Unmet needs in immigrant cancer survivors: a cross-sectional population based study

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ABSTRACT

Purpose

Social suffering, language difficulties and cultural factors may all make the cancer experience more difficult for immigrants. This study aimed to document unmet needs, and variables associated with these, in a population-based sample of first generation immigrants and Anglo-Australians who had survived cancer.

Methods

Participants were recruited via Australian Cancer Registries. Eligible cancer survivors had a new diagnosis 1-6 years earlier, and were aged between 18 and 80 years at diagnosis. Eligible immigrant participants and parents were born in a country where Arabic, Chinese (Mandarin, Cantonese, and other dialects), or Greek is spoken and they spoke one of these languages. A random sample of English-speaking Anglo-Australian-born controls was recruited.

Results

596 patients (277 immigrants) were recruited to the study (response rate 26%). Compared to Anglo-Australians, the adjusted odds ratios of Chinese immigrants for at least one unmet information/support need was 5.1 (95%CI: 3.1,8.3) and for any unmet physical need was 3.1 (95%CI: 1.9, 5.1). For Greek these were 2.0 (95%CI: 1.1, 4.0) and 2.7 (95% CI: 1.4, 5.2). Arabic patients had elevated, but not statistically significant, odds ratios compared to Anglo-Australians. Written information and having a specialist, support services and other health professionals who spoke their language were in the top 10 unmet needs amongst immigrants.

Conclusion

Immigrants cancer survivors, several years after initial diagnosis, are more likely to have an unmet need for information or for help with a physical problem than Anglo-Australians. They strongly desire information and support in their own language.

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Introduction

Global migration has increased the ethnic and cultural diversity in developed countries. Immigrants diagnosed with a serious disease like cancer face the challenge of navigating an unfamiliar health system, with sometimes insufficient language skills, reduced social support and a history of social suffering and low socio-economic status. A recent meta-analysis reported clinically significantly higher distress and worse health-related quality of life (QoL) in minority Hispanic patients in the USA versus majority cancer patients [1]. We have similarly found clinically significantly worse QoL and depression in first generation Arabic, Chinese and Greek speaking Australian immigrant cancer survivors [2]. Clearly there is a need to better meet the needs of this vulnerable group.

Asking patients about their *unmet* supportive care needs identifies problems that remain outstanding after standard care, and the degree of additional help required. An unmet need can be defined as "*problems for which people express a requirement for assistance, out of recognition of existing resource deficits, to enable problem resolution and attainment of goals*" [3]. Areas of unmet need are potential targets for health care intervention [4]. There is increasing evidence that unmet needs can have a detrimental effect on patients' well-being [5]. In English speaking cancer survivors, high levels of unmet needs have been reported in physical and sexuality domains [5]. Immigrants are likely to have additional and unique unmet needs [6].

To our knowledge, no previous studies have compared the prevalence and severity of unmet needs in immigrant versus native-born cancer patients or survivors. However, a handful of studies have explored unmet needs in minority groups. One study [7] explored unmet needs in 1040 cancer survivors recruited through cancer registries, and reported that non-White ethnicity predicted higher information needs. In another study, 248 oncology outpatients (25% African Americans; 19% Hispanic) completed an unmet needs survey. Ethnicity was the only predictor of needs, even after controlling for confounders. The percentage of needs reported by African Americans, Hispanics, and non-Hispanic whites was 81%, 85%, 70% for *informational*; 63%, 68%, 36% for *practical*; 69%, 73%, 48% for *supportive*; and 49%, 60%, 31% for *spiritual* needs [8]. Thus it does appear that minority groups have increased needs, although it is not clear whether minority groups (who may have been in the country for many generations) and first-generation immigrants have the same experiences of health care.

The current analysis is from a larger study exploring disparities in outcomes (unmet needs, QoL, anxiety and depression) in immigrants versus native-born cancer survivors; data on QoL and psychological morbidity are reported elsewhere.

The aims of the current study were to:

1. compare the prevalence and severity of unmet needs for help with physical, sexual and information/support issues in a population-based sample of first generation immigrant Australian cancer patients and Anglo-Australian-born controls, 1 to 6 years after diagnosis;
2. determine the prevalence and severity of unmet needs for help with immigrant specific issues;
3. explore correlations between unmet needs and anxiety, depression and quality of life;
4. explore demographic and disease factors associated with unmet needs;
5. explore the contribution of immigrant-related variables such as duration in Australia and quality of spoken English to level of unmet needs

We hypothesized that immigrant groups would have higher levels of, and more severe unmet needs than the Anglo-Australian-born control group. We also hypothesized that patient-reported difficulties in understanding the health care system and English proficiency would mediate immigrant status and the outcomes; i.e., that being an immigrant may be related to challenges in communication and navigating the health system, which in turn creates needs which are not well met by the current health system.

METHODS

Participants

Participants were recruited via cancer registries in the three most populous Australian states: New South Wales, Victoria and Queensland. By law, all cancer diagnoses are required to be reported to state-based cancer registries. Eligible cancer survivors had been diagnosed in one of these states with a new histologically confirmed cancer comprising one of the top 12 most common cancers by incidence (all stages) 1 to 6 years earlier, were aged between 18 and 80 years at the time of diagnosis, were still alive and resident in the same state at the time of recruitment, had a treating doctor assigned to their registry record, and had not been approached previously by the Cancer Registry regarding any other research study.

Eligible immigrant participants (and their parents) were born in a country where Arabic, Chinese (Mandarin, Cantonese, and other dialects), or Greek is spoken, had a family name indicative of this cultural background, and were subsequently confirmed to speak one of these languages. These language groups were chosen because they represent the three largest immigrant groups to Australia as shown in the 2006 census. Further they differ in religious background and cultural traditions, with Greek people most likely to be Greek Orthodox, Chinese people more commonly Buddhist and Arabic people more likely Muslim. A random sample of Anglo-Australian-born participants was selected from the same cancer registries in proportions matching the distribution of cancer types amongst immigrant survivors, and subsequently confirmed to have both parents born in a country where English is the primary language spoken.

Procedure

We established a community advisory group for each language group comprising consumers, health care professionals, community leaders and religious leaders who reviewed study procedures and all study materials and provided advice regarding recruitment strategies and interpretation of results.

Translation of measures not already available and validated in the required languages was conducted according to the European Organization for Research and Treatment of Cancer translation protocol [10] using accredited translators, back-translation, field testing and revision, as recommended by Schuman [11].

Participant flow is summarized in Figure 1. Registries sought confirmation from each potentially eligible survivor's referring doctor or general practitioner that they were of the relevant cultural background, were aware of their diagnosis, and were eligible for the study. Registries then contacted survivors by letter, and asked for consent for researcher contact, and confirmation of their eligibility for the study (i.e., confirmation that both they and their parents were born in a country where Arabic, Chinese (Mandarin, Cantonese or another dialect), Greek or English was spoken and spoke this language to some extent). Those who did not respond to the initial approach were sent one reminder. Eligible and interested survivors were contacted by phone or mail by researchers and invited to participate in the study. All contact was made by bilingual researchers in the survivor's preferred language. Survivors were mailed language appropriate study packages comprising a cover letter, questionnaire, information sheet, consent form, and reply-paid envelope. Non-responders were followed up by phone (with four attempts to make contact at varying times of the day), and then by one repeat mailing.

<Figure 1 about here>

Measures

Demographic and clinical details such as gender, age at diagnosis and type and stage of disease were obtained for survivors from the cancer notification held by the registry. Other demographic details were elicited from patients, including years lived in Australia, marital and employment status, religion, education level, having seen a counselor (social worker, psychologist, or similar), confidence speaking and understanding English, and understanding of the Australian health system.

Primary outcome (for this substudy)

Unmet needs were measured using the physical (7 item) and sexual (3 item) subscales of the Supportive Care Needs Questionnaire (SCNS) [11], a valid and reliable measure of unmet needs in cancer patients, where need for help is rated as follows: 1=not applicable, 2=satisfied, 3=low need, 4=moderate need, and 5=severe need. These subscales were selected because in other survivorship samples, these represented significant domains of unmet need [12].

In addition, using the same response options, we developed a 14 item cancer information and support unmet needs subscale, on the basis of earlier qualitative work with the same immigrant populations [6].The measure encompasses need for help with: language issues, navigation of the health system, general communication and information, and information about culturally specific treatments. Ten items, while commonly raised as issues by immigrant participants, were potentially applicable to all cancer patients regardless of origin. Four items about language were only relevant to immigrants. The psychometric properties of this new subscale were tested in the current sample, and found to be adequate, with Cronbach alphas for the 10 item (whole sample) and 14 item (immigrant-only sample) versions equal to 0.90 and 0.93 respectively. Exploratory factor analysis supported a single factor structure, thus summed scores were used in the analyses here.

Finally, to capture the more existential issues raised by immigrants in the earlier focus groups [6], and commonly reported as of primary concern to all survivors [13] we included four items regarding the future from the Cancer Survivors Unmet Needs measure (CASUN)[14]. These included fear of cancer recurrence, moving on in life, exploring spiritual issues and developing new relationships. The CASUN is a reliable measure of unmet needs in cancer survivorship, which was validated in a large heterogeneous sample of cancer survivors; [15] thus we were confident that these four items were well constructed and had face validity for diverse patients. The CASUN does not have a clear subscale structure, so to ensure these four items were reliable and valid, we conducted some additional analyses. Cronbach's alpha for these four items in this sample was 0.86 and exploratory factor analysis supported a single factor structure.

Secondary outcomes

Anxiety and depression was assessed using the Hospital Anxiety and Depression Scale (HADS)[14], comprising 7 items measuring anxiety and 7 measuring depression. The two subscale scores are valid measures of severity of anxiety and depression. Scores on each subscale above 10 are considered indicative of clinical morbidity. The HADS had already been translated and validated in Arabic, Chinese, and Greek [16,17].

Quality of life

The Functional Assessment of Cancer Therapy-General (FACT-G)[18] is a 27 item, widely used measure of QoL in cancer with high reliability (Cronbach's alpha=0.9) and high correlations with related measures. The FACT-G consists of 4 subscales assessing physical, emotional, social and functional well-being. The FACT-G had already been translated and validated in Arabic, Chinese and Greek [19,20].

Predictors

The primary predictor variable was ethnicity, assessed either as immigrant versus Anglo-Australian, or as the four individual language groups (Arabic, Chinese, Greek and English).

Covariates and potential confounders

Covariates and variables assessed for potential confounding to include in adjusted models were: *demographic variables*: age, gender, socio-economic status (SES - assessed with the Index of Relative Social Advantage and Disadvantage (IRSAD) based on postcode at diagnosis, and included in models as a continuous variables), education (low, medium, high), marital or partnered status, major city versus regional/remote place of residence and religion; *disease variables*: time since diagnosis, cancer type (prostate; colorectal; breast; leukaemia and lymphoma; bladder and kidney; head and neck; and other), currently on treatment, cancer stage (localized, regional spread or distant metastases). Categorization of cancer type included the most incident cancer diagnoses.

Immigrant factors

Immigrant only variables included interpreter (not needed, needed but not provided, or needed and provided some or all of the time), and difficulty understanding the health care system (assessed by asking all participants to rate their understanding of the Australian health system – e.g. how to get help when you need it, who to talk to, how to get the best care) on a 4 point scale which was dichotomized ('very well' and 'well' versus 'not so well' and 'not well at all').

Statistical Methods

Chi-squared and t-tests were used to compare demographics between respondents and non-respondents, and between immigrants and Anglo-Australian-born participants.

Unmet need items were scored according to the SCNS manual [21]. Briefly, total scores for the domains of physical (7 items), sexual (3 items), information/support (10 or 14 items), and future (4 items) unmet needs were standardized to 100. For each domain, missing items were imputed with the domain's mean of the non-missing items, if half or more of the items from that domain were answered. For prevalence analyses, we dichotomized each of the domains into no unmet need versus any unmet need. In analyses comparing Anglo-Australian-born participants and immigrants, only the 10 common information/support items were used.

Prevalence was modeled using unadjusted and adjusted logistic regression on the dichotomized unmet needs domain scores; odds ratios were computed for immigrant groups compared to Anglo-Australians. Severity was modeled using unadjusted and adjusted multiple linear regression. Because the domain score data were highly skewed, severity was modeled by using the logarithm of the total domain scores plus one. Estimates of regression coefficients were back-transformed. Pre-specified adjusted models included language group, age, gender, SES, education, marital or partnered status, time since diagnosis, and cancer type. We did not include cancer stage, as there was a 20% rate of missingness from the registry data. However, only 16 patients (3%) were coded as distant metastases, and according to patient self-report, 87% had cancer which had gone away, 6% reported their cancer had come back, and 6% that it had spread. However, we performed additional analyses to check the sensitivity of primary results to different assumptions about stage.

The correlation of information/support, physical and sexual unmet needs total scores with QoL, depression and anxiety was computed. The non-parametric Spearman's correlation was used because of the skewed distribution of the unmet needs domains. Factors associated with unmet needs in immigrants only were explored using regression.

We tested whether difficulties understanding the health care system mediated the effect of immigrant status and each of the outcomes by using the Sobel test [22] and Baron and Kenney's methods [23]. Difficulty understanding the health care system was considered a mediator if it was significantly related to both predictor (being an immigrant or not) and outcome (unmet needs), and if its inclusion in a model of predictor and outcome reduced the significance of the predictor. The total effect and indirect effect were also calculated using the methods of Baron and Kenney.

RESULTS

Participants

There were 4,369 potentially eligible cancer survivors identified across the three states, comprising 2842 immigrants and 1527 Anglo-Australian-born participants. Of these the registry received the referring doctors' consent to contact 2,307, 596 of which ultimately participated in the study (see Figure 1 for recruitment flow). Thus the response rate from initially eligible participants was 13.6%, and from those actually contacted was 26%. There were no significant clinical or demographic differences, including age, gender, time in Australia and cancer primary site, between participants and non-responders (results not shown).

Table 1 shows demographic and clinical details for participant by immigrant group. There were no statistically significant differences between Anglo-Australians and immigrants for sex, religion, marital status, currently on treatment, cancer type and stage, age and time since diagnosis. Education differed between immigrants and Anglo-Australians, with immigrants having higher proportions in both the low and the highly educated groups. Significantly more Anglo-Australian-born participants lived in regional/remote areas than immigrants (12% versus 1%) but the vast majority lived in major cities. Comparatively more immigrant survivors fell in the higher socioeconomic status category (29% versus 18%, and immigrants were slightly younger at diagnosis (58.5 versus 60.3).

Top unmet needs

The top 10 unmet needs for immigrant and Anglo-Australian participants are presented in Table 2. Immigrant unmet needs heavily featured language and information issues, while Anglo-Australian-born participants more commonly reported issues with side effects such as loss of energy and sexuality. More immigrants reported unmet needs; the top 10 unmet needs ranged in prevalence from 22 to 30% for immigrants as compared to 10 to 19% for Anglo-Australian-born participants.

Differences between groups in unmet need

Table 3 gives descriptive statistics for the unmet information/support, physical and sexual domain needs scores. Immigrants had a higher prevalence of unmet information/support and physical needs ($p < 0.0001$ for both), as shown in Table 4. In particular, Chinese participants had higher unmet information/support needs, 61%, as compared to Anglo-Australian-born participants' rate of 23%. The adjusted odds ratio (OR) for this was 5.1 (95% CI: 3.1, 8.3). Chinese participants also had the highest unmet physical needs, at a rate of 42%, as compared to Anglo-Australian-born participants' 25% (adjusted OR 3.1, 95% CI:1.9, 5.1), although in terms of severity, Arabic patients reported the most severe physical unmet needs (adjusted OR 2.2, 95% CI: 1.3, 3.5). Sensitivity analyses using stage showed no substantive differences from these results (not shown).

Correlation of unmet needs with anxiety, depression and QoL

Unmet needs were positively correlated with anxiety and depression, with correlations ranging from 0.26 to 0.54. Unmet needs were negatively correlated with QoL, with correlations ranging from -0.34 to -0.57. Correlations were strongest for Arabic participants (Table 3).

Immigrant only models

A number of variables were significantly associated with the severity of unmet needs of immigrants (Table 5). Immigrants who did not understand the health system had approximately 2 times higher unmet needs across domains, as compared to those who did. Participants who needed an interpreter had between 2 and 4 times higher unmet needs in all domains, as compared to immigrants who did not need an interpreter. Interestingly, whether the interpreter was actually provided or not did not appear to have much impact on unmet needs. Having accessed a counselor (psychologist, psychiatrist or social worker) was significantly associated with having higher unmet sexual needs, with trends to having greater unmet needs on other domains. Unsurprisingly, time since diagnosis was associated with unmet physical needs, with fewer needs as time passed.

Mediation

Understanding the health system partially mediated the association between immigrant status (immigrant versus Anglo-Australian-born) and information needs ($p<0.0001$), physical needs ($p<0.001$) and future needs ($p=0.002$). The indirect effect of understanding the health system accounted for 30% of the total effect of immigrant status on information needs, 30% of physical needs, and 50% of future needs. This implies, for example, that about one third of the effect of immigrant status on unmet information and physical needs is explained by whether or not the participant understands the health system.

DISCUSSION

This is the largest study internationally to explore differences between immigrant and native-born cancer survivors, controlling for potential confounders and exploring immigrant-specific contributors to unmet needs. In line with our hypotheses, this population-based study has shown that even when controlling for potential demographic and disease confounders, immigrants with cancer in the post-treatment survivorship phase have significantly higher unmet needs than Anglo-Australian-born cancer survivors matched on cancer diagnosis. Further, in line with previous research,[5] having unmet needs was significantly correlated with anxiety and depression and lower QOL, suggesting that failing to meet needs increases risk of poorer outcomes.

In particular, Chinese participants had higher unmet information/support needs and physical needs, with about half of Chinese participants reporting unmet needs in these areas. It is not clear that divergent religious backgrounds would explain these findings, as the Confucian tradition behind Buddhism teaches acceptance of change and an uncomplaining attitude. A greater proportion of our Chinese participants came from a high socio-economic background and had completed University, and may therefore have been more articulate in voicing their needs. Surprisingly however, within the immigrant group, diagnosis, age, gender, socio-economic status and education level were not related to information/support and physical needs. This is in contrast to previous studies which have found that socio-economic status partially explained differences in sub-group outcomes for minority groups. This divergent finding may be due to the fact that more immigrants than Anglo-Australian-born participants in this study were of higher (rather than lower) socio-economic status; thus poverty likely played less of a role in determining outcomes in this group. Alternatively, the explanation may be the use of a proxy measure for socio-economic status (postcode of residence) rather than individual income data. While all measures of socio-economic status have advantages and disadvantages, the accuracy of postcode as a proxy measure varies widely depending on the amount of time that has passed since the postcodes were categorized, and the degree of change within that area (patterns of movement, gentrification, levels of unemployment etc) [24]. Future research could explore this variable more closely through the use of composite measures.

In contrast, understanding the health system and confidence in understanding English (highly inter-correlated) were strongly associated with unmet needs in both the information/support and physical domains. Further, needing an interpreter (likely reflecting language and acculturation challenges) was also associated with poorer outcomes. Surprisingly, actually having an interpreter did not reduce unmet needs, suggesting that this intervention, often seen as the panacea to solve language problems, may not be the answer. Several studies have revealed problems with medical interpretation, including inconsistency [25,26] inaccuracy [27], and confusion regarding the interpreter's role [28]. Also, despite guidelines to the contrary, family members are often called upon to interpret, either because of patient preference or lack of alternative resources, which can result in more error and potentially unhelpful intervention (for example to protect the patient from accurate information) [27].

Thus, alternative strategies to overcome language barriers and improve understanding of the health system are required, if we are to reduce unmet need and improve outcomes for this vulnerable group. Some immigrants have suggested a role for bilingual cultural advocates who can advise health professionals about likely family needs, and provide relevant information, advice and support to patients [6]. Translated materials which patients can take home are also likely to be helpful.

Interestingly, having accessed a counselor (psychologist, psychiatrist or social worker) was associated with having *more* unmet needs in the sexual domain, with trends to greater unmet needs in other domains. It is not surprising that people with more needs make greater efforts to access support, but distressing that three years after diagnosis, these unmet needs are still extant despite access to counseling. However, it is possible that participants saw a counselor only once or twice (we did not collect data on length of contact) which would have had little impact on overall needs. Perhaps counseling more specifically focused on immigrant issues would be helpful.

Limitations, strengths and future directions

We recruited through cancer registries because we aimed to conduct a population based study. Our response rate was low, despite extensive follow-up and careful attention to study processes, although similar to other immigrant studies [29, 30]. A key factor which limited the response rate was the requirement to obtain the referring doctor's confirmation of patient eligibility before contacting patients. For 45% of potentially eligible patients, the referring doctor did not respond to this request. It is likely that a proportion of these patients would have been non-eligible, thus the response rate is likely an under-estimate. Nevertheless, this highlights the importance of developing alternative registry access procedures to avoid low response rates. In some state cancer registries within Australia, for example, doctor confirmation of eligibility is not required.

Even amongst patients who passed this hurdle, the response was relatively low (26%). This may have been due to the "opt in" procedure, whereby patients had to mail back a tear-off form indicating their willingness for researcher contact. As this is an ethical requirement under privacy laws in Australia, it is difficult to surmise how to overcome this barrier. It may be that future research would be more successfully conducted using hospital rather than registry based recruitment strategies to ensure a higher response rate. In similar research with immigrants conducted through hospitals, our group has achieved double these response rates. Reassuringly, in this study there were no significant differences between respondents and non-respondents from the registry, thus we are fairly confident the results are representative of the source populations.

It was not feasible to include more immigrant groups, and thus our results may not generalize to groups other than Arabic, Chinese and Greek immigrants.

The clinical implications of these findings are that greater effort is required to meet the needs of immigrants who have survived cancer, to ensure these citizens do not experience compromised quality of life. Our community advisory board contributed greatly to the research process, and it may be that such advisory boards could be established to collaborate with cancer services in determining optimal, culturally appropriate, strategies for each area. Because not understanding the health system was strongly associated with higher unmet needs, navigators may represent a possible way forward [31].

Future research needs to address unmet needs of cancer patients during the active treatment phase, explore needs met as well as those left unmet by the health system to identify our strengths, and to evaluate interventions as they are developed.

Conflict of Interest

The authors have no financial relationships with any of the organizations that sponsored the research. We have full control of all primary data and agree to allow the journal to review the data if requested.

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Table 1. Demographic and clinical characteristics by language group

Characteristic	Arabic N=57	Chinese N=141	Greek N=79	Anglo-Australian N=319	All immigrants	p-value (Anglo-Australians vs. immigrants)
	n (%)	n (%)	n (%)	n (%)	n (%)	
Age at diagnosis (yrs)						
18-49	10 (18)	21 (15)	5 (6)	33 (10)	36 (13)	0.1
50-59	13 (23)	44 (31)	13 (16)	59 (19)	70 (25)	
60-69	20 (35)	39 (28)	29 (37)	122 (38)	88 (32)	
70+	14 (25)	37 (26)	31 (39)	105 (33)	83 (30)	
Gender						
Male	30 (53)	70 (50)	49 (62)	157 (49)	149 (54)	0.3
Female	27 (47)	71 (50)	30 (38)	162 (51)	128 (46)	
Marital status	43 (75)	120 (85)	59 (75)	237 (26)	222 (80)	0.1
Education						
Did not complete high school	8 (14)	9 (6)	40 (51)	16 (5)	57 (21)	<0.0001
High school/tech college	26 (46)	61 (43)	31 (40)	229 (72)	118 (43)	
University	23 (40)	71 (50)	7 (9)	73 (23)	101 (37)	
Residence						
Major city	55 (100)	139 (99)	78(99)	274 (88)	271 (99)	<0.0001
Regional and remote	0 (0)	1 (1)	1 (1)	38 (12)	2 (1)	
Religion						
Yes	55 (96)	70 (50)	78 (99)	246 (77)	203 (73)	0.3
No	2 (4)	71 (50)	1 (1)	73 (23)	74 ()27	
Socio-economic status[b]						
Low	4 (7)	5 (4)	7 (9)	15 (5)	16 (6)	0.006
Medium	37 (67)	93 (66)	49 (63)	240 (77)	179 (66)	
High	14 (25)	42 (30)	22 (28)	56 (18)	78 (29)	
Cancer type						
Breast	21(37)	47 (33)	19 (24)	117 (37)	87 (31)	0.08
Prostate	17 (30)	34 (24)	23 (29)	80 (25)	74 (27)	
Colorectal	8 (14)	28 (20)	16 (20)	53 (17)	52 (19)	
Bladder, kidney	3 (5)	5(4)	7 (9)	27(8)	15 (5)	
Leukaemia, lymphomas	4 (7)	13(9)	6 (8)	22 (7)	23 (8)	
Head and neck	2 (4)	11 (8)	5 (6)	7 (2)	18 (7)	
Other	2 (4)	3 (2)	3 (4)	13 (4)	8 (3)	
Degree of spread at diagnosis						
Localized	28(49)	79 (56)	52 (66)	183 (58)	159 (57)	0.9
Regional	17 (30)	28 (20)	8 (10)	63 (20)	53 (19)	
Distant	0 (0)	6 (4)	1 (1)	9 (3)	7 (3)	
Unknown/ not applicable/missing	12 (21)	28 (20)	18 (22)	64 (20)	58 (21)	
Current treatment	7 (12)	9 (6)	7 (9)	17 (5)	23 (8)	0.1
Understands health system	27 (83)	93 (66)	61(66)	285 (89)	201 (73)	<0.0001
Interpreter at specialist appointments						
Not needed	39 (68)	98 (70)	61 (77)		198 (71)	
Needed, and provided some or all of the time	15 (26)	34 (24)	12 (15)		61 (22)	
Needed, but not provided	3 (5)	9 (6)	6 (8)		18 (7)	

	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	
Age at diagnosis	56.6 (10.8)	57.0 (10.9)	62.6 (10.4)	60.3 (10.5)	58.5 (11.0)	0.04
Age	60.7 (10.8)	61.2 (11.0)	66.3 (10.4)	64.1 (10.7)	62.5 (11.0)	0.07
Index of Relative Social Advantage and Disadvantage (IRSAD)	1019.7 (86.2)	1050.0 (82.8)	1031.1 (88.9)	1013.7 (79.7)	1038.5 (85.9)	0.0003
Years in Australia	26.9 (14.7)	23.7 (11.3)	44.7 (8.6)	63.8 (11.1)	30 (14.6)	<0.0001
Months since diagnosis	43.2 (20.3)	47.4 (28.6)	44.6 (21.6)	42.9 (20.3)	45.8 (24.6)	0.1
Anxiety[c]	5.5 (4.4)	4.7 (3.8)	5.6 (4.0)	4.8 (3.9)	5.1 (4.0)	0.2
Depression[c]	4.9 (4.2)	4.4 (3.7)	4.6 (4.0)	2.9 (2.9)	4.6 (3.9)	<0.0001
Quality of life[d]	74.0 (18.6)	77.3 (14.1)	77.4 (15.4)	81.1 (14.3)	76.6 (15.5)	0.0004

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[a] Except for spread of disease (stage), missing data rates ranged from 0-2%.

[b] Low=less than 1 SD below IRSAD population mean, medium=within 1 SD of mean, high=greater than 1 SD above mean.

[c] As measured by the HADS, possible range=0-21, with higher scores indicating worse anxiety or depression.

[d] As measured by the FACT-G, possible range=0-100, with higher scores indicating better QoL.

Table 2. Top unmet needs.

Immigrants	**N**	**Denominator**[a]	**%**
Managing concerns about cancer returning	50	169	29.6
Written information in own language	73	268	27.2
Information about cancer and treatment	71	268	26.5
Unable to do usual things	64	263	24.3
Not sleeping well	64	265	24.0
Medical guidance	64	267	24.0
Specialist who speaks my language	63	265	23.8
Information about complementary/alternative/cultural medicines	62	263	23.6
Help asking questions	60	262	22.9
Other health professional who speaks language	59	265	22.3
Anglo-Australians			
Unable to do usual things	60	315	19.0
Managing concerns about cancer returning	36	207	17.4
Changes in sexual relationships	44	263	16.7
Lack of energy	49	311	15.8
Not sleeping well	46	314	14.6
Changes in sexual feelings	39	267	14.6
Information about sexual relationships	37	262	14.1
Support services	33	314	10.5
Unable to work (including at home)	33	315	10.5
Moving on in life	21	213	9.9

[a] The denominator varies due to non-response.

Table 3. Descriptive statistics for the unmet needs domain scores (0-100 scale) and correlations with anxiety, depression and QoL.

Domain	% missing	median	inter-quartile range	correlation with anxiety	correlation with depression	correlation with QoL
Unmet information/support needs (10 items)						
Anglo-Australian	1	5.0	0, 15.0	0.41	0.35	-0.46
Arabic	0	7.5	0, 22.5	0.58	0.49	-0.45
Chinese	1	17.5	2.8, 37.5	0.38	0.40	-0.44
Greek	8	10.0	0, 25.0	0.17	0.17	-0.21
Unmet physical needs (7 items)						
Anglo-Australian	2	0	0, 14.3	0.34	0.54	-0.59
Arabic	2	7.1	0, 28.6	0.65	0.64	-0.61
Chinese	4	7.1	0, 25.0	0.35	0.40	-0.44
Greek	6	3.9	0, 25.0	0.43	0.54	-0.43
Unmet sexual needs (3 items)						
Anglo-Australian	18	0	0, 25.0	0.25	0.22	-0.32
Arabic	19	0	0, 16.7	0.47	0.50	-0.49
Chinese	24	0	0, 25.0	0.11	0.07	-0.28
Greek	47	0	0, 25.0	0.39	0.39	-0.45
Unmet future needs[a] (4 items)						
Anglo-Australian	35	6.3	1, 18.8	0.49	0.39	-0.47
Arabic	42	6.3	1, 25.0	0.64	0.47	-0.51
Chinese	36	6.3	1, 25.0	0.36	0.46	-0.39
Greek	43	6.3	1, 18.8	0.43	0.24	-0.30

[a] Participants were asked to skip these items if they had not completed treatment.

Table 4. Prevalence and severity[a] of unmet needs.

	Prevalence				**Severity[a]**		
	Prevalence (%)	**Unadjusted odds ratio (95% CI)**	**Adjusted[b] odds ratio (95% CI)**	**p-value[c]**	**Unadjusted estimates (95% CI)**	**Adjusted[b] estimates (95% CI)**	**p-value**
Unmet information/ support needs							
Anglo-Australian	23	Reference	Reference	<0.0001	Reference	Reference	<0.0001
Arabic	35	1.3 (0.7, 2.2)	1.4 (0.7, 2.8)		1.2 (0.8, 1.9)	1.3 (0.8, 2.0)	
Chinese	61	5.3 (3.4, 8.1)	5.1 (3.1, 8.3)		2.1 (1.6, 2.9)	2.2 (1.6, 3.1)	
Greek	30	2.1 (1.2, 3.7)	2.0 (1.1, 4.0)		1.4 (1.0, 2.1)	1.5 (1.0, 2.3)	
Unmet physical needs							
Anglo-Australian	25	Reference	Reference	<0.0001	Reference	Reference	0.0003
Arabic	38	1.5 (0.9, 2.6)	1.8 (0.9, 3.5)		1.7 (1.1, 2.6)	2.2 (1.3, 3.5)	
Chinese	42	2.1 (1.4, 3.3)	3.1 (1.9, 5.1)		1.6 (1.2, 2.2)	1.9 (1.4, 2.7)	
Greek	34	1.8 (1.0, 3.2)	2.7 (1.4, 5.2)		1.4 (0.9, 2.2)	1.4 (0.9, 2.2)	
Unmet sexual needs							
Anglo-Australian	19	Reference	Reference				
Arabic	20	1.7 (0.8, 3.5)	2.4 (0.9, 6.2)	0.3	1.0 (0.6, 1.7)	1.0 (0.5, 1.7)	0.9
Chinese	21	1.1 (0.7, 2.0)	1.1 (0.6, 2.2)		1.1 (0.7, 1.6)	1.0 (0.6, 1.5)	
Greek	29	1.0 (0.5, 2.2)	1.0 (0.4, 2.6)		1.2 (0.6, 2.0)	1.3 (0.7, 2.3)	
Unmet future needs							
Anglo-Australian	20	Reference	Reference		Reference	Reference	
Arabic	27	1.1 (0.5, 2.5)	1.3 (0.5, 3.2)	0.2	1.1 (0.6, 1.9)	1.0 (0.6, 1.9)	0.7
Chinese	36	2.2 (1.3, 3.8)	2.0 (1.1, 4.0)		1.5 (1.0, 2.1)	1.3 (0.9, 2.0)	
Greek	22	1.5 (0.6, 3.4)	1.4 (0.5, 3.4)		1.0 (0.6, 1.7)	1.1 (0.6, 1.8)	

[a] Severity is modeled on the log scale, estimates shown are back transformed. An estimate of 1.2, for example, indicates a 20% (1.2 fold) increase.

[b] Adjusted for age, sex, education, SES, time since diagnosis, and type of cancer.

[c] The p-value for each outcome is for the overall test of difference between culture groups from the adjusted model.

Table 5. Factors associated with the severity of unmet needs amongst immigrants[abc].

	Unmet information/ support needs (R^2=0.30)		Unmet physical needs (R^2=0.14)		Unmet sexual needs (R^2=0.19)		Unmet future needs (R^2=0.20)	
Explanatory variable	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
Immigrant group		0.09		0.6		0.4		0.8
Arabic	Reference		Reference		Reference		Reference	
Chinese	1.6 (1.0, 2.5)		0.7 (0.4, 1.4)		1.2 (0.6, 2.4)		1.2 (0.6, 2.6)	
Greek	1.2 (0.7, 2.0)		0.9 (0.5, 1.5)		1.8 (0.8, 4.3)		1.2 (0.6, 2.3)	
Interpreter		<0.0001		0.01		0.03		0.0004
Not needed	Reference		Reference		Reference		Reference	
Needed, and provided some or all of the time	2.9 (1.8, 4.5)		1.9 (0.8, 4.8)		2.5 (1.2, 5.2)		3.2 (1.2, 8.7)	
Needed, but not provided	2.8 (1.3, 6.0)		2.3 (1.3, 3.9)		3.0(0.8, 11.4)		3.2 (1.7, 6.0)	
Counsellor		0.3		0.08		0.03		0.09
Yes	1.2 (0.9, 1.7)		1.4 (1.0, 2.2)		1.9 (1.1, 3.3)		1.7 (1.0, 2.8)	
No	Reference		Reference		Reference		Reference	
Understanding health care system		0.0003		0.03		0.6		0.04
Yes	Reference		Reference		Reference		Reference	
No	2.0 (1.3, 3.0)		1.7 (1.1, 2.8)		1.2 (0.6, 2.4)		2.1 (1.2, 3.8)	
Sex		0.6		0.7		0.1		0.6
Male	Reference		Reference		Reference		Reference	
Female	1.1 (0.6, 1.9)		1.1 (0.6, 2.1)		0.5 (0.2, 1.2)		1.2 (0.6, 2.4)	
Age (per 10 years)	0.9 (0.7, 1.1)	0.2	0.6 (0.1, 5.3)	0.5	0.6 (0.5, 0.9)	0.004	0.9 (0.7, 1.1)	0.3
Socio-economic status (per 1 SD of IRSAD)	0.8 (0.7, 1,0)	0.1	1.0 (0.8, 1.2)	0.8	1.0 (0.7, 1.3)	0.8	1.2 (0.9, 1.6)	
Education		0.1		0.3		0.2		0.3
High	Reference		Reference		Reference		Reference	
Med	1.5 (1.0, 2.2)		1.4 (0.9, 2.3)		1.1 ()		1.1 (0.6, 1.9)	
Low	1.1 (0.6, 2.1)		1.1 (0.5, 2.2)		0.5 ()		0.4 (0.2, 1.0)	
Cancer type		0.09		0.6		0.2		0.2
Breast	Reference		Reference		Reference		Reference	
Prostate	0.7 (0.3, 1.4)		0.8 (0.4, 1.9)		2.6 (0.9, 7.9)		0.6 (0.2, 1.6)	
Colorectal	1.1 (0.6, 2.0)		1.2 (0.6,2.3)		0.9 (0.4, 2.2)		1.2 (0.5, 2.7)	
Bladder, kidney	2.5 (1.1, 5.8)		1.8 (0.7, 4.8)		1.2 (0.3, 5.0)		0.8 (0.2, 2.6)	
Leukaemia, lymphomas	1.4 (0.7, 2.9)		1.1 (0.5, 2.8)		1.0 (0.3, 3.2)		0.3 (0.1, 1.0)	
Head and neck	1.3 (0.6, 2.9)		1.6 (0.6, 4.0)		0.7 (0.2, 2.1)		1.2 (0.4, 3.4)	
Other	0.9 (0.3, 2.9)		1.2 (0.3, 4.8)		1.5 (0.2, 9.2)		1.0 (0.2, 7.1)	
Years since diagnosis (per 5 years)	0.99 (0.98, 1.0)	0.1	0.99 (0.98, 1.0)	0.002	0.99 (0.98, 1.0)	0.3	0.99 (0.98, 1.0)	0.09

[a] Severity is modeled on the log scale, estimates shown are back transformed. An estimate of 1.2, for example, indicates a 20% (1.2 fold) increase.

[b] Estimates are adjusted regression coefficients from 4 different models (1 for each outcome) which included all variables listed.

[c] The 14 item immigrant only scale was used.

Figure 1 – Recruitment outcomes