

Research Article

Psychosocial Experiences in an Australian Rural Cancer Service: Mixed-Method Insights into Psychological Distress and Psychosocial Service Barriers

Marisa Barnes ¹, Kylie Rice ¹, Kim Usher ¹, Einar B. Thorsteinsson ¹,
Clara V. Murray ¹ and Fiona Ord²

¹University of New England, School of Psychology, Armidale, NSW 2351, Australia

²Hunter New England Local Health District, Armidale Rural Referral Hospital, Locked Bag 4, Armidale, NSW 2350, Australia

Correspondence should be addressed to Kylie Rice; kylie.rice@une.edu.au

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Purpose. To examine psychosocial and well-being concerns throughout the cancer experience, from prediagnosis to survivorship. Whilst most oncology research focuses on patients, the role and experiences of families and caregivers are increasingly recognised as a core component of health service delivery. Moreover, research suggests that geography is an important consideration, with evidence of rural inequities in health service provision and access. **Aims.** (i) To examine the unique patient and caregiver experiences of rural people in three rural cancer treatment centres in New South Wales (NSW) and (ii) to examine the barriers to rural patients and caregivers accessing psycho-oncological support in NSW. **Methods.** A convergent parallel mixed-method evaluation of the psychosocial experiences of rural patients and caregivers accessing cancer services through three health services in rural NSW was undertaken ($N = 125$). Measures of psychological distress as well as quantitative and qualitative barriers data were collected. **Results.** Approximately, one-third of the participants reported moderate to severe distress. Patients and caregivers reported systemic, intrapersonal, interpersonal, and pandemic-specific barriers in accessing quality psychosocial healthcare. **Conclusions.** These results suggest that cancer patients and caregivers in rural NSW may experience elevated levels of psychological distress and barriers in accessing psychosocial care. The combination of high psychological need for patients and caregivers with reduced availability of psychosocial support services has substantial implications for psychological wellbeing and service provision. Underdetection of psychosocial need and a lack of support services pose a significant challenge for rural people with cancer and for those who care for them; this must be an urgent priority for quality improvement and equitable healthcare provision.

1. 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 caregivers is not unexpected, given the health and social changes a cancer diagnosis brings, and the cancer journey is known to seriously impact patients' and caregivers' wellbeing and increase psychological distress [2]. Psychological distress for people with cancer and their caregivers can be experienced anywhere along the cancer journey from prediagnosis 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 wellbeing and their ability to cope with a cancer diagnosis, symptoms, treatment, and survivorship. The psychological cost of the cancer experience is significant with identified links between psychological wellbeing and treatment outcomes [6].

1.1. 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 caregivers. However, two recent Australian studies suggested that 23% of the people with cancer evidence moderate to high levels of distress [7] and almost all caregivers of people with cancer (96%) report clinically significant levels of distress, with 66% identifying as severely distressed [8]. Other research studies have indicated that the mean prevalence of psychological distress varies approximately in the range of 4–50% 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 such as 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 are inconsistent across services and geographical areas and notably lacking in rural areas [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 [14]. Despite the importance of psychological wellbeing, about 20% of the cancer patients in Australia are never screened for psychological distress during their cancer care [15]. Where psychological distress is identified, only 50% of the patients are offered help for psychological distress [16]. Unfortunately, psychological wellbeing may often be an afterthought, taking a backseat to medical requirements and treatments [15], which is a critical missed opportunity to improve outcomes for a significant number of people.

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

However, findings suggest that caregivers 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 caregivers’ distress levels can actually exceed those of patients [8, 20]. When services do not systematically screen for caregivers’ 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 caregivers’ burden and distress [21]. Notwithstanding, the psychosocial needs of caregivers have similarly remained largely underidentified and underserved [21].

Arguably, caregivers’ needs should be assessed and attended to as an equal priority to that of patients.

1.2. Barriers in Accessing Psychosocial Support Services.

Australian research suggests that significant barriers impact the accessibility and acceptability of psychosocial support services. These include underdetection by healthcare providers [15], underoffering of services or lack of service availability [13], underutilisation of offered services as a result of both practical barriers (e.g., distance, expense, and 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 healthcare 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, and 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 [24]. Rurality, therefore, is an intersectoral disadvantage, bringing additional psychosocial stressors for cancer patients and their caregivers.

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 [25]. 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 [26, 27]. Given the multiple psychosocial stressors experienced by caregivers 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 caregivers 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 [28]. Therefore, the inclusion of formal and informal caregivers and family members forms a key component to understand psychological experiences and service access barriers for people in rural areas.

Research has also identified service-level barriers that impact access and engagement for rural populations accessing psychosocial support [29]. This includes historical mental health stigma [30] to professional barriers such as physician beliefs regarding psycho-oncology efficacy [31] and the lack of systematic integration of psycho-oncology support services into standard cancer care [32]. This might go some way to understand why even when people identify distress and are aware that support services exist, they often do not access them [23]. Many patients and caregivers “self-assess” and evaluate their symptoms as not “bad enough” to warrant services [23]. Some report feeling as though they need to “suffer in silence” to reduce the burden on their loved ones [20]. These barriers impact the ability and ease with which people with cancer, and those that care for them, can access supports. The specific needs of rural patients and

their caregivers are a further important consideration in providing quality psychosocial oncology care. Fradgley et al. [12] identified that there are critical gaps in the delivery of distress management as outlined in Australian evidence-based guidelines. However, research data have 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 patients' psychological wellbeing and to consider the psychological wellbeing of their caregivers in tandem. A recent parliamentary enquiry [13] indicated that not only residents of regional, rural, and remote places in New South Wales have poorer health outcomes but also this is compounded by inferior access to health and hospital services compared to those in metropolitan areas. Given the different service availabilities and barriers that may be experienced in different regional areas, a localised place-based approach to understand how this inequity might be experienced by rural cancer patients and their caregivers was needed to facilitate necessary and timely remediation. Whilst the main focus of the parliamentary enquiry was equity, a reply by McDonald and Malatzky [33] called for additional investigation to understand an arguably "metronormative" health service and to recognise and emphasise rural diversity and strength.

Recognising the challenges outlined by the NSW Parliamentary enquiry, combined with the need for localised, place-based understanding of psycho-oncology challenges in rural areas, the present study was designed to examine the unique experiences of rural patients and caregivers in three rural cancer treatment centres in NSW. The study specifically examined psychological distress symptomatology and the practical and perceived barriers to rural populations accessing psycho-oncological support in NSW.

Specifically, this study aimed to examine and explore the following:

- (1) The symptoms and prevalence of psychological distress of rural cancer patients and their caregivers in a local health district
- (2) Barriers in accessing psychosocial oncology support in rural NSW reported by people with cancer and reported by caregivers of people with cancer.

2. Methodology

2.1. Procedure

2.1.1. Population. Cancer patients and their caregivers attending one of the three participating NSW regional/rural treatment centres were invited to participate.

2.1.2. Setting and the Procedure. Participants were invited, via administration staff and displayed posters in the buildings, to complete an online survey. The participants had the option to complete the survey via iPads located in the waiting and treatment spaces in the three participating sites or by using a QR code to complete the survey on their own devices at any time. The participants were required to

provide consent prior to the questionnaires being displayed on the provided or personal devices. The survey was only available in English.

In addition to the following measures, participants also completed basic demographic data, including postcode and questions about their cancer type. The participants computed an anonymous unique matching code to return to the study if they were not able to complete the measures in the one sitting. Rurality was confirmed by postcode according to the Australian Statistical Geography Standard, Remoteness Structure [34]. The study was authorised by Hunter New England Local Health District (HNELHD), and approvals were obtained from both the HNE Human Research Ethics Committee and the University of New England Human Research Ethics Committee.

2.2. Measures

2.2.1. 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]'s cutoff scores yielded from their normative Australian sample of 717 participants were utilised. The patient and caregiver samples of depression, anxiety, and 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-21 normative data of 13% in these ranges for each DASS-21 subscale.

The DASS-21 has good internal consistency with Cronbach's alpha α ranging from 0.88 to 0.94 for depression, 0.82 to 0.87 for anxiety, 0.9 to 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 the participants responded 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 $\alpha=0.89$, anxiety subscale $\alpha=0.81$, stress subscale $\alpha=0.89$, and total score $\alpha=0.94$).

2.2.2. Barriers in Accessing Support. Patient and caregiver samples were also asked to identify barriers in accessing psychosocial cancer supports. These data were collected via two methods. First, quantitative data collection involved asking the 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 in accessing support reported at a regional cancer service and similar research [23]. Second, qualitative data collection involved asking participants, via nonmandatory 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.

3. Data Analysis

The study used a convergent parallel mixed-method study design that integrated a cross-sectional quantitative survey and a qualitative analysis [42] of open-text responses. The collection and analysis of quantitative and qualitative data were implemented simultaneously and in parallel and were addressed with equal priority [43]. 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-method approach [44], allowing the study of psychological distress and perceived service access barriers of both people with cancer and caregivers, enabling comparison and corroboration of their experiences [45]. IBM SPSS Statistics version 28.0 [46] was utilised to analyse the quantitative data, including descriptive statistics, *t*-tests, and chi-squared analyses, and QSR International's NVivo 12 [47] software was used for coding and content analysis and to store qualitative responses and manage codes.

The Elo and Kyngäs [48] process for content analysis was utilised to process, organise, and report the data. Two researchers independently coded the open-text survey response data using a constant comparative approach. The analysis used the three-phased coding process described by Elo and Kyngäs [48] that included preparation, organising, and reporting, with open coding, grouping, and categorisation of the content into higher-order categories, followed by results reporting descriptions of the categories and their meanings. The analyses were primarily deductive. Coding and content development, informed by the provision of predetermined example categories of barriers, was complemented by inductive analyses driven by the content of the responses. Where the open-text content only referred to a previously described barrier category, the data were not included in the inductive content analysis. However, if the data referred to barriers that were not already prescribed or added additional information that was not fully captured by the prescribed category, then they were coded for category groupings.

4. Results

4.1. Participants. Data are reported from 125 respondents, of which 91 identified as patients and 34 identified as caregivers. This sample size of 125 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 0.05 [49]. Given the small number of caregiver participants in this study, a post-hoc power analysis was conducted which suggested adequate power of

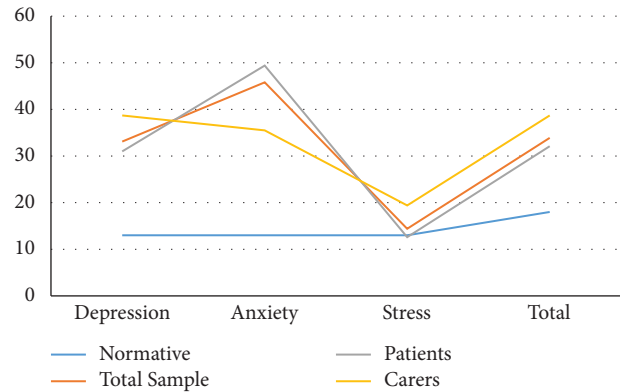


FIGURE 1: The proportion of scores in the moderate/severe/extremely severe ranges compared to normative population ($N=125$).

91% [50]. 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 [51]. 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. Females were overrepresented in our sample, with 19% identifying as male and 81% as female. The majority of the patients' samples reported breast cancer as their primary diagnosis (40%), followed by prostate cancer (11%), cervical/uterine/ovarian cancers (11%), colorectal cancers (8%), blood cancers (8%), melanomas (4%), lung cancers (3%), and oesophageal cancers (2%), with the remaining 13% made up of various less common cancers, such as germ cell. More than half the sample ($n=85$, 68%) reported a postcode in the Tablelands sector of HNELHD, which encompasses the Armidale Cancer Centre. Twenty percent of the participants were from the Peel Sector ($n=25$), which encompasses the North West Cancer Centre in Tamworth. Whereas, 6.5% of the sample was from the Moree Hospital's Mehi Sector ($n=8$) and 5.6% was from another geographical area outside of HNELHD (e.g., travelling from the Murrumbidgee Local Health District). In terms of distance travelled by the participants to their treatment centre, the longest distances travelled were round trips of approximately 400 km to the Armidale Cancer Centre, 600 km to Moree Hospital, or 300 km to the North West Cancer Centre.

The majority (80.8%) of the sample was identified as having an "Australian" cultural background, and 5 respondents (4%) were 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 [52]. The remaining 19 respondents were identified with different backgrounds, including English ($n=7$, 5.6%), New Zealand ($n=4$, 3.2%), and others (e.g., Germany) ($n=8$, 6.4%).

4.1.1. *Distress.* As presented in Figure 1, the level of depression, anxiety, and stress symptoms, and the total score, was significantly higher in the combined sample and also in both the patient sample and the caregiver samples compared to that of normative proportions for each DASS-21 subscale [35] and the total score [53].

A third (33.1%) of the combined sample (patients and caregivers) population reported a much higher depression symptoms level in the moderate, severe, and extremely severe ranges. This rose to just under half (45.8%) when considering all patients and caregivers who rated their depression symptoms level outside the “normal” range. For patients only, 31% reported moderate-to-extremely severe levels of depression symptoms. For the caregivers, 38.7% reported moderate-to-extremely severe levels of depression symptoms, 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 caregiver sample evidencing anxiety symptoms in the upper ranges (moderate/severe/extremely severe) of concern and over half (53.4%) reporting anxiety symptom levels above the “normal” range. For patients only, almost half (49.4%) identified anxiety symptoms in the moderate/severe/extremely severe range. The caregiver sample found 35.5% of the participants in the moderate/severe/extremely severe ranges for anxiety symptoms.

The combined patient and caregiver sample evidenced similar levels of stress to the normative population, with 14.4% identifying 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 caregivers, 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 the patients and caregivers 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 the patients (32.1%) endorsing moderate, severe, or extremely severe levels of distress. Similarly, 38.7% of the caregivers 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 [53]’s normative data. The mean level of the total score of psychological distress ($M=29.20$ and $SD=20.949$) was significantly higher than total DASS-21 scores reported by Crawford and Henry [53] ($M=18.38$ and $SD=18.82$), with a mean difference of 10.817, $t(121)=5.703$, and $p<0.001$. The patient and caregiver 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 ($M=29.25$ and $SD=20.321$), with a mean difference of 10.873, $t(90)=5.104$, and $p<0.001$. Similarly, the caregiver sample was significantly higher than the normative sample

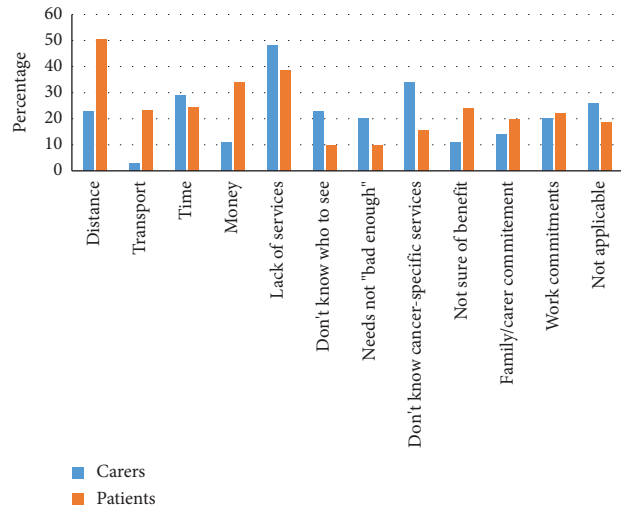


FIGURE 2: Barriers identified by caregivers and patients.

($M=29.03$ and $SD=23.047$), with a mean difference of 10.652, $t(30)=2.573$, and $p<0.01$.

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

4.1.2. *Barriers for Patients.* For patients (Figure 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 were 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 the patients reported having no barriers in accessing psychosocial support services.

4.1.3. *Barriers for Caregivers.* Quantitative barrier data indicated that about 26% of the caregivers did not believe they had experienced any barriers in accessing psychosocial support services for themselves. Of those caregivers that did report experiencing barriers, caregivers identified with all 11 predetermined barriers as hindering their access to psychosocial supports (Figure 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 caregivers (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%).

49 respondents provided responses to the nonmandatory open-text questions. Qualitative analysis revealed, in

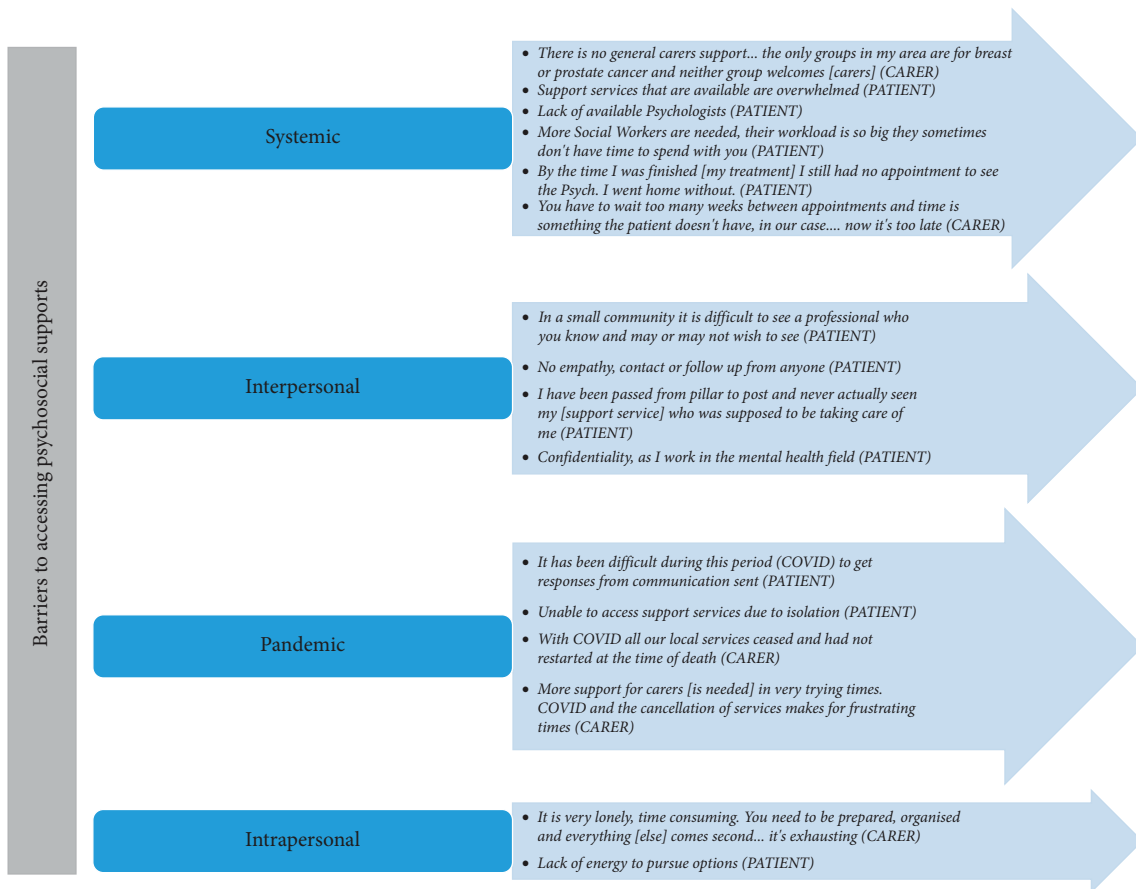


FIGURE 3: Additional qualitative categories and example quotes.

contrast to the quantitative barriers endorsed, the following additional categories of barriers in accessing psychosocial supports (Figure 3).

4.1.4. Systemic Barriers. Systemic barriers were the largest category identified by the qualitative respondents. Both patients and caregivers endorsed a range of health system issues in accessing psychosocial supports. The most common issues related to their areas were 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 systemic 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 caregiver needs. Caregivers spoke of services and

information catering for patients only, with caregivers 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 caregivers’ supports, caregivers also identified that any services that do exist are “overwhelmed with large caseloads.”

4.1.5. Interpersonal Barriers. In the context of discussing systemic 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, the participants from smaller communities identified specific local barriers around confidentiality concerns, where patients and caregivers may have additional personal connections with professionals with no alternative service options available. The impact of these types of barriers means patients and caregivers 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 are 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, the 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.”

4.1.6. Pandemic Barriers. Much of this research occurred at the peak 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 providers’ 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 caregivers as necessary whilst equally recognising that there are time constraints in cancer care with some caregivers 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-19) to get responses from communication sent regarding my health issues. . . (and) trauma.*”

4.1.7. Intrapersonal Barriers. Analysis revealed a final barrier category that was not clearly articulated by the pre-defined 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. Caregivers in particular referred to their demanding caregivers’ responsibilities, necessitating that they put themselves second to the patient, delaying their own care needs. Caregivers reported feeling lonely in their care experiences. There was recognition by caregivers 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 caregiver 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 (sic) 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.”

5. Discussion

This study examined levels of distress in patients and caregivers 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 caregivers” also increasingly being recognised [54]. 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 caregivers in this rural area who experienced levels of psychosocial distress within the moderate to severe range as measured by the DASS-21 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 caregivers identified in this study warrant an increased emphasis on screening, referral, and intervention practices within oncology services for both patients and caregivers. These results lend support to the internationally recognised concern that psychological distress in people with cancer often goes undetected and unmitigated [16]. Moreover, caregivers 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 Australia being a world leader in the development of comprehensive psychosocial care guidelines for people with cancer and leading the recognition of the necessity of conceptualising distress as the “sixth vital sign” [12], the psychological distress of patients and caregivers in this Australian 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 caregivers receive appropriate services to meet their needs and achieve positive health and well-being outcomes [55]. 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; [56]) may be usefully applied, given Canada’s approximately comparable socialised healthcare system including similar rural travel distances and their colonised indigenous population experiencing inequitable health outcomes. CAPO [56] 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. 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, the guidelines and the results of this study highlight the urgent need to review the available psychosocial 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 caregivers may face when attempting to accessing psychosocial support services. Whilst previous research has identified that some patients and caregivers 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 [23], this study has also shown that even when patients and caregivers do want support, there are significant and often insurmountable barriers in accessing this. The quantitative data indicated endorsement of commonly identified barriers to rural services access, such as distance. In comparison, 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 caregivers. Identifying these barriers is, however, only the first step in understanding the impact of these barriers on patients and caregivers 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, and 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 such as 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 [57], and these were similarly emphasised in this study. 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 caregivers in this study. The most prominently identified barriers were the lack of sufficient quantity and availability of psychosocial support services to adequately meet patient and caregiver 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 [58], with as many as 50% of the 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 such as 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 caregivers are not proactively requesting services. Furthermore, services cannot rely on patients and caregivers 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 caregivers (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) and so patients and caregivers not only clearly know “who” they can see but also 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 a 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 caregivers at multiple points throughout the cancer journey. Increasing clinician recognition that rural patients and caregivers 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 psychosocial oncology concerns for both patients and caregivers. 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.

5.1. Limitations. There is contention regarding the validity of describing the use of open-ended questions in surveys as sufficient qualitative research in mixed-method approaches, whilst others argue that the mixed-method approach is much more about the analysis and use of the data than the specific technique used to gather it [44, 59]. 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 caregivers. It is further recognised that common limitations associated with survey sampling, such as self-selection bias, self-report biases, and recall bias, are likely to be present. The impact of the pandemic context in relation to bias and respondent gender disparity [60] is recognised but unknown. Further sampling of other demographic characteristics (e.g., increasing the proportion of Aboriginal and Torres Strait Islander patients and caregivers), different geographic locations, and additional participant numbers may have identified different results and additional themes.

There is a scope for future research to compare rural patient and caregiver 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 caregiver sample in this study was smaller than the patient sample, and a larger caregiver sample to increase generalisability would be helpful in further understanding this important group in their own right.

6. Conclusions

These findings indicate that the rural cancer patients and caregivers 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 the patients and caregivers reporting moderate, severe, or extremely severe depression, anxiety, stress, and total psychosocial distress levels. However, despite this sizable proportion of rural patients and caregivers 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 caregivers, 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 caregivers and insufficiency and inaccessibility of psychosocial support services has substantial implications for service provision. Essentially, underdetection of psychosocial need and underoffering of support services are 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 need to improve the psychosocial oncology services on offer for this population and an obligation to ensure that patients and their

caregivers with clinically concerning levels of distress are identified and supported appropriately.

Data Availability

The data used to support the findings of this study are currently stored in UNE Qualtrics servers and can be made available upon appropriate request once this research project and its publications are finished.

Additional Points

What Is Known about This Topic? (i) The psychosocial wellbeing needs of people with cancer, and those of their caregivers, are an important component of holistic, high-quality cancer care. (ii) Rural inequities in health outcomes and healthcare service access are apparent across Australia and specifically in New South Wales. (iii) Both the people with cancer, and their caregivers, require equitable access to services and appropriate psycho-oncology interventions, irrespective of their geographical location. *What Does This Paper Add?* (i) The sample of rural people with cancer, and caregivers of people with cancer, in a localised rural health district is experiencing clinically elevated levels of psychosocial distress, at levels considerably higher than general population. (ii) Patients and caregivers report considerable barriers in accessing psycho-oncology care in this rural area, with interpersonal, systemic, pandemic, and intrapersonal themes emerging. (iii) This paper identifies key themes that may inform health service delivery, in order to address inequities for health outcomes and service access for people in rural areas.

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.

Disclosure

An earlier version of this work is available as a preprint [61].

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' 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.

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