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ORIGINAL ARTICLE

Indigenous cancer patient and staff attitudes towards unmet needs screening using the SCNAT-IP

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Abstract

Introduction Indigenous Australians have a higher cancer incidence, worse mortality and are less likely to receive optimal cancer treatment compared with non-Indigenous Australians. Culturally appropriate supportive care helps ensure that Indigenous patients engage in and receive optimal care. However, many existing supportive care needs tools lack cultural relevance for Indigenous people, and their feasibility with Indigenous people has not been demonstrated. The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) assesses the unmet supportive care needs of Indigenous cancer patients.

Purpose This descriptive study evaluates the clinical implementation of the SCNAT-IP in routine care.

Methods Two large tertiary cancer treatment centres and two regional oncology clinics participated. Participants included 10 clinical staff and 36 adult Indigenous cancer patients (mean age 54 years). Patients and clinicians completed brief, purpose-designed questionnaires and interviews.

Results Patients reported high ratings (means >8/10) for acceptability, helpfulness and timing items. The majority (≥80 %) of staff agreed that the SCNAT-IP was useful to clinical practice, should be used in routine care and was acceptable to their patients.

Conclusions The study provides empirical support for the feasibility and acceptability of the SCNAT-IP in routine cancer care with Indigenous Australians. Routine screening with the SCNAT-IP has the potential to improve cancer care for Indigenous people with cancer.

Keywords Indigenous · Aboriginal · Cancer · Oncology · Unmet needs · Screening

Introduction

Aboriginal and Torres Strait Islander people (henceforth referred to as Indigenous Australians) have a higher overall incidence of cancer compared with non-Indigenous Australians [1, 2]. They are also more likely to have more advanced stages of cancer at diagnosis and have cancers where the prospects of successful treatment are poorer [3]. Additionally, Indigenous Australians with cancer have more comorbidities than non-Indigenous Australians [2, 3], as well as poorer access to care, and are less likely to receive optimal cancer treatment [4, 5]. As a result, Indigenous Australians experience a 6 % higher overall cancer incidence, 50 % higher cancer mortality and 30 % lower 5-year cancer survival compared to non-Indigenous people [2].

Misunderstandings about cancer and health beliefs may affect Indigenous people's care-seeking behaviour [6]. Practical issues such as transport and accommodation, financial hardship and displacement from family and community during treatment

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may also prevent many Indigenous patients from accessing care and receiving optimal treatment [7–10]. Once engaged in treatment, a lack of access to culturally appropriate services, such as having an Indigenous health professional to talk to (e.g. Indigenous Health Workers [IHW]) and having cancer information in language that is easily understood, may also influence treatment decision-making and lead to a general sense of alienation within the hospital environment [7–10].

In recent years, there has been a considerable focus on reducing cancer outcome disparities for Indigenous Australians. For example, preventive health programs have attempted to increase Indigenous participation rates in cancer screening and reduce smoking rates [11–13]. Another emerging field which aims to improve cancer outcomes is research into the supportive care of Indigenous people with cancer. Supportive care aims to prevent, reduce and alleviate the symptoms of treatment, enhance communication between patients and clinicians and assist patients and their family to manage ongoing needs associated with the diagnosis and treatment of cancer [14]. In one of the first studies to examine Indigenous cancer patients' unmet needs, the most prevalent supportive care needs were 'money worries' (22 %); 'concerns about the worries of those close to you' (15 %); 'worrying about the illness spreading or getting worse' (14 %) and 'feeling down or sad' (13 %) [15].

There is currently limited data on the supportive care needs of Indigenous cancer patients, and until recently, no tools were available to adequately capture the unmet needs of Indigenous Australians with cancer. The Supportive Cancer Needs Assessment Tool for Indigenous Persons (SCNAT-IP) has recently been developed specifically for this purpose [8].

The original items of the SCNAT-IP were based on the Supportive Care Needs Survey-Short Form (SCNS-SF34), a tool which was developed to assess unmet supportive care needs amongst the general adult cancer population [16]. However, based on the feedback of Indigenous cancer patients and key informants in the initial stages of development, all SCNS-SF34 items were either adapted or removed and new were items added to reflect the specific cultural needs of Indigenous Australians. The full development and validation of the SCNAT-IP has been described elsewhere [8, 15]. In brief, the SCNAT-IP is a 27-item measure of unmet supportive care needs for Indigenous Australians, which is verbally administered and consists of four needs domains (*physical and psychological*, *hospital care*, *information and communication* and *practical and cultural)*. The SCNAT-IP takes approximately 15 min to complete [8]. Full scoring can be completed in less than 5 min; however, in clinical applications, results can be very quickly scanned to identify moderate to high needs items which require further exploration and possible follow-up. The SCNAT-IP has been demonstrated to have good construct [15] and face validity [8] as well as internal consistency [15].

There is growing consensus that assessment of psychosocial concerns and supportive care should be a routine part of cancer care, and these recommendations are incorporated into many national and international clinical guidelines [17]. However, relatively few studies have investigated the implementation of screening for unmet needs into routine clinical care [18]. Whilst a number of unmet needs assessment tools have been developed and validated for use within the general adult cancer population, relatively few studies have systematically explored the acceptability of these tools or their impact on process of care outcomes [19]. The SCNS-SF34 (the questionnaire on which the SCNAT-IP was based) however has reported high completion rates amongst cancer patients [16] and that patients prefer the SCNS-SF34 over other needs assessment and quality of life questionnaires [20]. In a study of acceptability of a computerised version of the SCNS-SF34, the majority of patients reported that the survey was easy to complete, it was a good way for doctors to get information about patients' well-being, and that they would be willing to complete the survey each time they visited their oncologist [21].

The newly developed SCNAT-IP could help cancer care professionals to better detect, monitor and address the psychosocial concerns of Indigenous cancer patients to ensure that they receive optimal cancer care. Whilst the SCNAT-IP has been psychometrically tested and used in a research setting, its use in clinical settings has not previously been explored. Therefore, the objective of the current study was to explore the feasibility of using the SCNAT-IP in routine cancer care and the degree to which Indigenous Australians with cancer and health professionals find the SCNAT-IP useful and acceptable in routine care.

Methods

Setting

Ethical approval for this study was obtained from relevant institutional human research ethics committees and the Aboriginal Health and Medical Research Council of New South Wales. Participants were recruited at one of four health services located in the Northern Territory, Victoria and New South Wales. Clinics were purposely selected for this study because they (a) represented a diversity of jurisdictions, Indigenous communities and geographical settings (urban, rural and remote and very remote) and (b) included a diversity of service models with differing staff and resource levels.

No participating clinics routinely used formal unmet needs screening measures prior to this implementation trial. Details of staff composition and number, services and existing unmet needs screening practices at participating sites are shown in Table 3.

Eligibility criteria

Patients

Participants were recruited from the participating cancer clinics during a 3 to 5-month recruitment period. Eligible participants were aged ≥18 years, of Indigenous Australian origin and diagnosed within the past 5 years with malignant cancer of any disease stage. Additionally, they were receiving or about to receive cancer treatment (including surgery and/or chemotherapy, radiotherapy, stem cell transplant, endocrine therapy or immunotherapy) or in follow-up care. As surveys and interviews were verbally administered, participants were required to have sufficient comprehension of spoken English. Those unable to give informed consent due to cognitive and/or physical impairments were excluded.

Staff

Eligible health professionals were cancer nurses, oncology social workers, IHW or other allied health professionals who were able to give informed consent and considered by their manager as involved in providing supportive care to cancer patients as part of their routine work.

Procedure

After written informed consent was obtained, health professionals (referred to here as 'trained clinical staff') completed a specifically developed 3-hour study training session. Following training, other staff at participating sites were asked to identify and refer all eligible Indigenous cancer patients to trained clinical staff for needs assessment. Trained clinical staff, including nurse social workers and one clinical trial coordinator, introduced the study to patients, gained written informed consent and conducted needs assessment at routine patient clinic visits. All patient data collection methods were verbally administered. Where moderate to high level of needs were identified by the SNCAT-IP (i.e. scores of 4 or 5 on any item), these needs were discussed with patients and they were offered assistance in accordance with usual care.

Immediately following completion of the needs assessment and acceptability items, a different trained clinical staff member (preferably IHWs) conducted an audio-taped face-to-face or telephone interview with patients. This interview gathered qualitative information about their attitudes towards unmet needs screening.

At the conclusion of the data collection period, trained clinical staff who used the SCNAT-IP completed a brief telephone interview with a member of the research team (BT). They were asked to verbally complete a five-item purpose-designed questionnaire and a brief follow-up telephone interview which qualitatively explored acceptability and feasibility of the SCNAT-IP. Non-clinical staff that did not use the SCNA T-IP in clinical practice (i.e. IHWs trained to complete patient follow-up interviews or managers) did not participate in the staff acceptability study. The results of the analysis of qualitative data are reported in a separate manuscript [22].

Measures

In addition to the SCNAT-IP, described above, patient data collection included the following:

Patient clinical and demographic characteristics Sociodemographic variables were collected to assess age, location of residence, Aboriginal and/or Torres Strait Islander status, marital status, education and parity. Clinical details including cancer type, disease status, treatment phase and cancer treatments were collected from medical records.

Patient acceptability survey This questionnaire included three purpose-designed items assessing (a) the degree to which patients liked being asked about needs ('like'), (b) the acceptability of the timing of needs assessment ('good time') and (c) the perceived helpfulness of needs assessment ('helpful'). Responses were recorded using a 0–10 visual analogue scale ranging from 0 '*not at all*' indicated by a sad emoticon to 10 '*very much so*' indicated by a happy emoticon, with five shown as a neutral emoticon.

Service delivery outcomes form Three items were completed by health professionals following SCNAT-IP administration to document the outcome of the needs assessment. These items recorded (a) whether a moderate to high need was identified on any item (yes/no), and (b) if so, what strategies/service options were offered to address this need(s) using pre-specified categories and an open-ended response option for 'other' services and (c) whether services were accepted or declined.

Health professional acceptability and feasibility survey This purpose-designed, written questionnaire included five items assessing utility, feasibility of use in routine care, patient acceptability, ease of use and interest in continued use of the SCNAT-IP in routine care.

Data analyses

Data was analysed using SPSS v22. Demographics and staff and patient acceptability data were analysed using descriptive statistics. Total acceptability ratings for patients were computed by summing the three patient acceptability items (i.e. score out of 30). Means, standard deviations and proportions with 95 % confidence intervals were used to aggregate patient acceptability ratings.

Results

Patient participants and response rate

Forty-five participants out of 89 potentially eligible Indigenous cancer patients were invited to this study. Reasons for non-approach included patients not attending scheduled appointments, staff workload and competing clinical demands, staff leave and difficulty in coordinating appointment times for needs assessment with patients especially for those from regional areas where distance and travel issues compounded these problems. Of those invited to participate, 36 patients consented to participate (90 % response rate), four declined and five were ineligible. Reasons for ineligibility included not self-identifying as of Indigenous background (n=2) or being too physically and/or mentally unwell to participate (n=3).

Patient participants were aged from 34 to 76 years (M=53.7 years, SD=11.2), the majority had partners (53 %) and living outside of major metropolitan cities (89 %) (Table 1). Sixty percent of the sample had not completed high-school matriculation (year 12). A substantial minority (42 %) nominated an Indigenous language as the primary language spoken at home. Breast (36 %) and colorectal cancer (19 %) were the most common forms of cancer amongst participants (Table 2).

Health professional participants and response rate

A summary of health professional characteristics in the evaluation cohort is shown in Table 3. All health professionals that were invited to participate consented (100 % response rate). The SCNAT-IP study training session included 22 health professionals. Staff who completed training included eight social workers, four nurse care coordinators, one radiation therapist, one clinical trial coordinator, five IHW and three service managers with an average age of 42 years (range 25–62, SD 11.4). Of those, 10 trained clinical staff conducted patient assessments using the SCNAT-IP and eight trained staff conducted the patient follow-up interviews only. All staff who administered and evaluated the SCNAT-IP were of non-Indigenous background.

Acceptability data

Patient acceptability

Mean ratings for all three acceptability items were high (>8/10), and the mean total acceptability score for patients was 26.1 out of a possible 30 (range=18–30, SD=3.7) (Table 4). Despite high mean acceptability, there was some variation of acceptability ratings with the greatest range of score (range=2–10) observed in relation to acceptability of timing. A high proportion of patients reported maximum acceptability ratings (10) on the acceptability items (like: 42.9 % (CI 25.6–60.1), helpful: 57.1 % (CI 39.9–74.4), good time: 45.7 % (CI 28.4–63.1), and one third of patients (34.3 % (CI 17.7–50.8) reported a maximum total acceptability rating of 30/30.

Staff acceptability ratings

In response to survey items exploring acceptability, the majority of staff (8/10) '*agreed*' or '*strongly agreed*' that the SCNAT-IP was useful to their clinical practice and that patients generally found the tool acceptable. Acceptability ratings were lowest for two items exploring (a) the feasibility of using the SCNAT-IP routinely with Indigenous cancer patients and (b) ease of scoring and interpretability for staff with seven out of 10 staff '*agreeing*' with these statements. Nine out of the 10 staff surveyed either '*agreed*' or '*strongly agreed*' that their clinic should continue to use the SCNAT-IP for all Indigenous cancer patients. See Table 5 for a summary of staff responses to acceptability items.

Service delivery outcomes

Moderate to high unmet needs (scores of 4 or above) were reported by 21 (58 %) participants, and these needs were discussed with patients following their needs assessment. All patients with moderate to high unmet needs were offered at least one intervention, with the majority being offered multiple interventions. No patients declined the interventions offered. These interventions included emotional support (15 participants), referrals to social workers or IHW (14 participants), information or patient education (12 participants), practical assistance (3 participants), referral to care coordinators (2 participants) and referral to a general practitioner (1 participant), oncologist (1 participant) or psychologist (1 participant). Whilst it is not possible to determine what services would have been offered in the absence of SCNAT-IP screening, we observed that at least one new referral to a health professional or service was generated for 16 of the 21 (76.2 % (CI: 56.3–96.1)) patients with moderate to high needs following needs assessment using the SCNAT-IP.

Discussion

In summary, the majority of Indigenous cancer patients in this study liked being asked about their unmet supportive care needs, found the questions and format of the SCNAT-IP

Table 1 Characteristics of the clinical population, staff resources and screening practices at participating sites

Clinic	Site description	Estimated annual new patient numbers	Estimated annual Indigenous patient numbers	Number of medical staff	Medical staff resident status	Number of nursing staff	Number of psychosocial staff (FTE)*	Number of specialist Indigenous health workers employed (FTE)*	Existing screening using formal unmet needs assessment measures	Staff completing SCNAT-IP screening
Setting 1	Metropolitan tertiary cancer treatment centre	9000	60	223	Resident and VMO[a]	350	23	0.8	No	Social workers
Setting 2	Tertiary cancer treatment centre servicing urban Indigenous population and remote/very remote communities	700	150	5	Resident and VMO	12	1	1	No	Clinic manager Clinical trials coordinator Clinical Nurse Consultant
Setting 3 clinic A	Rural oncology clinic	400	5–10	4	VMO	5.4	0.6	2	No	Social workers Care coordinator Breast care nurse
Setting 3 clinic B	Rural oncology clinic	525	5–10	5	VMO	6.5	0.6	2	No	Social workers Care coordinator Breast care nurse

**FTE* Full-time equivalent position

[a] *VMO* Visiting medical officer

Table 2 Demographic and clinical characteristics of the patient sample (n=36)

	n	%
Gender		
Male	11	31
Female	25	69
Indigenous descent		
Aboriginal	34	94
Aboriginal and Torres Strait Islander	2	6
Location of residence*		
Major city	4	11
Inner regional	6	17
Outer regional	20	56
Rural	3	8
Remote	3	8
Marital status		
Single	10	28
Married/ de facto	19	53
Widowed/separated/divorced	7	19
Children		
Yes	35	97
No	1	3
Main language spoken		
English	21	58
Indigenous language	15	42
Education[d]		
Year 10 or below	21	60
Year 12 (matriculation)	6	17
Diploma/trade	4	11
Tertiary	4	11
Employment[d]		
Employed	9	26
Unemployed	13	37
Retired/pension	11	31
Home duties	2	6
Treatment location[†]		
In-patient	2	6
Out-patient	34	94
Cancer type		
Breast	13	36
Bowel	7	19
Head and neck	6	17
Lung	3	8
Gynaecological	2	6
Haematological	2	6
Other	3	8
Treatment status		
Receiving treatment[b]	17	47
Newly diagnosed	5	14
Follow-up care	14	39

Table 2 (continued)

	n	%
Estimated cancer stage		
Local disease	12	33
Regional spread	6	17
Distal metastases	12	33
Not applicable	3	8
Not known	3	8
Comorbidities		
No known comorbidities	24	67
Diabetes	8	22
Cardiovascular	10	28
Respiratory	9	25
Other[c]	16	44
Surgery[d]		
Completed	23	64
Planned	3	8
No/not applicable	9	25
Chemotherapy		
Yes	23	64
No	13	56
Radiotherapy		
Yes	21	58
No	15	42
Other cancer treatments[e]		
Yes	14	6
No	22	94

*Classified according to Accessibility/Remoteness Criteria of Australia (ARIA) † at time of interview

[a] Non-Hodgkin's lymphoma

[b] Includes all active hospital-based cancer treatments

[c] Includes substance abuse, psychiatric, renal disease, neurological and gastrointestinal disorders

[d] Does not sum to total due to missing data

[e] Includes hormonal therapy, brachytherapy and microwave ablation

acceptable and found the process of needs assessment using the SCNAT-IP helpful. This trial included patients at all stages of the treatment continuum who were recruited from a diversity of service settings and geographic locations. This sample also included patients with a diversity of cancer types. The prevalence of cancer types observed in the present sample broadly represents the cancer incidence rankings seen in the Indigenous Australian population, with the exception of lung cancer which was under-represented in the present sample [1]. The high levels of patient acceptability observed in this study are consistent with the results of patient and key informant interviews conducted during the development of the SCNA T-IP [8] and consistent with past research which demonstrates the acceptability of the SCNS-SF34 amongst cancer patients in the general population. Acceptability of timing was the area in which the greatest range of patient acceptability ratings was recorded. This sample included patients at all stages of the treatment continuum. Whilst quantitative data reported here suggests that the timing of assessment was acceptable to the majority of patients, qualitative data from subsequent patient and staff interviews [22] suggests that many participants believed that SCNAT-IP assessment would be most useful at the beginning of the treatment trajectory, supplemented by reassessment at time points throughout the cancer journey.

Screening for unmet needs and distress has been shown to improve communication between patients and clinicians and enhance psychosocial referrals [18]. It may also help better meet the needs of under-served populations, such as Indigenous cancer patients, and this is an identified priority for future research [18]. A recent Australian study has demonstrated the acceptability and feasibility of routine psychosocial [23] screening using the Distress Thermometer [24] and Kessler Psychological Distress Scale (K-10) [25] with 154 rural cancer patients and 36 clinicians [19, 23]. However, the present study is the first to have explored the feasibility or acceptability of routine psychosocial screening amongst Indigenous people with cancer. Optimal and culturally appropriate supportive care may help to better engage Indigenous

Table 3 Trained clinical health professional characteristics

	Evaluation cohort (*n*=10) *n*
Gender	
Female	10
Male	0
Cultural background	
Indigenous	0
Non-Indigenous	10
Clinical role	
Oncology social worker	6
Nurse care coordinator/clinical trial coordinator	4
Education	
Bachelor	1
Post-graduate	9
Location	
Metropolitan	5
Regional/regional	5
Year of experience in current role	
Less than 2 years	1
2–5	4
6–10	3
More than 10 years	2
Prior needs assessment training	
Yes	4
No	6

Table 4 Patient acceptability ratings (n=35)**

	Mean*	Median*	Std. deviation	Minimum	Maximum
Item 1* I liked being asked about my needs	8.66	9.00	1.59	4	10
Item 2* I thought today was a good time for me to complete the questionnaire	8.63	9.00	1.88	2	10
Item 3* I found the questionnaire helpful for identifying what I needed help with	8.80	10.00	1.68	5	10
Total acceptability rating	26.09	26.00	3.72	18	30

*Ratings are 0–10 where 10 is highest possible

**One patient was unable to complete follow-up interview and had missing data for acceptability items

people in cancer care thus increasing the likelihood that they complete treatment and receive optimal cancer care.

Few previous studies of screening for unmet needs or distress involving the general adult cancer population have demonstrated a significant rise in service delivery outcomes following psychosocial screening [18]. Contrary to previous studies, however, the results of the present study provide some preliminary evidence that the use of the SCNAT-IP may translate into direct service-delivery outcomes. Although the present study examined the impact on services for those included in this trial, it did not include an unscreened control group or explore the long-term impact of needs assessment on patient-reported outcomes. Further studies including a randomised control trial of the implementation of the SCNAT-IP and longitudinal studies which include patient-reported outcomes are needed to fully evaluate the impact of the SCNAT-IP on clinical care. A large study of Indigenous cancer patient supportive care needs using a longitudinal design and patient-reported outcome is currently underway and is being coordinated by members of our research team (GG and PV). The results of that study will provide national benchmark data on the prevalence and course of supportive care needs amongst Indigenous Australians with cancer.

In considering the findings of this study, some limitations should be acknowledged. Firstly, this study included a relatively small sample as approximately half of all potentially eligible patients were not invited to participate for reasons outlined above. Despite targeting sites which saw relatively high numbers of Indigenous cancer patients, the small sample size achieved reflects the difficulties involved in gathering large samples of Indigenous cancer patients and the resource challenges of working with patients from socially disadvantaged groups [26]. Despite a lower than anticipated approach rate, a high patient response rate was achieved when patients received an invitation to the study and patients reported high mean levels of acceptability reported by patient participants. Qualitative results from staff interviews, reported in a separate manuscript [22], suggest that the difficulties encountered by staff arranging a suitable time for needs assessment with some patients would be overcome if the SCNAT-IP was routinely administered early in the treatment trajectory when other questionnaire data was also collected. A further issue which impacted upon the identification of eligible patients for this study was the inaccuracy of medical records of Aboriginal and/or Torres Strait Islander background. A small number of patients were identified by medical records as being Indigenous, but when approached for this study, they did not self-identify as being of Indigenous background. Another unforeseen circumstance during recruitment was the early onset of the wet season in the Northern Territory during this trial. This impeded patient transport from remote Indigenous communities in the Northern Territory to the clinic, thus reducing Indigenous patient numbers from remote communities during the trial. Despite these potential limitations which may impact on the generalisability of our findings, this study had a high recruitment rate and represents a sample size consistent with other

Table 5 Trained clinical staff acceptability ratings (n=10)

	Strongly disagree (n)	Disagree (n)	Neither agree or disagree (n)	Agree (n)	Strongly agree (n)	% that agreed or strongly agreed
The SCNAT-IP is useful to my clinical practice.	0	1	1	7	1	80
The SCNAT-IP is feasible to use routinely with Indigenous cancer patients.	0	1	2	6	1	70
Patients generally find the SCNAT-IP acceptable.	0	0	2	8	0	80
The SCNAT-IP is easy for staff to score and interpret.	0	3	0	7	0	70
I believe that the clinic I work in should continue to screen all Indigenous patients with the SCNAT-IP	0	1	0	8	1	90

screening implementation trials involving specialised patient groups [27, 28].

Conclusions

This study provides preliminary empirical support for the feasibility and acceptability of the SCNAT-IP for use in routine cancer care with Indigenous Australians. Gaining a better understanding of the level of unmet needs can assist policy and service development, and it also has the potential to reduce cancer outcome disparities amongst Indigenous people. However, more research is needed to fully evaluate its impact on clinical care. The SCNAT-IP is now available for use by clinicians and researchers working with Indigenous people with cancer and can be accessed free of charge by clinicians and researchers at (www.menzies.edu.au/supportivecaretool).

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Conflict of interest The authors have no conflicts of interest to declare.

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