



NOVA

University of Newcastle Research Online

nova.newcastle.edu.au

Bernardes, Christina M.; Beesley, Vanessa; Martin, Jennifer; Sabesan, Sabe; Baade, Peter; Meiklejohn, Judith A.; Garvey, Gail; Valery, Patricia C. "Unmet supportive care needs among people with cancer: a cross-cultural comparison between Indigenous and Non-Indigenous Australians". *European Journal of Cancer Care* Vol. 28, Issue 5, no. e13080 (2019).

**Available from:** <http://dx.doi.org/10.1111/ecc.13080>

This is the peer reviewed version of the following article Bernardes, Christina M.; Beesley, Vanessa; Martin, Jennifer; Sabesan, Sabe; Baade, Peter; Meiklejohn, Judith A.; Garvey, Gail; Valery, Patricia C. "Unmet supportive care needs among people with cancer: a cross-cultural comparison between Indigenous and Non-Indigenous Australians". *European Journal of Cancer Care* Vol. 28, Issue 5, no. e13080 (2019), which has been published in final form at <http://dx.doi.org/10.1111/ecc.13080>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions. This article may not be enhanced, enriched or otherwise transformed into a derivative work, without express permission from Wiley or by statutory rights under applicable legislation. Copyright notices must not be removed, obscured or modified. The article must be linked to Wiley's version of record on Wiley Online Library and any embedding, framing or otherwise making available the article or pages thereof by third parties from platforms, services and websites other than Wiley Online Library must be prohibited.

**Accessed from:** <http://hdl.handle.net/1959.13/1443780>

## Title page

**Title:** Unmet supportive care needs among people with cancer: a cross-cultural comparison between Indigenous and Non-Indigenous Australians

**Short running title:** Cross-cultural comparison of unmet needs

**Authors:** Christina M Bernardes<sup>1</sup>, Vanessa Beesley<sup>1</sup>, Jennifer Martin<sup>3</sup>, Sabe Sabesan<sup>4</sup>, Peter Baade<sup>5,6,7</sup>, Judith A Meiklejohn<sup>8</sup>, Gail Garvey<sup>2</sup>, Patricia C Valery<sup>1,2</sup>

**Affiliations:**

1. *QIMR Berghofer Medical Research Institute, Brisbane, Qld, Australia;*
2. *Menzies School of Health Research, Charles Darwin University, Darwin, NT, Australia;*
3. *School of Medicine and Public Health, University of Newcastle, Newcastle, NSW, Australia;*
4. *Department of Medical Oncology, Townsville Cancer Centre, Townsville Hospital and Health Services, Townsville, Qld, Australia*
5. *Cancer Council Queensland, Brisbane, QLD, Australia;*
6. *Menzies Health Institute, Griffith University, Gold Coast, Queensland, Australia;*
7. *School of Mathematical Sciences, Queensland University of Technology, Queensland, Australia*
8. *Orange Sky Australia, Remote and Indigenous Services Program, Brisbane, Qld, Australia;*

**Corresponding author:** Christina M Bernardes

QIMR Berghofer Medical Research Institute  
300 Herston Road, Herston QLD 4006  
Locked Bag 2000 Royal Brisbane Hospital, QLD 4029  
Tel 07 3845 3566 Fax +61 7 3845 3502  
e-mail [christina.bernardes@qimrberghofer.edu.au](mailto:christina.bernardes@qimrberghofer.edu.au)

**Conflict of Interest:** The authors declare that they have no competing interests.

**This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/ECC.13080](https://doi.org/10.1111/ECC.13080)**

This article is protected by copyright. All rights reserved

**Funding:** The NHMRC Project Grant (No. 552414) funded the '*Indigenous Study*' and the NHMRC Project Grant (No. 1004643) funded the '*Non-Indigenous Study*'. PC Valery was supported by an Australian Research Council Career Development Fellowship (No. 1083090). CB was supported by DISCOVER-TT Centre of Research Excellence; Research Fellowship (No. 1041111). The contents of the published material are solely the responsibility of the Administering Institution, a Participating Institution or individual authors and do not reflect the views of the NHMRC.

**Authorship:** VB, SS, PB, GG, PCV designed the study. CB, JM collected the data. CB, VB and PCV assisted with the data interpretation. CB drafted the manuscript and all authors revised it critically, contributed to its editing and approved final version.

**ORCID numbers:**

Christina M Bernardes: 0000-0002-8061-7013;

Vanessa Beesley: 0000-0002-5081-1800;

Peter Baade: 0000-0001-8576-8868

Gail Garvey: 0000-0001-5065-5716

Patricia C Valery: 0000-0002-8823-3006

Both studies were approved by the Human Research Ethics Committees of the participating hospital(s), Charles Darwin University, the Northern Territory Department of Health, and QIMR Berghofer Medical Research Institute.

DR. CHRISTINA M. BERNARDES (Orcid ID : 0000-0002-8061-7013)

DR. VANESSA L BEESLEY (Orcid ID : 0000-0002-5081-1800)

Article type : Original Article

**Title:** Unmet supportive care needs among people with cancer: a cross-cultural comparison between Indigenous and Non-Indigenous Australians

### Abstract

**Objectives:** This study describes and compares the unmet supportive care needs between Indigenous and Non-Indigenous people with cancer.

**Methods:** Data from two cross-sectional supportive care needs studies were matched in a 1:1 ratio for Indigenous (n=125) and Non-Indigenous (n=125) Australian adults diagnosed with cancer. Descriptive statistics were used to compare type and prevalence of 24 need items measured by the SCNS-SF34 and SCNAT-IP.

**Results:** A higher proportion of Non-Indigenous participants compared to Indigenous participants reported having any moderate-to-high level of unmet needs (70% vs 54%,  $p=0.013$ ) and the difference was consistently observed across non-matched characteristics. While concerns for caregivers, fear of recurrence and pain were central needs for both Indigenous participants and Non-Indigenous participants, there were some key differences in the specific unmet needs between groups. Physical issues including doing usual daily activities and dealing with fatigue were the top priorities for Non-Indigenous people, while money worries, dealing with psychological issues such as how to keep their spirit strong or hope about their future appeared to be priorities for Indigenous people.

**Conclusions:** Variations in the unmet supportive care needs between Indigenous and Non-Indigenous people with cancer may guide health professionals to target specific needs when preparing care plans.

**Key words:** cancer, unmet supportive care needs, Indigenous

## **Introduction**

Cancer is a major cause of illness and disease burden among Australians. In 2017, it was estimated that 134,174 new cases would be diagnosed in Australia that will eventually lead to premature death and disability(Au et al., 2011; Australian Institute of Health and Welfare 2017, 2017; Youl et al., 2016; Zucca, Boyes, Newling, Hall, & Girgis, 2011). Overall, mortality rates have fallen but Indigenous people with cancer continue to experience poorer outcomes and higher hazard of death than Non-Indigenous Australians even after considering the risks from other causes of death, socio-demographic factors, stage and cancer site(Australian Institute of Health and Welfare 2017, 2017; Tervonen et al., 2017). The disparities in outcomes may suggest that Indigenous people with cancer have higher unmet needs and perhaps cancer service providers are not identifying and/or addressing needs appropriately in this population.

The identification and management of unmet supportive care needs is an essential component of quality care for people with cancer(Harrison, Young, Price, Butow, & Solomon, 2009). This assessment provides a direct measurement of the persons own perceptions of their need for help as well as the magnitude of their desire for help with those needs(Boyes, Girgis, & Lecathelinais, 2009). Furthermore, unmet needs may be present or not depending on cultural factors and service delivery factors. Cross-cultural and international comparisons of unmet supportive care needs have shown that different groups tend to prioritize different domains e.g. Japanese(Akechi et al., 2011) and Caucasian(Youl et al., 2016) women with breast cancer prioritize psychological needs while Chinese(Au et al., 2011) women prioritize information regarding health systems.

There are validated supportive care needs instruments for Indigenous and Non-Indigenous Australians with cancer with good psychometric properties and with a culturally sensitive approach(Boyes et al., 2009; Garvey et al., 2015). However, no study has directly compared the unmet needs between Indigenous and Non-Indigenous Australians(Harrison et al., 2009). Previous research on the unmet needs of Queensland, Australian Indigenous people with cancer and demonstrated that money worries

(29%) and needs related to physical and psychological domains (11%) were the most frequently reported (Garvey et al., 2015). While Australian studies of cancer cohorts (Indigenous and Non-Indigenous combined) have reported that fear about their cancer spreading (40%) was most frequently reported (Sanson-Fisher et al., 2000). It is difficult to draw any conclusions about cross-cultural unmet needs from previous studies as they used different tools and assessed people with cancer in different times and locations. Additionally, in these cancer observational studies, differences between groups on confounding variables may have a significant effect on results when examining health outcomes (Reeve, Smith, Arora, & Hays, 2008), affecting the distinction of the factors that cause the health differential. As there is a significant disparity between Indigenous and Non-Indigenous health outcomes our approach to investigate the unmet needs was to case-match two cancer cohorts (one Indigenous and one Non-Indigenous combined) and create groups with similar characteristics.

Our aim was to describe and compare the prevalence and type of unmet needs between Indigenous and Non-Indigenous people with cancer. This comparison of unmet needs across different cultural settings is important as knowing the priorities of people with cancer and their prevalence of unmet needs can inform service planning and delivery.

## **Methods**

### **Participants**

This manuscript combines data collected from two cross-sectional studies carried out in Queensland, Australia that assessed the unmet needs of people with cancer: the Indigenous Supportive Care Needs Study (referred to here as '*Indigenous study*') (Garvey et al., 2015) and the Care and Wellbeing Study (referred to here as the '*Non-Indigenous study*'). The two studies were conducted by the same research team using similar recruitment and data collection procedures. In both studies data were collected through face-to-face interviews using a structured questionnaire. Indigenous and Non-Indigenous people with cancer (henceforth will be referred to as 'participants') were eligible if they were diagnosed with any type of cancer and receiving treatment in one of the hospitals included in the studies. Eligible participants were identified by hospital staff from daily appointment lists. Indigenous participants were identified in four public hospitals (Princess Alexandra, Royal Brisbane and Women's, Townsville Base and Cairns Base Hospitals) by an Indigenous Liaison Officer who had listed all Indigenous cancer patients admitted or receiving care as outpatients (centralized approach). Non-Indigenous participants were identified by hospital staff at target outpatient clinics and wards across the Princess Alexandra Hospital (dispersed approach). In both studies a trained interviewer provided information about the study, written informed consent was obtained and interviews were scheduled or conducted at the time and place of convenience to the participant and clinical data (diagnosis, stage of the disease and treatment) were extracted from medical charts.

## Assessment tools

In the Indigenous study, needs were assessed with the Supportive Care Needs Assessment Tool for Indigenous Patients (SCNAT-IP)(Garvey et al., 2015) which has 26 items to assess four domains: 'physical and psychological' [11 items]; 'hospital care' [4 items]; 'information and communication' [6 items] and; 'practical and cultural' [5 items] (Figure 1). The SCNAT-IP was developed through consultation with Indigenous cancer patients and key informants (from community health centres, public hospitals, Indigenous organizations and wider Indigenous Queensland community). The process involved qualitative research methods to assess the face and content validity of the Supportive Care Needs Survey – Short form 34 (SCNS-SF34) and a refining of this tool for Indigenous people with cancer (newly named SCNAT-IP). In particular, the SCNS-SF34 was modified by changing all items to use more appropriate language to Indigenous people (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)(Garvey et al., 2012).

In the Non-Indigenous study, needs were assessed with the SCNS-SF34(Boyes et al., 2009) and some of the questions of the SCNAT-IP (Figure 1). The 34-item survey measures needs across five domains: psychological [10 items], health system and information [11 items], patient care and support [5 items], physical and daily living [5 items], and sexuality needs [3 items]. Both surveys use a 5-point scale to measure unmet need: 1=no need, 2=satisfied with the help received; 3=need a little more help (referred to as '*low unmet need*'); 4=need some more help ('*moderate unmet need*'); 5=needed a lot more help ('*high unmet need*').

Sociodemographic characteristics were collected by interview. Patients residential postcodes were used to classify remoteness of residence using the Accessibility/Remoteness Index of Australia (ARIA+ classification)(Australian Institute of Health and Welfare, 2004), and socioeconomic status using the index of relative socioeconomic advantage and disadvantage (IRSAD)(Australian Bureau of Statistics, 2008).

## Matching criteria for the comparison groups

Based on systematic reviews of variables identified to be strongly associated with unmet needs, we matched Indigenous and Non-Indigenous participants in a 1:1 ratio by: age (<60 years/60 and more years )(Beesley, Alemayehu, & Webb, 2018; Fiszer, Dolbeault, Sultan, & Bredart, 2014; Harrison et al., 2009; Okediji, Salako, & Fatiregun, 2017), sex (male/female)(McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010; Okediji et al., 2017), education level (primary to high school/post-secondary school )(Okediji et al., 2017), marital status (partnered/no partner)(Okediji et al., 2017),

time since treatment ( $\leq 30$  days,  $>30$  days)(Harrison et al., 2009; Sanson-Fisher et al., 2000), and recurrence (yes/no)(Beesley et al., 2017).

### **Data analysis**

Matching pairs were identified using the case-matching command in SPSS; Indigenous status (Indigenous vs. Non-Indigenous) was used as the group indicator, matches were required to be exact on all variables (match tolerance equal to zero) and the case order was randomized when drawing matches. The matching was precluded if any of the matching variables was missing. Demographic and clinical characteristics were described. Data analysis was limited to 24 need items that were common to the tools used in both studies (Figure 1). We calculated the proportion of participants who: (i) had any unmet needs (scored 3, 4 or 5 for  $\geq 1$  of the 24 items); (ii) had moderate-to-high level unmet needs (scored 4 or 5 for  $\geq 1$  of the 24 items); and (iii) had at least five items with moderate-to-high level unmet need (scored 4 or 5 for  $\geq 5$  of the 24 items) stratified by Indigenous status. Chi-square or Fisher's exact tests (when cell counts  $<5$ ) were used to compare proportions. The median number (and interquartile range -IQR) of moderate-to-high unmet needs reported by participant was also calculated.

For the variables not used in the matching (socio-economic indexes for areas (SEIFA); remoteness of residence (ARIA); cancer group; cancer stage; patient admission status; time since diagnosis) we estimated the proportion of patients with moderate to high unmet needs by Indigenous status stratified by each unmatched variable to ensure these variables were not associated with Indigenous status (Figure 2). Chi-square was used to compare proportions. A supplementary table (Supplementary Table 2) was provided with the proportion of patients with moderate to high unmet needs with their respective 95%CI, by the unmatched variables and by Indigenous status.

Data were analysed using SPSS Statistical Software Package release 22.0(SPSS Inc., Chicago, IL).

Both studies were approved by the Human Research Ethics Committees of the participating hospital(s), Charles Darwin University (Northern Territory), the Northern Territory Department of Health and Menzies School of Health Research, and QIMR Berghofer Medical Research Institute.

### **Results**

The Indigenous study ascertained 396 eligible patients, 295 were approached and 252 interviewed (response rate of 85.4%). Four participants were subsequently excluded because they were not receiving treatment leaving a final study sample of 248. The Non-Indigenous study ascertained 809



eligible patients, 444 were approached and 290 interviewed (response rate 65.3%). Two participants were later excluded because they identified as Indigenous people, leaving a final study sample of 288.

Among the unmatched participants (Supplementary Table 1), Non-Indigenous more frequently than Indigenous participants, were older (60 years and more; 67% vs 34%), had post-secondary education (54% vs 46%), live in major cities (75% vs 25%) and had more advantaged socio-economic status (82% vs 70%). Non-Indigenous participants had a higher proportion of blood related cancers (25% vs 14%), were more likely to have received treatment in the last than 30 days (86% vs 69%) as inpatients (37% vs 18%). Lack of matching was mostly due to differences in age group, educational level and marital status between Indigenous and Non-Indigenous participants, and the missing data in both groups.

The characteristics of 250 participants included in the analyses after matching socio-demographic and clinical characteristics are described in Table 1. More than half of the participants were females (54%), aged less than 60 years (median 54 years; IQR 46.6-60.7), and were on average just over a year after diagnosis (median 130 days, IQR 62-335). The most frequent cancer types were breast, respiratory, blood related cancers, digestive organs and lip and oral cavity.

There were some differences in non-matched variables between the groups. Compared with non-Indigenous participants, Indigenous participants were significantly more likely to come from the most disadvantaged socio-economic areas, live in remote areas, have cancers of female genital organs and not blood related cancers, have a less advanced stage of disease at diagnosis and be closer to the time of diagnosis and receiving treatment as inpatient at the time of interview (Table 1).

### **Proportion of unmet supportive care needs by group**

A higher proportion of Non-Indigenous compared to Indigenous participants reported having at least one low-to-high unmet need (85% vs 74%,  $p=0.042$ ), at least one moderate-to-high level unmet need (70% vs. 54%,  $p=0.013$ ) and at least five moderate-to-high level unmet needs (62% vs. 26%,  $p=0.042$ ). The median number of moderate-to-high unmet needs varied across the two groups; for Non-Indigenous participants it was 3.0 items (IQR 0.00-7.00) and for Indigenous participants it was 1.0 item (IQR 1.43-2.50). Stratified analyses confirmed that the differences in the proportion of patients with moderate-high unmet needs between groups was consistent across non-matched characteristics including time since diagnosis, cancer types, disease stage, in-patient versus out-patient, and remoteness and area level socio-economic status of residence (Figure 2). While the proportion of patients with moderate to high unmet needs did not vary significantly by Indigenous status, for ARIA and time since diagnosis the numbers in some categories were small leading to wide confidence intervals (Supplementary Table 2).

Almost all of the differences related to the physical/daily living and psychological supportive care domains (Table 2), with a significantly a higher proportion of Non-Indigenous compared to Indigenous participants reporting needing help with physical/daily living needs. Health system, information and financial needs were reported a similar proportion between groups.

### **Priority unmet supportive care needs items by group**

There were variations in the top ten frequently reported unmet needs between groups (Table 3). While physical issues including doing things they used to do and feeling tired were priority unmet needs for Non-Indigenous participants, for Indigenous participants, money worries, dealing with sadness and keeping a strong spirit were higher priority in comparison. There were also some consistent items with concerns for those close to them, fear of recurrence and pain being among the top 5 need items reported by both Non-Indigenous and Indigenous people.

### **Discussion**

This study compares the perceived unmet needs of Indigenous and Non-Indigenous Australians undergoing treatment for their cancer. There were wide variations between the two groups top unmet needs which may mean that direct comparisons of the number of unmet needs is less important than considering the type of unmet needs. Perhaps the most striking variation between these groups was that physical issues including doing usual daily activities and dealing with fatigue were the top priorities for Non-Indigenous people, while money worries, dealing with sadness and keeping a strong spirit appeared to be more frequently reported by Indigenous people. Similar to participants in other cross-cultural and international settings(Clavarino, Lowe, Carmont, & Balanda, 2002; Harrison et al., 2009; Sanson-Fisher et al., 2000), we found the most frequently reported unmet needs for Indigenous and Non-Indigenous participants related to the physical/daily living and psychological domains and that concerns for caregivers, fear of recurrence and pain were central needs for both groups. However, a significantly higher proportion of Non-Indigenous compared to Indigenous participants report needing help with items in these domains which drove an overall significant difference between the groups in having unmet needs. On the other hand, health system, information and financial needs were reported at similar proportion between Non-Indigenous and Indigenous Australians which may suggest that the public hospitals in which these participants were recruited were sensitive to the information and hospital-based supportive care needs across cultures.

The finding that overall, a higher proportion of matched Non-Indigenous participants had unmet needs than Indigenous participants even within the different strata of the unmatched variables such as stage of disease, time since diagnosis, or rurality of residence, was unexpected. Indigenous people

more often than Non-Indigenous lived in rural or remote areas, making them travel lengthy distances to receive care that could exacerbate symptoms or side effects of treatments, limit service access and increase financial hardship(Loughery & Woodgate, 2015). Possible explanations may be that Indigenous people historically have been more exposed to adversity and trauma and therefore may have more resilience and less perceived unmet needs(Hopkins, Shepherd, Taylor, & Zubrick, 2015) or alternatively that Indigenous people have poorer access to services(Condon, Barnes, Armstrong, Selva-Nayagam, & Elwood, 2005) and because of this and/or other cultural factors have lower expectations of support provision when it comes to physical/daily living and psychological issues. Furthermore, people that live in rural areas may have chosen to do so by reason that directly affect their quality of life and well-being such as close-knit community support, positive cultural experiences and a sense of enhanced autonomy in daily life(Loughery & Woodgate, 2015). These perhaps helped Indigenous cancer patients feel more supported and with less needs.

It is not surprising that money worries was the most frequently reported unmet need for Indigenous participants. Indigenous Australians experience disadvantage across economic, education, and employment when compared to Non-Indigenous Australians(Australian Institute of Health and Welfare, 2015). However, it is also worth noting that almost a quarter of the Indigenous and Non-Indigenous participants had a moderate-to-high unmet need for help with money worries and that the need for financial assistance has been reported by 41% of participants in previous studies of Non-Indigenous people with cancer(A. Hall, D'Este, Tzelepis, Lynagh, & Sanson-Fisher, 2014; A. E. Hall, Sanson-Fisher, Lynagh, Tzelepis, & D'Este, 2015). The similar proportions reporting money worries may be partially explained by study design as recruitment of Indigenous and Non-Indigenous participants was carried out in public hospitals and patients therein would be expected to have similar socio-economic status(Australian Institute of Health and Welfare, 2016).

There were however other variations between the two groups top unmet needs that cannot be explained by study design and may reflect differences in the way the two groups cope with cancer, or their expectations of support. People with cancer transitioning from diagnosis through treatment and survivorship require personal adjustment in the physical domain but can be specially challenging in the psychological domain(Stanton et al., 2005). The individual perceptions about the support received and satisfaction with support associated with unrealistic expectations about physical recovery and ability to return to activities as before the diagnosis have been found to be associated with higher unmet needs(Bredart et al., 2013). In particular our study suggest Non-Indigenous people are less likely to accept functional deficits and may expect to keep up with their usual daily activities, whereas issues such as how to keep their spirit strong or hope about their future maybe a higher support priority for Indigenous Australians.

### **Strengths and limitations**

The strength and innovation of this analysis includes the use of data from studies with good response rates, valid tools to assess unmet needs, accurate clinical data from medical records and importantly matching of Indigenous and Non-Indigenous people with cancer on some of the factors known to affect unmet needs to create two groups with similar characteristics to compare.

Among the limitations, this work is of retrospective nature, with a disparity in recruitment sites and wording of survey items and the cohorts may not represent the source populations. Therefore some caution should be taken when interpreting results. Indigenous participants were recruited from 4 major hospitals in a centralized approach (through Indigenous Liaison Officers) and Non-Indigenous participants were recruited from a single hospital in a dispersed approach, also support service provision may be different by site. It also possible that because the assessment tools used in the two studies were different, where the Indigenous survey included some questions with examples while Non-Indigenous did not; this may have affected the interpretation by participants and may have answered the common items differently. However, the questionnaires were completed by trained interviewers, thus removing some of the inherent limitations of self-completed questionnaires. We were only able to compare the common individual items and not the domains scores. While the study participants were matched for known variables associated with unmet needs, individual differences in participants and possibly their interpretation of survey items may still contribute to some uncertainty in the reported findings. Lastly, we acknowledge that chance must be considered when interpreting the results.

This work extends the understanding of the unmet needs of people with cancer and priority issues for care plans. Nurses and other healthcare providers play an important role in screening and supporting people with cancer during their treatment. In addition to addressing the needs that are common to all patients around fear of recurrence, concerns for caregivers and pain management, this study indicates that for Non-Indigenous people, they may need to focus more on building self-efficacy, persuading their patients that they possess the requisite skills to manage daily living tasks, whereas for Indigenous people they may need to focus on screening and addressing psychological issues such as how to keep their spirit strong or hope about their future. Finally, the finding that Non-Indigenous people more frequently report unmet needs than Indigenous people with cancer highlights the importance of using needs assessment tools which allow the person to identify which issues he/she has a desire for help as opposed to using the distress thermometer and problem checklist (Hollingworth et al., 2013; Lee, Katona, De Bono, & Lewis, 2010), which is frequently used in cancer care to identify issues (in a yes or no scale). Thereafter in line with best practice (Clinical Oncology Society of Australia Model of Survivorship Care Working Group, 2016), a supportive care plan can be considered in the context of the individuals' circumstances and personal preferences for intervention.

## **References:**

- Akechi, T., Okuyama, T., Endo, C., Sagawa, R., Uchida, M., Nakaguchi, T., . . . Furukawa, T. A. (2011). Patient's perceived need and psychological distress and/or quality of life in ambulatory breast cancer patients in Japan. *Psychooncology*, 20(5), 497-505. doi:10.1002/pon.1757
- Au, A., Lam, W. W., Kwong, A., Suen, D., Tsang, J., Yeo, W., . . . Fielding, R. (2011). Validation of the Chinese version of the short-form Supportive Care Needs Survey Questionnaire (SCNS-SF34-C). *Psychooncology*, 20(12), 1292-1300. doi:10.1002/pon.1851
- Australian Bureau of Statistics. (2008). *Census of population housing: socio-economic indexes for areas (SEIFA), Australia, 2006*. Retrieved from ABS Cat. No. 2033.0.55.001. Canberra, ABS:
- Australian Institute of Health and Welfare 2017. (2017). *Cancer in Australia 2017*. Cancer series no.101. Cat. no. CAN 100. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2004). *Rural, regional and remote health: a guide to remoteness classifications*. Cat. No PHE 53. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2015). *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2015*. Cat. no. IHW 147. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2016). *Australia's hospitals 2014-15 at a glance*. Health services series no. 70. Canberra: AIHW.
- Beesley, V. L., Alemayehu, C., & Webb, P. M. (2018). A systematic literature review of the prevalence of and risk factors for supportive care needs among women with gynaecological cancer and their caregivers. *Support Care Cancer*, 26(3), 701-710. doi:10.1007/s00520-017-3971-6
- Beesley, V. L., Smithers, B. M., O'Rourke, P., Janda, M., Khosrotehrani, K., & Green, A. C. (2017). Variations in supportive care needs of patients after diagnosis of localised cutaneous melanoma: a 2-year follow-up study. *Support Care Cancer*, 25(1), 93-102. doi:10.1007/s00520-016-3378-9
- Boyes, A., Girgis, A., & Lecathelinais, C. (2009). Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *J Eval Clin Pract*, 15(4), 602-606. doi:10.1111/j.1365-2753.2008.01057.x
- Bredart, A., Kop, J. L., Griesser, A. C., Fiszer, C., Zaman, K., Panes-Ruedin, B., . . . Dolbeault, S. (2013). Assessment of needs, health-related quality of life, and satisfaction with care in breast cancer patients to better target supportive care. *Ann Oncol*, 24(8), 2151-2158. doi:10.1093/annonc/mdt128
- Clavarino, A. M., Lowe, J. B., Carmont, S. A., & Balanda, K. (2002). The needs of cancer patients and their families from rural and remote areas of Queensland. *Aust J Rural Health*, 10(4), 188-195.
- Clinical Oncology Society of Australia Model of Survivorship Care Working Group. (2016). *Model of Survivorship Care: Critical Components of Cancer Survivorship Care in Australia Position Statement*. Retrieved from
- Condon, J. R., Barnes, T., Armstrong, B. K., Selva-Nayagam, S., & Elwood, J. M. (2005). Stage at diagnosis and cancer survival for Indigenous Australians in the Northern Territory. *Med J Aust*, 182(6), 277-280.

- Fiszer, C., Dolbeault, S., Sultan, S., & Bredart, A. (2014). Prevalence, intensity, and predictors of the supportive care needs of women diagnosed with breast cancer: a systematic review. *Psychooncology*, 23(4), 361-374. doi:10.1002/pon.3432
- Garvey, G., Beesley, V. L., Janda, M., Jacka, C., Green, A. C., O'Rourke, P., & Valery, P. C. (2012). The development of a supportive care needs assessment tool for Indigenous people with cancer. *BMC Cancer*, 12, 300. doi:10.1186/1471-2407-12-300
- Garvey, G., Beesley, V. L., Janda, M., O'Rourke, P. K., He, V. Y., Hawkes, A. L., . . . Valery, P. C. (2015). Psychometric properties of an Australian supportive care needs assessment tool for Indigenous patients with cancer. *Cancer*, 121(17), 3018-3026. doi:10.1002/cncr.29433
- Hall, A., D'Este, C., Tzelepis, F., Lynagh, M., & Sanson-Fisher, R. (2014). Factors associated with haematological cancer survivors experiencing a high level of unmet need across multiple items of supportive care: a cross-sectional survey study. *Support Care Cancer*, 22(11), 2899-2909. doi:10.1007/s00520-014-2264-6
- Hall, A. E., Sanson-Fisher, R. W., Lynagh, M. C., Tzelepis, F., & D'Este, C. (2015). What do haematological cancer survivors want help with? A cross-sectional investigation of unmet supportive care needs. *BMC Res Notes*, 8, 221. doi:10.1186/s13104-015-1188-7
- Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N., & Solomon, M. J. (2009). What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer*, 17(8), 1117-1128. doi:10.1007/s00520-009-0615-5
- Hollingworth, W., Metcalfe, C., Mancero, S., Harris, S., Campbell, R., Biddle, L., . . . Brennan, J. (2013). Are needs assessments cost effective in reducing distress among patients with cancer? A randomized controlled trial using the Distress Thermometer and Problem List. *J Clin Oncol*, 31(29), 3631-3638. doi:10.1200/JCO.2012.48.3040
- Hopkins, K. D., Shepherd, C. C., Taylor, C. L., & Zubrick, S. R. (2015). Relationships between Psychosocial Resilience and Physical Health Status of Western Australian Urban Aboriginal Youth. *PLoS One*, 10(12), e0145382. doi:10.1371/journal.pone.0145382
- Lee, S. J., Katona, L. J., De Bono, S. E., & Lewis, K. L. (2010). Routine screening for psychological distress on an Australian inpatient haematology and oncology ward: impact on use of psychosocial services. *Med J Aust*, 193(5 Suppl), S74-78.
- Loughery, J., & Woodgate, R. L. (2015). Supportive care needs of rural individuals living with cancer: A literature review. *Can Oncol Nurs J*, 25(2), 157-178.
- McDowell, M. E., Occhipinti, S., Ferguson, M., Dunn, J., & Chambers, S. K. (2010). Predictors of change in unmet supportive care needs in cancer. *Psychooncology*, 19(5), 508-516. doi:10.1002/pon.1604
- Okediji, P. T., Salako, O., & Fatiregun, O. O. (2017). Pattern and Predictors of Unmet Supportive Care Needs in Cancer Patients. *Cureus*, 9(5), e1234. doi:10.7759/cureus.1234
- Reeve, B. B., Smith, A. W., Arora, N. K., & Hays, R. D. (2008). Reducing bias in cancer research: application of propensity score matching. *Health Care Financ Rev*, 29(4), 69-80.

- Sanson-Fisher, R., Girgis, A., Boyes, A., Bonevski, B., Burton, L., & Cook, P. (2000). The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer*, 88(1), 226-237.
- Stanton, A. L., Ganz, P. A., Rowland, J. H., Meyerowitz, B. E., Krupnick, J. L., & Sears, S. R. (2005). Promoting adjustment after treatment for cancer. *Cancer*, 104(11 Suppl), 2608-2613. doi:10.1002/cncr.21246
- Tervonen, H. E., Walton, R., You, H., Baker, D., Roder, D., Currow, D., & Aranda, S. (2017). After accounting for competing causes of death and more advanced stage, do Aboriginal and Torres Strait Islander peoples with cancer still have worse survival? A population-based cohort study in New South Wales. *BMC Cancer*, 17(1), 398. doi:10.1186/s12885-017-3374-6
- Youl, P. H., Dasgupta, P., Youlden, D., Aitken, J. F., Garvey, G., Zorbas, H., . . . Baade, P. D. (2016). A systematic review of inequalities in psychosocial outcomes for women with breast cancer according to residential location and Indigenous status in Australia. *Psychooncology*, 25(10), 1157-1167. doi:10.1002/pon.4124
- Zucca, A., Boyes, A., Newling, G., Hall, A., & Girgis, A. (2011). Travelling all over the countryside: travel-related burden and financial difficulties reported by cancer patients in New South Wales and Victoria. *Aust J Rural Health*, 19(6), 298-305. doi:10.1111/j.1440-1584.2011.01232.x

### Figure legend:

Figure 1. Diagram comparing supportive care need items common to the two studies and the domains from the SCNAT-IP and SCNS-SF34.

Figure 2. Proportion of patients with moderate to high unmet needs by unmatched characteristics (socio-economic indexes by area (SEIFA); rurality of residence (ARIA); cancer group (most common); cancer stage; patient admission status and time since diagnosis) and by Indigenous status.

**Table 1.** Demographic and clinical characteristics of the matched sample population

Characteristics	Indigenous	Non-Indigenous	p value
	N=125	N=125	
	n (%)	n (%)	
Sex			1.000

Male	58 (46)	58 (46)	
Female	67 (54)	67 (54)	
<b>Age group</b>			<b>1.000</b>
<60 years	89 (71)	89 (71)	
60+ years	36 (29)	36 (29)	
<b>Education level</b>			<b>1.000</b>
Primary school or less/high school	90 (72)	90 (72)	
Post-secondary school	35 (28)	35 (28)	
<b>Lives with a partner<sup>1</sup></b>			<b>1.000</b>
Yes	67 (54)	67 (54)	
No	58 (46)	58 (46)	
<b>Socio-Economic Indexes for Areas (SEIFA)<sup>2</sup></b>			<b>0.033</b>
Most Advantaged to Intermediate Disadvantaged	90 (72)	101 (84)	
Most Disadvantaged	35 (28)	20 (17)	
<b>Rurality of residence (ARIA)<sup>3</sup></b>			<b>&lt;0.001</b>
Major city	49 (39)	97 (80)	
Outer/Inner regional	58 (46)	23 (19)	
Remote /Very remote	18 (14)	1 (1)	
<b>Cancer Group<sup>4</sup></b>			<b>0.002</b>
Breast (C50)	29 (23)	23 (18)	
Respiratory and intrathoracic organs (C30 – C39)	15 (12)	20 (16)	
Lymphoid, haematopoietic and related tissue (C81 – C96)	15 (12)	36 (29)	
Digestive organs (C15 – C26)	15 (12)	20 (16)	
Lip, oral cavity and pharynx (C00 – C14)	13 (10)	10 (8)	
Male genital organs (C60 – C63)	8 (6)	4 (3)	
Female genital organs (C51 – C58)	9 (7)	0 (-)	
Eye, brain and other parts of CNS (C69 – C72)	8 (6)	3 (2)	
Unknown cancer primary site (C76 – C80) and others	13 (10)	9 (7)	
<b>Cancer Stage<sup>5</sup></b>			<b>0.037</b>
Local/Regional	77 (65)	59 (48)	
Distant	24 (20)	38 (31)	
Not applicable	18 (15)	25 (21)	
<b>Time since receiving treatment</b>			<b>1.000</b>
< 30 days	113 (90)	113 (90)	
30 days and more	12 (10)	12 (10)	
<b>Recurrence</b>			<b>1.000</b>
Yes	26 (21)	26 (21)	
No	99 (79)	99 (79)	
<b>Patient admission status<sup>6</sup></b>			<b>0.005</b>



Inpatient	54 (43)	30 (25)
Outpatient	71 (57)	89 (75)
<b>Time since diagnosis</b>		<b>&lt;0.001</b>
< 90 days	61 (49)	28 (22)
91 days and more	64 (51)	97 (78)

Notes: The two groups were matched for age, sex, education, recurrence, time receiving treatment and marital status.

1 Marital status and lives with a partner were combined, to input value when missing;

2 The socio-economic index used in this study was the Index of Relative Socio-Economic Advantage and Disadvantage (IRSAD). Four missing values for Non-Indigenous group;

3 Four missing values for Non-Indigenous group;

4 Other cancers category includes: malignant neoplasms of bone and cartilage (C40-C41); melanoma (C43-C44); soft tissue (C45-C49); urinary tract (C64-C68); thyroid and other endocrine glands (C73-C75).

5 Six missing values for the Indigenous group and three missing values in the Non-Indigenous group;

6 Six missing values for the Non-Indigenous group.

**Table 2.** Proportion of unmet needs of the matched cohort of Indigenous and Non-Indigenous people with cancer.

Supportive Care Needs Items	Indigenous			Non-Indigenous			p value Overall	p value No unmet needs Vs. Mod/High Needs
	No	Low	Mod/	No	Low	Mod/		
	Unmet	Need	High	Unmet	Need	High		
	needs* %	%	Needs %	needs* %	%	Needs %		
Physical pain <sup>a, f</sup>	81	10	10	59	14	28	<0.001	<0.001
Feeling tired <sup>a, g</sup>	79	12	9	37	26	37	<0.001	<0.001
Feeling unwell <sup>a, f</sup>	82	11	7	49	26	25	<0.001	<0.001
Work around the house <sup>a, f</sup>	81	11	9	54	19	28	<0.001	<0.001
Doing things you used to do <sup>a</sup>	87	5	8	41	18	42	<0.001	<0.001
Anxiety <sup>a, h</sup>	82	12	7	55	22	24	<0.001	<0.001
Feeling down or sad	80	10	10	55	23	22	<0.001	0.014
Worrying about your illness spreading <sup>f</sup>	78	11	11	50	19	32	<0.001	<0.001
Worry about the results of treatment <sup>e</sup>	79	11	11	60	12	28	0.001	0.001
Keeping you strong in your spirit <sup>a, e</sup>	82	9	10	66	15	19	0.021	0.046
Concerns about the worries of those close to you <sup>a, f</sup>	75	10	15	49	15	36	<0.001	<0.001
Support by staff that the way you feel is natural <sup>f</sup>	90	5	6	82	7	11	0.241	0.168
Having hospital staff attending quickly your physical needs <sup>e</sup>	92	6	2	83	9	8	0.070	0.051
Having hospital staff show sensitivity to and respecting your feelings and emotional needs	91	2	6	82	10	9	0.041	0.634
Being shown or given information about how to manage your treatment, illness and side-effects in hospital <sup>e</sup>	92	4	4	82	6	12	0.045	0.021
Being shown or given information about how to manage your treatment, illness and side-effects at home <sup>f</sup>	86	6	7	82	7	11	0.550	0.281
Explaining what the tests are for <sup>e</sup>	93	3	4	98	10	13	0.006	0.012
Understanding the good and bad effects of treatment before you chose to have them <sup>e</sup>	84	10	6	86	11	3	0.523	0.376
Being told about the things you can do to help yourself get well <sup>e</sup>	88	6	6	78	7	15	0.079	0.040
Being treated like a person not just another case or a number <sup>f</sup>	88	7	6	79	9	12	0.170	0.130
Finding a place to stop or stay while receiving treatment	90	2	8	85	5	10	0.493	0.661

Money worries <sup>b, f</sup>	67	10	24	68	10	23	1.000	1.000
Ensuring family members were able to be present when talking or seeing health professionals <sup>f</sup>	90	4	6	85	2	12	0.168	0.077
Directions to get to and around the hospital <sup>f</sup>	90	3	7	89	4	7	0.951	1.000

Note: cancer participants were matched for age, sex, education, recurrence, time receiving treatment and marital status;

\*No unmet needs combine responses of participants *with 'no needs'* and people with cancer *'satisfied with the help received'*

- a. One Indigenous participant with missing information in this item;
- b. Two Indigenous participants with missing information in this item;
- c. Three Indigenous participants with missing information in this item;
- d. Four Indigenous participants with missing information in this item.
- e. One Non-Indigenous participant with missing information in this item;
- f. Two Non-Indigenous participants with missing information in this item;
- g. Three Non-Indigenous participants with missing information in this item;
- h. Four Non-Indigenous participants with missing information in this item.

**Table 3.** The top ten most frequently reported moderate-to-high unmet need items among Indigenous and Non-Indigenous people with cancer in Queensland, Australia

Indigenous		Non-Indigenous	
Item	(%)	Item	(%)
Money worries	(24)	Doing things you used to do	(42)
Concerns about the worries of those close to you	(15)	Feeling tired	(37)
Worrying about your illness spreading	(11)	Concerns about the worries of those close to you	(36)
Worry about the results of treatment	(11)	Worrying about your illness spreading	(32)
Physical pain	(10)	Physical pain	(28)

Feeling down or sad	(10)	Work around the house	(28)
Keeping you strong in your spirit	(10)	Worry about the results of treatment	(28)
Feeling tired	(9)	Feeling unwell	(25)
Work around the house	(9)	Anxiety	(24)
Doing things you used to do	(8)	Money worries	(23)

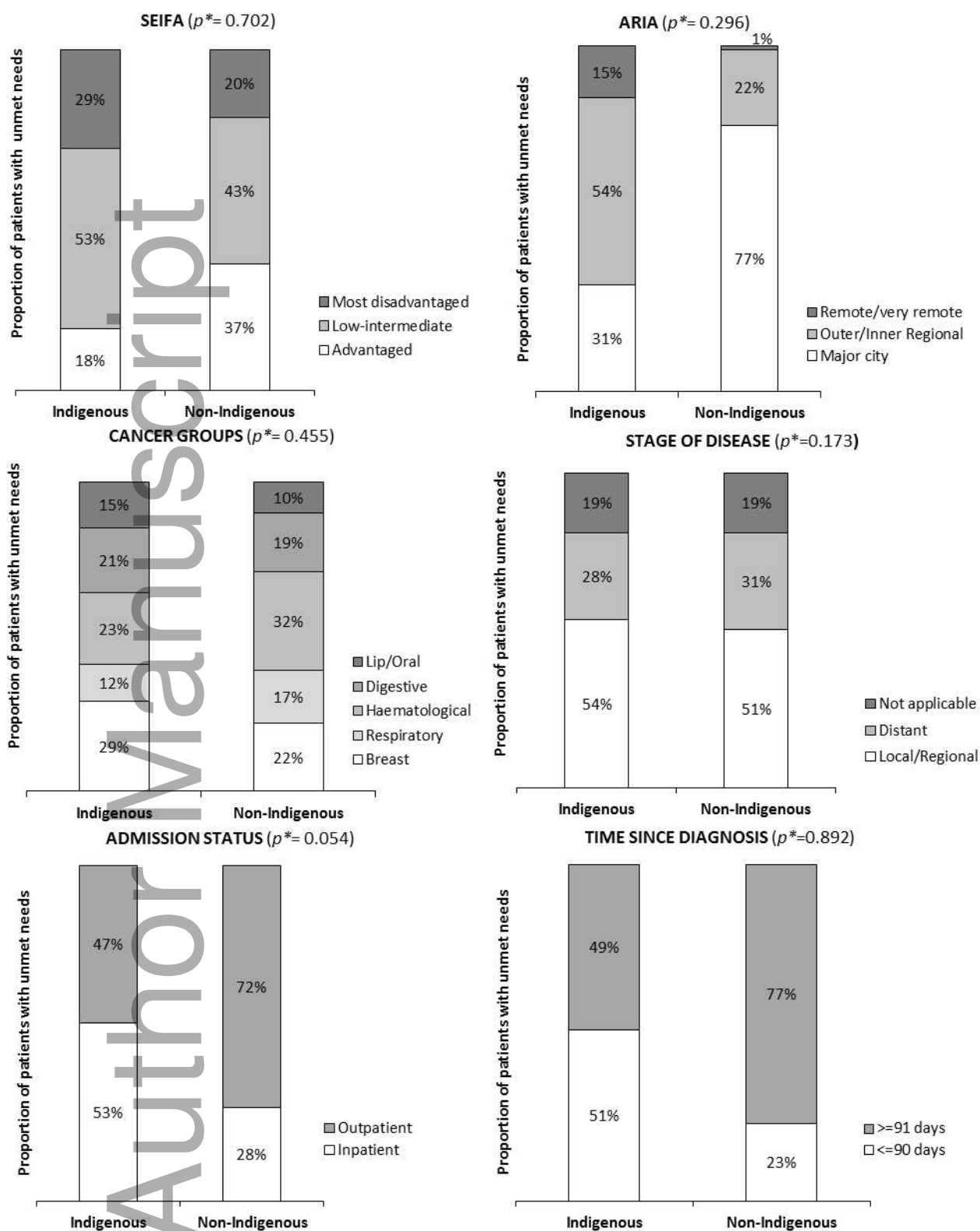
---

# Author Manuscript

# Author Manuscript

Indigenous Study		Non-Indigenous Study	
14 out of 35 SC/NAT-IP items (Garvey et al., 2015)	Domain name	26 out of 34 SC/N/S-34 items (Baker et al., 2009)	Domain name
Physical pain (e.g., hurt)	Physical and psychological	Pain	Physical and daily living
Feeling tired (e.g., sleeping OK)	Physical and psychological	Lack of energy/tiredness	Physical and psychological
Not feeling well (e.g., feeling rotten, cranky or sick) a lot of the time	Physical and psychological	Feeling unwell a lot of the time	Physical and daily living
Work around the home (e.g., washing, cooking, taking the yard, sweeping the floor)	Physical and psychological	Work around the home	Physical and daily living
Doing the things you need to do (e.g., bathing, walking, seeing family)	Physical and psychological	Not being able to do the things you need to do	Physical and daily living
Anxiety (e.g., worrying, fear, concern)	Physical and psychological	Anxiety	Psychological
Feeling down or sad	Physical and psychological	Feeling down or depressed	Psychological
Worrying about your illness spreading or getting worse	Physical and psychological	Fears about the illness spreading	Psychological
Worry about the results of treatment	Physical and psychological	Worry that the results of treatment are beyond your control	Psychological
Feeling you strong in your spirit (e.g., staying positive)	Physical and psychological	Keeping a positive outlook	Psychological
Concerns about the worries of those close to you (e.g., family and friends)	Physical and psychological	Concerns about the worries of those close to you	Psychological
Support by staff that the way you feel is normal (e.g., common, typical)	Hospital care	Reassurance by medical staff that the way you feel is normal	Patient care and support
Having hospital staff attending quickly to your physical needs (e.g., if you needed a nurse getting out of bed)	Hospital care	Hospital staff attending promptly to your physical needs	Patient care and support
Having hospital staff show sensitivity to and respecting your feelings and personal needs	Hospital care	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	Patient care and support
Being shown or given information (e.g., written, diagrams) about how to manage your condition, illness and side-effects in hospital	Information and communication	Being given written information about the important aspects of your care	Health systems and information
Being shown or given information (e.g., written, diagrams) about how to manage your illness and side-effects at home	Information and communication	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	Health systems and information
Explaining what tests are for	Information and communication	Being given explanations of those tests for which you would like explanations	Health systems and information
Understanding the good and bad effects of treatments before you chose to have them (e.g., having someone explain these to you)	Information and communication	Being adequately informed about the benefits and side-effects of treatments before you chose to have them	Health systems and information
Being told about things you can do to help yourself get well (e.g., self-exercises, what you eat)	Information and communication	Being informed about things you can do to help yourself to get well	Health systems and information
Being treated like a person not just another case or a number	Hospital care	Being treated like a person not just another case	Health systems and information
Having a place to stop or stay while receiving treatment	Practical and cultural needs	4 out of 35 SC/NAT-IP items Finding a place to stop or stay while receiving treatment	
Money worries (e.g., cost of accommodation, travel)	Practical and cultural needs	Money worries (e.g., cost of accommodation, travel)	
Ensuring family members were able to be present when talking or seeing health professionals	Practical and cultural needs	Ensuring family members were able to be present when talking or seeing health professionals	
Directions to get to and around the hospital	Practical and cultural needs	Directions to get to and around the hospital	

ecc\_13080\_f1.tif



ecc\_13080\_f2.tif