

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 and practice implications: 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. To reduce health disparities doctors need to address language difficulties and be aware of cultural differences.

Key words: Migrant cancer patient, treatment decision making, share decision-making, culture, qualitative research

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 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 minutes and interviews approximately 40 minutes 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.

Table 1: Participant demographic and clinical characteristics

Variable	<i>N</i> (%)
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

Breast	32 (35)
Colorectal	7 (8)
Lung	6 (7)
Other ^a	46 (50)

Stage

Local	65 (71)
Metastatic	14 (15)
Unknown	12 (14)

^aOther cancer types included nasopharyngeal, peritoneal, pancreatic, bladder, kidney, prostate, leukaemia, skin, ovarian, liver and stomach. ^b 4 participants did not disclose their age ^cDiagnosis and stage are reported both for patient participants and for carers (in the latter

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.

It's up to the doctor from the very beginning to the end, whatever the doctor says we just follow... It leaves you no room for decision. I just feel that it's not up to me to decide, I am not a professional doctor so I have to rely on the doctor, whatever he tells me to do (004, Cantonese patient)

Other participants saw their role as finding the most expert, experienced, senior doctor and having done this, they could then rely on the doctor to make the right decisions regarding cancer care and provide the best treatment available.

...of course we want to find the best doctor to see me, I don't need someone who can speak Cantonese, we want the best doctor who can treat me (049 Cantonese patient).

A few participants were less satisfied with their passive role during consultations and reported that they wanted to be involved in decision-making; however, perceived their doctor did not take their opinion or requests into consideration. These participants expressed their frustration at being excluded from decision-making.

For my case, the specialist never discussed with me, never took my opinion in consideration... The doctor won't listen to you. It's not that we didn't want, and it's not that we didn't initiate to know more, I really wanted to know, I felt helpless, felt myself helpless. He "HOLD" the "POWER". (013, Mandarin patient)

In contrast to taking a passive role during consultations, and consistent with a shared decision-making model of care, some participants perceived they were actively involved in decision-making. They saw the doctor's opinions as recommendations and that both the patient and the doctor worked together to come to a decision. They perceived their opinions held equal weight as the doctor's and their role in the discussion was to weigh up the options regarding which treatment option was most appropriate for their individual circumstances.

...I feel that patients in Australia usually have right of choice... So I think sometimes the doctor can give you choice... It means you have choice of treatment. (003, Cantonese patient)

3.2. Theme 2: Access to Information: too much or not enough?

Across language groups, access to information was a key issue influencing the role patients were able to play in treatment decision-making. The majority of participants reported the doctor gave less information than they had wanted, with approximately half of the participants reporting they had insufficient information about diagnosis and prognosis, reducing their understanding of their medical situation and hence their ability to be involved in treatment decision-making.

I asked him (doctor) how long I will live. ... The doctor won't answer me. He said 'you keep on taking the medication'. (023, Cantonese patient)

When I had to do chemotherapy I did it. The doctor said it and I did it...No (I did not consider another treatment) because I did not know if others existed. (015, Greek patient)

In contrast, some participants reported that their doctor provided sufficient information for them to make treatment decisions, which helped participants feel a sense of control over what was happening to them.

I feel more secure ... he (doctor) explain it very clearly, very detailed.. So I will be well prepared. (047, Cantonese patient).

For a few participants, the limited information provided was based on patient choice. These participants preferred that the doctor, or in some cases the family, made treatment decisions and perceived the provision of too much information as distressing.

I was so shocked and he gave me all this information! (laughs)... I don't want to hear, prefer to be in the dark and someone else understands for me and that's it, ... the patient really doesn't need to know, for me when he told me I was shocked and scared and left him (doctors surgery) straight away. ... I would prefer it if the doctor did not discuss this. (084, Arabic patient)

Participants who perceived they received less information than they wanted used a number of strategies to facilitate their understanding of treatment choices. Some participants did not have the knowledge to understand the options, so sought second opinions from other experts on the treatment recommendations of the treating doctor. This extended to seeking second opinions from doctors in their country of birth, as participants placed trust in the health systems more familiar to them. Seeking a second opinion can also be considered an extension of the patient's role of finding the 'best' doctor, as these participants reported the importance of reassurance that the treating team was well respected.

No the doctor first tell me you need this... and then I asked the other doctors and they say this is the best so of course I come back and say I want to do it because they all say it's the best. I don't know what's the best they do (089, Arabic patient)

well I try to ask some doctors in my country back home, through my brothers there (077 Arabic patient,)

Many participants also reported they relied on the internet and social networks to

supplement the information received during consultations. These informal sources in the participant's own language and often from participants' country of birth, were perceived as trusted sources of information helpful to patient understanding, regardless of source.

You can find it on the website in Chinese oncology hospital what you should take [treatment] they had it all (051 Cantonese patient)

3.2.1 Language as a barrier to decision-making participation

A major contributing factor to accessing information and therefore participation in treatment decision-making discussions was participants' level of English proficiency. A lack of English was reported to greatly hinder both understanding and communication during treatment discussions. Even participants with some level of English struggled with understanding medical terminology and did not feel comfortable engaging in discussions where they were unsure of the meaning of terminology.

Don't know how to communicate. I want to talk about something but don't know how to talk. The Caucasian think that you have nothing to ask, I feel it very hard to communicate my feelings (005, Cantonese patient)

I can read English but I don't understand the meaning of the words I have to take out the dictionary every time I come from the doctor's. I just sit there and say yes, yes but I leave his consultation and I didn't understand most things. I find it hard (094 Arabic patient).

3.2.2 Does written information facilitate discussions?

Given the language challenges during consultations, many participants reported a need for, and some expressed that they had expected to receive, written information to help understand their options and participate more fully in treatment decisions. Participants perceived that written

information could be shown to family members who understood English or translated at home. These participants highlighted a need for both general medical and individually tailored information including medical reports and scans.

There was no “ANY WRITTEN REPORT SAYING WHAT IT WAS!!”(the patient stressed this in English). Until now I still don’t have. Never...Never anything in writing. (013, Mandarin patient)

Some participants reported that written information was provided, but it was in English. These participants were distressed that information freely provided to English speaking patients was not available to them and perceived they were not fully informed of their choices. There were also some concerns raised about the quality of information available in patients’ own language. Participants reported that the information was often outdated, although English versions of the booklets had been updated.

I don’t understand English and everything they gave me was in English. No Greek person has spoken to me. Yes I have difficulties; I didn’t understand him in everything he said. (040, Greek patient)

3.2.3 Seeking out those who speak my language

Accessing doctors from the same cultural background was one way in which participants tried to overcome language barriers, however as there is no formal referral system, this was difficult, particularly if you were unfamiliar with the health system. Other participants made use of the interpreter services available. However, even when interpreters were present, several participants reported not being able to ask questions, to express their feelings and negotiate appointments, thus limiting their power in making decisions.

I made calls... I wanted to find one who spoke Chinese, its better for communication. Then I found Dr XXX speaks Chinese and his receptionist also spoke Chinese, then we could communicate. (005, Cantonese patient)

For us it is difficult. As Chinese in overseas, when we have a problem, we can't express our symptoms, so we find an interpreter. There are so many interpreters, they phone in. They don't say it right [the meaning of what is being said]. So often our message is not correctly delivered. The doctor doesn't understand us (023, Cantonese patient)

Family members commonly accompanied participants with limited English to consultations to act as translators. However, despite being able to speak English, they often struggled to translate medical terminology.

she [daughter] is educated here. She explains to us what he says... but there are medical terms, not everyone who just went to school here will understand these terms (037 Arabic carer).

3.3. Theme 3: Cultural influences on decision making

Exploration of the influence of culture on treatment decision-making highlighted that participants' differing attitudes towards treatment options and the influence of religion, did play a role in how participants approached treatment decisions.

3.3.1 Differing health concepts

A number of Chinese-speaking participants highlighted that differences in attitude towards inclusion of traditional Chinese medicines as part of standard care made it hard for the doctors and participants to understand each other, and to reach agreement about treatment. These participants perceived their doctors provided less than optimal care if traditional treatments were

not considered or their value derided. These participants A few participants also reported they were distressed during treatment discussions as the options proposed were inconsistent with cultural norms within their birth country.

I take Chinese herb, I asked my doctor. The doctor didn't agree with me at the beginning. for example during the chemotherapy, the doctor told me I shouldn't take anything, but I felt it would be better. I took Ling-Zhi and shark bone powder now. (009, Mandarin patient)

3.3.2 Impact of religious beliefs

Religious beliefs also impacted on treatment decision-making for a number of participants. Some participants perceived that God was directing their fate with respect to disease outcomes. This led to nihilism and for one participant a delay in treatment, despite doctor recommendations. Several participants passively accepted the treatment plans provided to them by doctors because they perceived that the doctor was acting in God's name. Others perceived that treatment options presented were inconsistent with their religious beliefs about the sanctity of the body.

The doctor tells me to do something, you shouldn't say 'no, I won't do it', this is in His [Gods] name, whatever they say, we do.(36, Arabic)

The doctor told me, if you are worried you can take out the uterus...This kind of explanation for Chinese is a forbidden, we don't talk about from a religious point of view, because when made human they give you in whole piece, they won't let you get rid of any organs easily... This might be to do with the Eastern and Western culture [difference] (079, Mandarin patient)

3.4. Theme 4: Involvement of family in decision-making

Consistent with non-migrant groups, participants described a range of family involvement in decision-making. Some participants discussed their treatment options with family and then made their own decisions, others did not involve family at all. However, participants from the Arabic groups generally held the view that family should make decisions on behalf of the patient, relieving the patient of the burden of having to weigh up options. Providing minimal information to patients was viewed as a means of protecting the patient from emotional distress. When patients who held this view were forced due to circumstance to decide for themselves, they reported significant pressure and feelings of being overwhelmed. For one participant, this resulted in delayed treatment and subsequent feelings of regret. This view was not as strongly held by Chinese and Greek patients.

I told him (doctor) ... 'don't open your mouth, talk with my husband, talk with my children, and have a meeting with all of them... Don't inform me, I don't want to know, I am happy this way. (036, Arabic patient)

4. Discussion and Conclusion

4.1. Discussion

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. Participants described a range of decision-making experiences, although the majority of participants experienced passive involvement during treatment consultations. Language rather than culture was a greater obstacle to active participation, with difficulties with communicating effectively in English reported as the most significant barrier to

participation in treatment decisions. To address this challenge, participants who wanted active involvement highlighted seeking second opinions, accessing information from informal sources, trying to find doctors who spoke their language and utilizing interpreters as strategies they frequently used to increase their ability to participate in treatment decision-making. Cultural factors such as differing attitudes towards treatment, the influence of religion and family involvement also influenced participants' tendency to be involved in treatment decisions.

The range of decision-making experiences reported in this study highlights different perceptions regarding the role of patients in deciding treatment. For some participants, the role of the patient was perceived to be that of a compliant patient who followed the doctor's expert advice. Other participants saw their role as finding the doctor best placed to treat their cancer and having done this, it was the patient's responsibility to follow the treatment plan. A smaller number of participants engaged in collaborative discussions with their doctors and defined their role as providing their unique perspective to the discussion regarding their individual circumstances.

Access to information was the primary driver in participants' ability to participate in treatment decisions and having unmet information needs was a source of frustration. Consistent with previous studies, an inability to communicate effectively resulted in limited exchange of information [8, 14]. To facilitate involvement and in contrast to the common cultural stereotype that migrant patients avoid disclosure, many patients in our study actively collected information in their language via the internet and their social networks. Across the language groups, patients also sought second opinions to ensure they received the most appropriate treatment and explored alternative treatments. They also sought out doctors who spoke their language and actively engaged with interpreter services, albeit with limited success. This suggests a strong desire to

contribute to treatment decisions.

Consistent with this view, participants reported they wanted greater involvement in decision-making but perceived they were denied the opportunity. In contrast to best practice guidelines [15], these participants perceived their opinions were not sought or taken into consideration by their doctors. For example, differing cultural views on use of traditional treatment were often not discussed or patient beliefs disregarded. This suggests when language is a barrier, some doctors may revert to a paternalistic model of care, overlooking their patient's desire for involvement. However, inconsistency between patient decision-making preferences and experiences is not unique to migrants, with a number of studies in a general breast cancer population finding less than half of patients (50% and 34% respectively), reach their desired level of participatory communication regarding decision-making [16-18]. Doctors therefore need to place greater emphasis on determining patient preferences for involvement, and take additional time during such discussions with migrant patients, due to the challenge of language differences.

Religious beliefs were also found to impact on treatment decision-making. For some patients, particularly those from Arabic backgrounds, treatment outcome was perceived as determined by God's will. These participants perceived treatment decision-making to be futile, as the future was in the hands of God. This is consistent with previous studies that have reported that some migrant groups attribute a cancer diagnosis as an act of God [6], a view seldom reported by Anglo-Australian patients. Differing attitudes to effective treatments between doctors and patients mean it can be difficult to reach consensus in treatment discussions.

Families can also play a significant role in migrant patients' decision making, [11, 19] acting as gatekeepers to protect patients from distress and having to make difficult decisions. In our study patients provided a range of expectations for family involvement. Some patients held the traditional view that it was the families' responsibility to protect patients from unnecessary emotional burden by making decisions on their behalf, although, however the majority preferred to make their own decisions, often in consultation with family. This view was inconsistent with previous studies in Australia [11, 14]. To ensure consultations are tailored to individual patient need, our study findings suggest it is necessary for doctors to ask patients about family involvement at the beginning of discussions.

This study is the first comprehensive investigation of migrant cancer patient experiences and preferences for treatment decision-making in Australia. However, the results need to be considered in light of a number of limitations. Firstly, as the focus groups and interviews were completed prior to analysis, we were unable to explore emerging themes further with patients. Participants also self-selected to participate so generalizability to other non-participating migrant groups is difficult. Similarly, as the data was self-report, objective measures are also needed in future studies to determine whether the answers provided reflect actual practice during consultations.

4.2. Conclusion

Migrant cancer patients participating in this study reported wanting to participate in treatment decision-making. Language rather than culture was a greater determinant of active

participation. To overcome the challenges associated with unmet information needs, patients and families actively sought second opinions and used informal sources to access information. Cultural differences such as views on traditional treatments and role of religion and families with respect to decision-making were perceived as secondary concerns when communication language was limited. The results of this study highlight the need for further investigation of the interplay between language and culture to optimize patient participation in treatment decision-making.

4.3. Practice Implications

To ensure patients are able to participate in treatment decision-making, appropriate resources in the patient's language are recommended. Migrant patients are likely to need additional time, support and information to be able to participate in decision-making due to language difficulties. Doctors also need to be aware of cultural issues, and be sensitive and mindful of patients' diversified preferences regarding treatment decision making.

I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

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