is consistent with the percentage of participants found in this study who identified total psychological distress in the moderate / severe / extremely severe ranges, demonstrating the need for psychological services for this rural population. Thus, these CAPO (2019) guidelines and the results of this study highlight the urgent need to review the available psycho-social oncology services in rural Australia, and the screening and referral practices for each cancer service.

The second aim of this study was to understand the barriers that patients and carers may face when attempting to access psychosocial support services. Whilst previous research has identified that some patients and carers choose not to seek help with their distress due to personal preferences such as preferring to manage by themselves, or self-assessing their distress as not severe enough to warrant support [e.g. 23], this study has also shown that even when patients and carers *do* want support there are significant and often insurmountable barriers to accessing this. In addition to the common barriers considered, four new barrier categories were identified from the qualitative data; i) systemic (e.g., health service system), ii) intrapersonal (e.g., individual personal assumptions or perceptions), iii) COVID-19 pandemic, and iv) interpersonal (e.g., community level or service provider/patient relationship) barriers were raised as issues by both patients and carers. Identifying these barriers is, however, only the first step in understanding the impact of these barriers on patients and carers and in recognising their clinical impacts. Importantly, systemic, pandemic and interpersonal barriers all provide opportunities for services to "do something different", whether that might be enhancing psychosocial support services

within oncology support services, to identifying clients for which the pandemic may have impacted inequitably, to assessment of workplace culture to centre patient experience and satisfaction. Psychosocial support services can further identify and assist with intrapersonal factors that may impact upon client ability to readily access care, such as screening for stressors like finances and family concerns.

Many barriers for rural people are well-recognised as unique to the geographical context, such as distance to travel to services. The impact of the COVID-19 pandemic was also a theme identified in the qualitative analysis in this study due to the time-period in which the study was undertaken. However, these were not the most common barriers identified quantitatively or qualitatively by patients and carers in this study. The most prominently endorsed barriers were the lack of sufficient quantity and availability of psychosocial support services to adequately meet patient and carer needs, and the inaccessibility of existing services for rural people due to both distance and the energy required to access it.

The inadequacy of psychosocial support availability is worth further consideration when combined with previous research from the metropolitan hospital within HNELHD that even people reporting high levels of distress may still feel their distress is not severe enough to warrant help [23]. This finding is not unique to rural cancer populations, with research into older Australians also noting attitudinal barriers in identifying need for psychological support [51], with as many as 50% of older adults believing their symptoms were normal for their circumstance and/or age. The results from this study, in combination with the known influence of personal characteristics identified in rural populations like stoicism and self-reliance [22], provide clear implications for service delivery. Rural cancer services cannot assume that the need for accessible and available psycho-oncology supports is low because patients and carers are not proactively requesting services. Furthermore, services can not rely on patients and carers to adequately self-assess their psycho-oncology needs and self-refer and proactively seek psychosocial supports. As noted above, whilst some barriers are personal issues for patients and carers (such as financial and transport/travel needs), many of the other commonly identified barriers fall within the realm of service quality improvement capacities (e.g., provision of adequate information about available services) so patients and carers not only clearly know “who” they can see but have a clear understanding of “why” accessing psychosocial support is important. This may go some way to reduce the impact of self-assessment of perceived need and reducing its ultimate impacts on access and achieving optimal health outcomes. Alongside improved screening, there is also scope for improved public health messaging and campaigning to assist in increasing the awareness of the importance of looking one’s mind and body to support and enhance outcomes along one’s cancer journey.

This research emphasises the need for greater access to psychosocial oncology services in this rural area, and for these services to proactively seek to assess and engage patients and carers at multiple points throughout the cancer journey. Increasing clinician recognition that rural patients and carers may not voice their needs for psychosocial oncology support is an important first step. However, arguably, the burden should not have to fall on clients to identify needs and proactively request support, given the well-documented importance of optimal cancer care being inclusive of attending to psycho-social oncology

concerns for both patients and carers. Whilst increasing service access is a clear need, the review of screening and referral practices, including benchmarking of identified distress in this at-risk population against known population norms, is equally recommended.

## Limitations

There is contention regarding the validity of describing the use of open-ended questions in surveys as sufficient qualitative research in mixed methods approaches, whilst others argue that the mixed methods approach is much more about the analysis and use of the data than the specific technique used to gather it [44, 52]. However, this study recognises that there may be richer information that could have been obtained through additional and more in-depth qualitative research techniques (e.g., interviews), and there is opportunity for future research to extend these findings. It is recognised that the findings must be interpreted as indicative of individual patient and caregivers' experiences, unique to this particular geographical region, rather than representative of all rural or Australian patients and carers. It is further recognised that common limitations associated with survey-sampling, such as self-selection bias, self-report biases, and recall bias may also be present. Further sampling of other demographic characteristics (e.g., increasing the proportion of Aboriginal and Torres Strait Islander patients and carers), different geographic locations, and additional participant numbers may have identified different results and additional themes.

There is scope for future research to compare rural patient and carer data to urban samples to further understand the psychological experiences of cancer and caring, and to design services that meet individual population needs of rural or urban contexts. The carer sample in this study was smaller than the patient sample, and a larger carer sample to increase generalisability would be helpful in further understanding this important group in their own right.

## Conclusions

These findings indicate that a high proportion of the rural cancer patients and carers who participated in this research were experiencing clinically elevated levels of psychosocial distress. These levels appear greater than what would be predicted for the general population, with more than a third of patients and carers reporting moderate, severe, or extremely severe depression, anxiety, stress, and total psychosocial distress levels. However, despite this sizable proportion of rural patients and carers arguably requiring psychosocial oncology support, there are a myriad of barriers that impact their ability to access appropriate supports. Commonly identified rural challenges, such as distance to services, were recognised, as well as intrapersonal barriers that are not necessarily within the scope of services to mitigate (e.g., financial, work, family). Novel findings of the study include system-level barriers emphasised by both patients and carers, suggesting that psychosocial support services are either simply not available in their health service or location, or where they do exist, those services are working beyond their capacity to provide adequate, timely, and effective services for their clients.

The combination of high psychological need for patients and carers *and* insufficiency and inaccessibility of psychosocial support services has substantial implications for service provision. Essentially, under-detection of psychosocial need and under-offering of support services is significant for rural people with cancer and for those that care for them. From a clinical standpoint, the results from this study suggest that health services have an urgent opportunity to improve the psychosocial oncology services on offer for this population and an obligation to ensure that patients and carers with clinically concerning levels of distress are identified and supported appropriately.

## Declarations

Ethical Approval – The study was authorised by HNELHD, and approvals from both the HNE Human Research Ethics Committee and the University Human Research Ethics Committee were obtained.

Competing Interests – There are no financial interests or benefits to the authors that has arisen from the direct applications of this research.

Author Contributions – All authors were involved in the design of the study. All authors contributed to the conceptualisation of the analyses. M.B wrote the main manuscript text and prepared the figures. All authors reviewed the manuscript.

Declaration of Funding – The first author is in receipt of an Australian Commonwealth Government RTP Scholarship. This research received funding from the Tour de Cure charity to assist with the data gathering phase.

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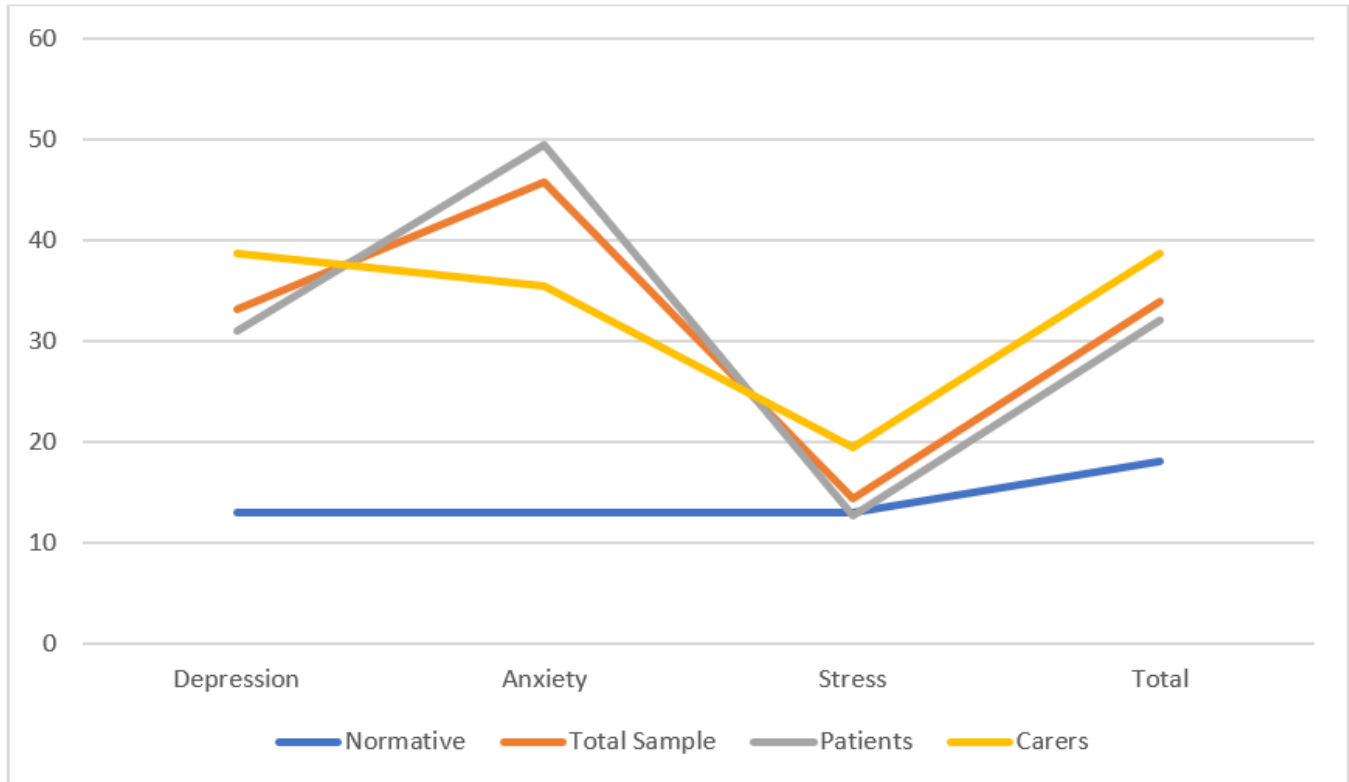


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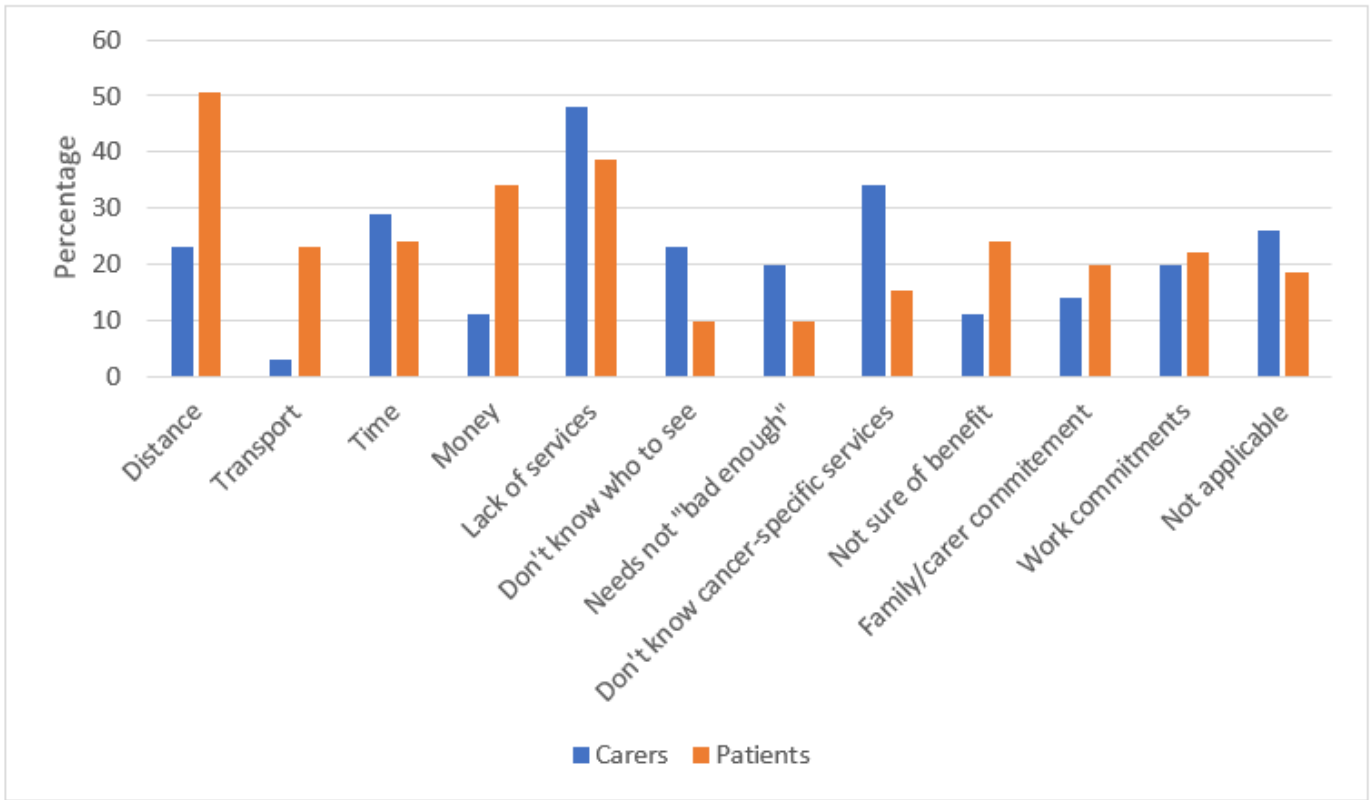
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## Figures



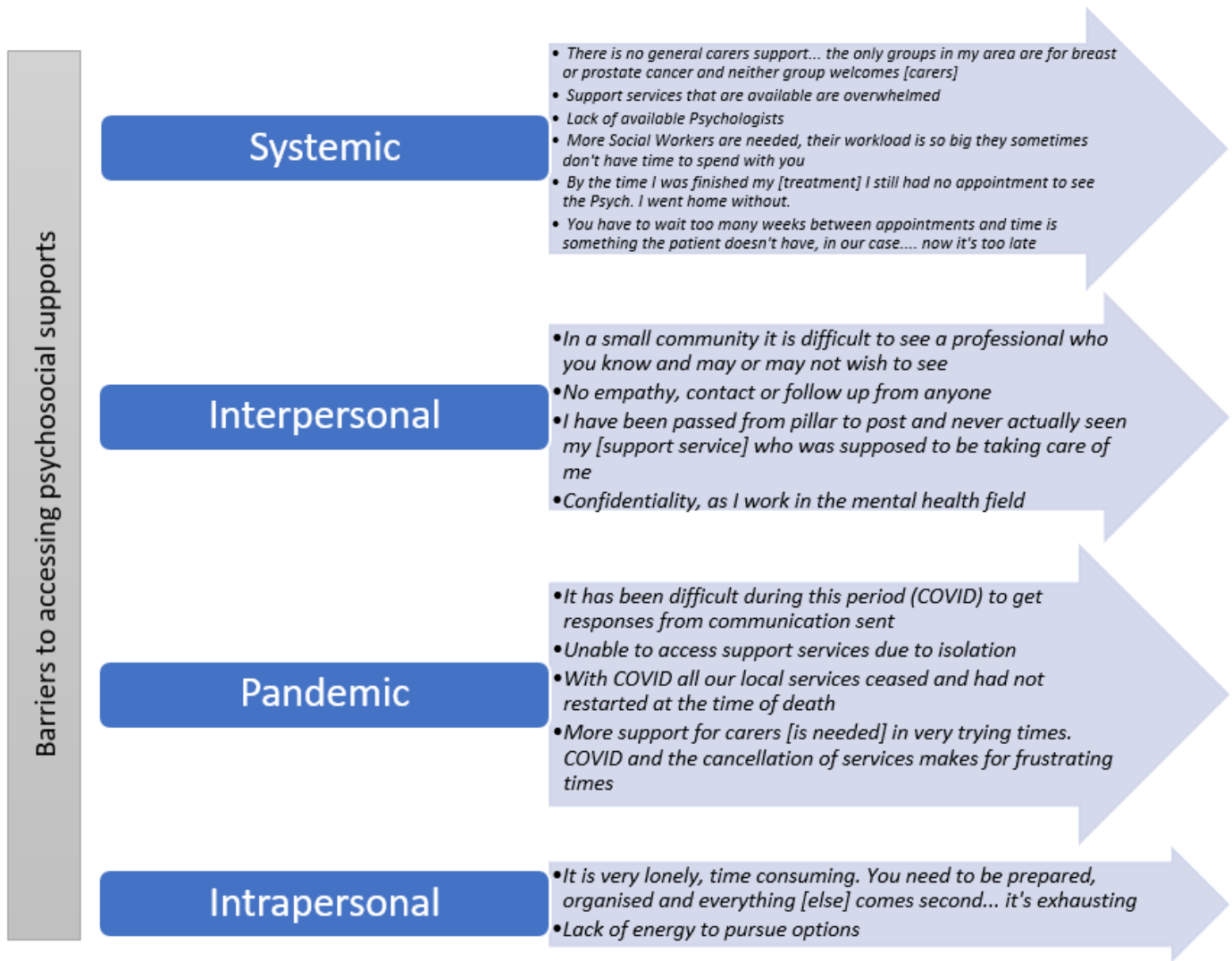
**Figure 1**

The proportion of scores in the moderate/severe/extremely severe ranges compared to normative population ( $N = 125$ )



**Figure 2**

Barriers identified by carers and patients



**Figure 3**

Additional qualitative categories and example quotes