



ORIGINAL RESEARCH

Unmet supportive care needs among Indigenous cancer patients across Australia

AUTHORS

Christina M Bernardes¹ PhD, Research Officer *, christina.bernardes@qimrberghofer.edu.au

Abbey Diaz² PhD, Senior Research Officer

Patricia C Valery³ PhD, Team Head, Cancer and Chronic Disease Research Group

Sabe Sabesan⁴ PhD, FRACP, Adjunct Professor, sabe.sabesan@health.qld.gov.au

Siddhartha Baxi⁵ MBBS, GAICD, FRANZCR, Radiation Oncologist and Director

Samar Aoun⁶ PhD, Professor of Palliative Care

Sandra C Thompson⁷ PhD, Professor of Rural Health

Mari Lashbrook⁸ RN, RAN, PhD student, mlashbrook@riverinacancercare.com.au



Gail Garvey⁹ PhD, Senior Principal Research Fellow

CORRESPONDENCE

*Dr Christina M Bernardes christina.bernardes@qimrberghofer.edu.au

AFFILIATIONS

¹ QIMR Berghofer Medical Research Institute, Cancer and Chronic Disease Research Group, Herston Road, Central Building, Level 4, Herston, Qld 4006, Australia

² Menzies School of Health Research, Wellbeing and Preventable Chronic Disease Division, Charles Darwin University, Level 10 East Tower, 410 Ann Street, Brisbane, Qld 4000, Australia

³ QIMR Berghofer Medical Research Institute, 300 Herston Rd, Herston, Qld 4006; and Menzies School of Health Research, Wellbeing and Preventable Chronic Disease Division, Charles Darwin University, Level 10 East Tower, 410 Ann Street, Brisbane, Qld 4000, Australia

⁴ Department of Medical Oncology, Townsville Cancer Centre, Townsville Hospital and Health Services, Townsville, QLD 4814, Australia

⁵ GenesisCare Gold Coast, John Flynn Hospital, 42 Inland Drive, Tugun, Qld 4224, Australia

⁶ Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria, Australia and The Perron Institute for Neurological and Translational Science, Nedlands, Western Australia, Australia

⁷ Western Australian Centre for Rural Health, University of Western Australia, PO Box 109, Geraldton, WA 6531, Australia

⁸ Riverina Regional Cancer Care Centre, 31 Meurant Ave, Wagga Wagga, NSW 2650, Australia

⁹ Menzies School of Health Research, Wellbeing and Preventable Chronic Disease Division, Charles Darwin University, Level 10 East Tower, 410 Ann Street, Brisbane, Qld 4000, Australia

PUBLISHED

16 September 2019 Volume 19 Issue 3

HISTORY

RECEIVED: 5 December 2017

REVISED: 30 May 2019

ACCEPTED: 12 June 2019

CITATION

Bernardes CM, Diaz A, Valery PC, Sabesan S, Baxi S, Aoun S, Thompson SC, Lashbrook M, Garvey G. Unmet supportive care needs among Indigenous cancer patients across Australia. *Rural and Remote Health* 2019; 19: 4660. <https://doi.org/10.22605/RRH4660>

This work is licensed under a [Creative Commons Attribution 4.0 International Licence](https://creativecommons.org/licenses/by/4.0/)

ABSTRACT:

Introduction: Indigenous Australians with cancer tend to be diagnosed with more aggressive and advanced-stage disease, receive less treatment, have poorer survival and lower quality of life than other Australians. Reducing these inequalities requires an understanding of the supportive care needs of this cancer group. This study aims to describe the type and extent of unmet supportive care needs of Indigenous Australian cancer patients.

Method: A multicentre, cross-sectional study recruited 145 Indigenous adults diagnosed with cancer in the previous 5 years in four Australian states and territories. Using a culturally specific tool, unmet needs were assessed in four domains: 'physical and psychological', 'hospital care', 'information and communication' and 'practical and cultural'. Moderate to high unmet need is that which requires some or a lot more help to be addressed.

Keywords:

Australia, cancer, Indigenous, prevalence, unmet needs.

Results: Two-thirds (65%) of patients reported at least one moderate to high unmet need and 20% of patients had moderate to high unmet needs with five or more items. Overall, patients most commonly reported moderate to high unmet needs in the physical/psychological (46%) and practical/cultural domains (34%), than the information/communication (23%) and hospital care domains (16%). More specifically, 'money worries' was the most frequently reported moderate to high unmet need (20%).

Conclusion: Most Indigenous Australians living with cancer experience unmet supportive care needs. Physical/psychological and practical/cultural concerns were identified as priority areas for Indigenous cancer patients. These findings may inform priority areas for intervention towards optimal care pathways for Indigenous Australians diagnosed and living with cancer.

FULL ARTICLE:

Introduction

Cancer outcomes in Australia have been reported as among the best in the world¹. However, a growing body of research has demonstrated there are large disparities in cancer outcomes between Indigenous Australians (Aboriginal and Torres Strait Islander people) and non-Indigenous Australians. Indigenous Australians are more likely to be diagnosed with advanced stage disease^{1,2}, receive less optimal treatment^{2,3}, be diagnosed with more aggressive cancers⁴ and have poorer cancer survival^{5,6}. The reasons underlying these disparities are thought to be multifactorial and include higher prevalence of comorbidities^{7,8}, greater social disadvantage⁹, restricted access to cancer and support care services¹⁰, and differences in cultural understandings of cancer and its treatment^{11,12}.

Receiving a cancer diagnosis and subsequent treatment may present numerous psychological, physical and practical challenges for the patient¹³⁻¹⁵ and their family^{16,17}. 'Supportive care' is a broad term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of unmet needs across the continuum of

care and is increasingly seen as a core component of evidence-based clinical care¹⁸. Needs assessments identify and prioritise unmet needs from the patient's perspective and the degree to which they require assistance from services. As such, unmet needs assessment can lead to better patient outcomes and provide the evidence necessary to redesign services and improve resources for people with cancer¹⁹.

A study undertaken in the state of Queensland, Australia²⁰ developed and validated a culturally specific tool to assess the unmet supportive care needs of Indigenous cancer patients and reported the prevalence of unmet needs among this group. The most frequently reported moderate to high unmet needs in this study were money worries (29%), and unmet needs related to physical and psychological concerns²⁰.

While these results identified the unmet needs among Indigenous cancer patients in Queensland, to date no information on the unmet needs of Indigenous cancer patients is available for the other Australian jurisdictions. As Australian states and territories differ in their geography and socioeconomic indices, which are likely to impact upon access of cancer and healthcare services, the

assessment of the unmet needs of Indigenous cancer patients in other states/territories is warranted.

The purpose of this multicentre study was to use a culturally specific tool to assess the supportive care needs of Indigenous Australian cancer patients and describe the prevalence of unmet need across the participating jurisdictions.

Methods

Study setting, patients and procedure

This multicentre study involved a tertiary metropolitan hospital in Victoria, regional cancer care and chemotherapy outreach centres in New South Wales and Northern Territory, and the Cancer Council Western Australia regional cancer support coordinator program. These institutions (referred to here as 'centres') vary in terms of geographic location, demographics of their service population, access and types of services they provide.

Patients were Indigenous Australians diagnosed with cancer within the previous 5 years, aged 18 years and older.

Local staff (cancer care coordinators, Indigenous liaison officer, registered nurses and social workers) recruited patients who were attending one of the study centres over a 12-month period (2014–2015). The patients' supportive care needs were assessed during a face-to-face interview held at a time convenient to participants. Staff made appropriate referrals for participants if unmet needs were identified during the interview. There were eight interviewers across the study sites, of which two were Indigenous Australians. The interviewers received standardised training using materials that were co-developed, conducted and guided by an Aboriginal senior researcher (GG). Recruitment strategies were adapted at each site to capture the local context. All participants provided written informed consent and were advised that withdrawing from the study would have no consequences for their treatment and care.

Instrument and data collected

The culturally specific and psychometrically tested Supportive Care Needs Assessment Tool for Indigenous Cancer Patients (SCNAT-IP)²⁰ was used to assess the needs of the patients recruited into the study. This tool has 26 items across four domains: 'physical and psychological' (11 items), 'hospital care' (4 items), 'information and communication' (6 items), and 'practical and cultural' (5 items). It uses a five-point scale to measure unmet need: 1='no need', 2='satisfied with the help received', 3='needed a little more help' (referred to as 'low need'), 4='needed some more help' ('moderate need') and 5='needed a lot more help' ('high need'). For this study, moderate and high needs were collapsed into one category ('moderate to high need').

At the time of the needs assessment, the staff members also captured patient-reported sociodemographic information. This included age at cancer diagnosis (categorised as 45 years or younger, 46–59 years, and 60 years or older), marital status (married or partnered v other), main language spoken at home

(English v other), education level (higher than completion of year 10 v year 10 or less completed) and employment status (employed v not employed). Address information was also collected, including each patient's community name, postcode and state. This information was then used to assign patients an Accessibility/Remoteness Index for Australia (ARIA+) 2011 score, which was then categorised into one of five remoteness categories²¹. Due to small participant numbers, these were collapsed into three categories: 'major city', 'inner/outer regional' and 'remote/very remote'. Residential information was also used to assign patients to a percentile of the Socio-economic Indexes for Areas (SEIFA) Index of Relative Socio-economic Advantage and Disadvantage (IRSAD)²². These were then categorised as 'most disadvantaged' (percentile 1–33), 'moderately disadvantaged' (34–66), and 'least disadvantaged' (67–100)²².

Clinical data were extracted from medical charts using a standard form in Northern Territory, New South Wales and Victoria. In Western Australia, clinical data were obtained from referral letters or self-reported. Clinical data collected included cancer type, date of diagnosis (categorised as less than 1 year prior to interview, 1–2 years prior to interview and more than 2 years prior to interview), cancer stage (localised, regional spread, distant metastatic spread, not applicable and unknown stage), comorbidities (diabetes, hypertension, cardiovascular disease, renal disease and respiratory disease), number of comorbidities (0, 1, 2–5), current treatment (had started but not completed a regime of chemotherapy, radiotherapy or hormone therapy at the time of interview) and past treatment (past receipt of surgery, completed chemotherapy or completed radiotherapy at any time prior to the interview).

Data analysis

Participant demographic and clinical characteristics are described. For each SCNAT-IP item the proportion of patients who had no unmet need (no need or satisfied need), little need, and moderate to high need are reported. Also reported are the proportion of patients who did not have unmet need for any of the 26 SCNAT-IP items; had at least one moderate to high unmet need, overall and within each SCNAT-IP domain; and had at least five items with moderate to high unmet needs. The median number (interquartile range (IQR)) of moderate to high unmet needs reported by patients is also presented.

For most of these outcomes, the results are presented for the multicentre study overall ($n=145$) and for Northern Territory ($n=75$) and New South Wales ($n=46$) separately. For comparison, the results for the previous Queensland study²⁰ are also presented. This information is not reported separately for Victoria and Western Australia, due to small participant numbers in these jurisdictions.

Statistical analysis was conducted using the Statistical Package for the Social Sciences v20 (IBM Corporation; <http://www.spss.com>).

Ethics approval

The study was approved by the Human Research Ethics Committees of Charles Darwin University, Northern Territory Department of Health and Menzies School of Health Research (HoMER 13-2038) and by the relevant states and territory institutional human research ethics committees (HREC/13/HNE/466; HREC-058/14; SSA/13/HNE/531), including the Aboriginal Health and Medical Research Council of New South Wales (ref. 938/13) and the Western Australian Aboriginal Health Research Ethics Committee (ref. 544).

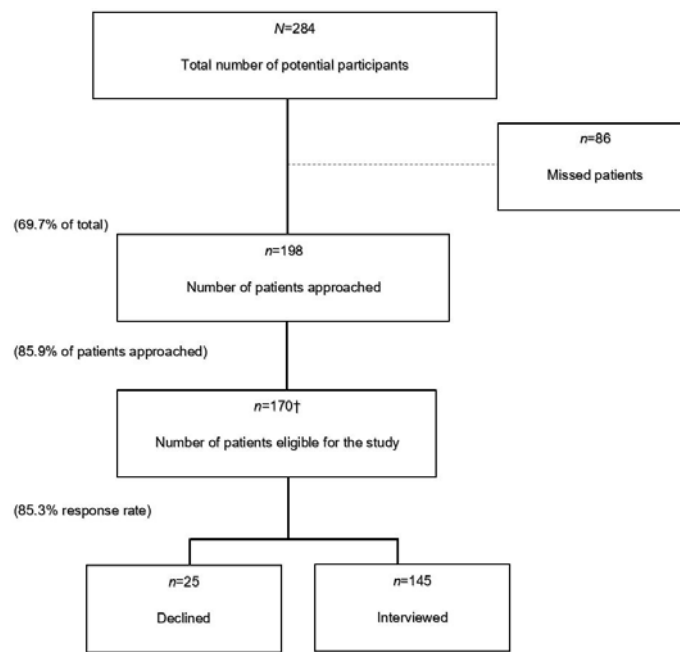
Results

Patients' characteristics

A total of 284 cancer patients were identified across the four participating jurisdictions (Fig1). Of those, 198 (70%) patients were

approached and 86 (30%) patients were missed (did not answer telephone calls, failed to attend appointments or no staff member was available to approach the patient). Of the patients approached, 170 (86%) patients were eligible for the study and, of these, 145 (85%) were interviewed.

Patient demographic and clinical characteristics are described in Table 1. Patients (57% female) were diagnosed at a median age of 57 years (IQR 47.5–64.5 years). On average, interviews were conducted just over 5 months after cancer diagnosis (median 158 days, IQR 53–497 days). The most common cancers among participants were digestive system (23%) and breast (21%) cancers; 36% of patients were diagnosed with localised disease. Most patients lived in inner or outer regional areas (33%) or in remote/very remote areas (48%), and the majority of patients lived in the most disadvantaged areas.



† 28 patients were not eligible to be included in the study due to being too ill to participate.

Figure 1: Patient recruitment flowchart.

Table 1: Demographic and clinical characteristics of Indigenous cancer patients in multicentre study across Australia (N=145)

Characteristic	n	%
Jurisdiction		
Northern Territory	75	52
New South Wales	44	30
Western Australia	15	10
Victoria	11	8
Sex†		
Male	62	43
Female	82	57
Age (years)		
≤45	31	21
46–59	51	35
≥60	63	43
Marital status		
Married or partnered	63	43
Not married or partnered	82	56
Employed		
Yes	30	21
No	115	79
Language at home		
English	82	57
Other	63	43
Education		
≤Year 10	86	59
>Year 10	59	41
Socioeconomic status (SEIFA)		
Least disadvantaged	17	12
Moderately disadvantaged	37	26
Most disadvantaged	91	63
Remoteness (ARIA)		
Major city	27	19
Inner/outer regional	48	33
Remote/very remote	70	48
Cancer type		
Digestive (C15-C26)	34	23
Breast (C50)	31	21
Lung (C30-C39)	22	15
Head and neck (C00-C14)	19	13
Blood related (C81-C96)	14	10
Gynaecological (C51-C26)	9	6
Other¶	16	11
Stage		
Localised	52	36
Regional spread	40	28
Distant metastasis	35	24
Not applicable	11	8
Not sure	7	5
Current treatment§		
Chemotherapy	52	36
Radiotherapy	33	23
Hormone therapy	15	10
Past treatment§		
Had surgery†	79	55
Completed chemotherapy	37	26
Completed radiotherapy	33	23
Completed hormone therapy	1	1
Comorbidities§		
Diabetes	37	26
Hypertension	53	37
Cardiovascular	36	25
Renal	24	17
Respiratory	36	25
Comorbidity level		
No conditions	52	36
1 condition	43	30
≥2 conditions	50	35
Time since diagnosis (years)		
<1	100	69
1–2	23	16
3–5	22	15

† One missing value.

¶ Other cancers include malignant skin cancer (C43-C44); urinary tract (C64-C68); bone and articular cartilage (C40-C41); eye, brain and other parts of central nervous system (C69-C72); thyroid and other endocrine glands (C73-C75); mesothelial and soft tissue (C45-C49); and male genital organs (C60-C63).

§ Patients could indicate multiple responses for this variable.

ARIA, Accessibility/Remoteness Index for Australia. SEIFA, Socio-economic Indexes for Areas.

Proportion of needs by domain and items

There was a wide variation in the unmet needs reported by Indigenous cancer patients across study jurisdictions. Overall, 65% of patients reported at least one moderate to high unmet need, 20% of patients had moderate to high unmet needs on five or more items and only 16% of patients reported no need or satisfied need across all SCNAT-IP items. A greater proportion of patients reported moderate to high unmet needs in the physical/psychological domain (46%) and the practical/cultural domain (34%) than in the information/communication domain

(23%) or the hospital needs domain (16%). This pattern was also observed separately for Northern Territory and New South Wales patients (Fig2).

While across the jurisdictions the most frequently reported moderate to high unmet need item was 'money worries' (20%) from the practical/cultural domain (Table 2), there were differences in terms of priority of the unmet need items. In the Northern Territory, for example, unmet need with 'money worries' was reported by 23% of patients (rank 1) compared with 16% in New South Wales (rank 7) (Table 3).

Table 2: Proportion of unmet need among Indigenous Australians cancer patients

Supportive care needs domain	n	No unmet need† (%)	Little need (%)	Moderate-high need (%)
Physical/psychological				
Physical pain	145	73	17	14
Feeling tired‡	145	72	8	10
Not feeling well a lot of the time‡	145	78	8	14
Work around the home‡	145	72	11	17
Doing the things you used to do	145	82	8	10
Anxiety	144	78	6	17
Feeling down or sad‡	144	77	10	13
Worrying about your illness spreading or getting worse§	145	77	5	17
Worry about the results of treatment	144	79	5	16
Keeping you strong in your spirit	145	86	7	7
Concerns about the worries of those close to you‡	145	74	8	15
Hospital care				
Support by staff that the way you feel is natural	143	90	4	6
Having hospital staff attending quickly to your physical needs‡	141	88	1	10
Having hospital staff show sensitivity to and respecting your feelings and emotional needs	141	88	4	8
Being treated like a person not just another case or number	140	93	3	4
Information/communication				
Being shown or given information about how to manage your treatment, illness and side-effects in hospital‡	142	80	9	10
Being shown or given information about how to manage your illness and side effects at home	143	80	8	11
Explaining what tests are for	145	79	11	10
Understanding the good and bad effects of treatments before you chose to have them	140	76	12	12
Being told about things you can do to help yourself get well				
Having an Indigenous person to interpret and help with communication with health professionals	145	90	3	6
Practical/cultural				
Having an Indigenous person to talk to and support you, someone who understands your culture‡	144	85	2	12
Finding a place to stop or stay while receiving treatment	144	85	4	12
Money worries (eg cost of accommodation, travel)	143	86	14	20
Ensuring family members were able to be present when talking/seeing health‡	144	85	6	8
Directions to get to and around the hospital	144	94	3	3

† Combines responses of patients with no unmet needs and patients satisfied with the help received.

‡ 1 patient with need missing information on the level of unmet need.

§ 3 patients with need missing information on the level of unmet need.

‡ 4 patients with need missing information on the level of unmet need.

* 2 patients with need missing information on the level of unmet need.

Table 3: Ten most frequently reported moderate to high unmet need items across three jurisdictions

Northern Territory (n=75)			New South Wales (n=44)			Previous Queensland study† (n=248)		
Item	Domain	%	Item	Domain	%	Item	Domain	%
Money worries (eg cost of accommodation, travel)	P/C	23	Anxiety	P/P	23	Money worries (eg cost of accommodation, travel)	P/C	22
Finding a place to stop or stay while receiving treatment	P/C	20	Work around the home	P/P	21	Concerns about the worries of those close to you	P/P	15
Understanding the good and bad effects of treatments before you chose to have them	I/C	14	Worry about the results of treatment	P/P	21	Worrying about your illness spreading or getting worse	P/P	14
Explaining what tests are for	I/C	13	Not feeling well a lot of the time	P/P	21	Feeling down or sad	P/P	13
Ensuring family members were able to be present when talking/seeing health	P/C	12	Feeling down or sad	P/P	21	Anxiety	P/P	12
Being shown or given information about how to manage your illness and side-effects at home	I/C	11	Worrying about your illness spreading or getting worse	P/P	18	Work around the home	P/P	11
Being shown or given information about how to manage your treatment, illness and side-effects in hospital	I/C	11	Money worries (eg cost of accommodation, travel)	P/C	16	Physical pain	P/P	10
Work around the home	P/P	11	Doing the things you used to do	P/P	16	Doing the things you used to do	P/P	10
Worrying about your illness spreading or getting worse	P/P	11	Feeling tired	P/P	16	Feeling tired	P/P	9
Being told about things you can do to help yourself get well	I/C	10	Physical pain	P/P	14	Having an Indigenous person to talk to and support you, someone who understands your culture	I/C	9

† Garvey et al (ref. 20).

* Due to less discrimination between proportions, 'little need' was taken into account in this item.

I/C, information and communication; P/C, practical and cultural; P/P, physical and psychological.

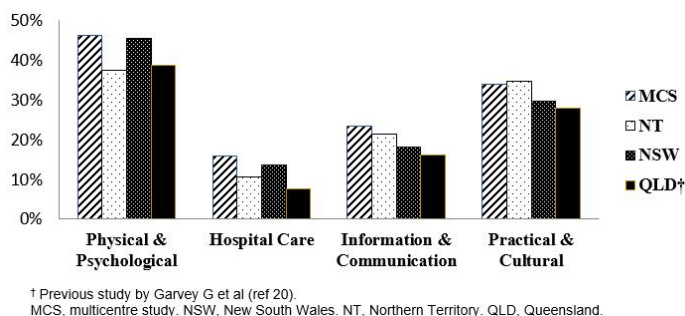


Figure 2: Proportion of unmet needs by domain and jurisdiction.

Comparison to previous Queensland study

Similar to what has previously been reported in Queensland²⁰, patients in the current multicentre study were more likely to report unmet need in the physical/psychological domain and the practical/ cultural domain than in other domains (Fig2). Also, patients in the current multicentre study most commonly reported unmet need with money worries (Table 2). Unmet needs related to information/communication were more frequently reported in the current multicentre study (Table 3).

Factors associated with unmet needs

In the present study, most patient demographic and clinical characteristics (ie age, sex, place of residence, area-level socioeconomic disadvantage, cancer type, stage at diagnosis, current treatment receipt and comorbidity) were not associated

with moderate to high unmet need. Exceptions were that a higher proportion of patients who had respiratory disease reported moderate to high unmet need with 'money worries' compared to those without this comorbidity (9% v 24%, $p=0.047$) and a higher proportion of patients with renal disease reported moderate to high physical and psychological unmet needs than those patients without this comorbidity (50% v 25%, $p=0.023$).

More patients who had been diagnosed with regional spread or distant metastatic cancer reported moderate to high unmet hospital care needs (23% v 8%, $p=0.026$) when compared to those diagnosed with localised disease. A greater proportion of patients diagnosed with respiratory cancer than those diagnosed with digestive system cancers and breast cancer had moderate to high domain need, except in the hospital care domain. The unmet domain needs for the three most common cancers in this sample are described in Figure 3.

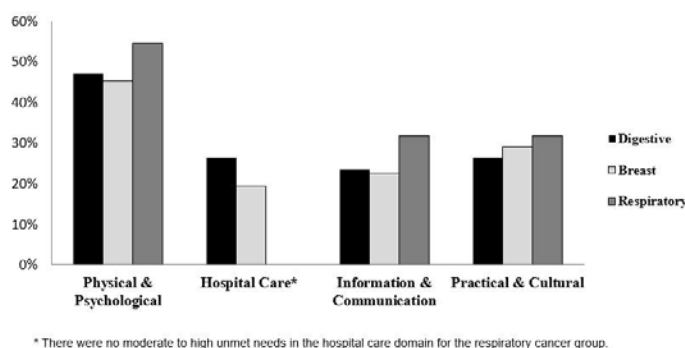


Figure 3: Proportion of patients with moderate-high unmet needs by cancer type.

Discussion

This study describes, for the first time, the unmet supportive care needs of Indigenous Australians diagnosed with cancer across multiple jurisdictions using a culturally specific and validated tool (SCNAT-IP). The present study findings suggest that many Indigenous Australians diagnosed with cancer have unmet needs that have not previously been identified or addressed by cancer services.

This study found that the physical and psychological domains contained the most commonly reported needs consistent with previous research with non-Indigenous Australians²³⁻²⁵. This

probably reflects the life-changing nature of a cancer diagnosis for all patients. For Indigenous Australians with a cancer diagnosis this is likely to be exacerbated by their social and economic circumstances. Physical and psychological needs among the patients in the current study were related to managing the impact of a cancer diagnosis on their daily life (work around the home), stress about prognosis and mortality (worry about the cancer spreading or getting worse) and anxiety. Patients most commonly required assistance with their physical pain.

The practical/cultural domain also ranked highly in terms of unmet needs, and these needs must be considered in providing optimal cancer care to Indigenous patients. In the practical/cultural needs

domain, the most frequently reported unmet need item was 'money worries'. This result is consistent with the findings in the authors' previous study of unmet support needs among Indigenous adults conducted in Queensland²⁰. It is also consistent with other Australian studies where the financial burden was found to be an important issue for cancer patients while travelling to receive treatment, or for other care expenses^{13,26}. Cost is a barrier to accessing healthcare services for both Indigenous and non-Indigenous Australians²⁷⁻²⁹. In 2016–17, 8% of people aged 15 years and over delayed access to health care due to concerns about the associated costs³⁰. Other practical and cultural unmet needs reported by participants of the present study were 'Having an Indigenous person to talk to and support you, someone who understands your culture' and 'Finding a place to stop or stay while receiving treatment'.

Interestingly, in the communication/information domain, a high proportion of participants (>76%) indicated not having any unmet needs. This is a positive finding, particularly given the reported communication/information challenges cancer service providers identified when communicating with Indigenous patients^{11,31}. However, the discrepancy could also arise because the needs assessment is capturing people's desired or perceived needs for additional information, and these depend upon a broader level of understanding of possibilities within the health system^{32,33}. As such, efforts to improve the utility and cultural appropriateness of cancer and health promotion information are still needed^{34,35}. Participants in this study had access to Indigenous staff (liaison officer and/or social workers) and were commonly escorted (approximately 88%) to the hospital by a family member or friend. This support may have assisted with information provision and effective patient–clinician communication.

It was also positive that 90% of participants reported that they had no unmet need related to language interpretation, despite 43% of participants speaking a language other than English as their main language at home. It may also reflect the fact that most of the participants who speak a language other than English as their main language at home were from Northern Territory and interpreters are available and accessible for the study interview at the Northern Territory study site.

Implications for practice, policy and research

The reported variation in unmet needs across some jurisdictions highlighted the need for locally tailored cancer services, programs and policies. Practical and logistical barriers (eg travel and treatment expenses or finding appropriate accommodation) to attend hospital or other cancer-related appointments can reduce the likelihood of patients to undergo and complete their cancer treatment. In Australia, optimal cancer care pathways recommend assessing supportive care needs at every step of a patient's pathway. Recommendations and initiatives to improve the identification and monitoring of unmet needs for Indigenous cancer patients include routine screening using culturally appropriate tools²⁰, facilitating access to cancer care for rural and remote communities through tele-oncology models³⁶ or providing

informative discharge summaries for continuity of care at community level³⁷. More recently, an optimal care pathway for Aboriginal and Torres Strait Islander people with cancer³⁸ has been developed to assist health professionals to provide optimal patient-centred care, including assessing and addressing their supportive care needs³⁸. While qualitative explorations into patient experiences and perceived barriers and enablers to optimal cancer care are essential, needs assessment tools that can systematically and reliably quantify patient needs are also critical. When implemented into routine care, such tools are a reliable and quick method to identify high-need patients who may require complex care. This can enable timely referrals to appropriate services and in turn result in improved outcomes for people diagnosed with cancer²⁰. A needs assessment tool also allows for the measurement of unmet supportive care needs over time to assist evaluation of changes in policy, practices or services. This study provides a baseline measure of the extent of unmet supportive care needs among Indigenous Australians with cancer and, by providing a means by which to prioritise these needs, may inform the development of targeted approaches to improve cancer care and outcomes for Indigenous Australians.

Strengths and limitations

This multicentre study used a validated and culturally relevant assessment tool to identify patients' needs and quantify the extent to which they remain unresolved. The interviews were conducted by trained staff members who were routinely in contact with patients and were able to establish a rapport with patients. Face-to-face interviews were employed as the authors have previously found this approach helps increase recruitment and completion rates, although it could also influence participants to respond more favourably to 'please' the interviewer. Participants were encouraged to answer truthfully by assurances that their responses would not affect their treatment or care, their anonymity would be protected, and only aggregated study findings would be shared beyond the research team.

The generalisability of these findings may be limited given the small sample size, and patients were recruited via a number of strategies and mostly from regional cancer services. Previous reports found that geographical isolation was associated with increased prevalence of unmet supportive care needs¹⁹. In Western Australia, recruitment was conducted via referral programs specifically for cancer patients with high needs. It is unclear if the needs of these patients reflect the needs of Indigenous cancer patients in Western Australia more broadly. It is possible that this recruitment strategy amplified the proportion of patients with moderate to high unmet needs; however, as the Western Australian patients constituted only 10% of study participants, the bias is likely to be modest. In Western Australia, cancer type and diagnosis date were extracted from referral letters or self-reported. This may mean that some patients were closer or further away from diagnosis than what has been reported; however, it is not possible to quantify this. In a previous Queensland study the authors found that cancer type was reported with reasonable consistency to medical charts³⁹. Due to lack of

statistical power, the authors could not explore further jurisdictional differences or undertake detailed examination of unmet needs by cancer type. Assessment of a more homogeneous sample of patients (ie same cancer type, stage of disease) would be difficult to achieve but could provide a deeper understanding of disease-specific unmet needs. Despite these limitations, the study highlights the variation of unmet needs across jurisdictions and provides evidence of common domains of unmet needs.

Conclusion

The findings of this study provide a snapshot of the unmet needs of Indigenous cancer patients in four jurisdictions in Australia. Most Indigenous Australians with cancer have at least one unresolved supportive care need. While there was variation in items that were most commonly reported as unmet, these items were primarily related to physical/psychological and practical/cultural concerns. The implementation of culturally appropriate needs assessments into routine care can help to ensure patients are receiving optimal cancer care and are being referred to appropriate services. The findings from this exploratory

study may also indicate that some of the areas of unmet need are quite challenging for health practitioners to deal with themselves. There is a need for change at a health system level where access to social welfare and cultural support have links with community-based health services. Information on unmet needs may be used to map out priority areas for intervention, resource allocation and service redesign.

Acknowledgements

This study was funded by the NHMRC-funded Centre of Research Excellence DISCOVER-TT (#1041111), and the Cancer Council NSW STREP Ca-CInDA (SRP 13-01, with supplementary funding from Cancer Council WA). AD is supported by a Menzies Early Career Accelerator Fellowship. GG is supported by a NHMRC Early Career Fellowship (#1105399). PCV was supported by the Australian National Health and Medical Research Council (Career Development Fellowship #1083090). The views expressed in this publication are those of the authors and do not necessarily reflect the views of the funders.

REFERENCES:

- 1 Koh E, Do V, Barton M. Frontiers of cancer care in Asia-Pacific region: cancer care in Australia. *Biomedical Imaging and Intervention Journal* 2008; **4(3)**: e30. <https://doi.org/10.2349/bij.4.3.e30> PMID:21611000
- 2 Moore SP, O'Rourke PK, Mallitt KA, Garvey G, Green AC, Coory MD, et al. Cancer incidence and mortality in Indigenous Australians in Queensland, 1997–2006. *Medical Journal of Australia* 2010; **193(10)**: 590–593.
- 3 Whop LJ, Bernardes CM, Kondalsamy-Chennakesavan S, Darshan D, Chetty N, Moore SP, et al. Indigenous Australians with non-small cell lung cancer or cervical cancer receive suboptimal treatment. *Asia-Pacific Journal of Clinical Oncology* 2016; e224–e231. <https://doi.org/10.1111/ajco.12463> PMID:26997361
- 4 Australian Institute of Health and Welfare. *Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview*. Canberra: Australian Institute of Health and Welfare, 2013.
- 5 Coory MD, Green AC, Stirling J, Valery PC. Survival of Indigenous and non-Indigenous Queenslanders after a diagnosis of lung cancer: a matched cohort study. *Medical Journal of Australia* 2008; **188(10)**: 562–566.
- 6 Cramb SM, Garvey G, Valery PC, Williamson JD, Baade PD. The first year counts: cancer survival among Indigenous and non-Indigenous Queenslanders, 1997–2006. *Medical Journal of Australia* 2012; **196(4)**: 270–274. <https://doi.org/10.5694/mja11.11194> PMID:22409695
- 7 Diaz A, Moore SP, Martin JH, Green AC, Garvey G, Valery PC. Factors associated with cancer-specific and overall survival among Indigenous and non-Indigenous gynecologic cancer patients in Queensland, Australia: a matched cohort study. *International Journal of Gynecological Cancer* 2015; **25(3)**: 542–547. <https://doi.org/10.1097/IGC.0000000000000375> PMID:25700033
- 8 Valery PC, Coory M, Stirling J, Green AC. Cancer diagnosis, treatment, and survival in Indigenous and non-Indigenous Australians: a matched cohort study. *Lancet* 2006; 1842–1848. [https://doi.org/10.1016/S0140-6736\(06\)68806-5](https://doi.org/10.1016/S0140-6736(06)68806-5)
- 9 Australian Institute of Health and Welfare. *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*. Canberra: Australian Institute of Health and Welfare, 2015.
- 10 Miller J, Knott V, Wilson C, Cunningham J, Condon J, Roder D, et al. *Aboriginal and Torres Strait Islander cancer control research project*. Surry Hills, NSW: Cancer Council South Australia, 2010.
- 11 Shahid S, Durey A, Bessarab D, Aoun SM, Thompson SC. Identifying barriers and improving communication between cancer service providers and Aboriginal patients and their families: the perspective of service providers. *BMC Health Services Research* 2013; **13**: 460. <https://doi.org/10.1186/1472-6963-13-460> PMID:24188503
- 12 Shahid S, Finn L, Bessarab D, Thompson SC. 'Nowhere to room ... nobody told them': logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment. *Australian Health Review* 2011; **35(2)**: 235–241. <https://doi.org/10.1071/AH09835> PMID:21612740
- 13 Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 2000; **88(1)**: 226–237. [https://doi.org/10.1002/\(SICI\)1097-0142\(20000101\)88:1<226::AID-CNCR30>3.0.CO;2-P](https://doi.org/10.1002/(SICI)1097-0142(20000101)88:1<226::AID-CNCR30>3.0.CO;2-P)
- 14 Sutherland G, Hill D, Morand M, Pruden M, McLachlan SA. Assessing the unmet supportive care needs of newly diagnosed patients with cancer. *European Journal of Cancer Care* 2009; **18(6)**: 577–584. <https://doi.org/10.1111/j.1365-2354.2008.00932.x> PMID:19549286

- 15** White K, D'Abrew N, Katris P, O'Connor M, Emery L. Mapping the psychosocial and practical support needs of cancer patients in Western Australia. *European Journal of Cancer Care* 2012; **21(1)**: 107-116. <https://doi.org/10.1111/j.1365-2354.2011.01270.x> PMID:21838725
- 16** Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC. Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychological Bulletin* 2008; **134(1)**: 1-30. <https://doi.org/10.1037/0033-2909.134.1.1> PMID:18193993
- 17** Oberoi DV, White V, Jefford M, Giles GG, Bolton D, Davis I, et al. Caregivers' information needs and their 'experiences of care' during treatment are associated with elevated anxiety and depression: a cross-sectional study of the caregivers of renal cancer survivors. *Supportive Care in Cancer* 2016; **24(10)**: 4177-4186. <https://doi.org/10.1007/s00520-016-3245-8> PMID:27146491
- 18** Department of Health and Human Services, Cancer Australia, Cancer Council. *Optimal cancer care pathway for people with hepatocellular carcinoma*. Melbourne: Victorian Government, 2014.
- 19** Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Supportive Care in Cancer* 2009; **17(8)**: 1117-1128. <https://doi.org/10.1007/s00520-009-0615-5> PMID:19319577
- 20** Garvey G, Beesley VL, Janda M, O'Rourke PK, He VY, Hawkes AL, et al. Psychometric properties of an Australian supportive care needs assessment tool for Indigenous patients with cancer. *Cancer* 2015; **121(17)**: 3018-3026. <https://doi.org/10.1002/cncr.29433> PMID:25946658
- 21** University of Adelaide. *Accessibility/Remoteness Index of Australia (ARIA+)*. 2011. Available: http://www.spatialonline.com.au/ARIA_2011/default.aspx (Accessed 10 March 2017).
- 22** Australian Bureau of Statistics. *Socio-Economic Indexes for Areas (SEIFA) – technical paper*. Catalogue no. 2033.0.55.001. Canberra: Australian Bureau of Statistics, 2011.
- 23** Boyes AW, Girgis A, D'Este C, Zucca AC. Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: a population-based cross-sectional study. *BMC Cancer* 2012; **12**: 150. <https://doi.org/10.1186/1471-2407-12-150> PMID:22510387
- 24** Dyson GJ, Thompson K, Palmer S, Thomas DM, Schofield P. The relationship between unmet needs and distress amongst young people with cancer. *Supportive Care in Cancer* 2012; **20(1)**: 75-85. <https://doi.org/10.1007/s00520-010-1059-7> PMID:21311915
- 25** Edib Z, Kumarasamy V, Binti Abdullah N, Rizal AM, Al-Dubai SA. Most prevalent unmet supportive care needs and quality of life of breast cancer patients in a tertiary hospital in Malaysia. *Health and Quality of Life Outcomes* 2016; **14**: 26. <https://doi.org/10.1186/s12955-016-0428-4> PMID:26898558
- 26** Janda M, Eakin EG, Bailey L, Walker D, Troy K. Supportive care needs of people with brain tumours and their carers. *Supportive Care in Cancer* 2006; **14(11)**: 1094-1103. <https://doi.org/10.1007/s00520-006-0074-1> PMID:16710653
- 27** Australian Health Ministers' Advisory Council. *Aboriginal and Torres Strait Islander Health Performance Framework 2017 report*. Canberra: Australian Health Ministers' Advisory Council, 2017.
- 28** Callander EJ, Corscadden L, Levesque JF. Out-of-pocket healthcare expenditure and chronic disease – do Australians forgo care because of the cost? *Australian Journal of Primary Health* 2017; **23(1)**: 15-22. <https://doi.org/10.1071/PY16005> PMID:28442033
- 29** Gordon LG, Merollini KMD, Lowe A, Chan RJ. Financial toxicity – what it is and how to measure it. *Cancer Forum* 2017; **41(2)**: 30-35.
- 30** Australian Institute of Health and Welfare. *Patients' out-of-pocket spending on Medicare services, 2016–2017*. Catalogue no. HPF 35. 2018. Canberra: Australian Institute of Health and Welfare, 2018.
- 31** Meiklejohn JA, Adams J, Valery PC, Walpole ET, Martin JH, Williams HM, et al. Health professional's perspectives of the barriers and enablers to cancer care for Indigenous Australians. *European Journal of Cancer Care* 2016; **25(2)**: 254-261. <https://doi.org/10.1111/ecc.12467> PMID:26918690
- 32** Leydon GM, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M, et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *British Medical Journal* 2000; **320(7239)**: 909-913. <https://doi.org/10.1136/bmj.320.7239.909> PMID:10742000
- 33** Mistry A, Wilson S, Priestman T, Damery S, Haque M. How do the information needs of cancer patients differ at different stages of the cancer journey? A cross-sectional survey. *JRSM Open* 2010; **1(4)**: 30. <https://doi.org/10.1258/shorts.2010.010032> PMID:21103122
- 34** Helitzer D, Hollis C, Cotner J, Oestreicher N. Health literacy demands of written health information materials: an assessment of cervical cancer prevention materials. *Cancer Control* 2009; **16(1)**: 70-78. <https://doi.org/10.1177/107327480901600111> PMID:19078933
- 35** Thompson VL, Bugbee A, Meriac JP, Harris JK. The utility of cancer-related cultural constructs to understand colorectal cancer screening among African Americans. *Journal of Public Health Research* 2013; **2(2)**: e11. <https://doi.org/10.4081/jphr.2013.e11> PMID:25170482
- 36** Sabesan S, Roberts LJ, Aiken P, Joshi A, Larkins S. Timely access to specialist medical oncology services closer to home for rural patients: experience from the Townsville Teleoncology Model. *Australian Journal of Rural Health* 2014; **22(4)**: 156-159. <https://doi.org/10.1111/ajr.12101> PMID:25123618
- 37** Meiklejohn JA, Garvey G, Bailie R, Walpole E, Adams J, Williamson D, et al. Follow-up cancer care: perspectives of Aboriginal and Torres Strait Islander cancer survivors. *Supportive Care in Cancer* 2017; **25(5)**: 1597-1605. <https://doi.org/10.1007/s00520-016-3563-x> PMID:28078479
- 38** Cancer Australia and Victorian Department of Health and

Human Services. *Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer*. Available: https://www.cancer.org.au/content/ocp/Optimal_care_pathways_ATSI_Report_August_2018.PDF (Accessed 20 May 2019).

39 Bernardes CM, Diaz A, Baade P, Garvey G, Valery PC. Australian Indigenous cancer patients' self-report of diagnosis, treatment and co-morbidity data: how does it compare to medical chart review? *European Journal for Person Centered Healthcare* 2016; **4(2)**: 330-339. <https://doi.org/10.5750/ejpch.v4i2.1093>

This PDF has been produced for your convenience. Always refer to the live site <https://www.rrh.org.au/journal/article/4660> for the Version of Record.