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**Title:** Psychometric properties of an Australian Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) with cancer

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**Condensed Abstract:** To date insufficient attention has been given to the psychosocial needs of Indigenous cancer patients. This newly developed and psychometrically tested tool is culturally relevant and sensitive to the needs of Indigenous Australians and can assist in addressing disparities in regards to support, information, services and resource allocation.

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**Abstract:**

**BACKGROUND.** There are significant disparities in cancer outcomes between Indigenous and non-Indigenous Australians. Identifying the unmet supportive care needs of Indigenous Australians with cancer is imperative to improve their cancer care. The purpose of this study was to test the psychometric properties of a supportive care needs assessment tool for Indigenous Australian (SCNAT-IP) cancer patients.

**METHODS.** The SCNAT-IP was administered to 248 Indigenous Australians diagnosed with a range of cancer types and stages, and received treatment in one of four Queensland hospitals. All 39 items were assessed for ceiling and floor effects and analysed using exploratory factor analysis (EFA) to determine construct validity. Identified factors were assessed for internal consistency and convergent validity to validated psychosocial tools.

**RESULTS.**

EFA revealed a four-factor structure (physical and psychological, hospital care, information and communication, and practical and cultural needs) explaining 51% of the variance. Internal consistency of four subscales was good, with Cronbach Alpha reliability coefficients ranging from 0.70-0.89. Convergent validity was supported by significant correlations between the SCNAT-IP with the Distress Thermometer ( $r=0.60, p<0.001$ ), and The Cancer Worry Chart ( $r=0.58, p<0.001$ ) and a moderately strong negative correlation with Assessment of Quality of Life questionnaire ( $r=-0.56, p<0.001$ ).

**CONCLUSION.** These data provide initial support for the SCNAT-IP a measure of multiple supportive care needs domains specific to Indigenous Australian cancer patients undergoing treatment.

## **Introduction**

A growing body of research highlights significant disparities in cancer outcomes (including incidence and mortality) between and within countries, ethnicities and Indigenous status.<sup>1-5</sup> A complex interplay of patient, health system, socio-economic and cultural factors contribute to these disparities.<sup>2,3,6,7</sup> Identification of high-risk groups will allow the development of targeted strategies to improve outcomes.<sup>3,5,8</sup>

Australia's Indigenous peoples, represent about 2.5% and comparatively, are more likely to live in remote or very remote areas, are less likely to be employed, or have post-school qualifications.<sup>9</sup> Indigenous Australians experience worse health status and lower life expectancy than other Australians.<sup>9</sup>

Cancer places a significant burden on Indigenous Australians. They have higher cancer mortality rates, are diagnosed at a more advanced cancer stage and have poorer survival rates.<sup>7,10,11</sup> Indigenous patients commonly have fatalistic views of cancer which may lead to lower treatment compliance, and lack of access to information and cancer treatment.<sup>12,13</sup>

Support needs may differ across cultures and to date there is limited information about the needs of Indigenous Australians with cancer. Accurate measurement is important to improve care for Indigenous cancer patients. Therefore, we developed the first supportive care needs assessment tool (SCNAT-IP) for Indigenous Australians with cancer.<sup>14</sup> Details about its development have been published elsewhere.<sup>14</sup> In brief, a qualitative study was conducted to assess the face and content validity, cultural acceptability, utility and relevance of the Supportive Care Needs Survey - Short Form 34 (SCNS-SF34)<sup>15</sup> for use with Indigenous Australian patients with cancer. Based on the qualitative results, several items were omitted

and the remaining items adapted while 12 new Indigenous-specific items were added. The design and response format was also modified.<sup>14</sup> Given the extensive modifications we considered it to be a new tool for psychometric assessment. In its first iteration, the SCNAT-IP-accommodates the language, customs and culture-specific needs of Indigenous Australians and was found to be acceptable, relevant and showed face validity.<sup>14</sup> The aim of this paper is to assess the SCNAT-IP's internal reliability, construct, convergent and discriminative validity.

## **Methods**

### ***Item Generation***

SCNAT-IP<sup>14</sup> responses were recorded using a 5-point response scale (1=no need; 2=satisfied with help received; 3=need a little more help; 4=need some more help; 5=need a lot more help). The initial 39 SCNAT-IP<sup>14</sup> items were assessed for ceiling and floor effects, ( $\geq 90\%$  of participants selecting the lowest or highest category respectively). Items with these effects were removed from further analysis ( $n=7$ ). The final SCNAT-IP items were selected based on a combination of statistical evidence and clinical relevance. To ensure the stability of each domain, a minimum of three items per domain were required. Domain scores were calculated by summing the item responses for each domain respectively. The total score is the summation of the retained items. As there are unequal numbers of items in each domain, the standardised Likert summated score was calculated for each domain and the total score, using the formula  $(\text{domain total score} - m) * 100 / (m * (k - 1))$ , in which  $m$  is the number of questions in a domain and  $k$  is the value of the maximum response for each items.<sup>16</sup> Higher scores represent higher levels of need. Missing values for individual items were imputed using the participant's domain item mean, provided that fewer than half of the items in that domain

were missing.<sup>16</sup> Domain total scores were checked to assess if the data were normally distributed using Shapiro-Wilk test.

### ***Sample***

Participants were recruited from four major Queensland public hospitals (November 2010 – December 2012). Inclusion criteria included: cancer diagnosis; Indigenous Australian; aged 18 years or older; received treatment for their cancer; able to understand English. Exclusion criteria: cognitive, verbal and/or physical impairment that impairs their ability to give informed consent (assessed in consultation with hospital staff from the recruiting site). Hospital staff (cancer care staff or Indigenous Hospital Liaison Officers) approached eligible participants, who were then contacted by a trained interviewer. Detailed information about the study; was provided, written consent obtained and interviews scheduled. Ethics approval was obtained from the Human Research Ethics Committees of QIMR Berghofer Medical Research Institute and the participating hospitals.

### ***Data Collection***

Socio-demographic variables were collected by interview. Clinical information (cancer diagnosis, disease stage, treatments received) was extracted from medical records. Area-level socio-economic status was calculated from participants' residential postcodes using the Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA).<sup>17</sup> Remoteness of residence was also calculated from residential postcodes using the Accessibility/Remoteness Index of Australia (ARIA).<sup>18</sup>

### ***Questionnaires***

The supportive care needs (using the initial 39 item version of the SCNAT-IP<sup>16</sup>), distress (measured by the Distress Thermometer (DT)<sup>19</sup>), worry (measured by the Worry Chart<sup>20</sup>) and quality of life (measured by the Assessment of Quality of Life - 4D (AQoL-4D)<sup>21</sup>) were delivered verbally by a trained interviewer. -Interviewers received standardized training, and interviews were monitored for consistency across study sites. Participants were given a hard copy of response categories and the interviewer recorded participant's responses.

The DT is the main distress management measure recommended by the National Comprehensive Cancer Network (NCCN)<sup>22</sup> with scores from 0-4 indicating low and scores of 8-10 high levels of distress.<sup>18</sup> The Cancer Worry Chart (CWC) is a validated visual analogue one item scale assessing breast cancer worry (responses range from 1-not at all to 5-extremely worried).<sup>20</sup> The CWC demonstrated a strong correlation (pearson correlation coefficient: 0.66,  $p < 0.001$ ) to the Cancer Worry Scale for measuring worry (seen as the gold standard measure). The receiver operator curve also identified favourable characteristics (AUC=0.86) of the CWC for identifying cancer worry-related mood or social role dysfunction.<sup>20</sup> The AQoL-4D is a reliable and valid utility instrument of health-related quality of life (HRQOL) with excellent psychometric properties (the range of reliability estimates is 0.73-0.84). Overall scores range from worst possible HRQOL state (-0.04; worse than death) to death (0.00) to full HRQOL (1.00).<sup>21</sup> These tools have been extensively validated though not specifically tested within an Indigenous population. However, during the earlier stages of SCNAT-IP development, they were used and preliminary evidence found them to be suitable with respect to content and language.

### ***Statistical Methods***

Statistical analyses were conducted by using SPSS v20. Demographic and clinical characteristics and prevalence of SCN were summarised using descriptive statistics. Bartlett's

test of sphericity and the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy were used to test appropriateness of sample size for conducting exploratory factor analysis (EFA). Factors with eigenvalues greater than one were identified using principal components analysis and the scree plots were used to determine where the decrease in eigenvalues became negligible. Three, four or five factor models were examined and the four factor model was selected as it resulted in the clinically most meaningful model. A further EFA was then conducted, forcing a four factor solution with varimax rotation. The conventional primary factor loading cut-off of  $\geq 0.55$  was used to identify items for retention<sup>23</sup>, which were then attributed to the factor with the highest loading. Items within identified factors were assessed for their internal consistency using Cronbach's alpha reliability coefficients. Items where participants reported  $\geq 15\%$  moderate-high level needs but had loadings less than the cut-off were retained due to clinical importance. Convergent validity of the total needs score was tested against the DT and Worry Chart using Spearman's rank order correlations and the AQoL-4D using Pearson correlation coefficient. We expected the SCNAT-IP scores to correlate at least moderately highly ( $>0.50$ ) with the DT, Worry Chart, and AQoL-4D. Discriminant validity<sup>36</sup> was assessed by comparing the median SCN scores using Mann Whitney or Kruskal Wallis tests.

## **Results**

### ***Participant characteristics***

Of the 396 eligible patients were identified, 295 (74.5%) were approached: 43 declined to participate and 252 (85.4%) were interviewed. Some eligible patients were not approached due to early discharge or they were discharged before contact was possible or they missed their planned outpatient appointments. Four participants were subsequently deemed ineligible because they were not receiving treatment, leaving a final study sample of 248.



The demographic and clinical characteristics of the final sample are shown in Table 1. Most participants were 40-59 years (55%), female (57%), had high school education level or higher (45%), and resided in inner/outer regional areas (55%)(Table 1). Most participants were recruited from outpatient cancer clinics (69%), 45% had been diagnosed within the last three months, 29% had distant metastases, 79% recently had adjuvant therapy. Breast (24%), respiratory and intrathoracic organs (14%), leukemia/lymphoma (13%), and digestive (13%) cancers accounted for the majority.

### ***Missing data***

The SCNAT-IP completion rate was high (92% answering all items) and the rate of missing data was low (0.4%-1.6% for each item).

### ***Item reduction***

Seven items had floor effects and were removed; these items addressed sexuality, health care choices (e.g. choice about the gender of the doctor) and provisions (e.g. wound dressings), and cultural considerations (e.g. access to traditional healers) primarily. No items had ceiling effects. The remaining 32 items were assessed using factor analysis.

### ***Construct Validity***

Bartlett's test was significant ( $\chi^2=309$ ,  $p<0.001$ ), indicating that factor analysis is appropriate. Sampling adequacy was confirmed by the KMO statistics of 0.53. Using EFA, eight factors with eigenvalues greater than one were identified. The scree plot indicated a flattening after 3 or 4 factors. A four factor model was identified to be most clinically meaningful therefore EFA was repeated forcing a four-factor solution with varimax rotation. Overall, 24 items achieved a factor loading of  $\geq 0.55$ . Two additional items were retained on the basis of their clinical importance and/or high prevalence of unmet need among the sample (Items#9 and #34). These 2 additional items did not contribute to the factor analysis. Six items failed to

achieve a  $\geq 0.55$  factor loading and did not report  $\geq 15\%$  moderate-high levels of need so were considered not clinically important and were excluded from the tool.

The four factors accounted for 50.9% of the total variance. See Supplementary Table 1 for detailed item factor loadings.

### ***Internal reliability***

The SCNAT-IP overall and the four domains had adequate Cronbach's alpha co-efficients  $\geq 0.70$  (range 0.70-0.89) (Table 4). The standardised median domain scores (possible range 0–100, least-to-greatest need) within the physical and psychological domain, hospital care needs domain, information and communication domain, and practical and cultural domain were 13.6, 0.0, 8.3 and 10.0 respectively (Table 4). The standardized median total needs score was 12.5.

### ***Convergent validity***

The total score for the SCNAT-IP tools correlated moderately with the three psychosocial tools, including the DT (Spearman correlation coefficient 0.60,  $p < 0.001$ ), Worry Chart (Spearman correlation coefficient 0.58,  $p < 0.001$ ) and the AQoL-4D (Pearson correlation coefficient -0.56,  $p < 0.001$ ).

### ***Discriminant validity***

The SCNAT-IP discriminated between the needs of important subgroups. Females reported more unmet needs in physical and psychological ( $p = 0.04$ ) and information and communication needs ( $p = 0.019$ ); inpatients reported more unmet needs in physical and psychological ( $p < 0.001$ ) and practical and cultural needs ( $p = 0.005$ ) than outpatients. The Kruskal-Wallis test indicated that the older age group reported less unmet needs for hospital care ( $p = 0.043$ ); participants with post-secondary school education level reported higher unmet needs in physical and psychological ( $p = 0.024$ ) and hospital care needs ( $p < 0.001$ ); participants living in remote and very remote reported higher unmet needs in practical and

cultural needs ( $p=0.004$ ). These known group differences suggest that the SCNAT-IP possesses good discriminant validity.<sup>36</sup>

### **Prevalence of supportive care needs items**

The most frequently reported unmet need items were: ‘money worries’ (29%), followed by ‘concerns about the worries of those close to you’ (27%) and ‘worrying about the illness spreading or getting worse’ (26%) (Table 3). Most of the commonly reported items were in the physical and psychological needs domain (Table 2). Overall, 175 (71%) participants reported at least one unmet need across the 26 items. There was no statistically significant difference between the levels of need in the socioeconomically disadvantaged sample and the rest of the sample ( $p=0.132$ ).

### **Discussion**

This article manuscript presents initial evidence for the psychometric properties of the SCNAT-IP, a measure of SCN of Indigenous Australians with cancer. The SCNAT-IP is the first tool with the ability to measure met and unmet needs across a range of domains important to Indigenous Australians. Whilst previous SCN surveys had a five factor structure,<sup>15, 24, 25</sup> analysis of the SCNAT-IP supported a four factor solution. Similarly, Au et al found four factors in the Chinese version of the SCNS (SCNS-SF33-C),<sup>26</sup> however, it's dimensions vary from the SCNAT-IP. The SCNAT-IP is also a more acceptable length, with only 26 items thereby easing the completion burden for participants.

The SCNAT-IP achieved a high completion rate. As with other studies conducted with underserved and minority patients we gave particular attention to length of the tool due to varying literacy levels amongst participants and used data collection methods suited to this population.<sup>27, 28</sup>

Several items addressing sexuality needs were eliminated due to floor effects. Questions about may be culturally inappropriate; therefore participants were given a forewarning prior to being asked these questions, potentially contributing to the low endorsement of these items and their elimination.<sup>14</sup> Few participants endorsed the item on having a choice about which hospital they attended. This may be due to geographical and/or insurance status as few Indigenous Australians have private health insurance.<sup>29</sup>

The SCNAT-IP demonstrated adequate construct validity, explaining 51% of the variance, however, this is lower than the explained variance reported for other similar tools.<sup>15,-24-26</sup>

Another 'Australian cancer survivors' unmet needs' measure reported a similar total variance (54%) on a much larger sample size (n=353).<sup>30</sup> The reduction in explained variance may also be due to cultural differences outweighing clinical factors as reported by Fielding et al (2013).<sup>31</sup> For example, in the development of the SCNAT-IP the removal of the sexuality factor due to the culturally inappropriateness for some Indigenous people may have reduced the explainable variance. Future qualitative research is needed to explore which SCN are not adequately represented by the 26 items, and how additional culturally appropriate questions could capture these.

Internal consistencies of the four domains were good with Cronbach's alpha coefficients between 0.70 and 0.89, demonstrating good structural reliability, and a coherent summed factor score. As reported for the SCNS-SF34, there is also good indication of validity when comparing the SCNAT-IP with similar patient-reported instruments (the DT and AQoL-4D).<sup>15</sup>

We also report the first prevalence of SCN amongst Indigenous Australians. Overall, our results are consistent with previous research conducted with non-Indigenous participants as our sample also-reported most unmet needs in the psychological and practical domains.<sup>32-34</sup> Similar items included ‘Concerns about the worries of those close to you’, ‘worrying about the illness spreading or getting worse’, ‘feeling down or sad’, and ‘feeling tired’ were among the ten most common needs identified by cancer patients.

Sanson-Fisher et al<sup>32</sup> reported 19% of cancer patients reported moderate to high unmet need for monetary allowance for travel, treatment and equipment expenses, this was similar to our participants with 22% reporting a moderate to high level unmet need for money worries. Given that Indigenous Australians experience disadvantage across a range of socioeconomic indicators and have a higher prevalence of psychological distress (anxiety and depression) these results are not surprising.<sup>35</sup>

Our participant characteristics reflect those of the Indigenous population in regards to geographical location<sup>9</sup> and tumour groups (breast and respiratory cancers, respectively).<sup>10</sup> As evidenced in this study the SCNAT-IP has applicability to a broad range of tumor groups and to patients at varying stages of their cancer journey.

The study had several limitations. Firstly, a sample size of 248 is at the lower end recommended for factor analysis.<sup>23</sup> However, while it can be very difficult to recruit Indigenous cancer patients this is the largest cross-sectional Indigenous-specific cancer study conducted in Australia to date. Secondly, we assessed internal reliability, but we did not conduct test-retest studies for reproducibility and this is still required. Thirdly, most participants were recruited through cancer outpatient clinics and further testing of inpatients

is needed. Fourthly, while interviewer administration has the advantage of overcoming literacy-related participation restrictions, this administration may have inadvertently influenced responses or restricted choices in extreme response categories. Interviewer administration accommodated for potential literacy problems. Future studies could compare self and interviewer-administered response patterns to determine the potential bias caused by each mode. Lastly, the lower SCNAT-IP variance is largely unexplained but as stated above may be due exclusion of the sexuality needs that were not included due to the culturally inappropriateness for some Indigenous people (Garvey et al., 2012) and also the measure containing only 4 factors whereas other need tools consist mainly of 5 factors.

Despite these limitations, the study provides good initial evidence that the SCNAT-IP is a valid instrument with good psychometric properties. For the first time we were able to comprehensively identify the specific unmet needs of Indigenous Australians with cancer and identify areas where help is required. These results support the need for greater financial and culturally appropriate psychological support to Indigenous cancer patients.

## **Conclusions**

Given the growing evidence and significant disparities in cancer outcomes between Indigenous and non-Indigenous people, insufficient attention has been given to the psychosocial needs of Indigenous cancer patients. The newly developed and psychometrically tested SCNAT-IP is culturally relevant and sensitive to Indigenous peoples' needs and has application in the clinical and research settings. The SCNAT-IP could assist cancer clinicians to better detect, monitor and address the unmet needs of Indigenous cancer patients, to-ensure these patients receive optimal cancer treatment. Cancer researchers could

utilize the SCNAT-IP to quantify needs, identify the most common needs and predictors, and evaluate the effectiveness of interventions amongst this population.

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### **Conflict of Interest Statement**

The authors have declared that no conflict of interest exists.



**Table 1. Demographic and clinical characteristics of the Indigenous Australian participants' who completed the SCNAT-IP (n=248).**

	N	%
<b>Age</b>		
20- 39 years	39	15.7
40-59 years	136	54.8
60+ years	73	29.4
<b>Sex</b>		
Male	107	43.1
Female	141	56.9
<b>Education level*</b>		
Primary school or less	80	32.5
High school	111	45.1
Post--secondary school	55	22.4
<b>Indigenous status</b>		
Aboriginal	189	76.2
Torres Strait Islander	47	19.0
Both Aboriginal and Torres Strait Islander	12	4.8
<b>Marital status</b>		
Married	115	46.4
Single	83	33.5
Separated /divorced	31	12.5
Widowed	19	7.7
<b>Socioeconomic advantage/disadvantage (SEIFA)</b>		

Most Advantaged/Advantaged	91	36.7
Low to Intermediate Disadvantage	94	37.9
Most Disadvantaged	63	25.4
<b>Rurality of residence (ARIA)</b>		
Major city	65	26.2
Outer/Inner regional	137	55.2
Remote /Very remote	46	18.5
<b>Patient Admission status</b>		
Inpatient	76	30.6
Outpatient	172	69.4
<b>Treatment</b>		
Surgery	26	10.5
Surgery and adjunct therapy	26	10.5
Adjunct therapy	196	79.0
<b>Time since diagnosis (months) *</b>		
less than or equal to 3 months	138	55.6
Over 3 months	110	44.4
<b>Cancer Groups**</b>		
Breast (C50)	60	24.2
Respiratory and intrathoracic organs (C30 – C39)	34	13.7
Lymphoid, haemotopoietic and related tissue (C81 – C96)	32	12.9
Digestive organs (C15 – C26)	31	12.5
Malignant neoplasm of lip, oral cavity and pharanx (C00 – C14)	22	8.9

Male genital organs (C60 – C63)	18	7.3
Female genital organs (C51 – C58)	18	7.3
Eye, brain and other parts of CNS (C69 – C72)	12	4.8
Other cancers*	16	6.5
Unknown cancer primary site (C76 – C80)	5	2.0
<b>Cancer Stage ***</b>		
Local	61	26.1
Regional	73	31.2
Distant	65	27.8
Not applicable	35	15.0

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\* Information missing for 2 participants

\*\*Other cancers: Thyroid and other Endocrine glands (C73 – C75), Bone and articular cartilage (C40 – C41), Urinary tract (C64 – C68), Skin (C43 – C44).

\*\*\*information missing for 14 participants

**Table 2. Factor categories and loadings.**

<b>Factors</b>	<b>Item</b>	<b>Item</b>	<b>Loading</b>
	<b>no</b>		
Factor 1 - Physical and psychological needs ( <i>11 items</i> )	1	Physical pain (e.g., hurt)	0.58
	2	Feeling tired (e.g., sleeping ok)	0.72
	3	Not feeling well (e.g., feeling rotten, crook or sick) a lot of the time	0.73
	4	Work around the home (e.g., washing, cooking, raking the yard, sweeping the floor)	0.61
	5	Doing the things you used to do (e.g., fishing, walking, seeing family)	0.67
	6	Anxiety (e.g., worrying, fear, concern)	0.72
	7	Feeling down or sad	0.72
	8	Worrying about your illness spreading or getting worse	0.67
	9	Worry about the results of the treatment	0.54
	10	Keeping you strong in your spirit (e.g., staying positive)	0.65
	11	Concerns about the worries of those close to you (e.g., family and friends)	0.61
Factor 2 - Hospital care needs ( <i>4 items</i> )	15	Support by staff that the way you feel is natural (e.g., common, typical)	0.74
	16	Having hospital staff attending quickly to your physical needs (e.g., if you needed assistance getting out of bed)	0.75

## Support needs tool for Indigenous People

	17	Having hospital staff show sensitivity to and respecting your feelings and emotional needs	0.86
	26	Being treated like a person not just another case or a number	0.75
Factor 3 - Information and communication needs (6 items)	18	Being shown or given information (e.g., written, diagrams) about how to manage your treatment, illness and side-effects <u>in hospital</u>	0.58
	19	Being shown or given information (e.g., written, diagrams) about how to manage your illness and side-effects <u>at home</u>	0.62
	20	Explaining what tests are for	0.59
	21	Understanding the good and bad effects of treatments before you chose to have them (e.g., having someone explain these to you)	0.68
	24	Being told about things you can do to help yourself get well (e.g., safe exercises, what you eat)	0.58
	33	Having an Indigenous person to interpret and help with communication with health professionals	0.57
Factor 4 - Practical and cultural needs (5 items)	28	Finding a place to stop or stay while receiving treatment	0.68
	29	Money worries (e.g., cost of accommodation, travel)	0.63
	30	Having an Indigenous person to talk to and support you, someone who understands your culture	0.56

## Support needs tool for Indigenous People

	34	Ensuring family members were able to be present when talking or seeing health professionals	0.52
	35	Directions to get to and around the hospital	0.67
Non-specific factor loadings	22	Being told about your test results as soon as possible	
	23	Being told about whether your cancer is in remission (e.g., fading or finishing)	
	25	Having access to professional counselling (e.g., psychologist, social worker, Aboriginal Liaison Officer) if you or family and friends need it	
	27	Having one hospital person you can talk to about your condition, treatment and follow-up	
	38	Getting information about your illness for your family and friends	
	39	Being treated in a hospital or clinic that is culturally supportive	

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**Table 3. Proportion of sample stratified by unmet supportive care needs and level of help needed (n=248).**

<b>Item number and the item</b>	<b>% with no need</b>	<b>% satisfied with help received</b>	<b>% needed a little more help</b>	<b>% needed some/a lot more help</b>
1 Physical pain (e.g., hurt) <sup>a</sup>	48.0	33.5	8.5	9.7
2 Feeling tired (e.g., sleeping OK) <sup>a</sup>	50.8	26.2	13.3	9.3
3 Not feeling well (e.g., feeling rotten, crook or sick) a lot of the time <sup>b</sup>	53.2	27.8	9.7	8.1
4 Work around the home (e.g., washing, cooking, raking the yard, sweeping the floor) <sup>b</sup>	49.2	30.6	7.7	11.3
5 Doing the things you used to do (e.g., fishing, walking, seeing family) <sup>c</sup>	62.9	20.6	6.0	9.7
6 Anxiety (e.g., worrying, fear, concern) <sup>a</sup>	53.6	23.0	11.3	11.7
7 Feeling down or sad	54.4	22.6	10.5	12.5
8 Worrying about your illness spreading or getting worse	49.2	24.6	12.1	14.1
9 Worry about the results of your treatment <sup>d</sup>	52.4	23.8	10.5	11.7
10 Keeping you strong in your spirit (e.g., staying positive) <sup>a</sup>	64.9	22.2	6.0	6.5
11 Concerns about the worries of those close	47.2	25.8	11.7	14.9

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	to you (e.g., family and friends) <sup>a</sup>				
15	Support by staff that the way you feel is natural (e.g., common, typical) <sup>a</sup>	78.2	12.9	4.4	4.0
16	Having hospital staff attending quickly to your physical needs (e.g., if you needed assistance getting out of bed) <sup>a</sup>	77.0	16.1	4.0	2.4
17	Having hospital staff show sensitivity to and respecting your feelings and emotional needs <sup>a</sup>	79.0	13.7	2.4	4.4
18	Being shown or given information (e.g., written, diagrams) about how to manage your treatment, illness and side effects in <u>hospital</u> <sup>a</sup>	66.5	25.4	2.4	5.2
19	Being shown or given information (e.g., written, diagrams) about how to manage your illness and side effects <u>at home</u> <sup>a</sup>	62.5	25.8	4.8	6.5
20	Explaining what tests are for <sup>c</sup>	63.3	27.8	4.0	4.0
21	Understanding the good and bad effects of treatments before you chose to have them (e.g., having someone explain them to you) <sup>a</sup>	55.2	29.8	6.5	7.3
24	Being told about the things you can do to help yourself get well (e.g., safe	63.7	23.8	5.6	6.9

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	exercises, what you eat)				
26	Being treated like a person not just another case or a number <sup>a</sup>	86.7	5.2	3.6	4.0
28	Finding a place to stop or stay while receiving treatment	78.2	12.1	2.0	7.7
29	Money worries (e.g., cost of accommodation, travel) <sup>b</sup>	54.4	15.3	7.3	21.8
30	Having an Indigenous person to talk to and support you, someone who understands your culture <sup>a</sup>	66.1	22.2	2.4	8.9
33	Having an Indigenous person to interpret and help you with communication with health professionals	85.5	9.3	1.2	4.0
34	Ensuring family members were able to be present when talking or seeing health professionals	75.4	15.7	3.6	5.2
35	Directions to get to and around the hospital	76.2	17.3	2.4	4.0

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<sup>a</sup> information missing for 1 participant

<sup>b</sup> information missing for 3 participant

<sup>c</sup> information missing for 2 participant

<sup>d</sup> information missing for 4 participant

**Table 4. Cronbach alpha reliability coefficient and response distribution for each domain****(standardized Likert summated score).**

<b>Domain</b>	<b>alpha</b>	<b>Mean Score</b> <b>(0-100)</b>	<b>SD</b>	<b>Median</b>	<b>IQR</b>	<b>% lowest</b> <b>score (floor)</b>	<b>% highest</b> <b>score (ceiling)</b>
Physical and psychological (n=248)	0.89	20.9	19.5	13.6	24	8.1	0.4
Hospital care (n=247)	0.86	8.3	17.2	0.0	6.3	64.5	0.4
Information and communication (n=247)	0.82	13.0	16.7	8.3	17.0	32.7	0.4
Practical and cultural (n=248)	0.70	14.6	18.5	10.0	20.0	29.8	0.4

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