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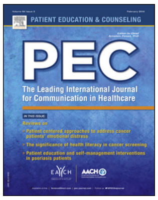

Medical Decision Making

Treatment decision making experiences of migrant cancer patients and their families in Australia

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ABSTRACT

Objective: To explore treatment decision-making experiences of Australian migrants with cancer from Arabic, Chinese, or Greek backgrounds and their relatives.
Methods: 73 patients and 18 caregivers from cancer support groups and oncology clinics participated in either a focus group ($n = 14$) or semi-structured interview ($n = 21$) conducted in the participant's own language. Participant treatment decision-making preferences were discussed as part of patients' overall treatment experience and a thematic analysis conducted.
Results: Four main themes emerged from the data: (1) perceived role of the patient in decision-making; (2) access to information and the impact of language; (3) cultural influences (4) family involvement. The majority of participants experienced passive involvement during treatment consultations, but expressed a desire for greater involvement. Language rather than culture was a greater obstacle to active participation. Difficulty communicating effectively in English was the most significant barrier to participation in treatment decisions. To overcome language challenges, participants actively sought information from alternative sources.
Conclusion: This study provides new insights into the influence of language and culture on the treatment decision-making experiences of migrants with cancer and their families within the Australian cancer care system.
Practice implications: To reduce health disparities doctors need to address language difficulties and be aware of cultural differences.

1. Introduction

Treatment decision-making is a complex interactive process. Improvements in detection and treatment of cancer mean that doctors and their patients are often presented with several treatment options and must weigh up the benefits of each against treatment side effects and patient-related factors, increasing the complexity of decision-making discussions.

Within the literature there are three broad models of medical decision-making: (1) paternalistic (2) informed and (3) shared decision-making (SDM) [1]. These models highlight differing levels of patient involvement in decision-making. There is consensus that active involvement in treatment decision-making increases patients' understanding of their illness, improves treatment adherence, leads to better health outcomes and increases patient satisfaction [2,3]. In Western cultures shared decision-making (SDM) is generally regarded as a gold standard of treatment decision-making as it respects both patients' autonomy and the doctors' expertise and avoids unbalanced sharing of power and responsibility [1]. A central tenet of shared decision-making is respect for the patient's preference for level of involvement [4].

Information and communication preferences are key features of treatment decision-making discussions, however individual patient attitudes are varied and influenced by a number of factors, including cultural background and religion [2,3]. For example in many cultures disclosure of diagnostic and prognostic information to the patient is discouraged in an effort to protect the patient from distress [5,6]. Cultural values and communication expectations common in non-western cultures [7,8] may prevail even when patients and families migrate to countries with different communication norms.

There have been a number of studies investigating differences in doctor-patient communication between migrant and non-migrant groups during medical consultations. These studies suggest migrant

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patients are more passive during medical consultations, ask fewer questions and have less understanding of cancer and treatment than non-migrants [2,5,9,10]. Other studies suggest migrants' information preferences are dependent upon their level of acculturation [11,12]. However little is known about the preferences of migrants with cancer to participate in treatment decision-making discussions.

Australia has one of the most culturally diverse populations in the world, with 26% of Australians born overseas and 2% of the population speaking English poorly or not at all [13]. Despite this, to date, few studies have investigated the impact of culture on the treatment decision-making of Australian migrants. The aim of the current study, therefore, was to explore factors that influence the cancer treatment decision-making experiences of first generation migrants with cancer from Arabic, Chinese, or Greek backgrounds.

2. Method

2.1. Participants

Patients were recruited from community-based cancer support groups and three oncology outpatient clinics in Sydney and Melbourne, Australia. Participants were eligible to participate if they were a first generation migrant from a Chinese (Cantonese or Mandarin), Greek or Arabic speaking country, had one of these languages as their first language, was aged 18 years or over and had been diagnosed with cancer within the previous three years or cared for a patient diagnosed within the preceding three years. These cultural groups were chosen as they represent the largest immigrant groups to Australia [12].

2.2. Procedure

Potentially eligible participants were approached by a support group leader or member of their treating team and provided with information about the study in their own language. Bilingual research staff obtained written informed consent. Those who consented to the study elected to participate in either a focus group or semi-structured interview conducted by bi-lingual researchers. Participant experiences and preferences for treatment decision-making were discussed as part of participants' overall experience of treatment, using open-ended questions and more specific probes. The semi-structured questions were informed by the treatment decision-making and migrant cancer experiences literature. Ethics approval was obtained from the Human Research Ethics Committee at the University of Sydney (03-2006/1/8914).

2.3. Data coding and analysis

Participant discussions were digitally recorded, translated and transcribed. A thematic analysis was conducted based on a grounded theory approach using a constant comparative methodology. All three researchers initially coded six randomly selected transcripts and a coding framework was developed. A further 14 transcripts were then coded (XZ, JS) to confirm the framework and higher order concepts. All inconsistent findings were discussed until consensus was reached by the authors. A further 16 focus group and interview transcripts were then coded (XZ) to confirm theoretical saturation.

3. Results

Focus groups were approximately 90 min and interviews approximately 40 min in length. Ninety-one participants (73 patients and 18 caregivers) participated in one of 14 focus groups (4 Mandarin, 4 Cantonese, 4 Greek and 2 Arabic groups) and 21 interviews (11 Arabic, 7 Greek, 2 Mandarin, and 1 Cantonese). Table 1 lists the demographic and clinical characteristics of the study sample.

Participants' narrative accounts of their cancer treatment highlighted a range of treatment decision-making experiences. Further analysis to explore factors that influenced these differing experiences identified four main themes: (1) the perceived role of the patient in decision-making; (2) access to information and the impact of language; (3) cultural influences and (4) involvement of family.

3.1. Theme 1: Perceived role of the patient in decision-making

Although participants' highlighted a range of treatment decision-making experiences the majority reported passive involvement in decision-making discussions. Participants across language groups perceived their doctor did not seek their opinion and many participants did not actively seek involvement in their treatment planning. For some, this passive role came about because they perceived the doctor, based on their expertise, was best placed to make treatment decisions on behalf of the patient. The patient's role was to follow the doctor's expert advice.

Table 1
Participant demographic and clinical characteristics.

Variable	*N* (%)
Language	
Greek	22 (22)
Chinese–Mandarin	23 (26)
Chinese–Cantonese	26 (29)
Arabic	20 (21)
Participant status	
Patient	73 (81)
Caregiver	18 (19)
Gender	
Male	27 (30)
Female	64 (70)
Age (years)[b]	
<40	6 (7)
40–49	18 (20)
50–59	25 (29)
60–69	25 (29)
>70	13 (15)
Time in Australia (years)	
<5 years	5 (6)
5–10	20 (22)
11–20	25 (27)
>20	41 (45)
Self-reported English proficiency	
Very good–good	29 (23)
Not very good–poor	62 (68)
Cancer type[c]	
Breast	32 (35)
Colorectal	7 (8)
Lung	6 (7)
Other[a]	46 (50)
Stage[c]	
Local	65 (71)
Metastatic	14 (15)
Unknown	12 (14)

[a] Other cancer types included nasopharyngeal, peritoneal, pancreatic, bladder, kidney, prostate, leukaemia, skin, ovarian, liver and stomach.

[b] 4 participants did not disclose their age.

[c] Diagnosis and stage are reported both for patient participants and for carers (in the latter case for the patients for whom they cared).