

From inside the bubble: migrants' perceptions of communication with the cancer team

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Abstract

Purpose Migrants with cancer struggle to communicate with their health care team. This study aimed to identify health-care related unmet needs and communication issues for migrants who develop cancer and factors associated with these challenges. In this paper, the findings related to communication issues are presented.

Patients and methods Seventy-three cancer patients diagnosed within the previous 3 years and 18 carers, who had migrated to Australia and spoke the designated languages, participated in focus groups or structured interviews. Participants were recruited from ethnic community support organisations, support groups and Oncology clinics within three metropolitan hospitals in two states of Australia. Focus groups and semi-structured interviews were conducted in participants' own language or English as preferred, audio-taped, transcribed and

translated into English and analysed using qualitative methods.

Results Four themes emerged: (1) cultural isolation, alienation and identification; (2) language and communication difficulties; (3) interpreter issues; and (4) advice for health professionals. Participants, especially those less acculturated, described feeling alone and misunderstood, failing to comprehend medical instructions, being unable to communicate questions and concerns and a lack of consistency in interpreters and interpretation.

Conclusions Migrants with cancer experience additional challenges to those of native-born patients. Participants provided cogent advice regarding optimal communication with people from their culture. There is clearly a need to develop strategies to increase the cultural competence of care to people from different countries.

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Introduction

Migration is increasing worldwide, with the number of people who do not speak the dominant language of the country in which they live similarly increasing. In Australia, the 2006 census showed that 24% of Australians were born overseas, 44% had at least one parent born overseas and over 560,000 people (3% of the total population) spoke English poorly or not at all [1].

Migrants diagnosed with cancer have poorer cancer outcomes than comparable non-migrant groups, with lower screening and survival rates [1, 2] and higher rates of reported side effects [3, 4]. Documented ethnic disparities in access to care and interactions with physicians [5, 6] may be due to unfamiliarity with health care processes, differing beliefs and attitudes about illness, death and treatment and language and communication barriers [7, 8]. Personal or historical experiences of discrimination, violence or institutionalised racism may also influence level of trust in health professionals and institutions [9]. Migrants often report that health professionals do not understand them, which may adversely affect their psychological and physical well being [10, 11].

Migrants appear to be vulnerable to higher levels of psychological disorder and distress than the general population, even when not ill [12, 13]. Thus, while cancer presents a major challenge to all people, it is likely that migrants with cancer have unique difficulties in accessing care. Despite this, no studies to date have reported on the specific needs of migrants with cancer.

This study aimed to identify health-care related unmet needs and communication issues for migrants who develop cancer and factors associated with these challenges. In this paper, we report on our findings relating to communication challenges.

Methods

A qualitative methodology was employed to examine this relatively new area of enquiry.

Community advisory boards

Three community partner advisory groups comprising oncologists, psychologists, general practitioners, community workers, religious representatives, community leaders and consumers from each language group were established to provide advice on recruitment methods, review documents

and procedures for cultural appropriateness and comment on study findings.

Participants

Inclusion criteria were: diagnosis with any type or stage of cancer within the previous 3 years or being a carer of such a patient; born in a country other than Australia; and speaking Arabic, Greek or Chinese (Cantonese or Mandarin)—three of the four largest non-English-speaking groups in Australia [1]. These language groups encompass diverse nationalities, dialects, religious affiliations and historical experiences, but participants' shared cultural identity was deemed sufficiently meaningful to warrant recruitment by language group. A narrower definition of ethnicity would have been stereotypical and may have resulted in unacceptable restriction of the sample and study generalisability.

Participants were recruited from the two most populous Australian states (New South Wales and Victoria), through ethnic community support organisations overseen by Cancer Councils, Chinese cancer support groups and three major metropolitan hospital Oncology clinics, with high catchments of the four language groups targeted. Efforts were made to achieve wide representation across gender, age and years since migration. Recruitment continued until information redundancy was achieved within each language group.

The Human Research Ethics Committees at the University of Sydney and at all participating sites approved the study. All participants gave informed consent.

Procedure

Patients were approached by community support staff or for patients attending Oncology clinics, by bilingual research staff. Consenting participants attended a focus group or face-to-face or phone semi-structured interview depending on availability and preference. Participants were invited to bring a family member or carer if they desired.

Focus groups and semi-structured interviews were conducted in the participants' preferred language by a trained bilingual researcher in community locations convenient and familiar to participants. Participants completed a measure eliciting demographic and disease variables and the Rissel Acculturation Scale, a theoretically grounded measure with proven psychometric properties used previously with Australian migrant cancer patients [14].

Focus groups and interviews followed a semi-structured format exploring experiences and needs within the following domains: information, decisional support, physical issues, emotional and psychological support, family, social and relationship support and culturally specific issues which arose during their treatment. Open-ended questions elicited responses, for example: 'What was your experience

of receiving care during your treatment for cancer?’ ‘Were there any challenges or difficulties that arose for you during that time?’ These were followed by more specific questions within each area, for example, ‘How did you find the information provided to you? Would you have liked less or more information?’ Focus groups and semi-structured interviews were audio-taped, transcribed and translated into English for analysis.

Analysis

Analysis followed what Stenner [15, p.114] has termed a ‘thematic decomposition’, a close reading which separates text into coherent themes or narratives which reflect subject positions allocated to or taken up by a person [16]. Three researchers independently read the interviews and noted major themes and sub-themes emerging from what participants said. The aim was to develop a coding frame (a set of themes and sub-themes) which summarised the content and meaning of all participant statements. That is, every statement could be reliably placed within a theme and within that theme, the set of statements together clearly exemplified the theme. The coders then met to finalise the coding frame based on consistency, commonality and the meaning of specific themes. Following this initial reading of the transcripts which revealed more similarities than differences between the language groups, it was decided to analyse all the data together, rather than separately analysing responses from Greek, Chinese and Arabic participants. Any disagreements were discussed until resolved. The whole data set was then coded, line by line, by two researchers, and entered into N-Vivo software (QSR International Pty Ltd, Victoria, Australia). Researchers then reviewed the themes, particularly those appearing with low frequency. Finally, sub-groups were examined to evaluate potential differences in each theme. Some differences were clear between language groups and according to acculturation. There were no obvious differences according to disease stage or time since arrival. In the ‘Results’ section, the content of each theme is described, with characteristic quotes presented below.

Themes identified in the focus groups related to communication, cultural understanding of cancer and its treatment, the burden of being ill and strategies for coping and gaining support. Findings related to direct communication with the cancer team are reported here; other findings will be presented separately.

Results

Ninety-one patients and carers participated in the study. Four focus groups were held with Mandarin, four with

Cantonese, two with Greek and two with Arabic speakers with six to ten participants per group. Nine individual interviews were held with Greek participants, 11 with Arabic and one with a Mandarin speaking patient. Most participants (81%) were patients, 70% were female, and their mean age was 56 years (see Table 1). While many (45%) had lived in Australia for over 20 years, 68% described their proficiency in English as not very good or poor, and 35% scored in the low acculturation range on the Rissel scale. The largest diagnostic group was breast cancer (35%).

Four themes emerged from the data: (1) cultural isolation, alienation and identification; (2) language and communication difficulties; (3) interpreter issues; and (4) advice for health professionals. Because of the relatively large sample size, the number of mentions and individuals raising each issue are reported under each theme.

Cultural isolation, alienation and identification

Participant responses fell into two sub-themes

(a) Cultural difference from the treating doctor

A sense of cultural estrangement between patient and the treating doctor was reported by all but one participant in 168 instances. It was reported as more strongly felt by Chinese participants and by those with moderate to low acculturation.

Some participants felt judged to some degree as different or alien. Others noted how much they wanted to be treated by ‘one of our own’ and would travel long distances to accomplish this, some to their home country to obtain a second opinion. They felt a kinship with and that their needs and views would be understood by people from their own culture, which was immensely comforting at a time of stress and threat. While almost all participants respected the medical expertise of Australian-born doctors, some felt that Western medicine ignored important aspects of health and illness and was not therefore able to offer them optimal care. Quotes illustrating this sub-theme are shown below.

And I think not many Chinese people see him [the doctor], so I feel he thinks I am kind of strange.

Cantonese patient

I have seen a Caucasian doctor. I have no problems with English because I work in an office. It has nothing to do with English - it is just that your mind is so confused and you can't take in things... Personally I would like to see a Chinese doctor and I have no choice and was helpless that I had to choose this doctor.

Cantonese patient

Table 1 Demographic and disease characteristics of the participants

Variables	Category	N (%)
Language	Greek	22 (24)
	Chinese—Mandarin	23 (26)
	Chinese—Cantonese	26 (29)
	Arabic	20 (21)
Patient or carer	Patient	73 (81)
	Carer	18 (19)
Gender	Female	64 (70)
	Male	27 (30)
Age (years) ^c	Below 40	6 (7)
	40–49	18 (20)
	50–59	25 (29)
	60–69	25 (29)
	Above 70	13 (15)
Time in Australia	<5 years	5 (6)
	5–10 years	20 (22)
	11–20 years	25 (27)
	>20 years	41 (45)
Self reported English proficiency	Good or very good	29 (32)
	Not very good or poor	62 (68)
Acculturation ^a	Low	29 (35)
	Medium	21 (25)
	High	33 (39)
Diagnosis ^d	Breast	32 (35)
	Colorectal	7 (8)
	Lung	6 (7)
	Other ^b	46 (50)
Stage	Local	65 (71)
	Metastatic	14 (15)
	Unknown	12 (14)

^a Only 83 participants completed the Rissel Acculturation Scale [13]

^b Other cancer types included nasopharyngeal, peritoneal, pancreatic, bladder, kidney, prostate, leukaemia, skin, ovarian, liver and stomach

^c Four participants did not disclose their age

^d Diagnosis and stage are reported both for patient participants and for carers (in the latter case for the patients for whom they cared)

This nurse was good because we were from the same place (same part of China).

Mandarin patient

Since they say there is no more treatment for me, I go back to China to get Chinese medicine. Because Chinese medicine treats the root of the illness, and Western medicine only treats the symptoms.

Cantonese patient

(b) Being treated differently because of ethnicity

This was raised in 28 instances by 18 individuals across all language groups, but particularly by those with low and medium acculturation.

Some participants suspected they received inferior care compared with native-born Australians as they felt their doctors could not relate to them, or considered them less worthy.

But the staff at the hospital behave differently towards an Australian and differently towards a migrant.

Greek patient

Sometimes this appeared to result from mismatched expectations. For example, one woman interpreted a question from her doctor regarding the nature of her work (often a strategy to establish rapport) as an assessment of her inherent worthiness which would influence the quality of her care.

...the doctor...[if] he reckons you won't do much good to the society or he thinks you are not significant... He judges your value to decide if he should save your life... The doctor sees if you can speak English, if not, you are a handicapped person.

Mandarin patient

Some participants were concerned that they had been given less information because the doctor did not take the time to overcome communication barriers or was withholding information out of misplaced paternalism. They felt very frustrated at this perceived gate-keeping of information about diagnosis and prognosis.

Those doctors are very obliged by the law, this is set by the law (to provide adequate information) but when they are dealing with Chinese patients they don't do it.

Mandarin patient

I don't know if there is racism in this country. If it is someone who doesn't speak English then they won't give you a straight answer.

Arabic patient

However many participants felt there were no differences in the care they received, compared to their Australian-born counterparts.

Language and communication difficulties

Participant responses fell into three sub-themes

(a) Understanding written and verbal communication

Difficulty communicating in and understanding written and verbal English was raised in 136 instances by 78 individuals. This was mentioned less frequently by Greek participants (who had been in Australia for longer) and those of high acculturation.

Many participants emphasised the importance of verbal and written material in their own language. When staff explained procedures by referring to English booklets, patients felt alienated from the information and switched off. They described their frustration at failing to understand much of what was said. Many described using the Internet to obtain more information in their own language.

They gave me some books where I did the chemotherapy, but I couldn't read them, they were in English.

Greek patient

The doctor brought the nurse and introduced her to me. She spoke English; they gave me a lot of information. I didn't know how to read. I didn't listen.

Mandarin patient

You know it is like the chicken talking to the duck. It's different voices.

Cantonese patient

He speaks, but what we hear is only 20%, understand 20%.

Mandarin patient

Some found it too hard or demeaning to request clarification and felt compelled to act as if they understood more than they actually did. This left them without adequate understanding of their situation. Others felt unable to ask questions or express their feelings. One patient said this was like being in a bubble, able to see, but unable to communicate with the outside world. This prevented them from expressing their needs and concerns, and therefore from receiving the reassurance and support they needed. Thus not only informational, but also emotional and support needs, were not met as can be seen in the quotes below.

I just sit there and say yes, yes, but I left his consultation and I didn't understand most things.

Arabic patient

Because we don't speak good English...sometimes we really want to ask but we don't know how to ask."

Arabic patient

You have no way to communicate you know... You can't hear, you can't speak. It's very frightening.

Mandarin patient

Some participants alerted the researchers to dangerous outcomes of poor understanding, such as missed appointments, non-adherence to medicine taking and poor self-care.

I knew a patient who also got nasopharyngeal, but he doesn't speak English... His surgeon is a Caucasian, so is his dentist...he couldn't understand what they said...so he skipped the dentist's appointment. He didn't see a dentist at all.

Cantonese patient

I knew there is medication for vomiting, but he [the doctor] didn't tell me I had to take it half an hour before I got up from bed...so for the first week that I had chemotherapy and radiotherapy I was almost dehydrated and I couldn't eat anything.

Cantonese patient

(b) Initiating communication with the health team

The impact of non-English-speaking on power and relationship building with doctors was mentioned in 44 instances by 29 individuals. Unable to advocate on their own behalf or to influence decisions, participants felt vulnerable and dependent on their treatment team, silent witnesses to their own health care.

Others noted difficulty forming a relationship or building trust without the subtleties of the spoken word. Being unable to be seen for who they were and reveal any depth to their own character, nor see depth in others, they remained mutually two-dimensional.

Sometimes we want to express things but we can't. So it's very difficult to relate to them...Psychologically it seems quite hard to relate to them.

Mandarin patient

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 [the doctor] 'HOLD' the 'POWER'. I could only listen to him... whatever

he said about me.
Mandarin Patient

(c) Difficulty navigating the health care system

Difficulties navigating the health system due to poor English and communication problems were mentioned in 28 instances by 23 individuals. Some people noted difficulties in making appointments, following instructions, knowing who to contact if a crisis arose or even following clinic procedures. While they often brought English-speaking relatives with them for assistance, this left them feeling helpless, powerless and sometimes infantilised. Sometimes, by luck, a staff person at the hospital or doctor's rooms spoke their language, and this seemed to make things easier although sometimes created other problems.

Some of the receptionists speak English – then I have no communication with them...Then I found Dr Lee speaks Chinese and his receptionist also speaks Chinese, then we could communicate. Then it was more smooth.
Cantonese patient

If you say you can call the Cancer Association, you must still be able to speak English to be connected to the person you want. Otherwise you don't get through.
Cantonese patient

I had a high fever...during chemotherapy... but I didn't know how to tell the Emergency people... Don't know how to say it (in English)...it is very difficult if you don't know how to say it.
Cantonese patient

Interpreter issues

Participant responses fell into three sub-themes

(a) Family versus professional interpreters

Eighty-six references were made to family versus professional interpreters by 28 individuals. Many participants reported taking a relative with them to oncology consultations, often a son or a daughter with university education, to help translate, provide emotional support and ensure that they received optimal treatment. The majority preferred family to a professional interpreter; many could not see the point of a professional interpreter when family was available.

[The family is] best, because the interpreter may not always know the whole story, and he may forget or

maybe the word he uses is expressing something else. No, no my son is the preferred interpreter.
Arabic patient

Because we can trust a family member.
Greek patient

Family member, they can tell the doctor what my situation is, if there is anything uncomfortable, ...they can ask him directly... The family are more caring, will ask more [act on her behalf].
Cantonese patient

Others, particularly Greek participants, preferred a professional interpreter as that person might understand the medical scenario better, more objectively convey the truth and take away the burden of translating from their family.

Professional interpreter should be better than your family, at least they should have studied those books.
Cantonese patient

The daughter might not translate something that the doctor said if it's very upsetting. I wouldn't like that because I want to know the truth. The interpreter won't hide the truth, they will tell you no matter what the truth is.
Greek patient

If I have some kind of pain and I haven't told the children, I want to protect them from getting upset, ... that's why it's better if the children stay out of it...us that have the problem we have to have the strength to face it, but the children...
Greek patient

Participant responses fell into three sub-themes

(b) Interpreter roles and intentions

The role of the interpreter was mentioned in 72 instances by 45 individuals, but less frequently by Mandarin participants and the high acculturation group. Many participants conceptualised the interpreter's role as primarily to accurately translate the spoken word from one language to another. Many participants expressed strong appreciation of the interpreter's skill in accurately translating patients' and doctors' speech and explaining complex medical terms.

[Their role is] to tell us exactly what the doctor was saying, the truth.
Greek patient

The interpreter was quite good, he explained every word, I paid good attention to what he explained, I knew he didn't deceive me.
Cantonese patient

Some noted the limits of the interpreter's role, recognising that this was a professional relationship with the goal of ensuring effective communication. They recognised that the patient was still responsible for communicating their needs even with an interpreter present.

The interpreters, they interpret whatever you want to ask...It's like that, if you didn't ask, they won't interpret it.

Cantonese patient

However, some participants expected more than translation from their interpreter, seeking emotional support, advice and advocacy. These patients felt the interpreter could understand them better than could their cancer health professionals because of their shared culture. Similarly, they felt they could communicate with interpreters more easily than with their health team.

Normally if you go to the hospital they will have an interpreter. You can talk to them about everything.

Cantonese carer

Yes of course, we feel like he [interpreter] is a psychologist.

Greek patient

Because I would feel that the interpreter would be like my family or close friends. Because you see the interpreter understands you... and will be able to get your message across better.

Arabic patient

(c) Problems with interpreters

Problems with interpreters, mentioned in 47 instances by 30 individuals, included: having a different interpreter at each hospital presentation (which patients found distressing as they could not build up trust and familiarity with the person); poor interpretation; being provided with interpreters who spoke the wrong language and interpreters often having to leave for another appointment. Such problems limited the benefits accrued from having an interpreter present.

I know there are several types of interpreters. One is, I talk to him for a few sentences and he interprets those few sentences. But we don't know whether the interpretation is correct... But some interpreters, they jot down notes while you are talking. Those are good interpreters. ... those immediate interpreters might get it wrong. It's bad interpretation.

Cantonese patient

Even if you find an interpreter, it's not necessarily good. I once saw once a person who speaks

Cantonese. They found him a Vietnamese interpreter. They didn't realise we have Cantonese and Mandarin amongst Chinese.

Cantonese patient

So I said 'today I need to see the doctor, I need Mr. Lee', but they told me 'Mr. Lee is not here today'... They said 'I will get you an interpreter on the phone'. But the interpreter wasn't as good as Mr Lee.

Cantonese patient

But the doctor spent longer in the last session, so there was only 15 min left and he [interpreter] had to go to another appointment, and the hospital doesn't have enough resources so he couldn't do his best, you can't blame him for that.

Cantonese patient

Advice for health professionals

Critical and appreciative comments about the Australian health system were made in 163 instances by 81 individuals, with the majority of comments being positive. Arabic participants were particularly supportive, while more Chinese tended to be critical.

Positive comments were made about the caring staff, excellent treatment, low costs involved and the overall quality of the health system. Critical comments related to poor information provision, use of medical jargon, lack of involvement in decision-making, waiting lists and poor medical care. Some participants conveyed a strong wish to improve the system, describing with considerable feeling instances where they perceived care to have been suboptimal.

Some participants noted the need for linguistic and cultural assistance, with suggestions for a 'cultural advocate' to accompany the patient, ensure their needs are met and remind them when appointments are due; medical reports being translated into their own language and training in cross-cultural issues for the health team.

Several participants recommended that doctors explore illness and health outside the dominant biomedical paradigm of Western medicine to provide better advice and information about varied therapies, including those considered as traditional and appropriate within their cultural group. Others discussed the importance of supportive and culturally appropriate spiritual care extending beyond the completion of treatment.

Many noted the importance of a softer, more hope-giving and caring communication style. They felt that bad news was often given abruptly, and that in conveying a poor prognosis, the doctor was giving up too early. They felt that doctors have a special responsibility, because of

their central role in patient care, to support the patient in maintaining hope and coping well.

Discussion

This study provides important new data on issues faced by migrants who develop cancer and their carers, often excluded from research because of their inability to speak the dominant language. Participants experienced feelings of cultural isolation, independent of their ability to speak English. Their inability to engage in social conversation created difficulties establishing rapport and trust with the doctor. Difficulty in understanding verbal and written exchanges was almost universally raised as an issue by study participants.

Participants suggested a range of solutions to these problems, such as providing more written material, both general and specific, in diverse languages. While potentially costly, patients ideally wanted a report outlining their diagnosis, prognosis and treatment options in their own language using lay terms. Participants also suggested establishing ‘cultural advocates’ to represent patients, assist them to navigate the system and provide cross-cultural training to health care staff. Such advocates may have a role akin to that of the patient navigator, which has been evaluated successfully in several US studies [17]. Community-based migrant services including culturally appropriate chaplaincy and spiritual services, already play an important role in the health care system, but are often under-funded and poorly linked to hospital and out-patient services. Such services could better assist patients to navigate the system with the introduction of more formal linkage processes, commencing from the point of diagnosis.

The perception by some that access to care and information was compromised by their ethnicity or lack of English clearly requires attention. Studies in other countries (e.g., UK) have reported that some migrants feel that society and the health care system are prejudiced against them, suggesting this is a universal problem [17]. There is evidence that some doctors believe that patients with particular characteristics (e.g., educated, middle-aged or white) are more capable of understanding or are in greater need of information than other patients [18] and that ethnic minorities receive less information in medical consultations [19]. Perhaps cross-cultural training for staff would prevent such unintentional disparities in care.

Verbal and non-verbal interactions were difficult for participants to manage, with common experiences including understanding only part of the discussion and experiencing information giving as somewhat brutal and unsupportive. This supports the findings of previous studies documenting the communication challenges experienced by

migrants with cancer [20]. Worryingly, potentially dangerous outcomes of misunderstanding including missed appointments, unnecessary distress and poor treatment decisions were reported. Careful use of communication strategies is essential to prevent such mishaps, including simple strategies such as active listening, checking understanding and checking preferences for information and involvement in decision-making [21], using allegories and lay language to communicate confronting or difficult concepts [22] and exploring explanatory models, beliefs and attitudes about cancer and its treatment (including traditional and alternative treatments) [23].

Interpreters were felt to be of enormous assistance in bridging the communication gap, but were not always sufficient or trouble-free. Problems with inaccurate translation and a mismatch of expectations about the interpreter role were reported. Medical interpreting standards of practise developed by the International Medical Interpreters Association in 2007 state that ‘an interpreter’s primary task is interpretation, that is, the transformation of a message expressed in a source language into its equivalent in a target language, so that the interpreted message has the potential of eliciting the same response in the listener as the original message [24].’ However, similar reports as our current findings of both patients and interpreters experiencing confusion regarding the interpreter role have been reported in the broader medical literature outside of the cancer context [25]. Thus there appears to be a need for further development of clear policy guidelines for interpreters defining the parameters and boundaries of their role, which can be effectively communicated to patients and their families.

Participants reported strong feelings of connection to the interpreter which were thwarted by a system that provides no continuity with interpreter–patient matching. In the absence of such continuity, many patients preferred to use their own family members as interpreters where possible. However, a recent systematic review concluded that optimal communication, patient satisfaction and outcomes and the fewest interpreter errors occur when migrant patients with little English have access to trained professional interpreters or bilingual providers [26]. Thus use of family members to compensate for system inadequacies is not recommended.

Further research is needed to clarify interpreters’ own perceptions of their role, the difficulties and challenges they face and potential improvements which could be made to the system. Health care professionals may also need specific training to effectively engage interpreters [27].

Limitations of the study and future directions

We chose to purposively sample patients with a range of diagnoses and stages of disease and their carers to ensure

all views were captured. However, it is possible that participants in focus groups may have been inhibited by the presence of heterogenous members and may have expressed different views if interviewed alone. However, we did not notice marked differences in themes emerging from the focus groups and semi-structured interviews. While some results may be specific to the Australian context, it is likely that the issues raised by study participants apply to migrant groups in other countries. Future research could usefully compare experiences across health systems and explore the prevalence of views in quantitative studies.

Conclusions

With growing migration rates worldwide, it is important that the voices of migrants are heard, to ensure that their informational needs are met and to assist health care systems to provide culturally appropriate care.

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