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TITLE: Prognostic Communication Preferences of Australian Migrant Patients and their Relatives

RUNNING TITLE: Communicating with Migrant Patients

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CONDENSED ABSTRACT: This paper demonstrates that a patient-centered communication approach may be appropriate for patients in the metastatic cancer setting, regardless of ethnicity. Understanding the dynamics within migrant families is also an important component in providing culturally sensitive communication.

FULL ABSTRACT: Background: Migrant patients comprise a significant proportion of Western oncologists' clientele. Although previous research has found that barriers exist in the communication between ethnically diverse patients and health professionals, little is known about their personal preferences for communication and information, or the concordance of views held between patients and family members. **Methods:** 73 patients (31 Anglo-Australians, and 20 Chinese, 11 Arabic, and 11 Greek migrants) and 65 relatives (25 Anglo-Australians, and 23 Chinese, 11 Arabic, and 7 Greek migrants) were recruited through 9 Sydney oncology clinics. Following prognostic consultations, participants were interviewed in their preferred language about their experiences and ideals regarding information and communication with oncologists. Interviews were audio-taped, translated and transcribed, and then thematically analysed using N-Vivo software. **Results:** Consistency was found in patient preferences, regardless of ethnicity, in that almost all patients preferred prognostic information to be delivered in a caring and personalised manner from an authoritative oncologist. Contrary to previous research, migrant patients often expressed a desire for prognostic disclosure. Discordance was found between migrant patients and their families. These families displayed traditional non-Western preferences of non-disclosure of prognosis and wanted to actively influence consultations by meeting with oncologists separately beforehand and directing the oncologists on what and how information should be conveyed to patients. **Conclusions:** A patient-centered communication approach may be appropriate for patients in the metastatic cancer setting, regardless of ethnicity. Understanding the dynamics within migrant families is also an important component in providing culturally sensitive communication. Future directions for research are provided.

KEYWORDS: Migrants, cancer, prognosis, communication, Chinese, Arabic, Greek, preferences, relatives

INTRODUCTION

Background

Migration is increasing world-wide. The literature suggests that minority groups experience poorer cancer outcomes, including lower rates of survival, higher rates of reported side effects, and poorer patient quality of life [1, 2, 3, 4]. Effectively communicating with migrant minority patient groups, who may lack English language skills, and who have been shown to have differing cultural beliefs surrounding cancer, is a challenging task for oncologists. However ensuring that cancer-related information is communicated accurately and in a culturally sensitive manner may be critical if equity and optimal care are to be improved for this population [5, 6, 7].

Existing research suggests that both linguistic difficulties and practitioner behaviour may contribute to poor communication and patient dissatisfaction. For instance poor English-speaking ability has been noted to cause serious misunderstanding of information and instructions [8, 9, 10, 11] while analyses of audio-taped consultations have found that practitioners tend to be less patient-centred, and less likely to engage in shared-decision-making with patients of a non-Anglo Saxon background compared to patients of Anglo-Saxon heritage [12, 13, 14]. These barriers, which have been acknowledged by patients and practitioners alike [10, 11], may explain findings that ethnically diverse patients report significantly less satisfaction and positive mood following medical consultations in comparison to Anglo Saxon patients [12, 13].

One challenging communication task within the oncological setting is that of delivering prognostic information, particularly when prognosis is poor. Surveys of patients demonstrating that most want detailed information about their prognosis [15, 16, 17] have been conducted with English-speaking patients, however little is known regarding the information and communication preferences of ethnic minority patients. The few qualitative

studies that have been conducted in this area suggest that migrants may prefer non-disclosure of prognostic information [18,19]. This is not surprising, given that past surveys of oncologists have shown that it is common in many Southern European, Asian, and Middle Eastern countries to conceal information from cancer patients, including the prognosis, stage of disease, and sometimes even the diagnosis [20, 21, 22].

In non-Western and collectivist countries, families tend to have a greater role and influence in the lives of individuals than they do in individualistic countries such as Australia [23]. Earlier work [18, 19] suggests that family members of migrant cancer patients may censor information that is passed to patients during consultations, and also may act as principal decision-makers on behalf of patients. Thus it is important that communication and information preferences not only of patients, but also of family members, are investigated in future research.

Aims

The current study aimed to explore communication preferences for prognostic information in English speaking and migrant patients and their families. This study is a component of a larger study, which is exploring communication of prognosis with migrant cancer patients and their families. The larger study involved audio-taping and objectively analysing the content of the first two consultations after diagnosis of metastatic disease, between oncologists and migrant and Anglo-Saxon cancer patients. The present study reports on structured interviews conducted following the second consultation with patients and family members, to elicit their experience and preferences of prognostic communication.

METHOD

Design

A qualitative approach was adopted, as this is a new area of enquiry, and patients and family members were regarded as expert informants on their own communication needs.

Participants

Eligibility criteria for patients included being Anglo Australian, or a migrant of Chinese, Greek, or Arabic speaking background (the three largest migrant groups in Australia); being older than 18 years; having a new diagnosis of metastatic cancer; and having attended two prognostic consultations with their oncologists. A new diagnosis of metastatic cancer was included as an eligibility criterion to maximise the likelihood that prognostic information would be discussed during the consultations prior to the interview. Information regarding cancer diagnosis was obtained from participants' oncologists. Attendance at two prognostic consultations was specified based on evidence that Anglo Australians commonly delay discussing prognosis until their second consultation [24].

Senior medical oncologists from nine Sydney oncology clinics identified patients who met the criteria during their first prognostic consultation. The oncologist informed these patients about the study and, if they were interested in participating, asked for their verbal consent for a research assistant to contact them by phone. A research assistant who spoke the patient's language telephoned interested patients, provided more information about the study, and if the patient gave verbal consent, organised to meet them prior to their next consultation in order to obtain written consent. Ethics approval was obtained from all participating hospitals.

Materials

Prior to the structured interview, patients completed a short questionnaire eliciting demographic details (age, gender, relationship status, religion, highest educational level achieved, language background, whether they had medical training, years lived in Australia)

and level of acculturation, using the 8-item Rissel Acculturation Scale [25]. Scores on this scale range from 8 to 35, with higher scores indicating greater levels of acculturation. Internal consistency in an Arabic population was strong (Chronbach's alpha = .88; [25]).

Interview Development

Interview questions were based on the prognostic literature [16, 17, 26], and reviewed by Chinese, Arabic, and Greek research advisory groups, comprised of prominent ethnic community members, health professionals, consumers, and religious representatives.

Questions shifted from asking informants about their experiences of prognostic communication within their two previous consultations, to eliciting their general preferences for prognostic communication and advice regarding the ideal way to communicate about prognosis with people of their cultural background.

Procedure

The structured interviews were held in the Oncology clinic, and were conducted by a bilingual researcher, trained in qualitative methods. Patients and family members were invited to attend the interview when consented; they chose who was to be present. Interviews were translated into English and transcribed for analysis.

Data Analysis

Descriptive statistics were used to analyse the demographic and acculturation data. Using NVivo 8 software [27], a thematic and comparative analysis approach [28] was used to code the transcripts line by line to elicit themes. Themes were then grouped together, checked for emerging patterns, variability, consistency, and commonality across participants, and compared between ethnic groups. The transcripts were also subjected to classical content analysis, which focuses on how frequently themes arise throughout the data [29]. Two researchers coded the first 15 transcripts and cross-checked their themes and sub-themes until consensus was reached on a thematic tree (see fig.1). The remaining transcripts were then

coded by one researcher, and any changes to the thematic tree were regularly reviewed by the second researcher. Characteristic examples were identified from the transcripts to serve as representative examples of the themes.

Because the sample is a relatively large one for a qualitative study, numbers as well as themes are reported in the results below to provide an indication of the frequency with which themes were raised. Nevertheless, as the study was not powered for frequency description or quantitative comparisons, these numbers should be interpreted with caution and are hypothesis-generating only.

RESULTS

Demographics

Tables 1a and 1b provide a demographic profile of the participating patients and family members, respectively. Seventy-three patients agreed to participate in the study (31 Anglo-Australians, and 20 Chinese, 11 Arabic, and 11 Greek migrants). The majority of patients were female (64%), older than 60 years (67%), and had a diagnosis of either lung (33%) or breast (26%) cancer. Sixty-six family members consented to participate in the study (25 Anglo-Australians, and 23 Chinese, 11 Arabic, and 7 Greek migrants). Most often, family members were the spouse (37%) or offspring (52%) of the patient. In 51 of the 73 interviews, patients were accompanied by one or more of their relatives. For the remaining 22 interviews, patients were interviewed alone.

Table 1a. *Patient demographics.*

DEMOGRAPHIC	Total	Anglo	Chinese	Arabic	Greek
Average Years in Australia					
Mean (years)	35.50	62.00	15.00	28.00	37.00
SD	19.84	15.04	7.01	14.80	13.51
Range (years)	0 to 82	33 to 82	0 to 54	0 to 44	0 to 54
DEMOGRAPHIC	Total [N (%)]	Anglo (n)	Chinese (n)	Arabic (n)	Greek (n)
Sample size					
	73 (100)	31	20	11	11
Cancer Type					
Lung	24 (33)	14	8	2	0
Breast	19 (26)	9	3	7	0
Other	17 (23)	8	3	2	4
Unknown	13 (18)	0	6	0	7
Age Group					
31-60 years	22 (30)	6	9	5	1
Over 60 years	49 (67)	25	13	5	8
Unknown	2 (3)	0	0	1	1
Sex					
Male	26 (36)	10	9	3	4
Female	47 (64)	21	11	8	7
Relationship Status					
Married/Defacto	49 (67)	19	15	7	8
Single	15 (33)	12	5	4	2
Unknown	1 (1)	0	0	0	1
Highest Education Level					
Grade 12 or below	51 (70)	23	10	10	8
TAFE	9 (12)	4	4	0	1
University	9 (11)	2	6	1	0
Unknown	4 (5)	2	0	0	2
Religion					
Christianity	51 (70)	29	6	7	10
Buddhism	6 (8)	0	6	0	0
Muslim	4 (5)	0	0	4	0
Other	3 (4)	1	2	0	0
Unknown	7 (10)	0	6	0	1
English Speaking Ability					
Poor	16 (22)	0	11	4	1
Average	18 (25)	0	8	4	6
Good	33 (45)	27	1	3	2
Unknown	6 (8)	4	0	0	2
Medical Background					
Yes	8 (11)	3	1	3	1

Table 1b. *Family demographics.*

DEMOGRAPHIC	Total	Anglo	Chinese	Arabic	Greek
Average Years in Australia					
Mean (years)	32.18	52.20	21.22	26.00	29.29
SD	13.75	14.64	10.95	16.23	18.25
Range (years)	0-78	30-78	0-54	0-42	0-44
DEMOGRAPHIC	Total [N (%)]	Anglo (n)	Chinese (n)	Arabic (n)	Greek (n)
Sample Size					
	66 (100)	25	23	11	7
Relationship to Patient					
Husband	13 (20)	6	4	2	1
Wife	11 (17)	5	5	1	0
Son	11 (17)	0	8	2	1
Daughter	23 (35)	12	2	4	5
Other	7 (11)	2	4	1	0
Unknown	1 (2)	0	0	1	0
Sex					
Male	27 (41)	6	13	6	2
Female	39 (59)	19	10	5	5
Education Level					
Grade 10 or below	18 (27)	11	6	0	1
Grade 12	14 (21)	6	3	5	0
TAFE	15 (23)	3	6	3	3
University	13 (20)	4	4	2	3
Postgraduate	5 (8)	1	3	1	0
Unknown	1 (2)	0	1	0	0
English Ability					
Poor	9 (14)	0	9	0	0
Average	9 (14)	0	7	1	1
Good	44 (67)	24	5	9	6
Unknown	4 (6)	1	2	1	0
Medical Background					
Yes	4 (6)	2	2	1	0

Acculturation

Family members scored higher on acculturation ($M = 17.57$, $SD = 4.14$) than patients ($M = 12.36$, $SD = 0.96$). Among patients, the Arabic ($M = 14.80$, $SD = 5.87$) scored highest, followed by the Greek ($M = 12.80$, $SD = 6.75$), and then the Chinese ($M = 12$, $SD = 5.49$). Among relatives, the Greek ($M = 22.29$, $SD = 6.42$) scored highest, followed by the Arabic ($M = 20.00$, $SD = 7.95$), and then the Chinese ($M = 15.87$, $SD = 6.15$). These scores indicated that both patients and relatives in all speaking groups had a moderate level of acculturation.

Thematic Findings

Analysis of the interview transcripts revealed three main themes in regards to participants' information and communication preferences about prognosis:

1. How Much Information to Disclose
2. When to Initiate Information-Giving
3. Manner of Information Delivery

It is important to note that the data presented below highlight themes that were frequently brought up in interviews, but not themes that were necessarily discussed by each participant in every interview. These themes may have been elicited either by the questions that the interviewers asked, or spontaneously raised by the participants themselves. Because the number of participants in each ethnic group varied, and to make it easier for the reader to make comparisons, the number of respondents are presented *relative* to the total number of participants in each sub-sample (e.g., “26/31 Anglo Australians patients” can be literally interpreted as “26 out of the 31 Anglo Australian patients”).

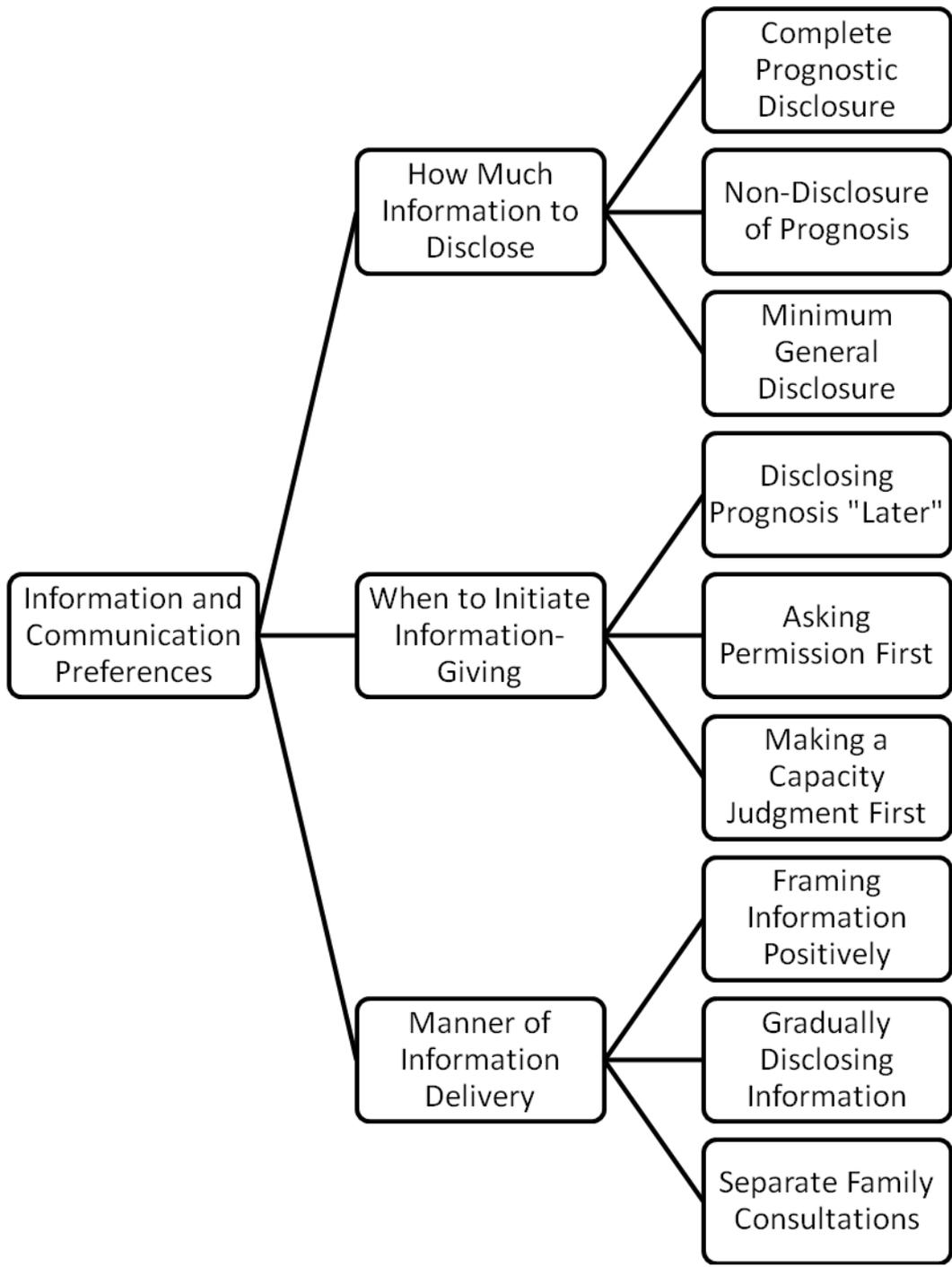


Figure 1. *Thematic tree*

How much Information to Disclose

Eleven of the seventy-three patients interviewed did not express a clear preference on whether they wanted prognosis disclosed.

Complete Prognostic Disclosure Thirty-one from seventy-three patients but only 17/66 relatives expressed a preference for oncologists to openly provide all details about patients' prognoses. Among patients, the Chinese expressed wanting disclosure more so than other migrants and Anglo Australian patients. Among relatives however, Anglo Australians were most likely to want prognosis disclosed, whilst few Chinese and Arabic and no Greek relatives expressed a preference for disclosure. The reasons most commonly cited for wanting prognostic information related to being able to plan and prepare for the future. Relatives also cited the patients' 'right' to know:

“Yes, I wanna know! More, more information! I want know everything! Like I mean I don't want, I don't want go in the road... ah... blind.”

- Female Arabic patient

“I think he should [disclose the prognosis] as there are many things...for example...ah... If there are something that you need to do, you can do it when you are still fine.”

- Female Chinese patient

Non-Disclosure of Prognosis

Twenty-four of the seventy-three patients and 30/66 relatives expressed a desire for non-disclosure of prognosis. A greater proportion of Anglo Australian patients expressed this preference in comparison to other ethnic patient groups. On the other hand, the proportion of relatives that expressed not wanting prognosis disclosed was high and fairly even across all ethnic groups. Reasons for this preference were similar across all groups. Patients holding this

view often stated that prognostic statistics were “inaccurate” and knowing them was “unnecessary”. Many patients and relatives felt patients needed to know only the minimum required for them to understand what they needed to do. Family members were often more passionate than patients in their plea to withhold prognostic information. And both patients and relatives believed that disclosure would result in deterioration of the patient’s condition and emotional distress:

“I think if um, if you know too, you are thinking all the time you know: ‘well what day is it going to happen?’. You don’t need that worry - you just need to be positive.”

- Female Anglo patient

“No, I don’t like to [be told the prognosis]. And they shouldn’t talk to people whose state doesn’t allow it. If someone has six months, then they wouldn’t be able to cope.”

- Female Arabic patient

Disparity between Patients and Family

In 35 of the 51 interviews in which family members accompanied patients, both the patient and their relative/s expressed a preference on the disclosure of prognosis; and in 11/35 of these interviews patients and their relatives disagreed on whether prognosis should be disclosed to the patient. Interestingly, a discordance where the patient wanted prognostic disclosure while the family did not occurred over 3 times more often in migrant patient-family dyads than it did with Anglo Australian patient-family dyads.

When to Initiate Information-Giving

Disclosing Prognosis “Later”

Eight out of the seventy-three patients and 7/66 relatives each mentioned that they would prefer doctors to provide prognostic information “later on”, when the situation has become

“worse” and the patient was closer to death. These participants had often also stated that they did not want to know their prognosis at the time of the interview, and are thus distinct from participants who were coded as wanting to know their prognosis (see above). These participants, who were mostly Anglo Australian patients and relatives, could see the benefits of prognostic disclosure in allowing people time to prepare for death, but were not yet ready to receive the information:

“No. I’d prefer not to know that... until it – you know until there’s a – until I’m really bad.”

- Female Anglo patient

“I think they need to tell when the situation is serious. I mean, I want to complete what I haven’t finished.”

- Female Chinese patient

Asking Permission First

Sixteen of the seventy-three patients and 14/66 relatives emphasized the need for the oncologist to always ask permission before providing information to the patient, in case there was information that the patient did not want to know. This request was most often stated by Greek patients and relatives, and least often by Arabic participants:

“I think if... I mean... if they’re being asked, then they should tell... but...I think they’d better not to tell if the patient doesn’t want to know at all.”

- Female Chinese patient

“She said that whatever he asks him she should answer. If he doesn’t ask, she doesn’t answer... It is his choice if he wants to ask and learn - it’s not hers.”

- Greek patient’s sister-in-law

Making a Capacity Judgment First

Fourteen of the seventy-three patients and 18/66 relatives thought that it was the doctor's role to make a capacity judgment of the patient to decide when they should discuss prognosis.

These participants felt that some patients were too emotionally unstable, elderly, or otherwise incapable of 'handling' information, and that doctors should detect these characteristics and tailor information accordingly. Chinese and Arabic patients and relatives were most likely to express this, whilst Greek participants were least likely to:

"Oh I think that... that's something that they [the doctor] should be deciding for herself or himself - whether the patient can handle too much bad news. I think the doctor has to decide that really..."

- Female Anglo patient

Manner of Information Delivery

Framing Information Positively

Twenty-five of the sixty-six relatives but only 9/73 patients talked about the need for doctors to positively 'frame' information that they give patients, in order to encourage their hope. This was most strongly expressed by Chinese patients, and Arabic and Greek relatives:

"He... I mean, if you, the doctor, can give him confidence... I mean, he [the patient] still has a battle to fight against, if you...you can give him hopes, he can be more confident in the battle."

- Female Chinese patient

"They [the doctors] have to encourage them [the patients] to be optimistic."

- Greek patient's daughter

Gradually Disclosing Information

The need to gradually expose patients to information, especially when negative, was expressed by 12/66 relatives and 5/73 patients, evenly across ethnic groups. Participants who

preferred this approach to information-giving believed that it would be easier to cope with the information if it was provided in a gradual way:

“But rather than having everything explained, because not everything is going to happen to me... I take it a day at a time... ‘cause it can be very scary when they tell you all those things.”

- Female Anglo patient

“Breaking the news in stages is a good thing, it’s not wrong.”

- Arabic patient’s son

Separate Family Consultations

Twenty-six of the sixty-six relatives, in particular the Chinese and Arabic, also desired separate consultations with doctors, without the patient present. These family members wanted to discuss separately with the doctor what information should be provided to the patient and in what manner. They also often wanted to find out information that they did not want the patients to know for themselves:

“He can tell the patient’s family but he can’t tell his patient directly.”

- Chinese patient’s wife

This type of family intervention was not expressed as preferential by any of the patients and the prospect of it occurring behind their backs sometimes caused notable distress for patients in the interviews, as seen in the individual comments expressed by this patient-husband dyad:

“Ah...At the earlier stage....They should communicate with the families.... to see when to tell the patient. It’d be the best to discuss with the family first.”

- Chinese patient’s husband

“This disease, even they don’t tell me directly... they and that doctor didn’t tell me... Deep down, I felt rather upset. Indeed, if you tell me directly, I wouldn’t be so bothered.”

- Female Chinese patient

DISCUSSION

The current study has shed light on the relatively unexplored field of ethnic minority patients' communication experiences within Western medical healthcare. The study is also novel in recruiting patients from the metastatic cancer setting; in recruiting patients' family members; in recruiting ethnic patients from multiple ethnic backgrounds within the one study; and in recruiting Anglo Australian cancer patients as an ethnic majority comparison group.

Almost all of the Anglo Australian and Chinese migrant patients, but only around half of the Greek and Arabic migrant patients in this study expressed an opinion on how much information they wanted disclosed from their oncologists. This may reflect varying degrees of comfort in declaring preferences between the ethnic groups in this study.

Surprisingly, more migrant patients (especially the Chinese) than Anglo Australian patients expressed wanting to know their prognosis. Furthermore, Anglo Australian patients expressed not wanting to know their cancer prognosis as often as migrant patients did. These preferences are contradictory to research that suggests that Anglo Australians prefer to know their prognosis [15, 16, 17]. Some Anglo Australian patients in the current study however did mention that they would eventually want to know their prognosis, which supports previous studies finding that Anglo Australians may put off being told their prognosis for some time following diagnosis of metastatic disease [17]. These disparate findings may also reflect the timing of assessment; previous studies surveyed patients many months after diagnosis of metastatic disease, while the current study elicited preferences immediately following diagnosis when prognostic information is most likely to be disclosed. Furthermore, the use of

qualitative methods may have allowed more nuanced responses than quantitative surveys which demand a yes/no answer.

Chinese patients in this study expressed a clear opinion on the manner in which information should be delivered, and in particular indicated that oncologists should attempt to frame information positively so as to provide or maintain the patient's hope. Indeed, past surveys with patients have shown that communicating in a confident and reassuring manner is viewed by patients as important in maintaining their hope [17, 30].

It was also sometimes expressed by Greek and Arabic patients that the oncologist should check with patients first before providing information or make a judgment on the emotional capacity of the patient before providing information. Similar preferences have been found amongst patients in other non-ethnic studies [31], and may reflect a general preference for non-disclosure.

Of particular interest in the current study are the ethnic differences found between patient and family member dyads in their views. Whilst there was usually concordance in views between Anglo Australian family members and patients, the information and communication preferences of migrant family members clearly differed from those of migrant patients. Families of Anglo Australian patients tended to support the prognostic disclosure preferences of patients. In contrast, migrant families expressed wanting non-disclosure of prognosis at least twice as often as migrant patients did, and migrant patients expressed wanting disclosure of prognosis two to three times more often than their families did.

Apart from preferring less information-giving to patients, some migrant family members in the current study also appeared to desire an active influence over what information was conveyed from the oncologist to the patient during the consultations. They preferred the oncologist to convey information to the family during separate consultations, rather than directly to the patient, and for the oncologist to allow them to direct what and how

much information was communicated to the patient. In contrast, migrant patients did not emphasise a need for separate consultations with family members, and a few patients were noticeably upset at the prospect of this type of communication occurring behind their backs.

The finding of discordance between migrant patients and their families in this study is unique. It has been assumed from previous studies that migrant patients and families have similar preferences for information and communication. For instance, interviews with migrants in Australia and the United States have reported that migrant cancer patients prefer non-disclosure of prognosis and for families to take the lead roles in decision making [34, 18, 19]. Two of these studies however were not conducted with migrants who had cancer at the time of the interview [19, 34]. Thus it is unclear whether participants were putting themselves in the position of a patient or a family member when responding. This ambiguity has been overcome in the current study by recruiting both patients with metastatic cancer as well as their family members, and by eliciting their individual preferences for information and communication.

The concept of cultural competence has been increasingly promoted as a necessary part of training in communication. Our findings suggest that this is by no means acquiring knowledge of cultural norms such as preference of information giving but rather represents the acquisition of a skill which recognises the diversity of views regarding delivery of prognostic information may be informed by culture but is always intensely personal. Assumptions about patients and their wishes based on cultural knowledge (competence) may not always lead to appropriate outcomes and discordance with expected cultural norms seems to be a key thrust of our findings.

Overall, family members displayed a clear and singular preference for oncologists to communicate in a caring and personalised manner with patients. These findings suggest that family members' preference for non-disclosure of prognostic information is primarily

motivated by a wish to protect the patient from emotional distress, as has been found in other non-ethnic qualitative studies [32, 33]. If oncologists are to openly discuss prognosis and negotiate patient and family discordance in preferences effectively, they will need to reassure family members that disclosure, even if contrary to culturally influenced views, will ultimately result in less emotional cost than secrecy, and will not affect cancer outcome [35, 36, 37]. The recognition of such nuances through research such as this will inevitably lead to improved patient satisfaction and potentially other outcomes such as compliance with therapy.

Conclusions

The current study has provided insight into the information and communication preferences of migrant and Anglo Australian cancer patients. Differences in the preferred level of information disclosure emerged between migrants and Anglo-Australians. Contrary to previous research, migrant patients, and not Anglo-Australian patients, reported a desire to be well informed of their disease, often including the disclosure of their prognosis. On the other hand, the preferences of migrant families differed from migrant patients, and tended to reflect the more traditional conceptualisations of non-Western attitudes to communication during cancer, including non-disclosure of prognosis and the mediatory role of the family between the oncologist and the patient. Cultural competence is likely to be a complicated interplay of insights into customs and beliefs balanced against individual modulation in the presence of life threatening illness.

Limitations and Future Research

Whilst the qualitative nature of the current study has allowed for new hypotheses to be generated regarding the communication preferences of migrant patients and their families, it has also limited the ability to draw concrete conclusions from the data. Thus, the next step forward in this research should be to design a quantitative survey based on the current

findings. It would also be useful for future Australian research to recruit patients and family members from other ethnic minorities, to explore other viewpoints.

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