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Distress and psychosocial support seeking: A comparison of rural and metropolitan oncology patient experiences

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Abstract

Introduction: Prevalence of distress in cancer patients is established at approximately 50%, yet uptake of psychosocial support is minimal.

Objective: This study aimed to understand why clinically distressed oncology patients choose not to access psychosocial support, including whether this differs by geographic location. It also aimed to determine the proportion of rural and metropolitan patients experiencing clinical levels of distress, and of these, the proportion who do not wish to access support.

Design: The study used a cross-sectional design. Two hundred and ninety-eight Australian cancer patients completed an online survey, including the Distress Thermometer and open-ended questions about reasons for declining support. Descriptive statistics and content analysis were used to analyse the data.

Findings: More than half (56%) of participants reported experiencing clinically significant levels of distress. Of these, almost half (47%) declined psychosocial support. Content analysis of reasons for declining psychosocial support resulted in six main concepts: I don't need support; I'm using personal resources to cope; negative perceptions and attitudes; life doesn't stop for cancer; I'm focussed on fighting cancer; and systemic barriers. Rural cancer patients most often indicated using personal resources to cope, while metropolitan participants most commonly indicated not needing support. A range of subconcepts were also identified. Perceiving distress as manageable or transient was almost exclusively reported by metropolitan participants, while stigma was almost exclusively reported by rural participants.

Discussion: The findings provided greater depth of insight into reasons cancer patients decline psychosocial support and identified several qualitative differences in the reasons provided by metropolitan and rural patients. Recommendations are provided for clinicians, in particular for clinicians who work with rural cancer patients and their supporters.

Conclusion: These findings can inform equitable resourcing of psychosocial support in rural areas and the adaptation of psychosocial interventions to be

more flexible and responsive to individual needs. This may help increase patient uptake of support, particularly in rural areas.

1 | INTRODUCTION

Approximately half of oncology patients experience clinically significant levels of distress.[1–5] This distress can occur from the point of diagnosis, throughout treatment and into palliative care or remission.[4,6] Further, up to 30% of cancer patients meet the criteria for a diagnosable mental health condition.[7–9] Although screening for distress is considered integral to quality cancer care[10] and predicts an increased likelihood of referral to psychosocial support services,[3,11] many distressed individuals do not access help.[12–15] This decision has clinical implications, with evidence suggesting that early intervention can prevent longer term physical and psychological morbidity.[6] Despite this, for cancer survivors in Australia, psychosocial care remains the most frequently reported unmet need.[16]

Psychosocial support refers to formal support services provided to cancer patients with the aim of addressing psychological, emotional and social needs.[11] Research in Australia has shown that cancer patients who are clinically distressed primarily decline psychosocial support because they prefer to self-manage, do not believe their distress is severe enough, or are getting help elsewhere.[12] This finding was consistent with an earlier systematic review of international research, which reported the most commonly perceived barrier for *all* cancer patients to accessing psychosocial care is lack of perceived need and receiving adequate support from elsewhere.[17] Cohen et al.[13] reported that in a Canadian sample, clinically distressed patients want to maintain a sense of normalcy, handle their problems alone, and perceive their problems as physical rather than psychological. For distressed German patients, Pichler et al.[14] found that perceived overload was the strongest predictor of declining psychosocial support, with male sex and low levels of agreeableness also significant predictors.

Much of the previous research on this issue has not adequately considered the rural and remote perspective or included this voice,[12,15] which is relevant in Australia given that 28% of the population live in rural and remote areas,[18] and that this population experiences inequity in access to cancer care services.[19] A recent study concluded that socio-demographic factors (age, gender, education and socio-economic status) made a minimal contribution to support-seeking behaviours in regional and remote cancer

What is already known on this subject?

- Approximately half of cancer patients experience clinical levels of distress and many decline offers for psychosocial support.
- The main reasons clinically distressed cancer patients decline psychosocial support include preferring to self-manage, not believing their distress is severe enough, or that they are getting help elsewhere.
- The differences between rural and metropolitan cancer patients on this issue has not been adequately explored, and a qualitative approach has been suggested.

What this paper adds

- This study provides increased depth of understanding of the reasons distressed cancer patients decline support. It also highlights differences in rural and metropolitan cancer patients′ reasons for declining psychosocial support.
- Findings suggest that rural cancer patients most commonly cite using personal resources to cope and experience stigma in relation to seeking support.
- Alternatively, metropolitan cancer patients most commonly perceive that they do not require support. They also perceive their distress as manageable or transient more often than rural participants.
- These results can inform equitable service delivery and help to target specific needs with the aim of increasing the uptake of support.

patients, and that contrary to commonly held beliefs, attitudinal factors such as minimising problems, self-reliance and a fatalistic outlook may not affect help-seeking behaviours for this population, suggesting an overall gap in the shared understanding of this issue.[20] Additionally, a recent systematic review reported that rural cancer patients commonly report unmet information needs relating to referrals for

psychosocial support services.[21] They also have more unmet needs compared to metropolitan cancer patients.[22] In addition to difficulty accessing treatment and psychosocial support services locally, the travel required to access services places pressure on family relationships and finances.[23–26]

Additionally, the limited response options used in previous Australian quantitative research[12] originated from the National Survey of Mental Health and Wellbeing of Adults,[27] which does not include oncology-specific issues raised in other studies.[13,14] It has been suggested that a qualitative approach would facilitate a fuller understanding of the issues, thus enabling service providers to respond appropriately.[12,15] While some research has explored reasons that cancer patients decline supportive care qualitatively, they either did not fully explore rural differences,[28] did not consider them at all,[29] or did not contrast them with metropolitan experiences.[30,31]

The primary aim of this study was to understand what contributes to the decision not to access psychosocial support for individuals experiencing clinical levels of distress, and whether this differs between metropolitan and rural patients. No a priori hypotheses were established in relation to this aim given its exploratory nature. To achieve this, we also aimed to determine the proportion of rural and metropolitan participants who were experiencing clinical levels of distress, and to determine the proportion of clinically distressed rural and metropolitan patients who do not wish to access support services.

2 | MATERIALS AND METHODS

2.1 | Design

The study was cross-sectional, with an online survey used to collect data. Anyone who met eligibility criteria (i.e., reported clinical levels of distress) was invited to respond to two open-ended survey questions.

2.2 | Participants

Participants were 298 cancer patients and survivors from across Australia who were 5 years or less since their cancer diagnosis. Of these, 166 (56%) were from metropolitan areas, and 132 (44%) were from regional, rural, or remote areas (herein referred to as rural). As a method of data collection, open-ended survey questions typically benefit from more participants than other qualitative data collection methods, with typical sizes ranging from 20 to well over 100.[32] The sample size for this study allowed for 79 eligible participants to complete the open-ended questions,

which provided sufficient breadth to also explore geographic differences.

2.3 | Procedure

Participants were selected using a convenience approach with social media advertising (on Facebook) used to promote the study Australia-wide and via cancer-specific groups and pages. Participation was voluntary and interested participants read an information sheet and provided consent online. Data was collected from September 2020 through to March 2021.

2.4 | Materials

The survey was initially constructed by a research team of psychologists with clinical training in consultation with a rural oncology service.

2.4.1 | Demographic information

Participants provided their postcode, age, sex, relationship status and cultural background. Geographic status was initially defined using the *Australian Statistical Geography Standard Remoteness Structure*.[33] Any postcode that at least partially fell within the *Major Cities of Australia* category was classed as metropolitan. All other postcodes were classed as rural. Table 1 presents participant demographic characteristics.

2.4.2 | Clinical characteristics

Patients provided information about the time since their diagnosis, type of cancer, current treatment stage (*pretreatment planning, treatment, treatment review, posttreatment monitoring, remission review, palliative care, other*) and cancer stage (*0–4*, or *I do not know*). Stage of cancer was recoded to: *I do not know*, *early* (stages 0 to 2) and *advanced* (stages 3 and 4). Table 2 presents participant clinical characteristics.

2.4.3 | Distress

All participants completed the *Distress Thermometer*, a single-item screening tool that is validated and used routinely to assess distress in oncology patients.[34,35] Participants indicated their current level of distress on an 11-point scale (0 = *no distress*; 10 = *the worst distress*

TABLE 1 Demographic characteristics of participants (*N* = 298).

Geographic status			Metropolitan	Rural	Total
Metropolitan	166 (56%)	**Age in years**			
Rural	132 (44%)	*M*	58.40	59.77	59.01
		(SD)	8.90	7.88	8.48
		Range	35–78	41–78	35–78

	Metropolitan		Rural		Total	
	n	*%*	*n*	*%*	*n*	*%*
Sex assigned at birth						
Female	123	56	96	44	219	73
Male	43	54	36	46	79	27
Relationship status						
Married	117	57	88	43	205	69
Separated/divorced	16	59	11	41	27	9
Single	13	59	9	41	22	7
Living with partner	15	42	21	58	36	12
Widowed/partner passed away	2	50	2	50	4	1
Engaged	1	50	1	50	2	1
Partnered but not living together	2	100	0	0	2	1
Cultural background						
Australian	124	54	104	46	228	77
Great Britain (English, Scottish, Welsh)	22	61	14	39	36	12
New Zealander	6	55	5	45	11	4
European	10	71	4	29	14	5
Aboriginal and/or Torres Strait Islander Australian	2	33	4	67	6	2
Other	2	67	1	33	3	1

imaginable). A cut-off score of four or higher warrants further clinical assessment.[34]

2.4.4 | Willingness to accept help

Participants who indicated clinically significant levels of distress were asked whether they would like help with their distress. Response options were *yes*, *no* and *I already am*, consistent with previous studies.[12,15]

2.4.5 | Open-ended questions

Participants who answered no to the previous question were then asked two open-ended questions about their reasons for declining help: "*What is the main reason you don't want to access support services?*" and "*What else can you tell us about why you don't want to access support services? You might like to share some other reasons, or you are welcome to expand on the reasons in the previous question*".

2.5 | Statistical methods

2.5.1 | Missing data

Of the cancer patients and survivors who consented to participate, 298 provided distress thermometer ratings. Seventy-seven of 79 eligible participants provided at least one valid response to the qualitative questions. Given the study was online, no information was available about reasons for non-completion.

TABLE 2 Clinical characteristics of participants ($N = 298$).

	Metropolitan		Rural		Total	
Time (years) since diagnosis						
M	1.89		1.86		1.88	
(SD)	1.36		1.42		1.39	
Range	0.08–5.00		0.08–5.00		0.08–5.00	
	Metropolitan		**Rural**		**Total**	
	n	**%**	***n***	**%**	***n***	**%**
Type of cancer (by primary site)						
Breast	84	58	60	42	144	48
Prostate	15	50	15	50	30	10
Gynaecological	15	58	11	42	26	9
Colon, rectal, and anal	11	48	12	52	23	8
Lymphoma	11	69	5	31	16	5
Other[a]	6	43	8	57	14	5
Skin	6	75	2	25	8	3
Head and neck	5	71	2	29	7	2
Bladder	3	43	4	57	7	2
Lung	3	43	4	57	7	2
Blood	2	33	4	67	6	2
Stomach	3	75	1	25	4	1
Kidney	1	33	2	67	3	1
Brain	1	33	2	67	3	1
Cancer stage						
Early	93	66	47	34	140	47
Advanced	54	47	60	53	114	38
I do not know	19	44	24	56	43	14
Current treatment stage						
Post-treatment monitoring	67	52	61	48	128	43
Treatment (includes maintenance therapy and drug trials)	54	57	41	43	95	32
Remission/cured	24	67	12	33	36	12
Treatment review	15	71	6	29	21	7
Palliative care	1	13	7	88	8	3
Pre-treatment planning	5	50	5	50	10	3

[a]Other includes cancer types that were indicated by two or less participants. These included: bone and bone marrow, thyroid, adenocarcinoma, adenoid cyst carcinoma, adrenal, ampullary, epithelioid haemangioendothelioma, oesophageal, liver, peritoneal, thymic.

2.5.2 | Quantitative analysis

Quantitative data analysis was undertaken using SPSS Version 28 (IBM, https://www.ibm.com/products/spss-statistics). Descriptive statistics (frequencies and percentages) report the presence of clinical distress, including by geographic location. Descriptive statistics and a graph illustrates the proportion of clinically distressed rural compared to metropolitan participants who expressed a desire to access psychosocial support.

2.5.3 | Content analysis

Content analysis, as described by Elo and Kyngäs,[36] using NVivo 12 (Lumivero, https://lumivero.com/products/nvivo/) was used to analyse participant responses to open-ended questions. The first author undertook the initial coding and subsequent identification of concepts and sub-concepts. An inductive approach was employed for coding, and data was examined at the manifest level. In the results, concepts are described as dominant if they were supported across the data, by at least 30 participants. By comparison, all other concepts and sub-concepts were supported by the responses of 20 participants or less.

As suggested by Noble and Smith,[37] *truth value* refers to the precision with which research findings accurately reflect the data and *consistency* refers to the level of trustworthiness of research methods. In terms of truth value, participant data checking was not possible due to participant anonymity; however, participants entered their own data into the survey. This data was revisited over many months during the coding process, and illustrative verbatim quotations are provided in the results section. In terms of consistency, two research team members (who are also clinicians) reviewed the coding. Processes and decisions made during coding were journalled within NVivo.

2.6 | Ethics approval

The University's Human Research Ethics Committee provided ethics approval. Data was collected from September 2020 through to March 2021, coinciding with the COVID-19 pandemic.

3 | RESULTS

3.1 | Quantitative results

Demographic information for participants is presented in Table 1 and medical information is presented in Table 2.

In total, 167 (56%) participants were experiencing clinical levels of distress as indicated by a score of four or more on the distress thermometer. This was 52% of rural and 59% of metropolitan participants. Of the 167 participants who reported clinical levels of distress, overall, 28 (17%) responded '*yes*' when asked if they would like help with

their distress, 60 (36%) reported already having access to help, and 79 (47%) reported not wanting help with their distress. For metropolitan participants, 14 (14%) agreed they would like help with their distress, 47 (48%) reported not wanting help with their distress, and 37 (38%) were already seeking help. For rural participants, 14 (20%) agreed they would like help with their distress, 32 (46%) reported not wanting help with their distress, and 23 (33%) were already seeking help. Figure 1 shows the desire to access help for distress based on geographic location.

3.2 | Content analysis results

All 79 eligible participants responded to the open-ended questions. There were nine invalid responses (e.g., "NA") excluded from analysis, with two participants providing invalid responses to both questions. Thus, 77 participant responses were analysed. Of the valid responses, 46 participants who responded were from metropolitan areas and 31 were from rural areas. Some responses were coded to more than one concept where relevant, recognising that some participants identified more than one reason for declining support, and that there is some overlap between concepts. Given there were two open-ended questions, some individuals also had more than one response coded to a concept.

Six main concepts were derived, with three of these being dominant concepts that were made up of two or more sub-concepts. A supplementary file with a coding tree is provided (Figure S1). The six main concepts were: *I do not need support*, *I am using personal resources to cope*, *negative perceptions and attitudes*, *life does not stop for cancer*, *I am focused on fighting cancer*, and *systemic barriers*. Table 3 presents frequencies and percentages for each concept and sub-concept, by geographic location. While there is some variation across all concepts and sub-concepts, unusual differences are discussed below.

3.2.1 | Concept 1 – I do not need support

This dominant concept describes the multi-faceted nature of cancer patients' perspectives that their distress does not warrant support, including that the decision to not access support is usually not dichotomous, but falls along a continuum represented by five sub-concepts. This concept was the most frequent concept for metropolitan participants, with more than half (54%) indicating they did not need support, compared to just 39% of rural participants.

I just do not need it
On one end of the continuum, relatively few patients indicated categorical unwillingness to engage with support services. This included explicitly denying needing support, or framing this positively, that is, that they were coping well.

> Don't feel I need them.
>
> (P73)

Others need it more
A few patients compared their level of distress to others who they felt needed it more, and thus were more deserving than them.

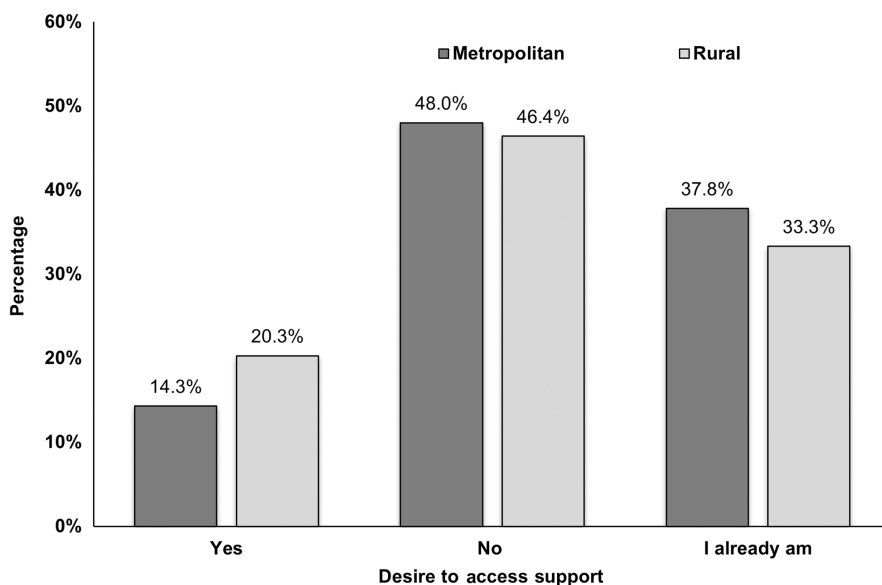> More people out there with worse conditions than mine who need the service.
>
> (P8)

FIGURE 1 Desire to access support in distressed metropolitan ($n = 98$) compared to rural ($n = 69$) cancer patients.

TABLE 3 Percentage of participant responses coded to each concept by geographic status ($n = 77$).

Concept	Metropolitan ($n = 46$)		Rural ($n = 31$)	
Sub-concept	n	%	n	%
I do not need support ($n = 37$)	25	54	12	39
I may access support in future	11	24	6	19
My distress is manageable or transient	8	17	1	3
I do access support when needed	4	9	3	10
I just do not need it	4	9	2	6
Others need it more	2	4	1	3
I am using personal resources to cope ($n = 35$)	19	41	16	52
Accessing informal support	11	24	9	29
Self-reliance	10	22	8	26
Negative perceptions and attitudes ($n = 30$)	16	35	14	45
About usefulness of support	8	17	5	16
I feel uncomfortable talking to strangers	6	13	3	10
Stigma	1	2	5	16
About healthcare providers and services	3	7	1	3
Life does not stop for cancer ($n = 16$)	11	24	5	16
I am focused on fighting cancer ($n = 12$)	7	15	5	16
Systemic barriers ($n = 12$)	6	13	6	19

My distress is manageable or transient

A little further along the continuum, patients normalised their distress and described it as an inevitable but temporary part of their journey. It was within their means to cope with. This sub-concept was almost exclusively indicated by metropolitan participants and appears to influence the difference between metropolitan and rural participants in the overarching concept, *I do not need support.*

> I am usually a very positive person. I know that things will improve, just not sure how long it will take.
>
> (P85)

I may access support in future

Moving towards the other end of the continuum, patient responses indicated more openness to support in the future. Timing was a key factor and patients were either not ready *yet* or could foresee a future need.

> I am in the middle of radiotherapy and may access support services when this is over.
>
> (P72)

I do access support when needed

Also at this end of the continuum were patients who identified as help-seekers (when needed) based on current or previous behaviour.

> I have accessed the services but not needed at the moment as treatment has finished.
>
> (P31)

3.2.2 | Concept 2 – I am using personal resources to cope

The second dominant concept reflected patients' preferences to draw on familiar resources to help manage their distress. Two sub-concepts (accessing informal support and self-reliance) illustrated the personal nature of managing distress associated with cancer. This was the most frequent concept for rural participants (52%) and the second most frequent concept for metropolitan participants (41%).

Accessing informal support

Comments about partners, families and friends indicated that these supports provide patients with adequate support to maintain resilience in the presence of distress.

> I feel l am managing the situation well with support from friends and family.
>
> (P72)

Self-reliance

Valuing one's independence and relying on non-specific internal resources were also commonly indicated. This included those who were stoic, describing a belief that they

were capable of, and responsible for, managing their distress independently.

> Having had therapy before, I sort of feel like I'm the only one who is going to change how I feel.
>
> (P14)

3.2.3 | Concept 3 – Negative perceptions and attitudes

This dominant concept related to patients having negative perspectives about accessing support services and was made up of four sub-concepts. Most commonly, patients did not believe support services could help them. Three less common sub-concepts related to discomfort talking with strangers, stigma, and negative opinions about support providers. Negative perceptions and attitudes was the second most indicated reason for declining support given by rural participants (45%), but the third most commonly indicated reason for metropolitan participants (35%). Notably, this result appears to be largely influenced by responses about stigma, most of which came from rural participants.

About usefulness of support
Sometimes the belief that support services would not be helpful stemmed from previous experience, while others were less explicit about their reasons but simply did not believe that support services would be helpful. Some patients believed that there was no solution for their emotional distress, for example, when it related to pain or a terminal diagnosis. Others wanted to avoid focusing on their distress, including on cancer or its symptoms, the inference being that this would be counterproductive.

> They can't solve the problem so I see no point in wasting time discussing it.
>
> (P43)

I feel uncomfortable talking to strangers
Some patients experience discomfort about disclosing or discussing their distress with formal support providers. As with the above concept of using personal resources to cope, there is the sense that someone who is closer, with a prior relationship is better placed to provide support.

> I feel uncomfortable talking to strangers about my feelings.
>
> (P3)

Stigma
Stigma was less common, although still a distinct sub-concept. For some, this was observed in a desire to be strong. For others, stigma was represented as a reluctance to acknowledge distress and/or seek help, sometimes including fear of judgement by others. Stigma was almost exclusively cited by rural participants as a reason for not wanting to access support services.

> Admitting something is wrong. Being negative. Not being strong. I do not want to be judged.
>
> (P77)

About health care providers
A minority of patients held negative perceptions about service providers. Specific qualities were identified as missing in staff, including skill, trust, respecting confidential information, and a caring nature.

> Most of the ones I have seen over a year ago had no idea.
>
> (P13)

3.2.4 | Concept 4 – Life does not stop for cancer

This concept reflects the fact that for cancer patients, other life stressors and competing priorities may contribute to, and leave little time for attending to their own emotional concerns. These included work commitments and issues, time, family or caring responsibilities and issues, and COVID-19 restrictions. Overall, metropolitan participants were more likely than rural participants to indicate competing factors as a reason for declining support.

> The things that distress or depress me have nothing to do with my Cancer.
>
> (P51)

3.2.5 | Concept 5 – I am focused on fighting cancer

While less frequent compared to previous concepts, some patients reported that they were focused on medical cancer treatment, results and/or their physical recovery. For some, their distress and/or need for support seemed to hinge on the outcome.

I know the cause of my distress and treatment is organised.

(P10)

3.2.6 | Concept 6 – Systemic barriers

The final concept was also less frequent and reflected systemic issues affecting availability and accessibility of services reported by patients. This included availability of services, COVID-19 related restrictions affecting access, financial and time costs, and distance. While overall the numbers of participants indicating systemic barriers was relatively low, notably, availability of services was only raised as an issue by rural participants, and the issue of distance to services was more common for rural participants. Further, COVID restrictions and costs (financial and time) were only reported by metropolitan participants.

Too much travelling involved.

(P7)

4 | DISCUSSION

The main purpose of our study was to understand why so many clinically distressed individuals with (or surviving) cancer, choose not to access psychosocial support, and whether this differs between metropolitan and rural patients. Our findings provided greater depth of insight into some common reasons cancer patients decline psychosocial support, and importantly, identified several qualitative differences in the reasons provided by metropolitan compared to rural patients.

Our study found that more than half (56%) of participants were experiencing clinical levels of distress, and of those almost half (48% of metropolitan, and 46.4% of rural participants) did *not* wish to access support for their distress. This result is similar to the findings of a Canadian study[13] but lower than two other Australian studies,[12,15] and another a German study,[14] which all reported between 53% and 72% of clinically distressed patients declining help. While still substantial, this result may have been influenced by the fact that our sample was drawn from the wider Australian population rather than a single oncology centre or region. It also seems likely that individuals who engage with research about psychosocial wellbeing may be more likely to seek psychosocial support. Nevertheless, our results indicate a substantial proportion of rural and metropolitan participants who *do*

wish to access support. Further, more rural participants than metropolitan participants expressed a desire to access support, and less rural participants than metropolitan participants indicated they were already accessing support. Taken together, these findings highlight that services should be distributed equitably to facilitate increased access for those in rural areas.

In terms of our main aim, our content analysis findings revealed six overarching concepts, including three dominant concepts: *I do not need support, I am using personal resources to cope*, and *negative perceptions and attitudes*. The finding of *I do not need support*, is partially consistent with previous research.[12,17] While there will always be a portion of those who are distressed who feel they do not need support, our research adds a novel understanding of this phenomenon, by identifying that this perspective falls on a continuum and is not necessarily a categorical or final response. In fact, almost half of those who responded that they did not feel they needed support, did indicate that they were open to support in the future. While this finding may appear less dire than previous findings, it highlights the importance of distress screening and offers of support being undertaken routinely and periodically throughout the cancer journey. This would allow support services to be responsive to patients when they are ready to access this support, and thus may increase the uptake of services. This practice is consistent with current guidelines for distress management[10]; however, in a recent Australian study, up to 38% of participating oncology services reported rarely or never screening patients for distress, and only a little more than half (54%) reported re-screening patients,[38] suggesting that service level barriers may also influence access to support.

The finding of *I am using personal resources to cope* (i.e., family, friends, and themselves), extends and clarifies the Australian findings[12] which reported that getting help elsewhere and a preference for self-management were two of the three main reasons patients identified for declining support. However, the format of that study did not allow for elaboration as to what other type of support patients preferred, that is, whether they preferred other formal or informal supports. Our finding for the value of informal supports for patients, is partially supported by Faller et al.[39] who found that cancer patients felt most able to talk about their problems with family as compared to friends or medical professionals. Loeffler et al.[40] suggest that spending time with family is a contributor to increased meaning during the cancer journey, where increased meaning is also related to decreased distress and greater overall wellbeing. Reliance on family and friends also brings into focus the potential burden experienced by family and friends in providing support while also managing their own (sometimes greater) levels of distress.[41] Further, it highlights the potential systemic nature of

distress within families and relationships,[42] although most of our responses related to this issue indicated a positive benefit for patients from supportive family and friends.

The final dominant concept, *negative perceptions and attitudes*, emphasises the importance of service providers actively promoting the benefits of psychosocial support, given that a substantial minority of patients report a perception of it not being helpful. This is reflective of findings in an earlier review, which reported lack of confidence in services, negative perceptions, and stigma, as patient perceived barriers to psychosocial care.[17] Previous Australian research has highlighted lack of resources (staff and time) and inadequate training as key barriers to effective implementation of appropriate distress screening and management.[38] Our findings that some patients report feeling uncomfortable talking to strangers, and/or having negative perceptions about service provider skills suggests that such training should include a focus on advocating the benefits of psychosocial support as well as interpersonal competence and engagement skills. It also provides additional evidence of the need for adequate resourcing to enable oncology services to achieve these important outcomes.

There were three less dominant, but still important concepts: *life does not stop for cancer, I am focused on the physical (and existential) issues* and *systemic barriers*. In terms of life not stopping for cancer, cancer may occur alongside various other commitments and stressors that pre-exist or coincide with their diagnosis. Similarly, focusing on fighting cancer is an understandable concern, given the myriad of appointments cancer patients must endure for tests, treatments, planning and monitoring. This somewhat contradicts previous Australian research which found that receiving treatment currently was associated with greater desire for help[12]; however, is consistent previous German research which highlighted the role of perceived overload (including treatment demands and physical health) in patients declining support.[14] In addressing these issues, and systemic barriers (discussed further below), flexibility of service delivery seems necessary; specifically, flexibility in mode, frequency, timing of offers of support and timing of appointments may increase participation in psychosocial support services.

Our content analysis findings also identified several qualitative differences between rural and metropolitan needs. The most common reasons given for declining support in rural participants related to using personal resources to cope, while for metropolitan participants, the most common reason was a perception of not needing support. Rural participants also rarely perceived their distress as manageable or transient, and very few specifically said they did not need support. These findings imply a greater overall perceived need for support despite declining formal support and are consistent with the finding of

Goodwin et al.[20] who reported that minimising or resigning to health problems did not significantly contribute to support-seeking behaviour in regional and remote cancer patients.

This suggests that other reasons were more important in their decision-making and is perhaps partially explained by the fact that rural participants most often indicated that they were using personal resources (self-reliance and informal support) to cope. In this regard, our findings contradict Goodwin et al.,[20] with respect to the role of self-reliance. Self-reliance and the use of informal support were also shown to be key motivators for declining support in a recent qualitative study with American rural cancer patients.[31]

Next, the presence of stigma related to seeking psychosocial support, was almost exclusive to rural participants. Clover et al.[12,15] interpreted stigma as being less influential than other factors for Australian cancer patients; however, did not identify this as a predominantly rural issue. While some previous qualitative research with rural-only samples has reported stigma as a barrier to their accessing support,[30,31] the present study adds to this knowledge base by highlighting the contrast between rural and metropolitan cancer patients.

In terms of systemic barriers, although these were indicated relatively less often, it is worth noting that availability of services was only raised by rural participants, and distance to services was more commonly raised for rural participants. This is an unsurprising finding but one that warrants further, more specific investigation.

4.1 | Clinical implications

With respect to intervention approaches, awareness of personal preferences in accessing informal supports may support clinicians in evaluating and offering suitable interventions that are deemed acceptable by individual cancer patients. Self-reliance is indicated as a common reason for declining support irrespective of geographic location, and it is possible that cognitive behavioural interventions may be preferred by self-reliant individuals. Alternatively, couples-focused, family, meaning-making and interpersonal approaches may feel more relevant for those who value the support of their family and friends.

Clinicians offering psychosocial support to patients from rural areas (including those who travel to metropolitan treatment centres) should be aware of the potential influence of stigma and a greater desire to use their personal resources to cope during psychosocial screening and needs identification. It would be important to maintain an individualised and flexible approach when working with rural cancer patients, as opposed to stereotyping all individuals

based on their geographic location. Additionally, for rural patients, DeGuzman et al.[31] suggested that rural cultural belief systems need to be better understood. They proposed the development of adapted, and culturally appropriate interventions (i.e., which go beyond deficits-based perspectives that focus on stigma and self-reliance as barriers) and instead recognise and draw upon rural strengths such as resilience and community networks. In Australia, rural cancer caregivers report accessing support for the person they are supporting less commonly than they access support for themselves.[43] Considering this alongside the systemic barriers experienced by those in rural areas, and our finding that patients value their informal supports, it may be relevant to streamline support for rural cancer patients and those who support them. Culturally responsive interventions for rural cancer patients are also salient in Australia,[30] where many rural cancer patients travel to metropolitan areas to receive treatment outside of a familiar context.[24] DeGuzman et al.[31] suggest a strengths-based approach that values rural experiences and focuses on self-affirmation.

Finally, systemic barriers such as distance and availability could be overcome through utilising remote service delivery options such as telehealth, especially for rural clients. Previous studies have reported increases in the level of psychosocial support services provided in oncology when these are offered via telehealth.[44–46]

4.2 | Limitations

It appears that attitudinal barriers dominate the reasons patients decline support; however, we did not specifically ask about systemic barriers that are likely to affect those in rural areas disparately to those in metropolitan areas.[23–26] Thus, the relative minority of participants who cited systemic barriers may not be truly reflective of the rural experience. The present authors have collected data focused on these issues and aim to publish this in due course.

Our focus was on a qualitative understanding of the issues explored and although our open-ended survey provided access to a good sample size, qualitative interviews may have yielded greater depth of understanding these issues. Additionally, a larger sample size would have yielded adequate power to form inferential statistical analysis on our findings, thus increasing their generalisability.

The sample size and patient responses may have been affected by the impact of COVID-19, which was associated with a decline in access to screening, diagnosis, and care.[47,48] It is also acknowledged that females and breast cancer patients are over-represented in our sample, which may affect the generalisability of findings. Finally, selection bias may have affected our results; we were not able to determine why potential participants chose not to participate or finish the study, or any differences in their characteristics.

4.3 | Conclusion

While approximately half of participants with clinical distress declined psychosocial support services, rural cancer patients more commonly indicated wanting support, and less commonly indicated already accessing it. Further, while there were some similarities in the reasons rural and metropolitan participants declined support, there were also obvious differences, namely a greater emphasis on relying on personal resources to cope and the experience of stigma. These findings can inform the equitable resourcing of psychosocial support in rural areas as well as the adaptation of psychosocial interventions provided so that they are more flexibly delivered and are more individually and culturally responsive. This may help to increase patient uptake of support, particularly in rural areas.

CONFLICT OF INTEREST STATEMENT
The authors declare no potential conflicts of interest.

DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The University of New England Human Research Ethics Committee provided ethics approval (Approval No. HE20-150). Data was collected from September 2020 through to March 2021, coinciding with the COVID-19 pandemic.

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