Immigrants’ perceptions of the quality of their cancer care – An Australian comparative study, identifying potentially modifiable factors.

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Introduction

Dramatic shifts in population through immigration are changing the demographic mix in many countries. In Australia over 27% of the population was born overseas.\textsuperscript{1} Reports suggest that cancer incidence and even mortality from some cancers is lower in migrants,\textsuperscript{1-3} attributed to their higher health status and differences in diet and other lifestyle factors.\textsuperscript{2,4,5} This effect is usually seen in males who arrive seeking employment opportunities; subsequent family reunification results in migrants with different health status, possibly accounting for the relative increase in mortality over time.\textsuperscript{2,6}

Of concern are recent data showing reduced mortality across all cancers in the general population but without a similar shift in migrant outcomes,\textsuperscript{4,6,7} resulting in negation or even reversal of the migrant effect noted above in some cancers, such as gastric cancer.\textsuperscript{4,6,7} Recent Australian and Danish data has suggested that initial presentation with more advanced disease may account for these disparities.\textsuperscript{6,12,13} These trends mandate an improved understanding of migrants’ health care experiences.\textsuperscript{7}

Controversy exists about the relative influence of socio-economic status (SES), education and ethnicity\textsuperscript{8-11} to account for documented differences in cancer outcomes for minority populations in the USA. These same factors in migrant population outcomes remain less explored; however, data corrected for these issues still suggests an independent effect of ethnicity\textsuperscript{14}. Whether this represents a biologic determinant, unfamiliarity with the health system or differential care is uncertain.\textsuperscript{14}
In this study we aimed to compare perceived patterns of care in migrants and native-born cancer patients, controlling for potential confounders such as education level and to explore the contribution of migrant-related variables such as understanding of the health system\textsuperscript{15}. The migrant sample comprised Chinese, Arabic or Greek speakers, these representing some of the largest migrant groups in Australia.\textsuperscript{16}

We hypothesized that:

1) Migrants would perceive an inferior quality of care, both medically and psychosocially;

2) Migrants would be less informed about their cancer (primary site and stage), and treatment received.

3) differences in patterns of care would be independently predicted by migrancy, irrespective of socio-economic and educational status.
Methods

This analysis utilized data from a larger study investigating disparities in patient reported outcomes in migrant versus Australian-born cancer patients. A cross-sectional, questionnaire-based survey was conducted with cancer patients recruited through 16 oncology clinics across the three most populous Australian states (New South Wales, Victoria and Queensland).

Participants

Eligible cancer patients had been diagnosed with a histologically-confirmed cancer (any stage) within the previous 12 months, had undergone at least one treatment commenced at least 4 weeks earlier, were aged between 18 and 80 years at time of diagnosis, and had a treating doctor who approved participation in this study.

Eligible migrant participants were born in a country where Chinese (Mandarin, Cantonese, and other dialects), Arabic, or Greek is spoken, had a family name indicative of this background, and were subsequently confirmed to speak one of these languages. A random sample of English-speaking, Australian-born participants was also approached. This study was approved by relevant ethical review boards.

Procedure

Community advisory groups for each language group reviewed study procedures and materials and provided advice regarding recruitment strategies and interpretation of results.
Participant flow is summarized in supplementary Figure 1. Potentially eligible participants were identified from clinic lists and ratified by the treating doctor. Bilingual research assistants approached patients in the clinic to confirm eligibility and invite participation. Interested patients were provided with language-appropriate study packages including a questionnaire and reply paid envelope. Non-responders were followed up by phone (four attempts at varying times), and then by one repeat mailing.

**Measures**

*Demographic details* included age at diagnosis, years lived in Australia, marital and employment status, religion, education level (low, medium, high), confidence speaking and understanding English, and understanding of the Australian health system (‘very well’ and ‘well’ versus ‘not so well’ and ‘not well at all’). Measures of rurality and SES were based on postcode. We categorized SES (low, medium, high) according to whether a patient fell within one standard deviation of the Australian population mean of the Index of Relative Social Advantage and Disadvantage (IRSAD).¹⁷

*Clinical details.* Patients provided date of cancer diagnosis, primary site, stage of disease at diagnosis and whether they were currently receiving cancer treatment. More detailed staging (1=stage I and II; 2=stage III; 3=stage IV and on active treatment; 4=Stage IV and receiving best supportive care) was abstracted from medical records by two research assistants for a sensitivity analysis. Two medical
oncologists (DG and WN) re-coded 22% of records to determine inter-rater reliability (high at 0.98).

**Primary outcomes**

*Patterns of care*

Patterns-of-care items were based on a previous study\(^{18}\) and our earlier qualitative work with the same language groups.\(^{19}\) Items explored four areas: *cancer detection/process* (time to diagnosis and treatment); *treatment* (treatment options offered and accessed, experience of information provision, perceived understanding, perceived choice); *hospital experience* (public versus private care, choice of specialist and hospital); *emotional support* (psychosocial services offered and accessed) and *clinical trials* (offered and accessed, information provided). Migrant-specific items included receipt of information in one’s own language, interpreting support provided (professional interpreter and/or family member) during medical consultations, and perceived impact of cultural background on care received.

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

Translation of measures proceeded according to the European Organization for Research and Treatment of Cancer protocol.\(^{20}\) The questionnaires were field tested as recommended by Schuman\(^{21}\) and revised.

**Statistical Methods**
Chi-squared tests were used to compare patterns of care between the four language groups (English, Arabic, Chinese and Greek). Significant and important differences, where feasible, were explored further for migrants, using logistic regression. Variables included age, sex, education, SES, confidence understanding English, understanding the health care system, illness perception and percentage of life lived in Australia. Nagelkerke’s generalized coefficient of determination $R^2$ is reported.\textsuperscript{22}

Patient reported data was compared with data extracted from medical records to assess agreement, on a subset of patients. Percent agreement and Kappa were computed. All statistical analyses were performed in SAS version 9.3 (Cary, NC).
**Results**

1603 potentially eligible patients were identified, of whom 1250 consented to participate and 903 sent back the questionnaire (response rate 62%). 58 Anglo-Australians born outside Australia were excluded from the final dataset, comprising 571 CALD patients (145 Arabic, 248 Chinese, and 178 Greek) and a control group of 274 Anglo-Australians. See supplementary Figure 1 for the study flow.

De-identified data were obtained on 89% of non-participants (n=484). Compared with participants, more non-participants were male (57.7% vs 42.9%), over 70 years old (43.1% vs 29.0%), had late stage cancer (46.5% vs 37.9%), and were on current chemotherapy/radiation treatment (77.1% vs 69.9%) (see supplementary Table 1). These variables were controlled for in analyses, to explore their independent impact on outcomes.

**Demographic and disease characteristics and variability across groups**

The average age of participants was 62; slightly more participants were female (57.2%). The most common cancer types were breast cancer (29.6%), lung cancer (17.2%) and colorectal cancer (15.9%). Significantly more immigrant than Anglo-Australian participants were married/partnered (76% vs 68%), had not completed high school (30% vs 8%), had difficulty communicating with the doctor (73% vs 29%), had problems understanding the health system (38% vs 10%), and had early stage cancer (64% vs 56%) (see Table 2). There were no significant differences in the distributions of age, gender, religion, cancer type, SES and on/off treatment.
Within the immigrant sample, 45% reported that they lacked confidence understanding English (Arabic 35%, Chinese 56% and Greek 37%) and over one third reported not understanding the health system (Arabic 20%, Chinese 52% and Greek 33%) in comparison with 10% of the Anglo-Australian sample.

**Patterns of care**

*Cancer detection/process variables,*

Differences among the four language groups were found in “difficulty knowing who to see” (Anglo-Australians 7%, Arabic 13%, Chinese 23% and Greek 10%; *p*=0.0002) and “length of time to confirm diagnosis caused concern” (Anglo-Australians 20%, Arabic 34%, Chinese 21% and Greek 19%; *p*=0.04) (see supplementary Table 3).

*Treatment*

Differences were found in self-reported chemotherapy treatment (Anglo-Australians 81%, Arabic 66%, Chinese 77% and Greek 64%; *p*<0.0001); self-reported hormone therapy (Anglo-Australians 11%, Arabic 26%, Chinese 15% and Greek 14%; *p*=0.0005); and feeling they missed out on treatment that they should have had (Anglo-Australians 3%, Arabic 5%, Chinese 11% and Greek 4%; *p*=0.0006).

*Hospital experience*

Differences were found in hospital type (*p*<0.00001); wanting more choice about a specialist (Anglo-Australians 7%, Arabic 27%, Chinese 59% and Greek 21%; *p*<0.0001); wanting more choice about hospital (Anglo-Australians 7%, Arabic 27%, Chinese 59% and Greek 21%; *p*<0.0001); being offered the opportunity to see a counselor (Anglo-Australians 73%, Arabic 58%, Chinese 61% and Greek 57%;
and actually seeing a counselor (Anglo-Australians 47%, Arabic 32%, Chinese 43% and Greek 26%; \( p<0.0001 \)).

**Emotional support**

Differences were found in feeling emotionally well cared for (Anglo-Australians 93%, Arabic 94%, Chinese 83% and Greek 94%; \( p<0.0001 \)); feeling physically well cared for (Anglo-Australians 97%, Arabic 95%, Chinese 89% and Greek 97%; \( p<0.0001 \)); feeling treated as a person (Anglo-Australians 86%, Arabic 74%, Chinese 58% and Greek 76%; \( p<0.0001 \)); and feeling that their cultural background improved their care (Anglo-Australians 11%, Arabic 30%, Chinese 11% and Greek 18%; \( p<0.0001 \)). See Table 2.

**Immigrant models: factors associated with process and perceptions of care**

Both SES and education were non-significant in all models, and the odds ratios for other variables changed by less than 10% when they were excluded. Therefore models are shown without these variables. Percentage of life in Australia was eschewed in favor of “understanding the health system” and “confidence understanding English” (highly correlated with % time in Australia), as the latter are potentially amenable to intervention.

Patients who had difficulties knowing who to see were more likely to be male, have low confidence understanding English and poor understanding of the health care system. Patients who wanted more choice regarding specialist and hospital were more likely to be Chinese, younger and consider illness more threatening. Low
confidence understanding English was marginally associated with wanting more choice. See Table 4.

<Table 4 about here>

Patients who felt looked after poorly emotionally or never felt treated as a person were more likely to be Chinese, have poor understanding of the health care system and to consider illness more threatening. Patients who felt looked after poorly physically were more likely to be Chinese and have higher levels of threatening illness perception. See Table 5.

<Table 5 about here>

Agreement between patient report and clinical notes:

1) Stage
Extra information was gathered from clinical notes for 757 patients. Among the 475 with early stage cancer, 341 (72%) reported their cancer was early stage, 73 (15%) reported it was late stage, 43 (9%) were not sure, and 18 (4%) did not answer the question. Among the 305 with late stage cancer, 160 (52%) reported their cancer was late stage, 111 (36%) reported it was early stage, 30 (10%) were not sure, and 4 (1%) did not answer the question. Among the 685 patients with non-missing data, kappa was 0.42, with 95% CI (0.35, 0.49), supplementary Table 6 shows agreement by language group, with values fairly similar: Anglo-Australians 73%, Arabic 69%, Chinese 76% and Greek 67%.
2) Treatment

Among patients who had these treatments, 14% (of 373) said they had never had cancer surgery, 12% (of 601) claimed they had never had chemotherapy, 21% (of 312) said they had never had radiotherapy, 48% (of 127) reported not having had hormone therapy, and 58% (of 26) said they had not had immunotherapy. Table 6 shows agreement by language group.
Discussion

We sought to understand the experience of cancer care for migrants with cancer compared to that of English-speaking Australian-born people. The literature regarding disparities in outcomes for minority groups, particularly Black and Hispanic populations in the US, is extensive, unlike that for migrants. This is in spite of large population movements in Europe and elsewhere. Australia with a high level of migration is well placed to contribute to this literature. This study has shown that migrants report worse experiences of cancer care, inferior quality of life and psychological wellbeing and greater unmet needs.15,24

A significant proportion of each of the migrant groups reported difficulties understanding English (between 35 and 56%) and understanding the health system (between 20 and 52%). There were no significant self-reported differences regarding how cancer was detected, length of time to see a health professional, or type of health professional first seen, however migrants were more likely to report difficulty knowing who to see. As hypothesized, migrants perceived more inferior care, both medically and psychosocially. They were more likely to believe that they had missed out on treatments they should have had, and that they had inadequate choice of specialist and treatment center. They were less likely to have been offered, or to have seen a counselor, despite reporting a greater need. Chinese-speaking migrants in particular felt less well cared for, both emotionally and physically.

We hypothesized that migrants would be less informed about their cancer and treatment received. However, when comparing self-reports with clinical notes we found similar levels of agreement to Anglo-Australians. Importantly a significant proportion of all patients did not know what treatments they had had, or the extent of their disease.

Unlike some other studies, we did not find significant differences according to SES and educational level. possibly reflecting a setting where publicly funded universal health care is available. Instead we found that understanding the health system and confidence understanding English were important factors associated with patterns of
care, related to feeling poorly looked after, emotionally, and not treated sufficiently ‘as a person.’

The disparities in cancer outcomes noted \textsuperscript{4,6,7,12, 13} require redressing. Current measures of health literacy include elements such as accessing health services, communication with health professionals, social support and attitudes to health.\textsuperscript{25} Bilingual social workers, patient advocates, and navigators may also be helpful in guiding patients through the health system. Each of these may be relevant when considering possible strategies to assist migrants. We are currently trialing provision of information in the person’s preferred language, question prompt lists and audio recordings of consultations for migrants with cancer, for which there is very good evidence in native-born populations.\textsuperscript{26,27}

Strengths of this study include the large sample, recruitment from many sites, and relatively high participation rate. The study also assessed factors which might confound migrant status, such as SES and education. The study design and conduct was guided by consumer reference groups for each of the language groupings.

Since our sample was somewhat skewed to a more educated group, with relatively high SES, we acknowledge that participants were not truly representative of all potential respondents. However adjusting the analyses accordingly did not change the results. Whether these findings apply to migrants from other languages and cultural backgrounds and can be extrapolated to other countries and health care systems is unknown.

In conclusion, this study confirmed that migrants with cancer perceive an inferior quality of cancer care, both medically and psychosocially, compared with Anglo-Australian cancer patients. We elucidated contributing factors that are potentially modifiable. There is an urgent need to redress the poor experience for migrants. Similarly, additional research is necessary to extend the field of enquiry, considering other migrant groups and other countries.
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Conflict of interest

The authors declare no conflict of interest.
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