PSYCHOSOCIAL ASPECTS OF CANCER CARE FOR INDIGENOUS AUSTRALIANS

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Doctor of Philosophy

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DECLARATION

I hereby declare that the work herein, now submitted as a thesis for the degree of Doctor of Philosophy at Charles Darwin University, is the result of my own investigations, and all references to the ideas and work of other researchers have been specifically acknowledged. I hereby certify that the work embodied in this thesis has not already been accepted in substance for any degree, and is not being currently submitted in candidature for any other degree.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying online via the University’s Open Access repository eSpace.

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December 2015
ABSTRACT

A growing body of research has reported significant disparities in cancer outcomes between Indigenous and non-Indigenous Australians, in part a result of factors relating to the accessibility, acceptability and effectiveness of health services. Although these disparities are starting to be addressed, relatively little attention has been directed towards identifying and focusing on the psychosocial aspects of cancer for Indigenous patients, a critical component in improving cancer care and outcomes.

This thesis reports on the development of a new Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) and presents the first research on factors affecting the prevalence of unmet support needs, distress and quality of life (QOL) in a cohort of Indigenous adult cancer patients in Queensland, Australia. The main research findings were:

1. Current supportive care needs tools do not meet the needs of Indigenous people with cancer with regard to factors such as language, culture and customs.
2. The newly developed SCNAT-IP improves acceptability, relevance and face validity for Indigenous-specific concerns.
3. The prevalence of these patients’ unmet support needs is high, especially in the psychological and practical need domain.
4. The use of the SCNAT-IP in the usual cancer care setting is feasible and acceptable to users.
5. Health-related QOL is lower among Indigenous cancer patients compared to other Australians. Several factors are associated with a higher median QOL score and with the relative odds of having ‘excellent’ health-related QOL.

6. Clinically-significant distress among the Indigenous cancer patients studied is consistent with levels identified in the existing literature. Some socio-demographic and clinical characteristics are associated with higher median distress score and with the relative odds of having clinically-significant distress.

These findings have implications for clinical practice and can be used to improve the management and care of Indigenous adults with cancer and to inform targeted policy development.
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Chapter 1  INTRODUCTION
1.1 Chapter overview

Cancer is one of Australia’s national health priority areas. Given the significantly poorer prognosis of cancer among Aboriginal and Torres Strait Islander Australians (hereafter respectfully referred to as Indigenous), this is an area that requires attention. There is increasing recognition that cancer causes multiple physical, emotional and social health issues as a result of many interacting influences, with cultural differences in the way Indigenous people perceive cancer and cope with their illness. Research identifying the psychosocial aspects of Indigenous people with cancer is therefore paramount to ensure their optimal management and care and in the long term improve their cancer survival rates. Patient reported outcome assessments are increasingly being used to assist health professionals to tailor their health practices to the individual needs of patients and improve patient care over time.

This introductory chapter provides a brief description of the health and well-being of the Indigenous Australian population followed by a summary of the significant disparities in cancer outcomes, disease burden and factors impacting on cancer outcomes between Australia’s Indigenous and non-Indigenous populations. The psychosocial aspects of cancer care and the barriers to Indigenous people accessing appropriate cancer care are summarised. Strategies such as using patient reported outcome measures to assist health professionals to tailor their health practices to meet the specific needs of individuals are also described. The review concludes with a summary of the research aims addressed by this thesis.
1.2 Aboriginal and Torres Strait Islander Australians

There are an estimated 517,000 Aboriginal and Torres Strait Islander people, constituting around 2.5% of the total Australian population. Torres Strait Islanders represent about 10% of the total Indigenous population, with the majority (61%) living in Queensland. About 23% of the total Indigenous population in Queensland are Torres Strait Islanders.

Australia's Indigenous population is much younger than their non-Indigenous counterparts, with a median age of 21 compared to 37 years, respectively. The age structures of the Aboriginal and Torres Strait Islander populations are somewhat similar to each other (Table 1).

<table>
<thead>
<tr>
<th></th>
<th>Aboriginal</th>
<th>Torres Strait Islander&lt;sup&gt;(a)&lt;/sup&gt;</th>
<th>Non-Indigenous</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age (years)</td>
<td>21 (combined)</td>
<td>37</td>
<td>37</td>
</tr>
<tr>
<td>% in each age group (years)</td>
<td>100</td>
<td>100</td>
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<tr>
<td>0–14</td>
<td>37</td>
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<td>15–49</td>
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<td>50</td>
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<tr>
<td>50+</td>
<td>11</td>
<td>16</td>
<td>31</td>
</tr>
</tbody>
</table>

<sup>(a)</sup>persons of Torres Strait Islander origin only (excludes persons of both Aboriginal and Torres Strait Islander origin).

Note: Not all percentages total 100% due to rounding.

Aboriginal and Torres Strait Islander people are a culturally diverse population, with over 60% of those aged 15 years and over identifying with a clan, tribal or language group. They are also linguistically diverse, with over 250 known Indigenous languages, of which approximately 145 are still spoken.⁹

Whilst Indigenous Australians reside in geographical locations across Australia, the majority (71%) live throughout three jurisdictions: New South Wales, Queensland and Western Australia. Around one-third of Indigenous people dwell in major cities (32%) with about one-quarter in remote (9%) or very remote (15%) areas of Australia.⁹ This varies from state to state. For example, in Queensland over half of the Indigenous population reside in outer regional, remote or very remote geographical areas. Figure 1 shows the geographical distribution of the Indigenous Australian population. Similar to the total population, the Indigenous population is concentrated along the east coast.

Source: Australian Institute of Health and Welfare, 2011.⁹; p.9

Figure 1 Distribution of the Indigenous Australian population
1.3 Aboriginal and Torres Strait Islander health

Before presenting the key indicators of the health status of Indigenous Australians, it is important to give some context within which these indicators should be considered.

The health and well-being of a population results from a complex interplay of factors known as the social determinants of health.

‘Social determinants of health are the conditions in which people are born, grow, work, live and age, and the wider set of forces and systems shaping the conditions of daily life. The social determinants of health are mostly responsible for health inequities—the unfair and avoidable differences in health status seen within and between countries.’

The World Health Organization (WHO) 2015

The factors that contribute to the substantial disparity between Indigenous and non-Indigenous health are multi-faceted and inter-related. These include, but are not limited to: lower levels of education, lower employment rates, higher rates of smoking, less physical activity, more sedentary behaviour, poor nutrition, and being more overweight and obese, as well as reduced access to and uptake of health services. Indigenous Australians are also more likely to live in more geographically remote areas than their non-Indigenous counterparts, where access to services is further limited in relation to primary healthcare services, educational and employment opportunities, and income.

Other factors such as the racism and discrimination experienced by Indigenous Australians compound these disadvantages.
Indigenous Australians experience poorer overall health than other Australians. Life expectancy at birth is estimated to be 67 years for Indigenous males and 73 years for Indigenous females, representing gaps of 11.5 and 9.7 years, respectively, compared with other Australians. Chronic diseases are estimated to contribute about 80% to the mortality gap.\(^9\)

Cardiovascular diseases are collectively the largest cause of death among Indigenous Australians, followed by cancer.\(^9\) Until recently, cancer has been under-appreciated in relation to the impact it has had on an already marginalised community,\(^{13,14}\) a situation confirmed by a growing body of research evidence.\(^{14-17}\) Cancer is an important and growing contributor to the health inequalities faced by Indigenous Australians.\(^{14,18}\)

The differential health status of Indigenous and non-Indigenous people is an ongoing challenge for the Australian Government.\(^9\) The Council of Australian Governments (COAG) has set specific targets and interventions aimed at improving the health and welfare of Indigenous Australians to close the gap between Indigenous and non-Indigenous Australians.\(^9\)

It is important in considering Indigenous health to understand how Indigenous people conceptualise health.

### 1.4 Indigenous concepts and understanding of health and cancer

According to the National Aboriginal Health Strategy there is no separate term in any Indigenous Australian language for ‘health’ as it is understood in western society.\(^{19}\) There are distinct differences in the way Indigenous Australians
conceptualise their health from other Australians. More specifically, Indigenous Australian concepts of health extend beyond the physical well-being of an individual to the social, emotional and cultural well-being of the whole community. Health in Indigenous terms encompasses everything important in a person's life, including language, land, environment, physical body, community, relationships, and cultural law. It is described in the National Aboriginal Health Strategy as 'a whole-of-life view and includes the cyclical concept of life-death-life'.

In-depth studies of Indigenous Australian beliefs about cancer have reported that there is no specific word or term in Indigenous Australian languages that defines cancer. Cancer is often referred to by many Indigenous people as 'a death sentence'. Indigenous people’s fatalistic views and misunderstandings of cancer come largely from a lack of appropriate cancer education and understanding about the disease, as well as a reluctance to talk about cancer in their communities. In some communities there are also underlying cultural beliefs that cancer is a form of ‘payback’ for an unlawful wrongdoing. A cancer diagnosis has also been associated with shame and embarrassment in some Indigenous communities. In such instances, these views have been attributed to a passive acceptance of the disease and have in some cases resulted in reluctance to seek medical advice, follow-up or cancer treatment.
1.5 Cancer in Australia - an overview

1.5.1 Cancer incidence

Cancer is a major cause of illness in Australia and contributes to up to 19% of the total disease burden. In Australia, new cancer cases have more than doubled over the last two decades (47,417 in 1982 to 123,920 in 2014). The reasons for the increase are largely due to a rise in incidence of prostate, breast and colorectal cancers and improved population health screening programs, and in technologies to identify and diagnose cancers. The most commonly diagnosed cancers in Australia in 2014 were cancers of the prostate (17,050 cases), colorectum (16,640), and breast (15,410), melanoma of the skin (12,640) and lung cancer (11,580).

1.5.2 Cancer mortality

In 2014, cancer accounted for 30% of deaths (based on the underlying cause) registered in Australia. The age-standardised mortality rate for all cancers combined was estimated at 168 per 100,000. The leading causes of cancer death in Australia in 2014 were lung cancer (8,630 deaths), colorectal cancer (4,120), prostate cancer (3,390), breast cancer (3,030) and pancreatic cancer (2,640). These cancers combined represented almost half (48%) of all cancer deaths, with lung cancer alone accounting for 19% of deaths.

1.5.3 Cancer survival

Australians generally have better five-year survival rates than people living in other countries and regions. Five-year survival from all cancers combined was
67% between 2007 and 2011. The five-year relative survival was highest for Australians diagnosed with testicular cancer (98%), thyroid cancer (96%), lip cancer (93%), prostate cancer (93%) or melanoma of the skin (90%), and lowest for those diagnosed with pancreatic cancer (6%) or mesothelioma (6%).

1.6 Cancer and Indigenous Australians

Cancer outcomes in Australia differ across population groups. The burden of cancer for Indigenous Australians has only recently begun to be fully appreciated. This is perhaps not surprising given the large number of health conditions that are many times more common among Indigenous Australians than among other Australians. As noted in section 1.7, our ability to provide an accurate assessment of the cancer burden is compounded by deficiencies in data. The following section is based on available data and may underestimate the cancer burden.

1.6.1 Cancer incidence

On average, 840 Indigenous Australians are diagnosed with cancer each year, representing 1% of all cancer cases diagnosed in Australia from 2005–2009. Compared with other Australians, Indigenous people have a slightly lower age-standardised incidence of all cancers combined (443 and 421 per 100,000, respectively). However, for rapidly fatal cancers, the age-standardised incidence rate was significantly higher for Indigenous Australians than other Australians (e.g. lung 1.7 times higher, liver 2.8 times higher) and lower for cancers with better survival (e.g. prostate 0.6 times, breast 0.7 times). In addition, many
cancers that would be amenable to prevention through reduction in exposure to risk factors, or that are detectable early through screening programs, are more common among Indigenous people (e.g. cervical cancer 2.3 times higher).\textsuperscript{2,15,18}

The higher incidence rates of lung cancer and liver cancer are consistent with Indigenous Australians’ higher rates of smoking, risky alcohol consumption and chronic infections.\textsuperscript{14,16,18} The higher rate of cervical cancer diagnosed for Indigenous Australians may be partly attributed to a higher prevalence of chronic infections, such as the human papilloma virus\textsuperscript{18} and lower levels of participation in cervical screening programs\textsuperscript{15,24,25} and to greater exposure to risk factors associated with cervical cancer (such as higher rates of smoking and having more children).\textsuperscript{15,26}

Indigenous Australians are more likely to have their cancers diagnosed at a later stage than non-Indigenous Australians, when the primary site is no longer apparent.\textsuperscript{14,25} This may contribute to lower incidence rates for specific primary sites but a higher incidence rate of cancers of unknown primary site for Indigenous Australians than for non-Indigenous Australians.\textsuperscript{14,18} The uptake of screening and diagnostic testing (such as breast and bowel screening and prostate-specific antigen [PSA] testing) is lower among Indigenous people,\textsuperscript{2,18,25,27,28} which may also contribute to a lower rate of diagnosis or at least a lower rate of early diagnosis.

\textbf{1.6.2 Cancer mortality}

Cancer is the second leading cause of death among Indigenous Australians,\textsuperscript{2,18} accounting for an average 459 Indigenous Australians’ deaths annually between
2008 and 2012 (1.5% of all deaths due to cancer). The age-standardised mortality rate for all cancers combined is significantly higher for Indigenous Australians than for their non-Indigenous counterparts (221 versus 172 per 100,000, respectively).

Mortality rates also differ by cancer group. The highest average number of deaths per year (2008–2012) were from lung cancer (115 deaths), liver cancer (34), breast cancer (30), and cancer of the unknown primary site (27). Lung cancer alone accounted for 25% of all Indigenous deaths from cancer. The mortality rate was significantly higher for Indigenous than for non-Indigenous Australians for cervical cancer (3.4 times), lung cancer (1.7), cancer of unknown primary site (1.5), pancreatic cancer (1.2) and breast cancer (1.1), but lower for non-Hodgkin lymphoma (rate ratio of 0.9), colorectal cancer (0.8) and prostate cancer (0.8).

The reasons for higher mortality rates for Indigenous Australians are multifactorial, but the disparities faced by Indigenous Australians across a range of health-related and socioeconomic indicators, as well issues such as discrimination and social and cultural marginalisation are likely to be key contributors. Indigenous people are also more likely to be diagnosed with cancer at more advanced stages, and with cancers that have higher mortality rates than their non-Indigenous counterparts. Indigenous Australians with cancer also have a greater number of co-morbidities than other Australians with cancer, with diabetes being the most commonly reported comorbidity.
1.6.3 Cancer survival

The stage at cancer diagnosis (i.e. the extent or spread of cancer when it was diagnosed) and subsequent treatment outcomes are important determinants of cancer survival. They can also reflect the extent to which improvements in survival are a result of earlier detection or better treatment. Indigenous Australians are more likely to present with advanced cancer at diagnosis, and have reduced access to, and uptake of, treatment. Other factors such as language barriers, a lack of culturally appropriate information and competing social, cultural and family demands may also result in less comprehensive cancer treatment and contribute to poorer cancer outcomes for Indigenous Australians.

While the incidence of many types of cancer is lower among Indigenous Australians than among non-Indigenous Australians, survival rates for Indigenous Australians diagnosed with cancer are much lower. Between 1999 and 2007, Indigenous Australians had a 40% chance of surviving at least five years after their initial cancer diagnosis, whereas the survival rate for their non-Indigenous counterparts for the same time period was 52%. A Queensland population-based study found that 50% excess in mortality for Indigenous Australians occurred in the first year after their cancer diagnosis (adjusted hazard ratio [HR], 1.50; 95% confidence interval [CI], 1.38–1.63).

Whilst Indigenous people are more likely to be diagnosed at advanced stages with certain cancers, or to receive less treatment, this does not completely explain the survival disadvantage. Indigenous patients treated in the public health system in Queensland were found to be 30% more likely to die from their cancer than non-Indigenous patients even after taking into account
stage at diagnosis, cancer treatment and presence of co-morbidities. Similar results were also reported in the Northern Territory.

Communication difficulties, knowledge of cancer symptoms and attitudes towards treatment and cultural appropriateness of the health service may be factors that contributed to the sustained poorer cancer outcomes. In a Queensland study, access to services and socioeconomic factors were unlikely to be the main causes of the early lower Indigenous survival, as outcomes were reported to be similar across categories of remoteness and socioeconomic disadvantage. Indigenous Australians continue to face a poorer survival outlook than their non-Indigenous counterparts and the factors leading to these poor outcomes after their cancer diagnosis remain unclear.

1.7 Cancer data and Indigenous Australians

Further complicating the picture is that many Indigenous cancer patients are not identified as being of Indigenous descent in administrative databases. Thus the figures presented in section 1.6 may underestimate the cancer burden among Indigenous Australians.

1.7.1 Cancer incidence

State and territory cancer registries are the key sources of data on cancer patterns. In Australia, all state and territory cancer registries collect information on Indigenous status. However, only four jurisdictions (New South Wales, Queensland, Western Australia and the Northern Territory) are considered to have information on Indigenous status of sufficient completeness.
for reporting. Whilst these four jurisdictions include over 80% of the Australian Indigenous population, the representativeness of these data for all Indigenous people is unknown.\textsuperscript{2,16} It remains an indictment that reliable national data on the diagnosis of cancer for all Indigenous Australians are not available; instead, Indigenous cancer incidence data are estimated from just four of the eight Australian jurisdictions.\textsuperscript{2} This, in turn, may result in an underestimation of the burden of cancer among Indigenous Australians.

1.7.2 Cancer mortality

The main data source used to report cancer mortality is the Australian Institute of Health and Welfare’s National Mortality Database (NMD). This database contains information about all deaths registered in Australia and is believed to have sufficient data quality on Indigenous status for reporting in five jurisdictions (New South Wales, Queensland, Western Australia, South Australia and the Northern Territory). This representation is slightly better than the cancer registry data as the NMD data represent jurisdictions where 89% of Indigenous people live.\textsuperscript{2}

1.7.3 Cancer screening programs

Australia has three national population-based cancer screening programs (breast, bowel and cervical). The capability of these population-based cancer screening programs to report on Indigenous data is varied.
1.7.3.1 BreastScreen

BreastScreen Australia was established in 1991 and its primary aim is to encourage women aged 50–69 years to have screening mammograms once every two years. This program is able to report on Indigenous women’s participation as well as their performance against other reportable indicators because self-reported Indigenous status is collected on the BreastScreen Australia form. The estimated participation rate for Indigenous women in the target age-range between 2010 and 2011 was 36%, compared to 54% for non-Indigenous women.\(^2\)

1.7.3.2 National Bowel Cancer Screening Program

This bowel cancer screening program commenced in Australia in 2006. The program offers free screening, using a faecal occult blood test (FOBT), to people turning 50, 55, 60 and 65 years of age. Identification of Indigenous participants in the National Bowel Cancer Screening Program is not known at the time of invitation, and is only collected once a person completes and returns the test.\(^2\) Therefore, it is not possible to calculate the participation rate for Indigenous people. Over a one-year period (between July 2011 and June 2012), 1,919 (0.6%) of all participants in this program identified as Indigenous Australians.

1.7.3.3 National Cervical Screening Program

Since its establishment in 1991, the National Cervical Screening Program has been unable to report on Indigenous Australian women’s participation in the program. The primary reason for this is that there is no national mechanism for reporting Aboriginal or Torres Strait Islander identification because pathology
forms (the main data source for Pap Smear Registers) do not collect Indigenous status. Therefore, national reporting of cervical screening indicators for Indigenous women is not possible. However, localised studies have consistently reported lower participation rates for Indigenous women,\textsuperscript{38,39} albeit with a large variation across communities. A large national data linkage study is currently underway to estimate participation and follow-up for the first time.\textsuperscript{24}

While our knowledge and understanding of cancer and its impact on Indigenous people with cancer has improved in recent years, important gaps remain and better data are required.

1.8 Summary

Indigenous Australians experience a higher incidence of high fatality cancers, more advanced stage of cancer at diagnosis, greater levels of co-morbid illness, poorer access to care and less comprehensive treatment.\textsuperscript{2,14,17,32,33} For many Indigenous people, cancer is seen as a death sentence and treatment is therefore not always regarded as a high priority.\textsuperscript{5,22} Competing social, cultural and family demands may also result in less comprehensive cancer treatment.\textsuperscript{3} Clearly there are significant disparities in cancer outcomes between Indigenous and non-Indigenous Australians and the need to improve cancer care and related health services for Indigenous Australians is apparent. To maximize Indigenous cancer survivors’ health and health care, cancer care providers also need to better respond to the psychological, social and cultural factors faced by Indigenous people with cancer.
1.9 Psychosocial aspects of cancer care

It is well documented that the patterns of cancer care between Indigenous and non-Indigenous patients differ, with Indigenous patients often receiving less optimal treatment and experiencing significantly worse cancer outcomes. Indigenous Australians’ engagement in cancer care is lower at all stages of the cancer continuum, including screening, early presentation at diagnosis, continuity of care, compliance with treatment and survivorship. This has resulted in significantly poorer cancer outcomes in terms of incidence, mortality and survival as outlined in section 1.6.

Aspects of the broader social environment can also influence (negatively or positively) the way individuals, families and communities engage with health care and manage their own health. Understanding Indigenous people’s experience of cancer must take account of the social determinants of health and the cultural context of people’s lives, and these should be reflected in service delivery models and in the delivery of cancer care. Accessing health services is an important determinant of health outcomes for preventative care and treatment, and many Indigenous people have poorer access to these services.

In recognition that there are cultural differences in the way many Indigenous people perceive cancer (a highly feared disease that equates to death), receive and process information about their cancer diagnosis and treatment, and cope with illness, research into the psychosocial factors and specific supportive care needs of Indigenous people with cancer is imperative. However, to date we know relatively little about the psychosocial issues and support needs of Indigenous cancer patients and their families, including what they require in order to engage productively with health services. This research is crucial.
for the provision of more appropriate supportive care for Indigenous people with cancer and to help reduce the disparities in cancer care among Indigenous people.

1.9.1 Barriers to accessing appropriate cancer care

Considerable qualitative literature exists that explores some of the barriers to accessing appropriate cancer care for Indigenous Australian cancer patients. These barriers are described in detail below, but in brief, they include, but are not limited to, infrastructure and logistical factors, health care system issues, communication and health literacy.

Basic infrastructure and logistical issues, such as lack of transport and suitable accommodation, are reported to impede Indigenous Australians’ access to cancer care and treatment services.\textsuperscript{3,4,12,44} Cancer patients often have to relocate to large metropolitan cities for their treatment, which may result in Indigenous patients feeling isolated, scared and disorientated.\textsuperscript{3} Additionally, patients are displaced from their family and community.\textsuperscript{3,45} These factors are often cited as reasons for Indigenous cancer patients not commencing or completing treatment.\textsuperscript{3} Although patients in Australia have access to a Patient Assisted Travel Scheme (PATS), not all benefit from this scheme.\textsuperscript{3,45} Many Indigenous people do not access PATS services or financial assistance programs, as they often feel intimidated, confused or overwhelmed when provided with significant amounts of new and technical information in the context of dealing with a major life event such as a cancer diagnosis.\textsuperscript{3,12}
The barriers to Indigenous Australians accessing and participating in cancer care should be considered within the broader sociocultural and political context including racism and mistrust of the system. Indigenous Australians’ collective experience of racism, discrimination, alienation and marginalisation has led to widespread distrust of health care systems including cancer care and treatment services. At the system level, it has been widely recognised that there is a lack of culturally appropriate health care services to engage Indigenous Australians. Differences in communication, information needs and language have inhibited Indigenous people’s engagement in cancer care. For example, in a study conducted in Queensland with cancer care health professionals, participants reported doubts about their ability to adequately communicate important information to Indigenous patients and they remarked that ‘Aboriginal patients seem to be a bit harder to identify what their concerns are, because they tend to shut down…’ Effective communication between patients and their physicians is essential to ensure optimal patient outcomes. Language used by health professionals could be viewed by Indigenous Australians as an indicator of cultural distance.

It is widely acknowledged that individuals with low health literacy want to be involved in health decisions but often lack the knowledge, skills and confidence to communicate with health professionals, navigate the health system, and engage in shared decision making. Importantly, they receive less information, ask fewer questions and are less satisfied with health care provider communication. Although many Indigenous Australians (83%) are proficient in English, language and literacy are commonly reported to be barriers to accessing health care and support services. These barriers may be due to
awareness, knowledge and understanding of cancer being largely absent from Indigenous people’s lives as well as a reluctance to talk about cancer in their communities as discussed in section 1.4. Additionally, cancer care professionals may not tailor their language to ensure that Indigenous patients fully comprehend their diagnoses, prognoses and treatment options.\textsuperscript{56} The differential in health literacy may also be due to the lack of access to appropriate cancer information tailored for the Indigenous population,\textsuperscript{4,57} thus illustrating the need for targeted cancer awareness programs among Indigenous people and their communities. As one report summed up the situation:

\begin{quote}
\textit{The maze that confuses so many cancer patients is completely un-negotiable for many Aboriginal people, given the financial, organisational, geographic and communication barriers. Many simply withdraw from active treatment after their initial experience of it.}\textsuperscript{58, p.18}
\end{quote}

There is a clear need to improve Indigenous patient cancer care.

\subsection*{1.9.2 Patient reported outcomes}

Increasingly, patient reported outcome (PRO) measures are being used to assess areas of patient care following a cancer diagnosis and to assist health professionals to tailor their health practices to the individual needs of the patient.\textsuperscript{6-8} PRO measures include a range of constructs that can be reported by the patient, including psychological symptoms and side effects (e.g. distress, pain, anxiety, nausea, fatigue), aspects of functioning (e.g. role, physical) and multi-dimensional constructs (e.g. health related quality of life).\textsuperscript{7,8} A number of
different strategies have been developed to assess various aspects of PROs, such as quality of life questionnaires, pain scales, satisfaction with care surveys and unmet supportive care needs questionnaires.

1.9.2.1 Supportive care in cancer

Supportive care in cancer settings aims to prevent, reduce and alleviate the symptoms of treatment, enhance communication between patients and clinicians, and assist patients and their family to manage needs associated with the diagnosis and treatment of cancer across a number of inter-related domains of care. These domains include physical needs, psychological needs, social needs and information and spiritual needs.

An expanding body of evidence demonstrates the value of supportive care approaches in improving experiences and outcomes for those affected by cancer. Although the provision of supportive care across the cancer trajectory is generally of a very high standard in Australia, it is recognised that disparities exist between groups.

The National Cancer Control Initiative recommended ‘[t]hat the needs of special populations, especially Aboriginal peoples, be the focus of special efforts to bridge the current gaps in access to and utilisation of culturally sensitive cancer service.’

Conducting a needs assessment allows health professionals to directly assess a cancer patient’s experiences as well as their desire for help in specific areas. Needs assessments identify gaps in service provision and can highlight where additional services and resources might be needed. Furthermore, screening
for unmet support needs among cancer patients is considered best practice and is associated with enhanced health outcomes, health care cost savings and better quality service delivery.

Given the poor cancer prognosis and the unique barriers Indigenous patients face in accessing quality cancer treatment and care, it is likely that Indigenous cancer patients are faced with specific and high levels of unmet supportive care needs. Currently, however, little is known about the supportive care needs of Indigenous Australians and their preferences for support throughout diagnosis, treatment and palliative care or survivorship.

Further, existing needs assessment tools have not been validated in an Indigenous cancer population, nor are there any needs assessment measures which incorporate Indigenous-specific questionnaire items.

1.9.2.2 Health-related quality of life

A cancer diagnosis and the subsequent treatment may have considerable impact on a patient’s quality of life. Increasingly, clinicians have recognised that while traditional endpoints such as morbidity and mortality are important factors for cancer patients, overall health-related quality of life (HRQoL) is fundamental to a patient’s care. HRQoL has been defined as a multidimensional construct that incorporates a person’s perceptions of his or her physical and psychological functioning and social well-being as well as physical symptoms of the disease, its treatment and side-effects. As illustrated in Figure 2 below, other factors (e.g. economic, disease symptoms, adverse drug
reactions [ADRs], patient education, etc.) can also impact on a person’s HRQoL.\textsuperscript{81}

\textbf{Figure 2 Factors affecting a patient’s quality of life}

Source: Deshpande et al.\textsuperscript{81, p.139.}

HRQoL is inherently subjective and therefore must be reported or rated by the individuals themselves.\textsuperscript{81} The use of patient-reported outcomes questionnaires has become standard practice for assessing HRQoL.\textsuperscript{81} A range of questionnaires of varying length and emphasis have been developed to assess cancer patients’ HRQoL.\textsuperscript{75} Quality of life measures are increasingly used in the assessment of almost all types of cancer and other health conditions among the general cancer population, but to date we know relatively little about the quality of life of Indigenous cancer survivors.
1.9.2.3 Distress

Cancer is not only a series of very different diseases requiring complex treatments, it is also a devastating and traumatic event and a threat to life itself. A significant proportion of all cancer patients at all stages of the disease will suffer social, emotional and psychological distress and challenges to their emotional well-being as a result of the disease and its treatment.\(^{73}\) It is likely that this is the case also for Indigenous cancer patients who often present with more complex health and well-being issues.\(^{4,17}\)

Cancer can affect a person in many ways.\(^{82}\) The diagnosis may cause fear, anxiety and depression. Psychological distress, the symptoms of cancer and side effects from its treatment can all impact negatively on well-being and affect everyday roles and activities.\(^{82}\) For example, a cancer diagnosis and subsequent treatment may impact on patients’ psychological and physical health, sexuality, body image, finances, relationships and their ability to continue to work and fulfil their role at home.\(^{82,83}\) For this reason, optimal care of the patient with cancer incorporates effective physical and psychological care through the disease trajectory and into survivorship.

Routine screening of cancer patients for psychological distress using validated measures is supported across the world.\(^{84}\) This international support has led to distress being endorsed by The International Psycho-Oncology Society and affiliated organisations as the sixth vital sign in cancer care.\(^{85}\)

Distress screening has been shown to be acceptable and feasible and has been demonstrated to lead to better patient outcomes, improved quality of service delivery and decreased health care costs.\(^{70}\) Given the poorer prognosis for Indigenous Australians with cancer, it is paramount that we gain a more
comprehensive understanding of Indigenous cancer patients’ psychological distress to ensure their optimal management and care.

1.10 Study aims and methods

This thesis is a direct outcome of recent important developments in the emerging field of Indigenous cancer control and reflects the paucity of research on psychosocial aspects of cancer care for Indigenous Australians. The overall aim of this thesis is to report on research on the psychosocial factors that may impact on the cancer care and outcomes of Indigenous Australian cancer patients.

1.10.1 Objectives

The specific objectives addressed by the studies included in this thesis are:

1. To comprehensively assess the suitability and relevance (face and content validity and cultural acceptability) of a commonly used measure, The Supportive Care Needs Survey—Short Form 34 (SCNS-SF34) for use with Indigenous cancer patients (Chapter 2).

2. To assess the content and construct validity and the internal reliability of the tool developed in Aim 1 (Chapter 3).

3. To test the feasibility of implementing the tool developed in Aim 2 for use in the clinical and cancer care setting (Chapter 4).

4. To report the prevalence of and selected demographic and clinical factors associated with quality of life of Indigenous cancer patients using an existing questionnaire (Chapter 5).
5. To investigate the prevalence of and selected demographic and clinical factors associated with distress among Indigenous cancer patients using an existing tool (Chapter 6).

1.10.2 Statement of ethical clearances

Approval for components of this work was obtained from a range of Human Research Ethics Committees (HREC). Approval for the research undertaken in chapters 2, 3, 5 and 6 was granted by The Queensland Institute of Medical Research (P1219); Royal Brisbane and Women’s Hospital, Metro North District, Queensland (HREC/09/QRBW/127); and Queensland Health Multi-site Toowoomba and Darling Downs Health Service District (HREC/10/QTDD/61). Reciprocal approval was also gained from the Northern Territory Department of Health and Menzies School of Health Research HREC (HREC-2-11-1691).

Approval for the research undertaken in Chapter 4 was granted by the Northern Territory Department of Health and Menzies School of Health Research HREC (HREC13/1994); Peter MacCallum Cancer Centre (HREC/13/45); Greater Western HREC (HRECI131GWAHSI39); and the Aboriginal Health and Medical Research Council of New South Wales (HREC/946/12). The content of the manuscript was subject to approval by the Aboriginal Health and Medical Research Council of New South Wales in accordance with the standard conditions of their ethical approval.
1.10.3 Methods and description of studies

The specific methods used and funding support for each project are described in each of the respective chapters. The study conducted in Chapter 2 was funded by an Australian Research Council, Indigenous Research Development grant (ARC-IRD DO1989086) in 2008–2009 titled ‘Evaluation of an instrument to assess the needs of Indigenous patients with cancer’ and the study conducted in Chapter 4 was funded by the Lowitja Institute in 2013–2014 and titled ‘Implementation and evaluation of a Supportive Cancer Care Needs Assessment Tool for Aboriginal and Torres Strait Islander people (SCNAT-IP) with cancer’.

Studies conducted in chapters 3 (psychometric assessment of SCNAT-IP), 5 (quality of life) and 6 (distress) were also a sub-set of a much larger longitudinal study conducted in Queensland to assess the unmet supportive needs and quality of life of Indigenous Australian adult cancer patients. This larger study, titled ‘Closing the divide: assessing and navigating the unmet supportive care needs of Indigenous cancer patients’ was funded by the National Health and Medical Research Council (NHMRC #552414) and is acknowledged in each of the respective chapters. The ‘Closing the divide’ study was conducted between November 2010 and December 2012 and adult Indigenous cancer patients were recruited from the four main cancer treatment public hospitals in Queensland (Figure 3). Nine Indigenous and four non-Indigenous trained interviewers collected data via interview, using a structured questionnaire at three time points: at recruitment (via face-to-face), three and six months after recruitment (via face-to-face or telephone).
Studies were conducted to address the aims of the thesis and in so doing, fill some of the knowledge gaps previously highlighted.

Whilst a range of guidelines, tools and educational resources have been developed to support health professionals in identifying and managing psychosocial aspects of care for cancer patients, there remains a need for cultural sensitivity in the assessment of supportive care needs. Chapter 2 assessed the suitability and relevance (face and content validity and cultural acceptability) of a supportive care needs tool (SCNS-SF34) that is widely used in the cancer care setting, and concluded that Indigenous people with cancer have language, customs and specific needs that are not accommodated within the...
standard supportive care needs tools. A new tool (SCNAT-IP) to assess the supportive care needs of Indigenous cancer patients was developed.

Chapter 3 evaluated the psychometric properties of the SCNAT-IP and for the first time in Australia described the prevalence of unmet support needs among the sample of Indigenous adults with cancer using the SCNAT-IP.

Chapter 4 tested the feasibility of using the SCNAT-IP among health professionals and Indigenous cancer patients in the usual cancer care setting.

Chapters 5 and 6 used existing patient reported outcome measures, not specifically developed for Indigenous cancer patients, to assess HRQoL and levels of distress among Indigenous adult cancer patients.

Chapter 7 summarises and discusses the thesis findings and limitations, and the work still needed in this area.
1.11 Bibliography


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Chapter 2  DEVELOPMENT OF A SUPPORTIVE CARE NEEDS ASSESSMENT TOOL FOR INDIGENOUS PEOPLE (SCNAT-IP) WITH CANCER
2.1 Preface

This chapter presents an assessment of the suitability and relevance (face and content validity and cultural acceptability) of a widely used supportive care needs tool (Supportive Care Needs Survey-Short Form 34 [SCNS-SF34]) for use with Indigenous Australian cancer patients.

This represents the initial stage of the development of a new Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP). This chapter has been written as a journal article of which I am the principal author. The article was published in *BMC Cancer* and is presented here in its entirety.


2.2 Statement of authorship

The contributions of all co-authors are clearly outlined below. Furthermore, all co-authors have emailed written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.

2.3 Author contributions

GG, PV, and VB conceptualised the study. GG, PV, VB, MJ, AG and PO contributed to the study design. GG, PV and CJ conducted the approval process and study coordination. GG and PV conducted the data analysis and GG drafted
the initial manuscript. All authors contributed to the revision of the manuscript, and read and approved the final draft.

2.4 Published article
The development of a supportive care needs assessment tool for Indigenous people with cancer

Gail Garvey, Vanessa L Beasley, Monika Janda, Catherine Jacka, Adèle C Green, Peter O'Rourke and Patricia C Valery

Abstract

Background: Little is known about the supportive care needs of Indigenous people with cancer and to date, existing needs assessment tools have not considered cultural issues for this population. We aimed to adapt an existing supportive care needs assessment tool for use with Indigenous Australians with cancer.

Methods: Face-to-face interviews with Indigenous cancer patients (n = 29) and five focus groups with Indigenous key-informants (n = 23) were conducted to assess the face and content validity, cultural acceptability, utility and relevance of the Supportive Care Needs Survey - Short Form 34 (SCNS-SF34) for use with Indigenous patients with cancer.

Results: All items from the SCNS-SF34 were shortened and changed to use more appropriate language (e.g. the word ‘anxiety’ was substituted with ‘worry’). Seven questions were omitted (e.g. items on death and future considerations) as they were deemed culturally inappropriate or irrelevant and 12 items were added (e.g. accessible transport). Optional instructions were added before the sexual items. The design and response format of the SCNS-SF34 was modified to make it easier to use for Indigenous cancer patients. Given the extensive modifications to the SCNS-SF34 and the likelihood of a different factor structure we consider this tool to be a new tool rather than a modification. The Supportive care needs assessment tool for Indigenous people (SCNAT-IP) shows promising face and content validity and will be useful in informing services where they need to direct their attention for these patients.

Conclusions: Indigenous people with cancer have language, customs and specific needs that are not accommodated within the standard SCNS-SF34. Our SCNAT-IP improves acceptability, relevance and face validity for Indigenous-specific concerns. Our SCNAT-IP will allow screening for supportive care needs that are specific to Indigenous cancer patients and greatly inform targeted policy development and practice.

Background

Aboriginal and Torres Strait Islander Australians (referred to here as Indigenous Australians) have a lower incidence of cancer overall compared to non-Indigenous Australians [1] although the incidence rates for some cancers are much greater e.g. cervical cancer (18 vs. 7 cases/100,000, respectively) [1]. Additionally, Indigenous Australian cancer patients are more likely to be diagnosed with cancer at advanced stages, and with cancers that have higher mortality rates; they also have a greater number of co-morbidities [2,3]. As a result Indigenous Australians have cancer mortality rates up to 45% higher than other Australians [3-5]. Indigenous Australians, as do Indigenous peoples from other countries such as New Zealand, Canada and the US differ from their non-Indigenous counterparts in the way they conceptualize health and their cultural and belief systems [5]. They have a long history of dispossession, discrimination and social and economic marginalization [1] which may contribute to the disparity in mortality.
Although many Indigenous people (83%) are proficient in English, language is commonly reported as a barrier to accessing health care and support services [4]. Whilst accessing health services is an important determinant of health outcomes for preventative care and treatment, many Indigenous people do not access these services [5,6]. For example in Australia, Canada, New Zealand and the United States, Indigenous women are less likely to participate in cervical screening programs in comparison to the respective country uptake rates [5]. Basic infrastructure and logistical issues such as the lack of transport and having appropriate travel arrangements, and suitable accommodation for both the patient and their support person/companion may also impede Indigenous people’s access to cancer care and treatment services [7]. In recognition that there are cultural differences in the way most Indigenous peoples perceive cancer (a highly feared disease that equates to death), receive and process information about their cancer diagnosis and treatment, and cope with illness [5,8-12], research into the specific supportive care needs of Indigenous populations is crucial for provision of appropriate supportive care. These underlying beliefs can bring on additional stress and may also prevent them from accessing cancer services and/or commencing or completing cancer treatments.

To assess the supportive care needs of cancer patients, a number of self-administered questionnaires have been developed [13-15]. The Supportive Care Needs Survey Short Form 34 (SCNS-SF34) is commonly used to measure the perceived support needs of adult cancer patients across five domains (psychological, health system and information, physical and daily living, patient care and support and sexuality needs) [14,16]. However, the ability of this tool and others like it to detect and accurately measure the supportive care needs of Indigenous people with cancer remains untested. To date, none of the existing need assessment tools have been validated in an Indigenous cancer population, nor are there any supportive care needs assessment measures which incorporate Indigenous-specific survey items.

This study employed qualitative research methods to assess the face and content validity of the SCNS-SF34 for Indigenous people with cancer and to develop new Indigenous-specific items for use in conjunction with the modified instrument.

Methods

Participants and recruitment

All participants resided in Queensland, were Indigenous adults, able to understand English, and physically and mentally capable of participating in the study.

Indigenous cancer patients were eligible to participate in the study if they were hospitalised or attending a hospital outpatient clinic at one of two major Queensland public hospitals for their cancer diagnosis, treatment or follow-up care. Indigenous patients were initially approached by hospital staff who informed them about the study and gained consent to give their contact details to project staff. They were then contacted by project staff, given more detailed information about the study and after written consent was obtained, an interview was organized.

Indigenous key-informants were recruited from community health centres, public hospitals, Indigenous organizations, and the wider Indigenous Queensland community. Key-informants were eligible to participate if they had a good understanding of the Indigenous community as a whole and/or had a particular interest or involvement in the field of health and/or cancer management.

Data collection

Members of the research team (C.J. S.M. L.W & G.G) conducted, and audio-recorded for later transcription, semi-structured interviews with individual Indigenous cancer patients and focus group discussions with Indigenous key-informants (Figure 1).

Stage 1: Patient interviews and key informant focus groups

Patient Interviews

Participants were shown the SCNS-SF34 [14] in its entirety (introduction; 34 need items; and a 5-point response scale), and provided with two examples on how to complete the SCNS-SF34. In addition, participants were presented with an alternative response scale used in an amended version of the SCNS-SF34 for culturally and linguistically diverse patients (CALD-UNS) (Figure 2) [17]. Participants indicated the preferred survey response scale they wanted to use for the remainder of the interview. Once selected, the interviewer verbally administered the SCNS-SF34 aided by a ‘participant response booklet’ developed specifically for this study, to enable participants to visually see and choose their response option. Verbal administration of the survey was used to increase participation and survey completion rates in this cultural group where difficulty with reading is often reported [1]. Participants commented on the appropriateness of content, relevance, acceptability of the items, and if any items were difficult to understand. They provided suggestions on how to re-word such items, and suggested any additional items that they felt were important and but were not already included. Furthermore, participants commented on the format of the questionnaire including response categories, layout, and length of the survey.

Key informant focus groups

Participants were presented with the study definition of supportive care: ‘Supportive care is the services or resources
that helps cancer patients with their physical, information, practical, emotional, psychological, social and spiritual needs; and identified any 'support issues' that Indigenous cancer patients may need help with during diagnosis, treatment or follow-up care. Brainstormed ideas were summarized and later transcribed from a whiteboard.

Participants were provided with a copy of the SCNNS-SF34 items with the lead in instructions and response scale from the CALD-UNS, as it was conclusive from the patient interviews that the CALD-UNS response format was overwhelmingly preferred. Participants were provided general comments on the questionnaire format,
presentation of the questions, and any items that might be ambiguous or difficult to answer.

The group then undertook a closer review of each of the individual survey items (Table 1). Items that were deemed unclear, culturally inappropriate or irrelevant by two or more participants were discussed further to identify if they should be rephrased or discarded. Finally, upon reflection on existing items and the brainstormed list of support issues for Indigenous cancer patients, new items to include in the survey were suggested by participants. The focus groups ranged from 2 to 3 hours in length, including refreshment breaks.

Transcripts were provided to each member of the study team and discussed at a team meeting, resulting in version 1 of the Supportive Care Needs Assessment Tool - Indigenous People (SCNAT-IP).

Stage 2: Further refinement of the items and rating of importance of items

Stage 1 procedures were repeated using version 1 of the SCNAT-IP with seven newly recruited Indigenous cancer patients and 10 key-informants (Figure 1). Key-informants were asked to rank the importance of individual items using a 3-point Likert scale (not important at all, important, top priority) with the aim of reducing the overall number of items by discarding the items deemed not important at all (scored 1). The outcomes of this stage resulted in version 2 of the SCNAT-IP.

Stage 3: Final refinement of selected items and modification to survey instructions

A final focus group was held with 4 key-informants. The purpose of this stage was to finalize three items where agreement had not been reached previously and to finalize the introductory instructions of the tool. Participants were given the wording of the original item from the SCNS-SF34, and the various iterations of these items from previous stages. They were asked to suggest how best to word the items and instructions. The outcomes of this stage resulted in version 3 of the SCNAT-IP.

At the completion of each interview/focus group, participants completed a short questionnaire about their demographic characteristics (Indigenous status, age, gender, place of residence, family income, level of employment and cancer diagnosis and treatment (if appropriate). All participants were offered reimbursement of parking and travel costs. The study was approved by Queensland Institute of Medical Research Human Ethics Committee and the ethics committees from the participating hospitals.

Results

Participant characteristics

In total, 54 participants were included: 29 Indigenous cancer patients and 23 Indigenous key-informants.

The patient participants had an average age of 53 years (range 29 to 75 years). They were mostly women (n = 19, 66%), married or living with a partner (n = 17, 59%), had completed part or all of high school (n = 14, 49%), and lived in accessible/highly accessible areas (n = 17, 59%). Participants were newly diagnosed with gynecological (n = 9, 31%), lung (n = 7, 24%), breast (n = 5, 14%), blood (n = 3, 10%), bowel (n = 2, 7%), brain (n = 1, 3%), prostate (n = 1, 3%), or thyroid (n = 1, 3%) cancers and all were receiving cancer treatment at the time of the study. Most patients (n = 24, 83%) attended the Royal Brisbane and Women’s Hospital.
<table>
<thead>
<tr>
<th>Original item</th>
<th>Final items in SCNAT-IP</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Pain</td>
<td>Physical pain (e.g., hurt)</td>
</tr>
<tr>
<td>2 Lack of energy/tiredness</td>
<td>Feeling tired (e.g., sleeping ok)</td>
</tr>
<tr>
<td>3 Feeling unwell a lot of the time</td>
<td>Not feeling well (e.g., feeling rotten, crock or sick) a lot of the time</td>
</tr>
<tr>
<td>4 Work around the home</td>
<td>Work around the home (e.g., washing, cooking, raking the yard, sweeping the floor)</td>
</tr>
<tr>
<td>5 Not being able to do the things you used to do</td>
<td>Doing the things you used to do (e.g., fishing, walking, seeing family)</td>
</tr>
<tr>
<td>6 Anxiety</td>
<td>Anxiety (e.g., worrying, fear, concern)</td>
</tr>
<tr>
<td>7 Feeling down or depressed</td>
<td>Feeling down or sad</td>
</tr>
<tr>
<td>8 Feeling of sadness</td>
<td></td>
</tr>
<tr>
<td>9 Fears about the cancer spreading</td>
<td>Worrying about your illness spreading or getting worse</td>
</tr>
<tr>
<td>10 Worry that the results of treatment are beyond your control</td>
<td>Worry about the results of the treatment</td>
</tr>
<tr>
<td>11 Uncertainty about the future</td>
<td></td>
</tr>
<tr>
<td>12 Learning to feel in control of your situation</td>
<td></td>
</tr>
<tr>
<td>13 Keeping a positive outlook</td>
<td>Keeping you strong in your spirit (e.g., staying positive)</td>
</tr>
<tr>
<td>14 Feelings about death and dying</td>
<td></td>
</tr>
<tr>
<td>15 Changes in sexual feelings</td>
<td>Changes in sexual feelings (optional question)</td>
</tr>
<tr>
<td>16 Changes in your sexual relationships</td>
<td></td>
</tr>
<tr>
<td>17 Concerns about the worries of those close to you</td>
<td>Concerns about the worries of those close to you (e.g., family and friends)</td>
</tr>
<tr>
<td>18 More choice about which cancer specialists you see</td>
<td></td>
</tr>
<tr>
<td>19 More choice about which hospital you attend</td>
<td>Having choice about which hospital you attend</td>
</tr>
<tr>
<td>20 Reassurance by medical staff that the way you feel is normal</td>
<td>Support by staff that the way you feel is normal (e.g., common, typical)</td>
</tr>
<tr>
<td>21 Hospital staff attending promptly to your physical needs</td>
<td>Having hospital staff attending quickly to your physical needs (e.g., if you needed assistance getting out of bed)</td>
</tr>
<tr>
<td>22 Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs</td>
<td>Having hospital staff show sensitivity to and respecting your feelings and emotional needs</td>
</tr>
<tr>
<td>23 Being given written information about the important aspects of your care</td>
<td>Being shown or given information (e.g., written, diagrams) about how to manage your treatment, illness and side-effects in hospital</td>
</tr>
<tr>
<td>24 Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home</td>
<td>Being shown or given information (e.g., written, diagrams) about how to manage your illness and side-effects at home</td>
</tr>
<tr>
<td>25 Being given explanations of those tests for which you would like explanations</td>
<td>Explaining what tests are for</td>
</tr>
<tr>
<td>26 Being adequately informed about the benefits and side effects of treatments before you chose to have them</td>
<td>Understanding the good and bad effects of treatments before you chose to have them (e.g., having someone explain these to you)</td>
</tr>
<tr>
<td>27 Being informed about your test results as soon as possible</td>
<td>Being told about your test results as soon as possible</td>
</tr>
<tr>
<td>28 Being informed about which treatment is under control or remission (e.g., report, clear, new)</td>
<td>Being told about whether your cancer is in remission (e.g., fading or finishing)</td>
</tr>
<tr>
<td>29 Being informed about what you can do to help yourself get well</td>
<td>Being told about things you can do to help yourself get well (e.g., safe exercises, what you eat)</td>
</tr>
<tr>
<td>30 Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it</td>
<td>Having access to professional counselling (e.g., psychologist, social worker, Aboriginal Liaison Officer) if you or family and friends need it</td>
</tr>
<tr>
<td>31 To be given information about sexual relationships</td>
<td>To be given information about sexual relationships (optional question)</td>
</tr>
<tr>
<td>32 Being treated like a person not just another case</td>
<td>Being treated like a person not just another case or a number</td>
</tr>
</tbody>
</table>
Table 1 The original SCNS-SF34 items and wording changes included in the SCNAT-IP (Continued)

<table>
<thead>
<tr>
<th></th>
<th>Being treated in a hospital or clinic that is as physically pleasant as possible</th>
<th>Having one hospital person you can talk to about your condition, treatment and follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>33</td>
<td>Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up</td>
<td></td>
</tr>
</tbody>
</table>

Key-informants had an average age of 44 years (range 18 to 64 years), were mostly women (n = 15, 60%), lived in accessible/highly accessible areas (n = 21, 84%), had completed high school and/or done further training (n = 18, 72%), and their main occupations were hospital liaison officers (n = 5, 20%) or community health workers (n = 5, 20%).

Outcomes of Stage 1

Instructions and response scale

All patients preferred the CALD-UNS survey instructions. Several found the ‘participant response booklet’ useful, however it was of little help to a few patients who had poor reading ability. The participants agreed that the 3 sexual items should be moved together and prefaced with the following instructions: The next 3 questions are about sexual needs. If you prefer not to answer these, please tick this box and go to the next question. The shading of the alternative items in the original SCNS-SF34 was confusing and was therefore removed.

Modified items

Participants modified 17 items from the original SCNS-SF34. This mostly involved alteration of a specific word (s), simplification of wording or addition of example(s) to give an increased understanding of the item e.g. ‘Not being able to do the things you used to do’ was changed to ‘Doing the things you used to do (e.g., fishing, walking, seeing family). ’Fears about the cancer spreading’ was re-worded to ‘Worrying about your illness spreading or getting worse’ as participants reported ‘It’s a death sentence, just the word cancer.’

Some items e.g., ‘fears about the cancer spreading,’ uncertainty about the future’ and ‘concerns about the worries of those close to you’ (items 9, 11 and 17 respectively) were deemed to induce negative feelings and concerns that were not previously there. These items were deleted (item 11) or re-worded (items 9 and 17).

Omitted items

Item 14 ‘Feelings about death and dying’ was removed as it was deemed culturally inappropriate. Participants comments included ‘In general, we don’t want to bring on those [death and dying] thoughts and “We talk about keeping a positive outlook here, so why bring in, well you’re going to die, in that”.’ Item 18 ‘More choice about which cancer specialists you see’ was removed due to redundancy; participants reported “As a public patient you have no choice about which cancer specialists you see” and “You don’t have a choice of what treatment or what doctors you get”. Item 7 ‘Feeling down or depressed’ and Item 8 ‘Feeling of sadness’ were reported to have the same meaning and were combined and re-worded to “Feeling down or sad”. One participant reported “It’s shame saying you’re depressed”.

Newly developed items

Participants identified additional support issues that Indigenous cancer patients may need help with. These included financial burden, logistic needs (e.g. transport, accommodation and being given adequate directions from the airport to accommodation and to hospital), communication (e.g. receiving information that patients and their family can understand about their cancer and treatment, having the ‘right’ person to talk to about their cancer and treatment options) and cultural issues (such as having an Indigenous person to talk to whilst in hospital, having ‘bush tucker’ [traditional foods] in hospital). Twelve new support needs were added to the SCNAT-IP (see Table 2). Participants provided a range of comments about why these new items were important:

“Family want me to go with them because they’re not understanding what the doctors are saying. There’s some fear for them to ask questions; cause that’s the doctor and they know everything and I don’t know anything.”

“They become loners [Indigenous people with cancer], she would go outside, sit by herself because she had no one. She felt alienated.”

“Transport would’ve been good. We did enquire about that but they said, no there was nothing.”

“It’s good if someone’s able to say, this is where you need to go next. I’ll wait for you and we’ll take you back to x, y, z place.”

Outcomes of Stage 2

Instructions

All participants agreed that the instructions required further modification. Some suggested breaking questions down to a ‘yes’ or ‘no’ initial response to each need item and adding an introduction statement. However, agreement on this was not reached, so a further focus group was conducted.
Table 2 Additional indigenous-specific items

1. Finding a place to stop or stay while receiving treatment
2. Money worries (e.g., cost of accommodation, travel)
3. Having an indigenous person to talk to and support you, someone who understands your culture
4. Having traditional bush Tucker in hospital
5. Having access to traditional healers or medicine
6. Having an indigenous person to interpret and help with communication with health professionals
7. Ensuring family members were able to be present when talking or seeing health professionals
8. Directions to get to and around the hospital
9. Getting care items such as dressings, pads or colostomy bags
10. Getting a doctor with the gender (e.g., sex) that you feel comfortable with for treatment, examinations and discussions (women’s and men’s business)
11. Getting information about your illness for your family and friends
12. Being treated in a hospital or clinic that is culturally supportive

Modified items

Seven items (2, 3, 4, 10, 13, 17 and 28) from version 1 of the SCNAT-IP were modified to include specific examples e.g. Item 4, 'Work around the home (e.g., washing, cooking, raking the yard, sweeping the floor)'. Minor wording modifications were made to 16 items e.g. the word 'informed' was replaced with 'told' (item 27) and 'promptly' was replaced with 'quickly' (item 21) as all agreed these words would not be understood by many Indigenous people. Items (1, 19, 23, 24, 25, 26, 29, 30, and 31) were reworded to ensure cultural appropriateness, for example Item 1 'Pain' was reworded to 'Physical pain (e.g. hurt)' and Item 25 'Being given explanations of those tests for which you would like explanations was reworded to 'Explaining what tests are for' (Table 1).

Omitted items

Item 11 'Uncertainty about the future' was not considered by participants as part of Indigenous ways of thinking and was removed: 'We don’t plan for the future. Most of us just live day to day' or 'We plan from pay day to pay day’. Item 12 ‘Learning to feel in control, of your situation’ was removed as it was thought that ‘having the cancer was out of their control’ and that ‘they have no choice but to use the mainstream health system if they want to access doctors and cancer treatment’. Item 33 ‘Being treated in a hospital or clinic that

Figure 3 SCNAT-IP Introduction and Response Scale Categories.
is as physically pleasant as possible' was dropped due to redundancy after an additional but similar item 'being treated in a hospital or clinic that is culturally supportive' was suggested.

**Newly developed items**

Participants identified an identically themed list of additional support issues for Indigenous cancer patients' to participants in stage 1, thus re-affirming the inclusion of the 12 new items (Table 2).

**Outcomes of Stage 3**

**Instructions**

Participants reported "The instructions need to be set out more clearly and taking out a few words can make a lot of difference" and "having it formatted and having a yes or no answer first makes the survey look easier to fill out even though they [patients] are having it read out to them". In accordance with key informants' suggestions, the introduction and instructions were simplified (reduced from 127 to 96 words) and a yes/no response to the opening question was also included (Figure 3).

**Modified items**

Minor changes were made to items 6, 10 and 20. For example, item 6 'Anxiety' was expanded to include a range of examples (e.g., worrying, fear, concern) to assist participants to gain a better understanding of the word.

The final SCNAT-IP contains 39 supportive care needs items (Tables 1 and 2) and one open-ended question "In the last month, did you need any help with: any other things?". The SCNAT-IP takes approximately 15 minutes to complete.

**Discussion**

Patients' quality of life, distress and supportive care needs have been shown to independently predict survival, particularly in cancer patients with advanced disease [18,19]. While quality of life measures have been used for many years, a more recent approach aims to assess patients' need for supportive care services as well as whether those needs are being met [20-23]. This measurement approach allows identification of individuals and/or groups with higher levels of need. Health services can be mobilized or interventions can be developed to prevent or reduce health care problems in the future [14,15] by offering appropriate care provisions or interventions to these vulnerable populations.

The SCNAT-IP differs in a number of ways from the existing tool (SNCS-SF34). Firstly, all items from the SCNS-SF34 were rephrased and seven items were dropped following in-depth discussions with study participants. Whilst all questions are optional, participants are given a forewarning prior to asking questions about their sexual needs. During the interviews it became apparent that some Indigenous people may find these questions culturally inappropriate. This may be particularly so, when a female interviewer is asking a male cancer patient about their sexual needs ("men's business") (or vice versa) or a younger interviewer is interviewing an older patient. Thirdly, some items were re-ordered to have similar questions grouped together (e.g. SCNS-SF34, item 17 moved after 13) to make it easier for patients to express their needs in this domain. Twelve new Indigenous specific items were developed that were not sufficiently represented in the SCNS-SF34. The instructions and response format of the original SCNS-SF34 were deemed confusing by participants and were simplified. The tool was further modified to allow participants to initially give a yes/no response to each item before quantifying their need.

The SCNAT-IP is intended to be administered orally and has an accompanying "participant response booklet". This method of administering surveys to Indigenous people is widely accepted and has been used in the development of and/or validation of other tools [24,25]. Having an interviewer read aloud the questions and choice of responses will also assist those participants who have low literacy levels. It is envisaged that the tool will be utilised in hospitals by Cancer Care Coordinators to assist them to better meet the ongoing needs of their Indigenous patients. In addition the tool will be used in research to measure how needs in this population change overtime and/or in response to intervention. The outcomes of this study and other studies that have adapted psychometric and other tools for use with Indigenous Australians are comparable [24-26].

The data here, is itself a rich reflection of the issues commonly faced by Indigenous Australians when accessing the health care system. For example, many aspects of participatory concerns overlap with issues of ownership, control, access, and possession [27], such as knowing where to go within the hospital, having a person to speak to and having appropriate food. The reluctance to have certain "culturally loaded" words such as "cancer" or "death" included in the IP version of the survey provides important insights into how services can utilise a more patient-centred approach to Indigenous healthcare. While many of these issues are relevant to non-Indigenous people with cancer as well, the impact of public health campaigns to educate the general population and allay their fears about cancer, early detection, treatments and cures have been much more successful amongst the non-Indigenous population [5]. Further adding to Indigenous peoples' fatalistic views about cancer is the reality that overall Indigenous Australians have much higher cancer death rates than their non-Indigenous counterparts [1].
The participants were broadly representative of Indigenous people with cancer [28] with a diversity of educational and employment backgrounds, ages, marital status, and cancer types, and the patients were mostly receiving treatment for their cancer. However, the participant numbers for each cancer group were small and more likely to reside in locations with good to average health care access (59%) compared with the overall Indigenous cancer population (34%) [28]. Despite these limitations the newly developed supportive care needs assessment tool for Indigenous people (SCNAT-IP) does provide a mechanism to standardize the assessment of the supportive care needs of Indigenous adults with cancer in a culturally appropriate manner. Additional data collection is underway to further develop and test the psychometric properties of this new tool.

Conclusions
The SCNAT-IP shows promising face and content validity for Indigenous people with cancer. This tool among others will be useful in informing services where they need to direct their attention for these patients.

Competing Interests
The authors declare they have no competing interests.

Authors’ contributions
GG contributed to the study design and drafted the initial manuscript. GG and PV coordinated the study and conducted the analysis. PV, VB, MJ, AG, and PO contributed to the design of the study and revisions of the manuscript. CJ assisted in the study coordination. All authors read and approved the final manuscript.

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Chapter 3  PSYCHOMETRIC ASSESSMENT OF THE SUPPORTIVE CARE NEEDS ASSESSMENT TOOL FOR INDIGENOUS PEOPLE (SCNAT-IP) WITH CANCER
3.1 Preface

The main focus of Chapter 3 is to evaluate the psychometric properties of the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) with cancer, the development of which was reported in Chapter 2. The final SCNAT-IP is listed in Appendix 1. A second purpose of this chapter is to describe the prevalence of unmet support needs among a sample of Indigenous adults with cancer using the SCNAT-IP. This chapter has been written as a journal article of which I am the principal author. The article was published in Cancer and is presented here in its entirety.


3.2 Statement of authorship

The contributions of all co-authors are clearly outlined below. Furthermore, all co-authors have emailed written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.

3.3 Author contributions

GG, PV, and VB conceptualised the study. GG, PV, VB, MJ, AH, AG and PO developed the methodology. GG and PV conducted the approval process and study coordination. GG, VB and VH conducted the data analysis and GG, VB,
PO, PV, MJ, JC and VH interpreted the data. GG drafted the initial manuscript. All authors contributed to the revision of the manuscript, and read and approved the final draft.

3.4 Published article
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Chapter 4  INDIGENOUS CANCER PATIENT
AND STAFF ATTITUDES TOWARDS UNMET
NEEDS SCREENING USING THE SCNAT-IP: A
QUANTITATIVE ASSESSMENT
4.1 Preface

The focus of Chapter 4 is to quantitatively assess the staff and patient perspectives on the feasibility and utility of using the SCNAT-IP developed in the previous chapters in the routine cancer care for Indigenous Australians with cancer. The study provides an assessment of the clinical implementation of the SCNAT-IP in four diverse geographical and cancer care settings in Australia. A companion qualitative paper has been written (Appendix 2), but is not included as a chapter in this thesis because I was not the principal author.

This chapter has been written as a journal article of which I am the principal author. The article has been published in *Supportive Care in Cancer* and is presented here in its entirety.


4.2 Statement of authorship

The contributions of all co-authors are clearly outlined below. Furthermore, all co-authors have emailed written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.
4.3 Author contributions

GG, BT, ED and AG conceptualised the study and developed the methodology. GG, BT and ED conducted the ethical approval process and Indigenous community engagement. ED and VH entered the data into the study database. BT managed the overall project and conducted the staff interviews. AH and members of the SCNAT-IP Implementation Group conducted the patient interviews. GG, BT and VH analysed the data and performed the initial interpretation of the data, and all authors contributed to the interpretation of findings. GG and BT drafted the initial manuscript; all authors contributed critically to the revision of the manuscript, and read and approved the final draft.

4.4 Published article
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Chapter 5  **Health-related quality of life among Indigenous Australians diagnosed with cancer**
5.1 Preface

The primary focus of Chapter 5 is to present the reported levels of health-related quality of life (HRQoL) and the factors associated with HRQoL among Indigenous Australian cancer patients. Unlike the assessment of supportive care needs where we developed and used a specifically designed tool to assess unmet need among Indigenous adults with cancer, here we used a pre-existing validated tool to assess HRQoL. The Assessment of Quality of Life Questionnaire (AQoL-4D) has been used in a range of epidemiological, public health and acute care studies and across a range of populations, including cancer populations and provided a useful first step to exploring the HRQoL amongst Indigenous cancer patients.

This chapter has been written as a journal article of which I am the principal author. This article has been published online in *Quality of Life Research*. The paper is presented here in its entirety.


5.2 Statement of authorship

The contributions of all co-authors are clearly outlined below. Furthermore, all co-authors have emailed written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.
5.3 Author contributions

GG and PV conceptualised the study, developed the methodology and conducted the approval process and study coordination. GG, VH and JC conducted the initial analysis and interpretation of the data and MJ contributed to subsequent analysis and interpretation. GG drafted the initial manuscript and all authors contributed critically to the revision of the manuscript, and read and approved the final draft.

5.4 Published article
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Chapter 6   DISTRESS AMONG INDIGENOUS AUSTRALIAN CANCER PATIENTS
6.1 Preface

The focus of Chapter 6 is to present the reported levels of distress and the factors associated with distress among Indigenous Australian cancer patients. Similar to Chapter 5 we used a pre-existing validated tool to assess distress. The Distress Thermometer has been widely used in a range of cancer care studies and across a diverse range of cancer groups.

This chapter has been written as a journal article of which I am the principal author. The article was submitted to *Psycho-Oncology* and is presented here in its entirety.


6.2 Statement of authorship

The contributions of all co-authors are clearly outlined below. Furthermore, all co-authors have emailed written approvals regarding their contribution towards the manuscript, their approval of the final manuscript and the inclusion of the manuscript in this thesis.

6.3 Author contributions

GG and PV conceptualised the study, developed the methodology and conducted the approval process and study coordination. GG, VH and JC conducted the data analysis and GG, VH, JC and MJ undertook the initial interpretation of the
data. GG drafted the initial manuscript and all authors contributed critically to the revision of the manuscript, and read and approved the final draft.

6.4 Submitted article
Target journal: Psycho-Oncology

Title: Distress among Indigenous Australian cancer patients

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Conflict of Interest: The authors declare that they have no relevant conflicts of interest.
Abstract:

**Purpose.** To identify the level of and factors associated with distress in 155 Indigenous Australian adult cancer patients approximately six months post-diagnosis.

**Methods.** The Distress Thermometer (DT) was used to assess clinically significant distress (defined as having a DT score ≥4). Logistic regression was used to identify socio-demographic and clinical factors associated with clinically significant distress.

**Results.** The mean distress score was 2.7 (SD 2.9), with about one in three participants reporting clinically significant distress (35%; n=54). After adjusting for age and sex, clinically significant distress was more likely among those who were separated/divorced/widowed than those who were married (OR=2.99, 95%CI 1.21–7.35, p=0.017) and less likely among those residing in remote areas than those in major cities (OR=0.23, 95%CI 0.08–0.71, p=0.001) and in those receiving non-surgical treatment only compared with surgery only (OR=0.24, 95%CI 0.08–0.68, p=0.008).

**Conclusion.** Despite distress being endorsed as the 6th Vital Sign in cancer care and the increasing screening for distress in cancer care, this is, to our knowledge, the first published assessment of distress among Indigenous Australians with cancer. There is a need to examine the cultural appropriateness of the DT among Indigenous cancer patients and to identify the best practice approaches to identifying and implementing programs to reduce distress to improve cancer outcomes and increase quality of life for Indigenous Australians.

**Keywords:** distress, Indigenous, cancer, Australian
Introduction

Australia’s Aboriginal and Torres Strait Islander peoples (hereafter respectfully referred to as Indigenous Australians) experience disadvantage across a range of socioeconomic indicators and have poorer overall health than other Australians.[1] It has been consistently reported that Indigenous Australians have a higher prevalence of self-reported psychological distress than non-Indigenous Australians.[1-4] Data from national population health surveys report approximately one in three Indigenous adults experience high to very high levels of psychological distress, which is up to three times the rate for non-Indigenous Australians.[1, 3]

The prevalence of distress amongst Indigenous Australians varies by clinical, cultural, and socio-demographic characteristics.[1-4] High to very high levels of psychological distress are reported to be associated with having a disability or long-term health condition (43% compared with 19% among those without a disability or long-term health condition) and having experienced discrimination (44% compared with 26%). [1, 3]

Clinically significant distress is also highly prevalent among cancer patients.[5-8] This is not surprising given cancer is, for most people, a traumatic life event. Whilst prevalence rates vary depending upon the cancer type and cancer stage, as well as patients’ socio-demographic and clinical characteristics, the prevalence of distress from a pooled analysis of seven studies was 29.6%. [9]

Hence distress has been endorsed as the 6th Vital Sign in cancer care and screening for distress in cancer care has been recommended.[10, 11] The risk factors associated with distress are not always directly related to the cancer, and may include education, younger age, minority ethnicity, being female,
comorbidities, having problems at home, experiencing physical symptoms and side effects of cancer and treatment (e.g. fatigue, nausea), struggling to carry out the usual activities of daily living and having psychological issues (depression or other mental or emotional problems).[12]

Cancer also places a significant burden on Indigenous Australians. Despite having a lower overall cancer incidence rate, Indigenous Australians have a significantly higher age-standardised cancer mortality rate than non-Indigenous Australians (221 versus 172 per 100,000, respectively).[13] They are more likely to have cancers that have a poorer prognosis, be diagnosed at a later stage of their cancer (due to a combination of late presentation and lower participation in screening programs), and have a greater number of co-morbidities, and are less likely to receive optimal treatment.[13, 14] Some Indigenous cancer patients have fatalistic views of cancer, which may lead to lower treatment compliance, and a lack of access to information and cancer treatment.[15, 16] They also experience high levels of unmet support needs especially in the psychological and practical need domain.[17]

Identifying the levels of clinically significant distress amongst Indigenous cancer patients is an important element of improving cancer care and ultimately cancer outcomes for Indigenous cancer patients. There is evidence amongst non-Indigenous cancer patients that identifying and intervening to reduce distress can lead to improvements in treatment adherence and reduce medical costs.[18] However, we are not aware of any studies on the prevalence of distress among Indigenous cancer patients. The present exploratory study aimed to address this gap by describing the levels of psychological distress in a cohort of Indigenous
Australian cancer patients and identifying the socio-demographic and clinical factors associated with clinically significant distress amongst this group.

**Methods**

*Sample and Recruitment*

This study was conducted in Queensland, Australia, as part of a larger longitudinal study (n=248) to assess the unmet supportive care needs of Indigenous Australian adult cancer patients, previously described elsewhere.[17] In brief, Indigenous Australian adults diagnosed with cancer were recruited from one of four major Queensland public hospitals between November 2010 and December 2012. Eligible participants were approached by hospital staff (cancer care staff or Indigenous Hospital Liaison Officers); if they expressed interest in the study, they were asked for permission to provide their contact details to study staff. Those who agreed were then contacted by a trained interviewer, given detailed study information and an interview was conducted after written informed consent was obtained. The current analysis was limited to 155 participants who were interviewed at approximately six months (range 4–9 months; mean 182.7 days) after their cancer diagnosis.

*Data Collection*

Individual interviews were conducted to collect self-reported inpatient/outpatient status and socio-demographic information including the participant’s age, ethnicity (Aboriginal, Torres Strait Islander or both), sex, marital status, employment status, educational level, postcode of residence, main language spoken at home, and the degree of contact with other Indigenous Australians (no contact, few contacts, some contacts, main contacts). Hospital
medical records of participants were reviewed to confirm participants’ cancer type, date of diagnosis, stage and treatments received. Distress was assessed using the ‘Distress Thermometer’ (DT).[19]

The DT is widely recognised and recommended as a screening tool to quickly identify individuals who may be psychologically distressed.[5, 20-22] It has been used with cancer patients with mixed diagnoses and at varying stages of disease.[9] The DT is a single-item visual analogue scale in the form of a thermometer, where zero indicates no distress and 10 indicates extreme distress. Patients in our study were asked ‘On a number scale from 0-10 what number best describes how much distress you have been experiencing in the past week, including today?’.[19]

This study was a part of a much larger study with a central focus on supportive care needs. In order to avoid participant overload, we did not use the accompanying problem check list and were therefore unable to provide further insight into the specific aetiologies of distress.

Participants were allocated to statistical local areas (SLAs) based on postcode of usual residence. SLAs were used to determine both remoteness of residence, defined using the Accessibility/Remoteness Index of Australia (ARIA+ classification)[17], and an area-based measure of socioeconomic status (SES), using the Index of Relative Socioeconomic Advantage and Disadvantage.[18] Remoteness of residence was categorised into three groups: major city, regional (including inner and outer regional), and remote (including remote and very remote). Area-level SES was categorised into three groups: advantaged (top two quintiles based on all-Australian cutoffs), disadvantaged (bottom quintile) and intermediate (third and fourth quintiles).
Ethics approval was obtained from the Human Research Ethics Committees of Charles Darwin University, Northern Territory Department of Health and Menzies School of Health Research, QIMR Berghofer Medical Research Institute and from the four participating hospitals.

**Data Analysis**

In accordance with the recommended cut-off score [5, 20, 21] participants were classified as having ‘clinically significant distress’ if their DT score was ≥4. ‘Low distress’ was defined as DT score between one and three, inclusive; ‘no distress’ was defined as DT score of zero.

Logistic regression models were used to calculate the crude and age- and sex-adjusted Odds Ratios (OR) and 95% Confidence Intervals (95%CI) of clinically significant distress (relative to no/low distress). All variables of a priori interest were included one at a time in an initial crude model, as well as in a model adjusted for age group and sex. Similar results were achieved for crude and age- and sex-adjusted models, and only the latter are presented in Table 2 and in the results. Variables with \( p < 0.05 \) were assessed for inclusion in the final model. The final adjusted model for distress included age group, sex, treatment type, marital status and remoteness of residence. No other variables were significant at \( p < 0.05 \) when added to this model. All analyses were conducted using IBM SPSS Statistical software package (v22).
Results

The 155 participants in this study were interviewed at approximately six months (mean 182.7 days; range 4–9 months) after their cancer diagnosis. The socio-demographic and clinical characteristics of these participants are shown in Table 1. The average age of participants was 51.6 years (range 20–78), over half were female (60%), most were unemployed (72%) and were not admitted to hospital at the time of their first interview (64%). The most common primary cancer diagnosis was breast cancer (27%), followed by digestive cancers (12%), cancers of the respiratory and intrathoracic organs (12%), and leukaemia/lymphoma (12%).

The mean distress score was 2.7 (SD 2.9). As shown in Table 1, about one in three participants (35%; n=54) were categorised as having clinically significant distress. The pattern of DT scores varied by socio-demographic and clinical characteristics (Table 1). The proportion of participants with clinically significant distress decreased with age and with remoteness. Distress was more common among males than females, those who received surgical treatment than those who did not, and those who were separated/widowed/divorced than among married people.

The age- and sex-adjusted odds of having clinically significant distress were significantly higher for participants who were separated/divorced/widowed than those who were married (OR=2.99, 95% CI:1.21–7.35, p=0.017). Participants residing in remote areas had significantly lower odds of clinically significant distress than those residing in a major city (OR=0.23, 95% CI:0.08–0.71, p=0.001), as did those receiving non-surgical treatment only compared with those who received surgery only (OR=0.24, 95% CI:0.08–0.68, p=0.008) (Table 2).
The patterns of surgical and non-surgical treatment varied significantly by age, cancer type and cancer stage (Table 3). For example, about three-quarters of participants with breast cancer (75.6%) had both surgical and non-surgical treatment, while most participants with respiratory/intrathoracic cancer (77.8%) or leukaemia/lymphoma (77.8%) had non-surgical treatment only. Those with a more advanced cancer stage were more likely than those with a less advanced stage to have non-surgical treatment only (45.2% for distant versus 23.3% for local and 27.1% for regional).

The age- and sex-adjusted odds ratios relating to marital status, remoteness, and treatment type were virtually unchanged in a model including all three variables in addition to age and sex (Table 2). No other variables were significantly associated with clinically significant distress, whether adjusted for age group and sex only or when added to the final model. There was virtually no change in the estimate for non-surgical treatment only when cancer type was added to the final model (OR 0.19, 95% CI 0.06–0.64; p=0.007) but there was some attenuation of the association when cancer stage was added to the final model (OR 0.36, 95% CI 0.10–1.24), and the association was no longer statistically significant (p=0.11).

Discussion

In this exploratory study using the DT, over a third (35%) of Indigenous participants were experiencing clinically significant levels of distress approximately six months after their cancer diagnosis. Our results are consistent with previously reported rates of distress amongst cancer patients [7, 9, 18]. They are also similar to the proportion of Indigenous adults with ‘high’ to
very high’ levels of psychological distress (27.8%) in a national population health survey.[1, 2] Although the use of different instruments across studies means that comparisons must be made with caution, this finding suggests that the level of clinically significant distress, as measured by the DT, is not too dissimilar to the level of distress observed in the broader Indigenous adult population, despite our participants having a cancer diagnosis and having recently received or about to undergo treatment for their cancer.

Clinically significant distress in our study was associated with marital status, remoteness and current treatment type as well as with age.

Being separated, divorced or widowed was strongly associated with clinically significant distress in our study, even after adjusting for other demographic and clinical variables. Lam, et al. (2012) reported that unmarried patients were at an elevated risk for continuous distress,[23] while Tuinman and colleagues (2015) found that widowed patients reported the least distress.[24] In a study by Jacobson, et al. (2005) of a mixed race group with a broad range of cancer diagnoses, married patients were more likely to have high levels of distress.[25] Our results are consistent with data from the general Indigenous population, in which very high distress was significantly less likely among married people than unmarried people for females in remote and non-remote areas and for males in remote areas.[3]

Living more remotely was associated with significantly lower reporting of clinically significant distress in this study, which is consistent with the lower levels of distress in remote areas observed in the general Indigenous population.[3] However, given our participants had a recent cancer diagnosis, and that people living in remote areas of Australia are often disadvantaged in
relation to accessing cancer care, this may reflect a possible selection bias as participants in this study were only recruited if they had succeeded in accessing cancer care and were in receipt of treatment. It is also possible that the DT performs differently for Indigenous people in remote and non-remote areas and this needs to be assessed in more detail in future studies.[4]

We observed lower levels of clinically significant distress among participants who had non-surgical treatment only compared with those who received surgery only. This is contrary to the results of a large study conducted in the Netherlands, in which patients (mean time since diagnosis 2.0 (SD +3.0 [0.0–33.8]; 44% under active treatment; 54% follow-up after active treatment) receiving treatment other than surgery only were at higher risk of distress.[26] The lack of consistency of our results with this study may be due to our study including only Indigenous cancer patients, for whom the understanding of surgery may be different. For example, it has been reported that Indigenous people have uncertainty about what happens in hospitals which often creates very real fears.[27] Also, despite hospitalisation rates being relatively higher for Indigenous people, they are less likely than other Australians to undergo a procedure such as surgery while in hospital.[1] Larger studies are needed to confirm our finding, and in-depth interviews may assist to identify why surgery may be particularly distressing for Indigenous people.

Younger participants in our study were more likely to report clinically significant levels of distress than older participants, which is consistent with other studies, [28-31] including a recent population-based cross-sectional study of Indigenous Australians in the Australian state of Victoria.[4] The higher levels of distress among younger patients in our study may be due to a range of factors such as poor adjustment to their cancer diagnosis, the threat of
premature death, difficulties relating to employment and other responsibilities such as having a young family.[32]

Cancer type has been reported to have a significant effect on DT score.[7, 26, 33] For example, in previous studies, the observed rate of clinically significant distress varied from 10–51% among lung cancer patients [5, 34], to 10–15% in ovarian cancer patients,[35] to 36% in patients with breast cancer.[36] However, in our study we did not find any substantial variation in the levels of distress by cancer site among our mixed group of Indigenous cancer patients, with levels of clinically significant distress ranging from 27–37% across cancer types. In addition, neither cancer site nor stage explained the relationship between treatment type and clinically significant distress. However, the relatively small number of participants in our study means that we are limited in our ability to look in detail at the relationships among cancer type, stage and treatment type.

Since the introduction of the DT, it has been routinely used in cancer care across cultures and countries, with a reported 21 non-English translations of the DT.[37] The mean DT in our study (2.7; SD=2.9) was lower than that seen in other cultural groups.[37] For example, a mean of 3.98 (SD=3.00) was reported in a Spanish study in which 50% of patients were in the non-advanced stages of cancer [38] and a mean of 4.11 (SD=2.33) was observed in a study of Korean cancer patients with a mean of 14 months since diagnosis.[39]

A recent report, based on the larger cohort from which our participants were drawn, found that over 70% of Indigenous Australian cancer patients experienced high levels of unmet support needs, with most unmet needs being in the psychological and practical domain.[17] Indigenous cancer patients in that study reported needing ‘a little to a lot more help’ with, ‘Concerns about the
worries of those close to you’ (27%), ‘Worrying about the illness spreading or getting worse’ (26%), ‘Feeling down or sad’ (23%), ‘Anxiety (e.g., worrying, fear, concern)’ (23%) and ‘Feeling tired’ (23%).[17] In view of these high levels of unmet need in the psychological and practical domain[17] and the prevalence of very high psychological distress among the general adult Indigenous Australian population[1, 3], as well as the poorer overall health and worse socioeconomic circumstances,[1] and significantly higher cancer mortality rates faced by Indigenous Australians in comparison to other Australians,[13] we would have expected to find greater levels of clinically significant distress for participants in this study. This raises questions about the validity of the DT in this population group and about its ability to discriminate effectively between patients with and without clinically significant distress using a cut-off score of four. Additional work is needed to establish the operating characteristics of the DT in Indigenous populations.

Limitations

These results should be interpreted in light of some important study limitations. First, this was the first time the DT has been used to detect clinically significant distress among a cohort of Indigenous Australian cancer patients. Second, while interviewer administration has the advantage of overcoming literacy-related participation restrictions, this administration mode may have inadvertently influenced responses or restricted choices in extreme response categories. Future studies could compare self- and interviewer-administered response patterns to determine the potential bias caused by each mode. Third, the sample size is relatively small. However, this is what we understand to be the largest study of Indigenous Australian cancer patients to date, and the first to
investigate distress in this population. Lastly, the study may have been impacted by selection bias, with participants including only those who had been receiving treatment in a major hospital and participants were alive and well enough to participate at around 6 months after their cancer diagnosis, and this may have introduced a bias by excluding those who had died or were too unwell to participate at six months after diagnosis.

Conclusions

This exploratory study is the first reported evidence of the level of, and factors associated with, clinically significant distress amongst Indigenous Australians with cancer. Based on our findings, the prevalence of clinically significant distress detected by the DT in our study of Indigenous Australian cancer patients was broadly consistent with the existing literature. However, further research is required to assess the validity of the DT to detect clinically significant distress among Indigenous Australians, given their significant health, psychosocial and economic challenges and poorer cancer outcomes in comparison with other Australians.

It is also essential that appropriate systems are implemented to detect distress and the specific aetiologies of such distress, and to assist patients in managing these through the provision of, and coordination of, culturally sensitive and tailored support. This may in turn lead to a lower cancer burden on the individual, the family, the healthcare system and the broader community.
Table 1. Levels of distress by socio-demographic and clinical characteristics, for 155 Indigenous adult cancer patients in Queensland, Australia.

<table>
<thead>
<tr>
<th></th>
<th>Level of Distress</th>
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<td>Low (score 1-3)</td>
<td>High (score ≥4)</td>
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<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
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<td>Age group</td>
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<tr>
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<td>10</td>
<td>34.5</td>
<td>7</td>
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</tr>
<tr>
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<td>54.2</td>
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<td>28.6</td>
<td>28</td>
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<tr>
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<td>52.4</td>
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<th>Count</th>
<th>Percentage</th>
<th>Mean</th>
<th>SD</th>
<th>IQR</th>
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### Main language spoken at home

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<th>SD</th>
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### Contact with Indigenous people

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<th>SD</th>
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<tr>
<td>Few</td>
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<td>15.5</td>
<td>11</td>
<td>45.8</td>
<td>6</td>
</tr>
<tr>
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### Remoteness of residence

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### Area-level socioeconomic status

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<th>SD</th>
<th>IQR</th>
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### Patient admission status

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<th>IQR</th>
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<td>40.4</td>
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### Cancer type

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<th>Mean</th>
<th>SD</th>
<th>IQR</th>
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<td>20</td>
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<table>
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<td>Surgery and non-surgical treatment</td>
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<td>32.1</td>
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<tr>
<td>Non-surgical treatment only</td>
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<td>33.5</td>
<td>25</td>
<td>48.1</td>
<td>15</td>
<td>28.8</td>
<td>12</td>
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- Information missing for 1 participant
- Information missing for 13 participants
- Non-surgical treatment refers to cancer-specific treatment other than surgery, including chemotherapy, radiation therapy and hormone therapy. (Note: in this study, all participants receiving hormone therapy also had surgery.)
Table 2. Relative odds of clinically significant distress (DT score ≥4) by socio-demographic and clinical characteristics, for 155 Indigenous adult cancer patients in Queensland, Australia.

<table>
<thead>
<tr>
<th></th>
<th>Age- and sex-adjusted model&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Final adjusted model&lt;sup&gt;b&lt;/sup&gt;</th>
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<td></td>
<td>OR</td>
<td>95% CI</td>
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<td><strong>Age group</strong></td>
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<tr>
<td>20-39 years</td>
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</tr>
<tr>
<td>40-59 years</td>
<td>0.82</td>
<td>0.34-1.96</td>
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<tr>
<td>60+ years</td>
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<td>Female</td>
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<td>0.29-1.18</td>
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<td><strong>Indigenous group</strong></td>
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<td>0.36-2.10</td>
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<td>Both Aboriginal and Torres Strait Islander</td>
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<td><strong>Remoteness of residence</strong></td>
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<sup>a</sup> Final adjusted model includes age, sex, and socio-demographic and clinical characteristics.

<sup>b</sup> Relative odds of clinically significant distress (DT score ≥4) by socio-demographic and clinical characteristics for Indigenous adult cancer patients in Queensland, Australia.
### Contact with Indigenous people

<table>
<thead>
<tr>
<th>Level</th>
<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>p value</th>
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<td>Main</td>
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<td>Some</td>
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### Area-level socioeconomic status

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<th>Odds Ratio</th>
<th>95% Confidence Interval</th>
<th>p value</th>
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### Patient admission status

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### Cancer Type

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### Cancer stage

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<th>p value</th>
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<tr>
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<td>Regional</td>
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<td>Distant</td>
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### Current treatment type

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<td></td>
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<tr>
<td>Surgery and non-surgical treatment&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>0.17-1.17</td>
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<td>Non-surgical treatment only&lt;sup&gt;c&lt;/sup&gt;</td>
<td>0.24</td>
<td>0.08-0.68</td>
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<sup>a</sup>Odds ratios shown are from a model including age group and sex plus one other variable at a time. Odds ratios for age group and for sex are from a model with only those two variables.<br>
<sup>b</sup>Odds ratios shown are from a model including age group, sex, marital status, remoteness of residence and treatment type. No other variables were significant at p < 0.05 when added to this model.<br>
<sup>c</sup>Non-surgical treatment refers to cancer-specific treatment other than surgery, including chemotherapy, radiation therapy and hormone therapy. (Note: In this study, all participants receiving hormone therapy also had surgery.)
Table 3. The distribution of selected independent variables by treatment type.

<table>
<thead>
<tr>
<th></th>
<th>Surgery</th>
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<th>Non-surgical treatment only</th>
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<tr>
<td></td>
<td>n</td>
<td>%</td>
<td>n</td>
<td>%</td>
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<td>Male</td>
<td>10</td>
<td>16.1</td>
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<tr>
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<td>Leukaemia/Lymphoma</td>
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<td>5.6</td>
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<td><strong>Cancer Stage</strong></td>
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<td>Distant</td>
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References


Chapter 7  **Final Discussion and Conclusions**
7.1 Chapter overview

This chapter summarises the key findings of the research program, describes contributions to the field of Indigenous health and psychosocial aspects of cancer care, discusses limitations of the research program and suggests directions for future research.

7.2 Summary of main findings

Previous work has documented the disparities in cancer incidence, mortality and survival for Indigenous Australians relative to other Australians (Chapter 1). There is a considerable body of qualitative literature that has explored some of the barriers to accessing appropriate cancer care for Indigenous Australians (Chapter 1). This thesis addresses a significant gap in knowledge by exploring the psychosocial well-being of Indigenous adults with a cancer diagnosis and the cultural appropriateness of existing supportive care needs tools.

The need for improved delivery of cancer services, along with improved outcomes for patients and their families, has been identified as a priority for both the state and federal Australian governments. For example, Cancer Australia, the national Australian government agency working to reduce the impact of cancer on all Australians, recently launched The National Aboriginal and Torres Strait Islander Cancer Framework (the Framework). The Framework provides high-level guidance and direction for individuals, communities, organisations and governments to address disparities and improve cancer outcomes for Indigenous Australians. Quality cancer care within the Framework includes ‘care that is person-centred so that the whole person (including family and cultural role) is considered, and the psychosocial, cultural...
and supportive care needs and preferences of Indigenous people are addressed across the continuum of care.\textsuperscript{1} The enablers to achieve this within the Framework include ‘Identifying the supportive care needs of Aboriginal and Torres Strait Islander patients and families (including youth and children) at the time of diagnosis and throughout the rest of the cancer continuum through the use of culturally relevant validated tools as part of routine practice\textsuperscript{1}. This thesis is the first program of work in Australia that has directly addressed this key area.

7.2.1 Development of a Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) with cancer

The findings from the work reported in Chapter 2 highlight important questions about the cultural appropriateness of existing tools used to identifying and addressing the unmet supportive care needs of Indigenous cancer patients.

We have demonstrated that Indigenous cancer patients have specific language, customs and needs that are not accommodated within existing supportive care needs questionnaires. The newly developed SCNAT-IP is the first validated and specifically designed tool to assess the supportive care needs of Indigenous adults with cancer. It showed promising acceptability and relevance, and appears to measure the specific concerns of Indigenous adults with cancer.

7.2.2 Psychometric Assessment of the Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) with cancer

The initial SCNAT-IP tool contained 39 items. After conducting exploratory factor analysis, as reported in Chapter 3, this was reduced to 26 need items and
one open-ended question. This final 26-item tool was assessed for its validity as a measure of multiple supportive care need domains specific to Indigenous Australian cancer patients undergoing treatment. The modified tool was found to have indications for good psychometric properties. In conducting this study among a sample of 248 patients treated at four Queensland Hospitals, we also found that the prevalence of unmet support needs among Indigenous Australian cancer patients is high and that most unmet needs fall in the psychological and practical need domain.²

7.2.3 Indigenous cancer patient and staff attitudes towards unmet needs screening using the SCNAT-IP: a quantitative assessment

Following initial psychometric analysis, a clinical implementation study was carried out to explore the acceptability of the SCNAT-IP amongst Indigenous cancer patients and clinical staff and to evaluate its feasibility for routine use in a variety of clinical settings (Chapter 4).

The data provided in Chapter 4 demonstrate that the SCNAT-IP is operational and applicable to both research and clinical cancer care settings. The results indicate that this tool could be useful if administered to cancer patients at a single point in the cancer journey or repeatedly over time. It may be most appropriate early in the treatment trajectory as Indigenous Australians with cancer have poorer access to care and are less likely to receive optimal cancer treatment than non-Indigenous Australians.³⁴ The data presented in Chapter 4 indicate that the use of the SCNAT-IP in the usual cancer care setting is feasible and well accepted by cancer care staff and Indigenous cancer patients.
In the research context, the SCNAT-IP could be used to quantify needs, identify changes in unmet needs over time and determine the efficacy of interventions that aim to reduce unmet needs. For clinical purposes, we recommend that the SCNAT-IP be used at a point early in the treatment trajectory with reassessment at subsequent time points dependent on individual patient need. More specifically, the SCNAT-IP may greatly assist cancer care providers who wish to identify Indigenous cancer patients’ unmet needs within their service and enable priorities to be set for action to respond to those specific unmet needs. Further, whilst it has not been tested, the SCNAT-IP may also assist cancer care providers to assess the adequacy of their services to address patients’ needs and to identify areas for service improvement. Although it was not possible to determine what services would have been offered in the absence of SCNAT-IP screening, we observed at least one new referral to a health professional or service was generated for 76.2% of the participants in the study in Chapter 3. Additional findings suggest the SCNAT-IP improves patient-clinician communication and may detect issues not identified by current care protocols. Others have recommended steps to enhance patient-provider communication and the patient’s experience of and satisfaction with cancer care. Such interventions may have the potential to bring about positive changes to patient management and improve cancer outcomes for Indigenous Australians.

### 7.2.4 Health-related quality of life among Indigenous Australians diagnosed with cancer

In the absence of previous studies exploring health-related quality of life (HRQoL) among Indigenous Australians with cancer, we conducted an
exploratory study as outlined in Chapter 5 to assess HRQoL amongst Indigenous Australian adults with cancer in Queensland. As expected, given the significant burden of cancer amongst Indigenous Australians, on average participants in our study reported a lower mean HRQoL compared to average scores observed in previous studies conducted in Australia. However, of most interest were the socio-demographic variables that were associated with having good HRQoL, such as speaking an Indigenous language at home, contact with other Indigenous people and living outside major cities.

There is evidence to suggest that HRQoL instruments may elicit different responses for the same health states across different population groups. This has been explored in a variety of areas including, for example, comparisons of different ethnic groups, those of different ages, as well as in patients compared to general population samples. Even amongst our cohort of Indigenous Australians we did find some variation in mean HRQoL by Indigenous sub-groups. Torres Strait Islanders had significantly higher odds of having excellent HRQoL than Aboriginal participants, and they were also more likely to speak an Indigenous language at home and have their main contacts with other Indigenous people. Whilst the numbers of participants from the different Indigenous sub-groups were small, these findings raise important broader questions about the role of Indigenous language and acculturation and their impact on the health and well-being of Indigenous Australians in general, and not just those with a cancer diagnosis.
7.2.5 Distress among Indigenous Australian cancer patients

Along similar lines to the HRQoL study, we conducted an exploratory study of psychological distress amongst Indigenous cancer patients, using an existing, commonly-used instrument, the Distress Thermometer.

Given that Indigenous cancer patients often present with more complex health and well-being issues compared to non-Indigenous Australians,\textsuperscript{18,19} we would have expected their levels of distress to be significantly higher than the levels reported for other cancer patients. However, the levels of clinically significant distress in our study were similar to the reported levels among other groups of cancer patients\textsuperscript{20} as well as to the levels reported among the general Indigenous Australian population.\textsuperscript{21,22}

Whilst there were some socio-demographic and clinical variables associated with high levels of distress, some of these were not consistent with the associations observed in other groups of cancer patients. As with quality of life as discussed above, the Distress Thermometer may perform differently for sub-groups of Indigenous people, and further investigations are required with much larger numbers of Indigenous cancer patients.

7.3 Limitations

Each of the studies included in this thesis has specific limitations, as described in the respective chapters. In addition, there are other limitations which are relevant to the interpretation of the results.

The studies reported in chapters 3, 5 and 6 were part of a much larger study investigating the supportive care needs of Indigenous Australian cancer patients.
in Queensland, Australia as described in Chapter 1, section 1.10.3. Whilst there were many benefits of being a part of a much larger study, there were also some constraints. For example, we were limited in regards to the additional questions and/or items we could use to investigate quality of life and distress. To be more specific, we did not use the problem check list which accompanies the Distress Thermometer, because the bigger study already required participants to answer a large number of questions and we did not want to make the overall study questionnaire too onerous for participants. As a result, we were unable to provide further insight into the specific aetiologies of distress. This would have been useful, particularly as some of the results were unexpected, such as clinically significant distress being significantly less likely among those receiving non-surgical treatment only compared with surgery only.

The AQOL-4D was selected to enable a health economic analysis to be conducted in the future. Whilst the Assessment of Quality of Life (AQOL-4D) questionnaire has been shown to be reliable\textsuperscript{7} and has been used in epidemiological, public health and acute care studies and across a range of different population groups and chronic diseases, including cancer populations,\textsuperscript{6,23,24} there have been relatively few published studies, particularly among cancer patients that have used this measure. This questionnaire had also not been previously used in an Indigenous population. The absence of such studies made it difficult to compare the results of our study against similar groups of participants.

The larger study included a total of 248 Indigenous adult cancer patients, of whom 155 were interviewed approximately six months after their cancer diagnosis. The studies on quality of life and distress included in this thesis included only the latter participants. The main reason for this was to investigate a more homogeneous group with respect to time since diagnosis, rather than a
much larger, but more varied group of participants. However, this also resulted in fewer participants in each subgroup, thus limiting the power to detect small differences in quality of life and distress. It is important to note that whilst participants in the larger study (n=248) were judged to be well enough to participate in the study at baseline, around 16% (n=39) were lost to follow-up due to death. This impacted on the number of participants included in the studies in this thesis. Additionally, participants included in the studies in chapters 5 and 6 were alive and well enough to participate at around six months after their cancer diagnosis, and this may have introduced a bias by excluding those who had died or were too unwell to participate at six months after diagnosis. These losses, however, also reinforce the need for early detection and intervention such as identifying and addressing levels of distress, quality of life and unmet support needs, as soon as a cancer diagnosis is made.

Whilst acknowledging the limitations of the research, it is important to also acknowledge that the exploratory studies in this thesis provide the first reported evidence of the levels of, and factors associated with, quality of life and distress amongst Australian Indigenous cancer patients.

The study outlined in Chapter 4 whilst modest in size provides the first empirical evidence of the feasibility and utility of the SCNAT-IP in routine cancer care for Indigenous Australians with cancer. The cancer care services and health professional staff recruited to conduct the patient interviews volunteered to participate in these studies. This may have inadvertently influenced the outcomes of the study as these services actively demonstrated interest in improving cancer outcomes for their Indigenous cancer patients, and therefore may not adequately represent all cancer care services.
7.4 Future research

The work presented in this thesis has identified important areas for additional research and practice. New work in some of these areas is already underway, as described below. I plan to undertake additional work in the coming years as a National Health and Medical Research Council Early Career Fellow (AppID#1105399), commencing in July 2016.

7.4.1 Supportive care needs assessment tool for Indigenous people (SCNAT-IP) with cancer

To enable wider uptake and use of the SCNAT-IP, a manual is currently being developed that describes the recommended procedures for administering, scoring and interpreting the SCNAT-IP. The health professional training unit developed and delivered in the clinical implementation study undertaken as a component of this PhD is currently being revised based on the evaluation feedback received from staff who participated in the training. Funding is being sought to develop an online version of the SCNAT-IP, and to offer training to cancer care services across Australia to increase awareness and use of the SCNAT-IP. Further evaluation will occur regarding the feasibility of the tool’s use in the usual care setting.

The supportive care needs of Indigenous cancer patients have been reported for one Australian jurisdiction (Queensland) as a component of this PhD. It is not known whether the needs of Indigenous cancer patients in other jurisdictions are the same as those reported in Queensland. Therefore, a nationwide cross-sectional study using the SCNAT-IP is currently being conducted (expected completion date December 2016) to determine the prevalence of supportive care
needs of Indigenous Australian adults with cancer in other jurisdictions, and to see the extent to which these differ across Australia. Recruitment of Indigenous adult cancer patients from cancer care services, including large treating hospitals and regional cancer centres in each Australian state and territory, has commenced. These participants will be interviewed by health professionals trained in using the SCNAT-IP. The results of this study will also enable more reference data to be developed for gender, age, spread of disease and some cancer sites, against which individual and group comparisons can be made. In addition, data from this study will enable confirmatory factor analysis to test how well the measured variables represent the number of constructs in the SCNAT-IP. This project is being conducted under the auspices of the Centre of Research Excellence in Discovering Indigenous Strategies to improve Cancer Outcomes Via Engagement, Research Translation and Training (DISCOVER-TT CRE), which is funded by the National Health and Medical Research Council’s Centre of Research Excellence program and Cancer Council New South Wales’ Strategic Research Partnership program.

Future work is required to address a range of other questions, including:

- What interventions are required to decrease the unmet supportive care needs of Indigenous Australians with cancer? Identifying unmet needs is not sufficient to improve outcomes without action to address the needs, but more work is required to determine what service interventions would be most effective.

- Does using the SCNAT-IP in the usual cancer care setting translate to improved access and use of support services from relevant mainstream hospital/community cancer support services? The SCNAT-IP is a means
to an end, rather than an end in and of itself. Is the SCNAT-IP appropriate to assess the needs of Indigenous adults with chronic diseases? Supportive care issues are a concern for many people whose health is suboptimal, not only for those who have been affected by cancer. This research question is specifically directed towards supportive care and whether the principles, model and SCNAT-IP tool are applicable to other disease groups.

- Does interviewer administration of the SCNAT-IP influence the participant response patterns? While interviewer administration has the advantage of overcoming literacy-related participation restrictions, this form of administration may have inadvertently influenced responses or restricted choices in extreme response categories. Future studies could compare self- and interviewer-administered response patterns to determine the potential bias caused by each mode.

### 7.4.2 Patient reported outcome measures

As described in Chapter 1, patient-reported outcome assessments are an important component of identifying and evaluating appropriate interventions to improve the health and well-being of Indigenous cancer patients. However, further research is required to provide more evidence for the validity, specificity and sensitivity of patient-reported outcome measures to detect low HRQoL and high distress among Indigenous Australians. Such measures also need to incorporate Indigenous preferences and conceptions of health.

To obtain meaningful information from HRQoL instruments, it is vital that they capture and accurately measure the components of HRQoL that are valued by
the study population.\textsuperscript{25} It has been argued that existing HRQoL instruments limit the focus of quality of life measures to narrowly defined indicators of disease and associated treatment, to the detriment of considerations of the broader social determinants of health important in the context of Indigenous populations.\textsuperscript{12,26,27} Clearly, such assessments are an important component of identifying and evaluating appropriate interventions to improve the health and well-being of Indigenous cancer patients. The results of our exploratory study do not remove the existing uncertainty about the appropriateness and value of using existing HRQoL instruments in Indigenous communities. Future studies may include developing a multi-attribute utility instrument specifically for Indigenous Australians to measure quality of life. Such a tool would measure and value quality of life dimensions important to Indigenous people in a culturally appropriate and sensitive way. Conducting such a study would initially involve qualitative research to determine the relevant dimensions of HRQoL for Indigenous people, beyond those captured in existing instruments, and later move towards developing a descriptive system for a quality of life instrument that appropriately captures these dimensions.

Identifying the levels of clinically significant distress amongst Indigenous cancer patients is also an important element of improving cancer care, and ultimately cancer outcomes, for Indigenous cancer patients. However, as with HRQoL measures, we need to ensure that the measures used to assess distress amongst this cohort are relevant and able to detect significant levels of distress, as well as be able to discriminate effectively between patients with and without clinically significant distress. More work is needed in this area.
7.5 Final conclusions

The studies described in this thesis have contributed to the knowledge in the emerging field of psycho-oncology and more specifically to the topic of psychosocial research among Indigenous Australian cancer patients. Although more work is needed to fully realise the potential of this work in improving outcomes for Indigenous people with cancer, psycho-oncology is now recognised as a critical area in Indigenous cancer control, as demonstrated by the language used in the recently-released *National Aboriginal and Torres Strait Islander Cancer Framework*. While measuring supportive care needs, HRQoL and distress are important first steps in providing appropriate and effective care; measurement alone is not enough. We must also develop effective strategies and interventions to address patients' concerns if we are to improve the health and well-being of Indigenous cancer patients and reduce their existing disparities in outcomes relative to other Australians.
7.6 Bibliography


17. Stevens K, Ratcliffe J. Measuring and valuing health benefits for economic evaluation in adolescence: an assessment of the practicality and validity of the child


APPENDIX 1: SUPPORTIVE CARE NEEDS
ASSESSMENT TOOL FOR INDIGENOUS PEOPLE
(SCNAT-IP) WITH CANCER
Supportive Care Needs Assessment Tool For Indigenous People (SCNAT-IP)

HEALTH PROFESSIONAL INSTRUCTIONS

Prior to using the SCNAT-IP please ensure you have read and understood the ‘SCNAT-IP Scoring and Administration Manual’ which accompanies this questionnaire.

A copy of the manual is available on the Menzies School of Health Research Website. See the resources tab at: www.menzies.edu.au/supportivecaretool

This questionnaire will take approximately 15 minutes to complete. If using the tool for clinical purposes, please allow some additional time following completion of the questionnaire to explore and address any needs identified. Priority should be given to moderate to high needs (i.e. scores of 4 or 5 on any item).

The tool has been found to be comprehensible and acceptable amongst Indigenous people with cancer in many parts of Australia. However the socio-demographic and linguistic characteristics of Australian Indigenous communities vary considerably. Where respondents have very low English fluency, please consider using health care interpreters for questionnaire administration. Where this is not possible, some words or concepts in this questionnaire may require additional explanation or clarification in English to make them more relevant to local conditions.

Please read the "Patient Instructions" (see next page) verbatim and use the visual aids supplied as shown over page.
PATIENT INSTRUCTIONS

(Read these instructions out loud to respondents prior to administering the questionnaire)

The questions I am about to read to you ask about how well your needs have been met in the past month.

We would like to know if you have received the type of help you need since your cancer diagnosis. This will help us to better plan our services and provide you with the help that you need.

Not every question will be relevant to your situation but I will ask each one to make sure I cover everything. There are no right or wrong answers, just tell me what you think.

For every question, I will ask if you needed help with an issue in the last month as a result of having cancer. There are 2 possible answers to choose from YES or NO.

If you say YES you needed help in the past month, I will ask you to tell me exactly how much help you needed using this scale.

Place Response Scale Visual Aid in front of patient.
Point to each score on the response scale as you read the next section.

Satisfied with help received- this means you got the help you needed.
Needed a little more help- this means you needed only a little bit of help with an issue.
Needed some more help- this means more than ‘a little more help’ but less than ‘a lot more help’.
Needed a lot more help- this means you needed lots of help with an issue.

Let me show you two examples:

Place Examples Visual Aid in front of patient

Example 1: If you said YES you needed help with pain and you said you were ‘Satisfied with help received’ here (Point to aid), it means that you had pain but you were satisfied with the help you got to manage your pain.

Example 2: If you said YES you needed help with ‘Being told about things you can do to help yourself get well’. Then, you said “Needed some more help” here (Point to aid) it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore you needed some more information.

Does that make sense?
Do you have any questions before we begin?

Remove Examples Visual Aid and place
Response Scale Visual Aid in a visible place in front of respondent during questionnaire administration.

NOW TURN TO THE QUESTIONS
**Response Scale Visual Aid**

In the last month, did you need help with ......

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<th>Yes</th>
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</thead>
<tbody>
<tr>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

If you answered **YES**, How much help did you need?

- Satisfied with help received
- Needed a little more help
- Needed some more help
- Needed a lot more help

SCNAT-IP v1 (June, 2015)
**Examples Visual Aid**

**In the last month, did you need any help with:**

<p>| | | | | | | |</p>
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<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>2</td>
<td>Being told about things you can do to help yourself get well</td>
<td>No □</td>
<td>Yes ☑</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
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### SCNAT-IP QUESTIONS

**In the last month,** did you need any help with:

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<td>Yes □</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Feeling tired (e.g., sleeping OK)</td>
<td>No □ 1</td>
<td>Yes □</td>
<td></td>
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<tr>
<td>3</td>
<td>Not feeling well (e.g., feeling rotten, crook or sick) a lot of the time</td>
<td>No □ 1</td>
<td>Yes □</td>
<td></td>
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<tr>
<td>4</td>
<td>Work around the home (e.g., washing, cooking, raking the yard, sweeping the floor)</td>
<td>No □ 1</td>
<td>Yes □</td>
<td></td>
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</tr>
<tr>
<td>5</td>
<td>Doing the things you used to do (e.g., fishing, walking, seeing family)</td>
<td>No □ 1</td>
<td>Yes □</td>
<td></td>
<td></td>
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<tr>
<td>6</td>
<td>Anxiety (e.g., worrying, fear, concern)</td>
<td>No □ 1</td>
<td>Yes □</td>
<td></td>
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<tr>
<td>7</td>
<td>Feeling down or sad</td>
<td>No □ 1</td>
<td>Yes □</td>
<td></td>
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</table>
In the last month, did you need any help with:

<table>
<thead>
<tr>
<th>Question</th>
<th>Satisfied with help received</th>
<th>Needed a little more help</th>
<th>Needed some more help</th>
<th>Needed a lot more help</th>
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</thead>
<tbody>
<tr>
<td>8  Worrying about your illness spreading or getting worse</td>
<td>No □ 1</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>9  Worry about the results of treatment</td>
<td>No □ 1</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>10 Keeping you strong in your spirit (e.g., staying positive)</td>
<td>No □ 1</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>11 Concerns about the worries of those close to you (e.g., family and friends)</td>
<td>No □ 1</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>12 Support by staff that the way you feel is natural (e.g., common, typical)</td>
<td>No □ 1</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>13 Having hospital staff attending quickly to your physical needs (e.g., if you needed assistance getting out of bed)</td>
<td>No □ 1</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
</tr>
<tr>
<td>14 Having hospital staff show sensitivity to and respecting your feelings and emotional needs</td>
<td>No □ 1</td>
<td>2 □</td>
<td>3 □</td>
<td>4 □</td>
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In the last month, did you need any help with:

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<tbody>
<tr>
<td><strong>15</strong></td>
<td>Being treated like a person not just another case or a number</td>
<td><strong>If you answered YES, How much help did you need?</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Satisfied with help received</td>
<td>Needed a little more help</td>
<td>Needed some more help</td>
</tr>
<tr>
<td>No</td>
<td>Yes</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
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</table>

| **16** | Being shown or given information (e.g., written, diagrams) about how to manage your illness and side-effects in hospital |   |   |
| No | Yes | 2 | 3 | 4 | 5 |

| **17** | Being shown or given information (e.g., written, diagrams) about how to manage your illness and side-effects at home |   |   |
| No | Yes | 2 | 3 | 4 | 5 |

| **18** | Explaining what tests are for |   |   |
| No | Yes | 2 | 3 | 4 | 5 |

| **19** | Understanding the good and bad effects of treatments before you chose to have them (e.g. having someone explain these to you) |   |   |
| No | Yes | 2 | 3 | 4 | 5 |

| **20** | Being told about things you can do to help yourself get well (e.g. safe exercises, what you eat) |   |   |
| No | Yes | 2 | 3 | 4 | 5 |

| **21** | Having an Indigenous person to interpret and help with communication with health professionals |   |   |
| No | Yes | 2 | 3 | 4 | 5 |

SCNAT-IP v1 (June, 2015)
In the last month, did you need any help with:

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<tr>
<td></td>
<td>Satisfied with help received</td>
<td>Needed a little more help</td>
<td>Needed some more help</td>
<td>Needed a lot more help</td>
</tr>
<tr>
<td>22</td>
<td>Finding a place to stop or stay while receiving treatment</td>
<td>No ☐ 1 Yes ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
</tr>
<tr>
<td>23</td>
<td>Money worries (e.g., cost of accommodation, travel)</td>
<td>No ☐ 1 Yes ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
</tr>
<tr>
<td>24</td>
<td>Having an Indigenous person to talk to and support you, someone who understands your culture</td>
<td>No ☐ 1 Yes ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
</tr>
<tr>
<td>25</td>
<td>Ensuring family members were able to be present when talking or seeing health professionals</td>
<td>No ☐ 1 Yes ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
</tr>
<tr>
<td>26</td>
<td>Directions to get to and around the hospital</td>
<td>No ☐ 1 Yes ☐</td>
<td>2 ☐</td>
<td>3 ☐</td>
</tr>
<tr>
<td>27</td>
<td>Any other things that you need support with that we have not asked you about?</td>
<td>No ☐ 1 Yes ☐</td>
<td>IF YES, please tell me about them</td>
<td></td>
</tr>
</tbody>
</table>

(SCNAT-IP v1 (June, 2015))
APPENDIX 2: RELATED MANUSCRIPT: ROUTINE SCREENING OF INDIGENOUS CANCER PATIENTS’ UNMET SUPPORT NEEDS: A QUALITATIVE STUDY OF CLINICIAN ATTITUDES
Target Journal: *International Journal for Equity in Health*

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Affiliations:

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Abstract

Objective: Indigenous Australians experience higher poorer cancer outcomes compared with non-Indigenous Australians. The Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP) is a validated 26-item questionnaire developed to assess their unmet supportive care needs. This qualitative study reports patient and clinician attitudes towards feasibility and acceptability of SCNAT-IP in routine care.

Method: Participants included 10 clinical staff and 34 Indigenous cancer patients (mean age 54.4 years) with heterogeneous tumours. Four cancer treatment centres participated in the study. Patients and clinicians completed face-to-face or telephone interviews.

Results: Many participants found needs assessment beneficial. Clinical staff valued the systematic nature of the SCNAT-IP and associated opportunities for early intervention. Time required, language and response format were identified as potential barriers. Improved team communication was described by some staff. Staff and patients reported that new referrals to support services were directly triggered by completion of the SCNAT-IP. Staff interviews identified areas for scaled improvement.

Conclusions: Staff and patients found the SCNAT-IP acceptable and supported universal screening for Indigenous cancer patients. Results provide further empirical support for use of the SCNAT-IP in routine care with Indigenous Australians. However, interpreters are recommended when using the tool with Indigenous patients with low English fluency. A refined version of the SCNAT-IP is now ready for use in clinical settings. Further research is needed to explore the validity of the SCNAT-IP for Indigenous people from other nations.
Background

Indigenous people comprise about six percent of the world’s population.\textsuperscript{1} Inequalities with regard to Indigenous cancer outcomes have been documented in Australia, New Zealand, Latin America, the Caribbean and the United States.\textsuperscript{2-6} In Australia, cancer remains the second leading cause of death among Indigenous people.\textsuperscript{7} The patterns of cancer care between Indigenous and non-Indigenous patients differ, with Indigenous patients often receiving less optimal treatment.\textsuperscript{8-10} Indigenous Australians’ engagement in cancer care is lower at all stages of the cancer continuum including screening, early presentation at diagnosis, continuity of care, compliance with treatment and survivorship.\textsuperscript{11-14} This has resulted in significantly poorer cancer outcomes in terms of incidence, mortality and survival.

Aspects of the broader social environment can also influence the way individuals, families and communities engage with health care and manage their own health.\textsuperscript{15} Understanding Indigenous people’s experience of cancer must come from consideration of the social determinants of health and the cultural context of people’s lives, and these should be reflected in service delivery models and in the delivery of cancer care.\textsuperscript{16}

In recognition that there are cultural differences in the way many Indigenous people perceive cancer (a highly feared disease that equates to death), receive and process information about their cancer diagnosis and treatment, and cope with illness,\textsuperscript{11,17-19} research into the psychosocial factors and specific supportive care needs of Indigenous people with cancer is imperative.

Improved supportive care for Indigenous cancer patients is an important strategy for promoting their participation in optimal care, which may ultimately
help address current disparities in cancer outcomes. Many questionnaires have been developed to assess the unmet needs of cancer patients. Some have been developed for specific cancers or settings, but little attention has been given to assessing the appropriateness of existing tools for minorities or developing tools that assess the culture-specific needs of ethnic groups. In Australia, Indigenous cancer patients share many supportive care needs with non-Indigenous cancer patients, but they have additional culture-specific needs which are not addressed by existing measures. To address this gap, a Supportive Cancer Needs Assessment Tool for Indigenous People (SCNAT-IP) has been developed.

As part of a broader clinical implementation feasibility study reported elsewhere, this qualitative study describes patient and staff attitudes towards the acceptability and feasibility of the SCNAT-IP in routine care. Additionally, this study aimed to identify refinements needed to prepare the SCNAT-IP for use in clinical settings.

Methods

Ethical considerations, Study Sites and Participant Eligibility Criteria

Ethical clearance was obtained from the following Human Research Ethics Committees: NT Department of Health & Families and the Menzies School of Health Research (HREC13/1994); Peter MacCallum Cancer Centre (HREC/13/45); Greater Western Human Research Ethics Committee (HRECI131GWAHSI39) and the Aboriginal Health and Medical Research Council of New South Wales (HREC/946/12). The content of the manuscript was subject to approval by the Aboriginal Health and Medical Research Council of...
NSW in accordance with the standard conditions of their ethical approval.

Participants were recruited from one of four participating sites: a tertiary cancer centre in the Northern Territory (NT) servicing outer regional and remote areas; a large metropolitan tertiary cancer centre in Victoria; and two regional cancer clinics in New South Wales. These four services represented a diversity of geographical locations, service models and Indigenous communities.

Eligible patients were over 18 years of age, of Australian Indigenous background, were diagnosed five years or less ago with malignant disease, and were either receiving or about to receive treatment (including surgery, chemotherapy, radiotherapy, stem cell transplant, endocrine therapy or immunotherapy) or were in follow-up care. Recruitment was conducted over a three to five month period (November 2013 to March 2014). Interviews were verbally administered, and health care interpreters were available upon request by staff at the NT site where many Indigenous people speak a language other than English. Those unable to give informed consent due to cognitive and/or physical impairments were excluded. Trained health professionals were cancer nurses, oncology social workers, Indigenous Health Workers (IHW) or other allied health professionals identified by their manager as providing supportive care to cancer patients.

**Procedure**

After written informed consent was obtained, all health professionals involved in this study completed a specifically developed three-hour training session, which included background information, clinical use of the SCNAT-IP and the research protocol. Following training, all 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 (oncology social workers, nurses, clinical trials coordinators) introduced the study to patients, gained written informed consent, and conducted needs assessment at routine patient clinic visits. Where moderate to high level of needs were identified (i.e. scores of four or five on any SCNAT-IP item), these were discussed with patients and they were offered assistance in accordance with usual care.

Following needs assessment, patients completed quantitative questionnaire items exploring the acceptability and feasibility of the SCNAT-IP together with a trained clinical staff member, the results of which are reported elsewhere. Immediately following this, a trained IHW (or a trained clinical staff member if the IHW was unavailable), conducted an audiotaped face-to-face or telephone interview which aimed to gather qualitative information about patient attitudes towards unmet needs screening. At the conclusion of the data collection period, trained clinical staff completed a brief telephone interview with a member of the research team (BT). Recruitment continued until saturation of data was achieved. Patient clinical details were collected by clinical staff from medical records.

**Measures**

*Patient Clinical and Demographic Characteristics:* Socio-demographic variables were collected by interview. Clinical details including cancer type, disease status, treatment phase, and cancer treatments were collected from medical records.

*Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP):* The SCNAT-IP is a 27-item (including 1 open-ended question) verbally-administered
unmet needs measure. The SCNAT-IP consists of four domains: physical and psychological needs (11 items); hospital care needs (four items); information and communication needs (six items) and practical and cultural needs (five items). For each item, respondents report if a need was present in the past month and, if it was, the degree to which they required help on a scale ranging from ‘satisfied because my needs were met’ (scored as one) to ‘a lot more help needed’ (scored as five). The SCNAT-IP accommodates the language, customs and culture-specific needs of Indigenous Australians and excludes items which are culturally-inappropriate in the screening context (e.g. sexual needs). The tool also includes culture-specific items such as ‘having an Indigenous person to talk to and support you, someone who understands your culture’. It takes approximately 15–20 minutes to complete and has been demonstrated to have good construct and face validity as well as internal consistency in a large sample of Indigenous cancer patients.

Patient Acceptability Interview: A brief semi-structured face-to-face interview was used to qualitatively explore patient participants’ attitudes towards needs assessment. Interview questions explored: perceived benefits of needs assessment, acceptability, appropriateness of content and timing, and attitudes towards universal screening for Indigenous patients.

Health Professional Characteristics: Items were developed to assess demographic characteristics, role, education, employment location, years of experience, and prior supportive care needs assessment training.

Health Professional Acceptability and Feasibility Telephone Interview
Six semi-structured interview questions assessed perceived benefits, barriers to use, impact on workload, impact on team communication/referral pathways, and recommendations for changes to the SCNAT-IP.

Data Analyses

Demographic data were analysed using descriptive statistics. Interview audio recordings were transcribed verbatim. Transcripts were subjected to manual thematic analysis using standard qualitative methods involving pinpointing, examining, and recording patterns (or ‘themes’) within qualitative data. Thematic analysis was performed in six phases including: familiarisation with data, generation of initial codes, searching for themes among codes, reviewing themes, defining and naming themes, and synthesising the final results. The generation of coding was conducted by one member of the research team (BT), and verified by a second member of the research team (GG) who double-coded 10% of transcripts to ensure inter-coder agreement. Where discrepancies arose in coding or definition of themes these were resolved through discussion until consensus was reached.

Results

Response Rate and Patient Characteristics

Of the 89 potentially eligible participants, 45 (51%) were invited to participate in the study, 36 (80%) of those invited agreed to be interviewed, and two participants were further excluded leaving a final study sample of 34 (Figure 1).
Participants were aged 34–76 years (Mean=54.4, SD=11.0), most were female (68%), just over half were partnered (53%), the majority were living outside metropolitan cities (89%), and some had not completed high-school (60%). Breast cancer was the most common cancer type (35%), 31% had local disease, and 47% were receiving active treatment (Table 1).

Health Professional Participants and Response Rate

The SCNAT-IP study training session included 22 health professionals with an average age of 42 years (range 25–62, SD 11.4) and a diverse set of professional backgrounds including social workers (n=8), nurse care coordinators (n=4), a radiation therapist (n=1), a clinical trial coordinator (n=1), IHW (n=5), and service managers (n=3). Of those, 10 trained clinical staff conducted needs assessments using the SCNAT-IP and all were non-Indigenous and female. More were oncology social workers (n=6) with post-graduate qualifications (n=9) and had no previous needs assessment training (n=6). Half (n=5) had six years or more experience in cancer care and worked in regional locations. The remaining health professionals conducted follow-up interviews only or supported the study as service managers.
Patient Interviews

The results are reported for the combined group as participant views were common across genders, age groups, cancer types, geographical locations and mode of interview.

*Feasibility and Acceptability*

The majority of participants liked being asked about their needs, did not mind taking the time to answer questions and generally found the process very helpful.

Some said they liked the process of needs assessment because it made them feel heard and it linked them to services. As one participant who lived in a regional area said:

‘This is just a god send to me because now I know I’m going to get some help because it’s always been a real battle for me.’

(Female, 50 years)

Another female participant reported feeling ‘empowered’ by the process of needs assessment. Several participants appreciated that health professionals were interested in their needs and, in particular, that they showed an interest in the needs of Indigenous cancer patients.

‘It’s made me feel good that someone’s showing interest, you know. That there are people out there who are trying to improve things, not only for cancer patients but for Indigenous people.’

(Male, 45 years)
Only one participant reported negative feelings about the SCNAT-IP saying she felt ‘uptight’ being asked about her unmet needs but later clarified ‘cause [I] told her [health professional] a few things that she didn’t know.’ Another participant did not find the process of needs assessment helpful as they had visited the centre many times in the last seven years, commenting ‘we’re pretty well used to it’, but further remarked ‘these sort of questions would have been more helpful in the beginning.’

Format and Language

Most participants found the tool very easy to understand and all liked the format of being asked the questions by health professional staff. No participants directly reported problems of comprehension.

Ideal Timing and Frequency of SCNAT-IP Screening.

This sample included patients at all stages of the treatment continuum, from diagnosis to follow-up care. Most participants reported being satisfied with the timing of the questionnaire; however, several said it would have been more useful completed earlier in their cancer journey.

‘To be perfectly honest it would have been helpful while I was having treatment done. It’s a little bit late because my last appointment was today.’

(Male, 35 years)

Another participant at the beginning of her treatment for breast cancer said the questionnaire should be completed closer to time of diagnosis. Whilst another remarked these questions should be asked early so they have ‘some information about it, [and are] not left in the dark.’
However, a newly diagnosed male participant suggested that SCNAT-IP assessment should not occur too soon after diagnosis and some subjects were ‘a bit touchy’ because patients are still coming to terms with their illness.

Although most patients favoured early administration, there were diverse views about the ideal frequency ranging from ‘once a week’ or ‘every time I go in [to the cancer centre]’ to ‘every six months’ or ‘at every [cancer treatment] stage’. The majority of participants believed the SCNAT-IP assessment should be repeated throughout treatment. Some believed it should be asked once only at the beginning of the cancer journey and/or in the middle of cancer treatment.

**Perceived Benefits of Services Offered Following Screening**

All participants with moderate to high needs (n=21; 58%) were offered services to help address unmet needs and many reported experiencing benefits.

‘Yes she [social worker] gave me some information because of some of my answers. I don’t think I would have got that information otherwise.’

(Female, 51 years)

‘I have now been referred to psychology and what I said is, “I wish this had happened two years ago.”

(Female, 55 years)

There was also a real sense of appreciation and trust felt by participants of the staff asking these questions as one participant described ‘it was good to be asked...[even though]... I do have a lot of help from my family’ and another commented ‘...a lot of that which builds up in you, you like to talk to somebody
about it, but it’s hard, hard for people just to listen’. Another participant from a more rural location commented ‘I’m not going back there [home]...apprehensive and worried and scared to what I usually have been....[social worker] is going to organize all the things. So when I go back it will all sort of follow; so there will be no stress. All I would need to worry about is just getting well.’

**Attitudes to Universal Screening**

Many patients supported the idea of universal screening for Indigenous cancer patients noting that it would educate staff about Indigenous patient needs.

‘A lot of them [staff] don’t understand there is problem like family problem, money problems.’

(Female, 47 years)

Others said it helped educate patients about what help is available to them and what to expect during treatment. Some participants believed needs screening should be optional to promote control and self-determination.

‘Give ‘em the choice, you know, ‘cause a lot of ‘em feel like they’re already being controlled by other people in their lives as it is and they don’t need, ‘specially in a place like this, they don’t need to get a view of it like “okay here’s another government organisation that’s gonna be telling me what to do”’.

(Male, 45 years)

Some participants without current unmet needs believed needs assessment was more worthwhile for others for altruistic reasons.
‘I’m pretty articulate and pretty aware of what the processes are within hospitals and so forth, but for somebody else you know, I think it’s something that needs to be done.’

(Male, 61 years)

Whilst being generally satisfied with the SCNAT-IP and willing to complete it, some participants believed that for other Indigenous people needs screening is important because of cultural factors such as being ‘shy;’ and ‘a reluctance to talk about problems or articulate their needs.’

Despite the SCNAT-IP being specific to Indigenous people, several participants said that SCNAT-IP would be relevant for all cancer patients irrespective of race. Two participants interviewed did not support universal screening for Indigenous people with cancer, one because she believed some questions were ‘too personal’ and a second said he was ‘not sure’ why.

‘They might think that you’re violating that little part of their life that they can hold tight.’

(Female, 60 years)

**Staff Qualitative Data**

**Perceived Benefits of Screening**

Many staff said there were multiple benefits of the SCNAT-IP including: its comprehensiveness, the systematic approach to needs assessment, and opportunities for early intervention which other less formal assessments methods did not offer.
'It picks up things that I think that would never have come up until we were at a real crisis point.'

Several staff said it helped to build rapport, made patients feel ‘heard’, and helped clarify patients’ expectations of services. Some staff reported they liked using an Indigenous-specific questionnaire because it fostered positive and collaborative relationships with Indigenous patients.

‘The feedback I've got from patients was they've certainly felt like they were heard which I think is something Aboriginal patients here have found difficult in the past.’

‘I think it allows people then to have a connection with the social work team here as well. I've found that people that may otherwise not have had any contact with the social workers here have been able to make contact in a way that has been positive.’

Staff also identified that using the SCNAT-IP helped educate staff members less familiar with working with Indigenous clients about culturally-specific needs and services.

‘I think it’s also a good opportunity for staff who may not be as experienced or you know trained or working with people of Indigenous background to have to sort of specific tools to use. It can make some people a little bit more comfortable being able to ask some of these
questions otherwise they may not know where to start or the right 
language to use.’

The verbal format of the tool was seen as a distinct advantage over other written scales.

**Barriers to use of the SCNAT-IP in routine care.**

The most commonly identified barriers to using the tool were the time needed to arrange an appointment and to complete the interview at the patient’s pace. SCNAT-IP interviews (including follow-up discussion of needs) lasted between 6 and 45 minutes with an average duration of 23 minutes.

‘As much as we want to sit and have a really good yarn with people, having so many questions in it [the questionnaire], it probably encourages them to yarn a lot more...I think there’s a potential for there to be a lot of breaks in between the questions for yarning and you need to allow a bit more time.’

Logistical problems were especially common for rural or remote patients, impacting on the ability to make sufficient time to conduct the assessment; many attend clinics infrequently and have long travel times to consider.

Difficulties with comprehension of the tool were only reported at one site where many patients spoke an Indigenous language as their primary language. Despite the fact that health care interpreters were available upon patient or staff request at this site, they were only requested for one interview. Instead, many patients and/or staff preferred to conduct interviews in English or by relying on accompanying family members to assist with translation.

Some staff reported that some patients had difficulty distinguishing between
lower levels of need (e.g. ‘a little more’ versus ‘some more’ help), hence requiring further clarification by staff. Rapport building and allowing plenty of time to complete the interview were reported to have helped to reduce comprehension difficulties.

Several staff also reported that some questions were not relevant to patients because of the time frame (i.e. ‘in the past month’) because of the patient’s stage in the treatment trajectory (e.g. hospital items for newly-diagnosed patients).

Whilst one staff member identified a cultural tendency for Indigenous people to be private or reluctant to disclose personal information as a potential barrier to using the SCNAT-IP, another staff member saw the structured and direct nature of the tool as a benefit in this respect.

‘Often in my experience Indigenous people are quite private and they’ll say things are fine or they don’t need any help but it’s good actually having those questions as prompts.’

**Impact on Workload**

The majority of staff said that completing the questionnaire took additional time but there were concomitant time savings because they had a better understanding of patient needs and could therefore provide early intervention.

‘I think it definitely makes up for it later on because you can activate services a bit earlier.’

Some staff reported it reduced their workload. Others said it increased workload but this was sometimes appraised in a positive way.

‘I mean it’s...it’s increased my workload but that’s ok, I see that as fine. It’s increased my workload but that’s good practice. It’s part of
Experience using screening tools was reported to reduce the time required. One staff member believed the impact on workload would be less if the questionnaire were conducted at the time of initial service entry when other questionnaire information is routinely gathered.

**Team Communication**

Several benefits to team communication were reported by staff including improved communication with IHW, and nursing and medical staff.

‘It’s probably given me the confidence to liaise more with our Aboriginal Liaison Officers which I haven’t done in the past very much.’

One staff member identified that using the SCNAT-IP identified gaps in patients’ understanding of their diagnosis or treatment. This staff member reported the SCNAT-IP:

‘… helps the doctors here understand how they need to change the way they explain things to their Indigenous patients.’

Making SCNAT-IP results available to nursing and medical staff in patient files was reported to facilitate improved communication about patients’ psychosocial needs. One staff member believed there were greater opportunities for the SCNAT-IP to have a positive impact on team communication if it were used early in the treatment trajectory.
Impact on Referral Pathways

Many staff reported that using the SCNAT-IP triggered new supportive care referrals. One clinician from a metropolitan hospital, who interviewed a number of patients from regional areas, observed that completing the SCNAT-IP increased her awareness of her need to better understand referral networks in regional areas. However, staff based in regional clinics observed little or no impact on referral pathways which was attributed to the relatively small numbers of Indigenous patients assessed at those clinics. Also the fact that most of the patients assessed in the regional clinics were not newly-diagnosed and already linked to local support services.

Suggested Changes

Several staff suggested minor changes to the wording or format of the tool including: further simplifying the wording; modifying the response time frame (i.e. ‘in the past month’) to make it more applicable across the whole treatment continuum, grouping items by domain and using domain headings to help clarify item content, and revising the preamble to clarify the purpose, structure and response format and highlight the fact that some items were not relevant to all patients. More advice for staff members about the time required to complete the instrument and follow-up discussion about needs was also recommended. Contradictory views about who should complete the assessment were noted, with one staff member suggesting wider use, including by treating doctors or ward nursing staff, and another expressing reservations as to whether medical or ward staff would be the best team members to assess and respond to unmet needs.
Discussion

Overall patient acceptability of the SCNAT-IP was very good. These results are consistent with the results of a quantitative analysis of acceptability and feasibility in this sample.\textsuperscript{23} They are also consistent with the results of patient and key informant interviews conducted during the development of the SCNAT-IP\textsuperscript{21} and with previous experiences which demonstrated the acceptability of the unmet needs assessment screening in the research setting.\textsuperscript{21, 22} Both patients and staff in this study believed SCNAT-IP assessment would be most useful early on in the treatment trajectory, with reassessment throughout treatment tailored to individual need.

Whilst this study provides additional evidence for the feasibility and acceptability of the SCNAT-IP, some staff identified comprehension difficulties amongst patients with low English literacy as a potential barrier. However, patients who spoke Indigenous languages at home did not report any comprehension difficulties.\textsuperscript{25} Reasons for this discrepancy are not clear. In most parts of Australia less than 10\% of the Indigenous population speak Indigenous language at home; in the NT this figure rises to over 60\%.\textsuperscript{26} Given the verbal nature of the tool and the fact that most clinicians are non-Indigenous, health care interpreters are a preferred delivery method. Despite trained health care interpreters being available in this study, they were under-utilised suggesting staff may over-estimate the English proficiency of Indigenous patients. Using family members as interpreters is not recommended practice when health communication is of a complex or sensitive nature as it can lead to serious misunderstandings.\textsuperscript{27} Our study did not formally assess participants need for an interpreter. Future studies should consider using more formal methods of assessing need for an interpreter and/or consider mandating use of trained...
health care interpreters for participants who primarily use Indigenous languages.

This trial included sites servicing Indigenous people living in metropolitan areas, remote communities, and those living in rural or regional areas who either accessed services locally or in major cities. Although rural and regional people patients attending small regional clinics (n=4) were under-represented in the final sample, our aggregated data suggests that the SCNAT-IP is acceptable and feasible to use in a variety of service settings.

Although conducted in Australia and involving Indigenous Australians exclusively, this is the first study to explore feasibility and acceptability of an Indigenous-specific psychosocial screening tool. Further research is needed to explore the validity and possible adaption of the SCNAT-IP for other Indigenous groups.

An interesting and somewhat unexpected finding of this study was the inter-cultural benefits of the SCNAT-IP, with a positive and bi-directional exchange of information and cultural knowledge reported when using the SCNAT-IP. In addition to the direct service delivery benefits of the SCNAT-IP, the results of the present study suggest that there may be qualitative benefits such as cultural knowledge exchange and improved inter-cultural collaboration and relationships that come from using a culture-specific tool like the SCNAT-IP. Whilst not the focus of this study, future studies should consider expanding study outcomes to include broader cultural benefits in addition to the more traditional service delivery outcomes and patient self-report measures which have formed the focus of many previous screening trials.
In considering the findings of this study some limitations should be acknowledged. Firstly, although the study aimed to recruit all eligible Indigenous cancer patients seen during the study period, more than half of all potentially eligible Indigenous cancer patients were not invited to participate in this study for reasons outlined above. A small number of patients identified in medical records as being Indigenous did not self-identify as Indigenous when invited to the study. Inaccuracy of medical records to identify cancer patients of Aboriginal Torres Strait Islander background may have influenced the results. Another unforeseen factor was the early onset of the wet season in the NT which impeded patient transport from remote communities to the clinic, subsequently reducing overall patient numbers during this trial. Despite these potential biases which may impact generalisability, this study had a high recruitment rate and a relatively large sample size for qualitative studies.

Conclusions

This study provides further evidence for the feasibility and acceptability of the SCNAT-IP. Results have informed minor modifications to the SCNAT-IP to enhance its clarity and suitability for use in a variety of settings. Strategies to promote and disseminate the SCNAT-IP are currently underway.
Figure 1: Study recruitment and response rate

89 Indigenous cancer patients identified by health professional staff

Inclusion Criteria:
- Australian Indigenous person
- Adult (≥ 18 years)
- Cancer diagnosis 5 years or less
- Attending hospital for their cancer
- Able to understand English
- Cognitive and physical ability to provide informed consent

Initial exclusions:
- Not contactable, e.g. missed appointment, early discharge, staff workload and leave (n=44, 49%)

45 (51%) approached to be interviewed

Additional exclusions:
- Ineligible, not Indigenous or were physically and/or mentally unwell (n=5, 11%)
- Declined to participate (n=4, 11%)

36 (80%) of those approached were interviewed

Further exclusions:
- Lost to follow up and audio recording was of poor quality (n=2, 6%)

Final study participants n=34
Table 1. Demographic and Clinical Characteristics of the Patient Sample (n=34).

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<tr>
<th></th>
<th>n</th>
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<tr>
<td>Female</td>
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<td><strong>Remoteness of residence</strong>*</td>
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<td>Regional spread</td>
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| Distal metastases      | 12 | 35  

179
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**Treatment status**

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**Treatment type**

**Surgery**

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**Chemotherapy**

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**Radiotherapy**

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**Other cancer treatments\(^d\)**

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**Comorbidities**

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<td>Diabetes</td>
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<td>Cardiovascular</td>
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<tr>
<td>Respiratory</td>
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<td>Other (^c)</td>
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</table>

Notes: \(^†\) May not sum to 100% due to rounding; \(^*\) classified according to Accessibility/Remoteness Criteria of Australia (ARIA) for further information see AIHW\(^28\); \(^††\) at time of interview; \(^a\) Non-Hodgkins Lymphoma; \(^b\) includes all active hospital-based cancer treatments; \(^c\) includes: Substance Abuse, Psychiatric, Renal disease, Neurological and Gastrointestinal disorders; \(^d\) Includes: hormonal therapy, brachytherapy, microwave ablation.
Competing Interest

The authors declare that they have no competing interests.

Authors’ Contributions

BT conceived and designed the research protocol and was primarily responsible for project management, data analysis, data interpretation, and drafted the manuscript. GG conceived and designed the research protocol and assisted in the data analysis, data interpretation, and drafted the manuscript. ED contributed to the design of the study and data entry. AG contributed to the design of the study. PCV contributed to the design of the study. KG, AH, VJ, and DY contributed to the local project management and study coordination. VH provided critical guidance on the statistical component of the paper and the interpretation of data. Members of the SCNAT-IP Implementation Group were primarily responsible for patient recruitment and data collection. All authors reviewed the draft, read and approved the final manuscript.

Acknowledgements

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Institute. PCV was supported by an Australian Research Council Future Fellowship (#FT100100511). The authors wish to thank Mrs Margaret Lawton and Ms Celia Moore (Indigenous consumer representatives) and Dr Mick Adams for their assistance with developing training materials for this study. We also thank the Indigenous people with cancer and staff who participated in this study for their time and enthusiasm. The views expressed in this publication are those of the authors and do not necessarily reflect the views of the funding agencies. The content of the manuscript was subject to approval by the Aboriginal Health and Medical Research Council of New South Wales in accordance with the standard conditions of their ethical approval.
References


27. Department of Health and Families Northern Territory Government. Guidelines to determine whether an Indigenous language interpreter is required In: Department of

APPENDIX 3: CITATIONS OF OTHER RELATED PUBLICATIONS PRODUCED AND RELATED FUNDED PROJECT GRANTS OVER THE COURSE OF MY PHD ENROLMENT
Citations of other related publications


Related funded project grants

2013–2014  Lowitja Institute  Thews, B and **Garvey G.** Implementation and evaluation of a Supportive Cancer Care Needs Assessment Tool for Aboriginal and Torres Strait Islander people (SCNAT-IP) with cancer: $47,000


Quality of Life of Indigenous and non-Indigenous people with lung, head & neck, breast or gynaecological cancers: $610,731

2009–2011 NHMRC Project Grant #552414
PC Valery, VL Beesley, Garvey G, Anna L Hawkes, J Elston. Closing the divide: assessing and navigating the unmet supportive care needs of Indigenous Cancer Patients: $520,263

2008 ARC Discovery Project Grant
Garvey G, VL Beesley, PC Valery, M Janda, PK O'Rourke, AC Green. Evaluation of an Instrument to Assess the Needs of Indigenous Patients with Cancer: $185,000