Traditional Expectations Versus US Realities: First- and Second-Generation Asian Indian Perspectives on End-of-Life Care

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BACKGROUND: Although end-of-life care preferences vary across racial/ethnic groups, little is known about how cultural values affect end-of-life care preferences among South Asian immigrants and their offspring in the US.

OBJECTIVE: To examine the perspectives of first- and second-generation South Asians living in the US regarding end-of-life care.

DESIGN: Focus group study. Discussions explored participant preferences and experiences with family members facing the end of life.

PARTICIPANTS: Twelve first-generation and 11 second-generation self-identified Asian Indians living in the mid-Atlantic region.

APPROACH: Content analysis of focus group transcripts.

RESULTS: First-generation participants ranged in age from 41 to 76 years and were evenly split by gender. Second-generation participants ranged in age from 23 to 36 years and included seven women and four men. All participants were highly educated, and two thirds were either studying or working in a health care field. All but two subjects were Hindu. Several themes emerged that highlighted cultural differences and challenges for this population in the context of end-of-life care: attitudes toward death and suffering; family duty; and preferences for information disclosure and decision making. Participants described cultural challenges due to the evolution of traditional roles, lack of explicit discussion between patients and family members about preferences and care expectations, and a tension between wanting to meet traditional expectations and the challenges in doing so given US social realities.

CONCLUSIONS: Traditional cultural values, such as duty to family, greatly influenced end-of-life care preferences and retained importance across generations. Clinicians caring for Asian Indian patients at the end of life may be better able to assess care preferences after exploring the complex interplay between traditional expectations and specific social realities for each patient. Particular attention should

be given to attitudes toward death and suffering, family duty, and preferences for information disclosure and decision making.

KEY WORDS: cultural differences; end-of-life care; advance directives; immigrant health; qualitative research.

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BACKGROUND

The Institute of Medicine describes high-quality medical care as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensur[es] that patient values guide all clinical decisions”.¹ These features of quality care are particularly relevant to palliative care where knowledge of the cultural values (e.g., collectivism, individualism, paternalism) underlying patient preferences helps illuminate individual decision-making preferences.² However, ethnic minorities, particularly Asians, are less likely than whites to report satisfaction with their care^{3–5} and more likely to report that their providers don’t understand their background or values.³ Responding to this challenge is difficult because certain Asian subgroups hold particular values and preferences that differ significantly from those held by whites and blacks.^{6–9}

South Asians are one of the fastest growing immigrant communities in the US with a population of 3.5 million, of which Asian Indians make up 2 million.¹⁰ Despite the growing numbers of South Asians in the US, the medical literature on end-of-life preferences in this population consists of two studies on advance directives.^{11,12} Although these studies identified a preference for family-centered decision making and low rates of advance directive completion, research exploring the cultural values behind such practices has not been conducted among this population. Furthermore, little is known about the perspectives of younger, second-generation South Asians who will likely act as primary caregivers and surrogate decision makers for their aging parents. Therefore, in this study, we explore the end-of-life care perspectives of a sample of older, first-

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generation South Asians and younger, second-generation South Asians living in the US.

METHODS

Study Design

We conducted four focus groups between March and May of 2010 with 23 participants recruited from the South Asian community in the mid-Atlantic region. We elected to use focus groups since our study objective was to explore participants' cultural perspectives and group discussion would facilitate exchange of personal perspectives in the context of a social environment. We posted flyers at the Johns Hopkins University graduate and medical campuses and sent an electronic version to South Asian religious, cultural, and professional organizations. Those expressing interest in the study were asked to refer others who might be interested in participating (snowball sampling). We used these strategies to identify participants until we had a sufficient number (6–8) for each focus group. About half of the final study sample was recruited through flyers and the other half through snowball sampling. All participants provided written informed consent and were compensated \$50 for participation in the study. This study received approval from a Johns Hopkins Medicine Institutional Review Board.

Participants

Participants were eligible if they self-identified with the term "South Asian" or with one of the countries represented by this term (India, Pakistan, Bangladesh, Nepal, Sri Lanka, or Bhutan), were above the age of 18, spoke English fluently, and had lived in the US for at least 5 years. Additional eligibility criteria included either self-identification with Hinduism, Sikhism, or Buddhism, or no religious affiliation. Those who identified themselves as Muslim or Christian were excluded given fundamental differences in religious beliefs about death and dying between Hinduism, Islam, and Christianity, and our limited resources to hold additional groups. These criteria were based on communications with community members who suggested that, given the sensitive nature of discussion about death and dying, participants may feel more comfortable openly discussing their beliefs with those of similar religious backgrounds. Accordingly, subjects identifying with Buddhism and Sikhism were included in the study given the historical ties between Hinduism, Buddhism, and Sikhism and common beliefs about death and dying.¹³

Participants were grouped into two categories: those born and/or raised in the US (referred to as "second-generation" participants in this paper) and those who immigrated to the US after the age of 18 ("first-generation" participants). Those who immigrated between the ages of 12 and 18 were excluded as their primary cultural influences would be more difficult to ascertain.

Data Collection

A focus group guide was developed after extensive literature review and discussion among the investigators. The objective of the guide

was to facilitate discussion of values and beliefs about end-of-life care in the context of participant experiences with family members at the end of life. All groups were conducted in English, audio-taped, and lasted 60–90 min. The groups were moderated by RS, a second-generation Asian Indian physician. After the session, participants completed a brief questionnaire that assessed socio-demographic information and included a modified version of the Marin Short Acculturation Scale.¹⁴

Data Analysis

Audio-recordings of the focus group sessions were transcribed verbatim. Participant identifiers were removed from the transcripts to maintain confidentiality. Two investigators (RS and NK) independently reviewed the transcripts, coded all passages of speech using an editing style analysis, and generated their own list of codes.¹⁵ The two coders then met in person to discuss each coded passage, the code lists, and to group the individual codes into conceptual themes. All discrepancies were discussed and resolved by consensus. ATLAS.ti 6.0 (Scientific Software Development GmbH, Berlin) was used for data management and to facilitate analysis. Questionnaire data were analyzed using Stata version 10.0 (College Station, TX).

RESULTS

Sample

Study sample characteristics are displayed in Table 1. First-generation participants had a mean age of 51.7 ± 9.8 (group 2) and 63 ± 10.8 years (group 4), and included six men and six women. About half of the participants had been living in the US for 11–20 years, half greater than 20 years, and one person less than 10 years. Second-generation participants had a mean age of 28 ± 5.5 (group 1) and 27.4 ± 4.2 years (group 3), and included seven women and four men.

All participants had at least a college education, and one third were employed in professions outside of health care, primarily as engineers or IT professionals. Four participants were physicians (internist, psychiatrist, nephrologist, and pediatrician), two were social workers, and ten were graduate or medical students. All participants indicated Asian Indian ethnicity. The characteristics of our sample reflect the demographic makeup of the Asian Indian population in the US: 69% have a Bachelor's degree or higher (compared to 27% of the general US population), 77% are fluent in English, and 60% are employed in management, health care, and other professional occupations.¹⁰ Using a modified Marin Short Acculturation Scale, the mean scores for groups 1, 3, and 4 were in the 40s (scale range 12–60 with higher numbers reflecting higher level of acculturation). Group 2 participants had lower scores (32.7 ± 5.6), indicating lower levels of acculturation.

Thematic Domains

In this article, we report the themes that were discussed in all four focus groups related to the role of cultural values

Table 1. Study Sample Characteristics

	Group 1	Group 2	Group 3	Group 4
	(n=6)	(n=6)	(n=5)	(n=6)
Age: mean years (SD)	28 (5.5)	51.7 (9.8)	27.4 (4.2)	63 (10.8)
Time in US				
Since birth	4	0	3	0
5–10 years	0	1	0	0
11–20 years	0	3	2	2
>20 years	2	2	0	4
Gender				
Female	3	0	4	6
Male	3	6	1	0
Marital status				
Married	1	5	2	4
Divorced/widowed	0	1	0	1
Education				
College	0	1	0	0
Graduate school*	6	5	5	6
Occupation				
IT/engineer	0	4	0	1
Business/consultant	0	2	0	0
Physician	0	0	1	3
Graduate/medical student	6	0	4	0
Social worker	0	0	0	2
Religion				
None	1	0	0	0
Hindu	5	5	5	6
Sikh	0	1	0	0
Jain	1†	0	1†	0
Languages spoken‡				
Hindi	2	6	2	4
Punjabi	1	3	0	1
Tamil	1	0	1	0
Telugu	2	0	0	1
Other	0	0	2	3
Marin score§	48.5 (4.5)	32.7 (5.6)	44.0 (4.7)	43.2 (5.7)

*Includes those currently enrolled in graduate school

†Participants could list multiple religious affiliations

‡Participants could list multiple languages spoken. Other included: Gujarati, Kannada, Marathi, and Oriya

§Marin Short Acculturation Scale: adapted for use in South Asians; score ranges from 12, which indicates low acculturation, to 60, which indicates high acculturation

in the context of end-of-life care: attitudes toward death and suffering; family duty; and preferences for information disclosure and decision making. Below we present each of these themes, illustrating them with representative participant quotes.

Attitudes Toward Death and Suffering. Both first- and second-generation participants felt that Indian culture was more accepting of death than American culture. Participants pointed to Hindu concepts of reincarnation, *karma*, fatalism, and *ashramas* (the four stages of life) as the basis for this attitude. In thinking about the end of life, both first- and second-generation participants expressed fears of isolation, the unknown, being a burden on others, and experiencing pain and suffering. Although both first- and second-generation participants mentioned the Hindu belief that suffering results from one's *karma*, most stated that this belief should not impede the treatment of pain and suffering at the end of life. However, the following exchange between two first-generation participants highlights the challenges of reconciling traditional beliefs

around suffering and use of medical treatments in the twenty-first century.

Participant 23 (female, age 66): According to Hindu philosophy, suffering is the result of your past...

Participant 20 (female, age 71): Karma.

Participant 23: Yes, your karma. So some people say, let that person suffer.

Participant 20: But then you are God, right?

Participant 23: But there is something available to reduce that pain so, are you doing the right thing or wrong thing?

Participant 20: Are you in a position to make that decision? Am I in a position to make that decision? Then the whole of medicine is bunkum, right?

Participant 20: My thinking is this...I'm a devout Hindu...But I feel that...there are so many advances made in...biological medicine. Our thinking, our approach to certain things has to keep up with it.

Family Duty: Dynamics, Specific Roles, and Expectations.

Family Dynamics and Sources of Conflict. Both first- and second-generation participants emphasized how close parent-child relationships and a strong sense of duty to family drove much of the dynamics within Asian Indian families. In turn, complex family dynamics led to interpersonal conflict and emotional stress for those involved in end-of-life decision making. Other complicating factors included the large size of Asian Indian families, great geographical distances between relatives, differing views on allopathic versus alternative medicines, and traditional beliefs related to gender roles and primogeniture (the role of the eldest son). Determining where the patient should receive medical care (e.g., US vs India or home vs hospital) was also a common source of conflict between family members.

Gender Roles and the Role of the Eldest Son. First- and second-generation participants explained that traditionally sons, particularly the eldest son, were responsible for taking care of their aging parents. First-generation male participants emphasized the strong sense of filial duty among sons and five of six expressed guilt at not being able to fulfill this duty in instances where their parents were living overseas. In the following quote, one participant explains the traditional belief behind these gender roles:

"The belief system and the culture is that you marry a family. You give away your daughter. So when you give away your daughter, she's no more your own. She now belongs to that family. Your son stays with you, is a part of your family. So when the situation like a terminal illness comes, you expect your own to take care of yourself. So that means, sons should take care of you, not someone who is now a member of another family. And daughters are considered as members of another family after marriage in...India,...which is of course not true here." First-generation male, age 50

At the same time, several participants commented on how tension between traditional and modern views regarding family roles caused family conflict. Both first- and second-generation participants described situations in which traditional roles still drive end-of-life decision making and caregiving. Yet, they also discussed ways in which gender roles are changing due to urbanization, education, and globalization. In the following quote a participant describes how roles have evolved over time but still vary across families:

"It really doesn't make a difference in our family because my brother and I will make joint decisions and that's just the value that we have in our family. It's really not about gender. It certainly was an issue with my grandparents in terms of...at the death of a family member, the oldest son, you know, cremates or lights the fire and so forth and all these traditions where the males have played a role and continue to play that role traditionally." Second-generation female, age 36

Intergenerational Expectations of Care. First- and second-generation participants expressed feeling stuck between two cultures and discussed the challenges of meeting traditional care expectations while in the US. However, while first-generation participants spoke of a strong sense of duty to take care of their parents, five explicitly stated that they did not expect their children to maintain the same sense of filial duty. Some attributed these "lowered expectations" to the influence of the more individualistic American culture on their children. Others spoke of a desire to spare their children from making sacrifices to uphold filial duty although this desire did not always translate into a total lack of care expectations as the following quote illustrates:

"But then we have also expectations when we grow old and if we are in that situation. 'Who's going to look after us?' It's very selfish for us to expect that our children will come or move closer to us just to take care of us. At the same time, we expect that they should be there when we need them. So it's more like an issue of moving from India to the US. Like those questions will never come to my mind if I was in India. Or maybe they may come because now in India, everybody moves out of the home where they are born." First-generation male, age 51

However, all 11 second-generation participants expressed a strong sense of duty to care for their parents and cited multiple reasons for this, including having observed the way their parents practiced filial duty, feeling a sense of reciprocity given their parents' sacrifices in raising them, the Hindu concepts of *dharma* and *karma*, and having a close parent-child relationship as the following quote illustrates:

"I think you also feel it's your duty to some extent, right? Like [your parents have] taken care of you until you're 50 or 70 or whatever and then it's

your job to take care of them, to pay back. Yeah, I think that's just built into you from the beginning and you see your parents take care of their parents the same way." Second-generation female, age 24

Participants thought that their parents expected them to care for them as they got older, and even the two participants who said that their parents had told them otherwise reiterated that they felt a duty to care for them as they aged.

Preferences for Information Disclosure and Decision Making.

Information Disclosure. In describing experiences in the US and in India, first- and second-generation participants reported both situations where information about a terminal diagnosis was disclosed to and withheld from the patient. Participants expressed mixed opinions on whether or not they agreed with those decisions and discussed the challenges of reconciling the traditional Indian practice of non-disclosure with the Western emphasis on information disclosure to facilitate autonomous decision making. However, among the first-generation participants who expressed their own personal preferences, all preferred full disclosure. One first-generation participant described the way in which social realities in the US, such as isolation and lack of social support, altered his preferences for information disclosure:

"And I feel that my views have completely changed. It's very geographic based. In India...I firmly believed that doctors should not tell the patient. The reasons were very simple. You could assume the support system...People are going to be there with you to help you. So why tell the patient and whatever limited time that person has, and make that time very difficult for him, that he's going to die...Here, my decision has completely changed. If I am here, you better tell me because...I've got to take care of, make arrangements for myself...I cannot depend on many people around me." First-generation male, age 50

Decision Making. Several first-generation participants expressed a desire to explicitly communicate their end-of-life care preferences with their family members and three volunteered that they had completed an advance directive. However, several pointed out that Asian Indians were generally less likely than other Americans to have filled out an estate will or advance directive and that this desire for advance care planning represents a departure from traditional practices. All nine participants who expressed personal preferences regarding decision control felt that end-of-life decisions should be made by the patient. However, several participants based this preference on a desire to spare family members the emotional burden of having to make difficult end-of-life decisions rather than on a desire to promote patient self-determination. This view is reflected in the following quote:

"And sometimes when the near and dear ones have to make a decision, it's a heart-wrenching

decision. They cannot make the decision because how can you say 'just go ahead and kill my mother' or 'go ahead and end life support.' Therefore, I feel that that decision should be made by the person whose life basically it is. So while we are in our full senses, while we have a full capacity to think and rationalize...we should make these decisions so that it doesn't become hard for the people who are around us later to... deal with these issues and...then nobody gets blamed." First-generation male, age 47

At the same time, both groups shared stories of relatives who considered independent decision making burdensome for the patient and preferred family-centered decision making. Participants supported this preference in these cases, even if they personally preferred independent decision making, out of concern that enforcing unwanted autonomy would cause harm. In the following quote, a second-generation participant explains the rationale for family-centered decision making in the case of her grandmother who had been diagnosed with Parkinson's disease and was living with the participant and participant's parents in the US:

"So it was diagnosed...[and] treated early, but [my parents] didn't tell her...I still don't judge that decision because it's one of the most paternalistic beliefs I have,...I think autonomy is what you want it to be. And for some, like a woman who never had any sense of autonomy, not that we should exploit that, but I don't think that was really a concept she valued. I mean, in the same way that my parents feel a commitment to...taking care of her, I think that it was okay to do things to make it easier on them...They were worried that she would give up, and then it would just become even harder to keep her at home. And I think,... she didn't want to take on that burden of knowing everything, and making decisions, especially hard decisions." Second-generation female, age 29

The same participant goes on to say that when communication about end-of-life preferences does occur, it may need to account for cultural values such as filial duty and reciprocity. In the following quote, she describes how her family dealt with the possibility that her grandmother would not reveal her true preferences to her children out of a sense of duty to them in light of their years of caregiving.

"I mean we did, at the very end, we did ask her 'What do you want?'...actually it was very important, we had a very long family discussion about it, that my parents not ask her, because she might respond to them differently out of an obligation to them to live...because of the dynamic, because my parents had taken care of her for so long that she wouldn't feel right letting them down. So we had someone who'd married into the family that she was still close to...and he was a medical doctor, so then there was that kind of a professional barrier and distance there too. And he asked her, 'Okay, now you're in this position...do

you still want us to treat you, or do you want to just get medication for pain?"

Both first- and second-generation participants expressed a desire to discuss end-of-life care preferences with their family members. However, only two participants volunteered that they had actually done so. Participants cited several barriers to having such conversations, including an unclear prognosis, physical distance between family members, unresolved conflict between family members, and discomfort with discussing end-of-life care.

DISCUSSION

To our knowledge, this is the first study to explore the perspectives of first- and second-generation Asian Indians settled in the US regarding end-of-life care. Several themes emerged that highlight the cultural differences and challenges for this population: attitudes toward death and suffering; family duty; and preferences for information disclosure and decision making. We found that many traditional cultural values, such as a strong sense of duty to care for family, retained importance across generations and greatly influenced end-of-life preferences and care expectations among our study participants. However, few had explicitly discussed these preferences and care expectations with family members. We also found that US social realities, such as isolation and lack of social support, further complicated end-of-life care planning for our first- and second-generation participants who struggled to meet traditional expectations. Furthermore, our findings suggest that a departure from traditional cultural preferences among first-generation Asian Indians (for example, on the topic of information disclosure) may not reflect a rejection of traditional values, as much as an adaptation to social realities in their new home country.

The participants in our study described a strong sense of family duty, which echoes findings from studies of other Asian subgroups in the US, UK, and Canada.¹⁶⁻¹⁸ As in those studies, our second-generation participants retained the value of filial duty and emphasized close parent-child relationships. The retention of such core cultural values even among study participants with higher acculturation scores suggests that clinicians should not assume that Asian Indian patients who appear more acculturated have adopted Western values in the context of end-of-life care. Surprisingly, acculturation scores of group 4 (first-generation women) were higher than for group 2 (first-generation men) and resembled the scores of the second-generation groups. The higher total scores resulted from higher item scores in the domain of social interaction with non-South Asians. Possible explanations for this finding are that the group 4 participants lived in neighborhoods with fewer South Asians or developed closer relationships with non-South Asians in their working environment than group 2 participants.

A particularly interesting finding from our study was the way in which the related concepts of family duty and reciprocity influenced patient communication about end-of-life preferences. As one participant described, the ability of the patient to honestly communicate her end-of-life preferences to her family was impaired by her sense of duty and reciprocity for the decades of care provided by her children. The family's concern

that she might respond to her children differently out of an obligation to them to continue living prompted the involvement of a third party to assess the patient's end-of-life preferences. This case illustrates how conventional Western approaches to end-of-life communication may need to be modified for certain patient populations. In such cases, clinicians might consider asking the patient whom they feel comfortable discussing their care preferences with and facilitate discussion accordingly.

While studies suggest advance directive completion rates of 15–25% among the general US population,¹⁹ studies of Asian Indians¹² and Indo-Caribbean Hindus in the US¹¹ found completion rates of 9% and 6% among the respective study samples. However, while Doorenbos et al.¹² found that preference for family-centered decision making was negatively associated with advance directive completion, our findings suggest that advance care planning may be particularly important for those who value family-centered approaches to care. Not only did the majority of our first-generation participants speak positively about the use of advance directives, but many also specifically advocated for advance directives as a way to reduce the decision-making burden on family members. Our findings are consistent with a study of Japanese Americans that found participants endorsed family-centered decision making and viewed advance directives as a tool to reduce conflict between the patient's wishes and duty to prolong the life of a family member.²⁰ Therefore, framing the utility of advance care planning in the context of family-centered approaches to care may be one way to address the low rates of advance directive completion among South Asians. Furthermore, modification of advance directives to include communication and decision-making preferences related to the role of the family may be particularly relevant to this population and merits further investigation.

There are several limitations of this study. First, our participants had a high education level, and many worked in health care fields, which may have influenced their personal preferences and understanding of end-of-life care. However, the characteristics of our sample reflect the demographic makeup of the Asian Indian population in the US.¹⁰ Furthermore, we would expect the cultural tensions our study participants discussed to be even more pronounced among those with lower socioeconomic status, lower levels of education, less English fluency, and less familiarity with the US health care system. Second, the first-generation groups were homogenous with regard to gender and a few of the participants in the groups knew each other. Although the gender homogeneity occurred as a result of scheduling requirements, it may have affected the content of the discussions. However, given the sensitive nature of the topic and the fact that there were dissenting opinions voiced in each focus group session, any familiarity that participants had with each other seemed to only facilitate an open and highly personal discussion. Third, all of the participants were of Asian Indian ethnicity, and there may be differences among non-Indian South Asians. Our findings also do not reflect the perspectives of Muslim and Christian Asian Indians, and our results may not apply to these groups. Finally, while our findings reflect the perspectives of the participants in the study and may apply to other Asian Indians in the US, these results are not intended to describe the perspectives of all Asian Indians in the US.

In conclusion, our study provides insight into the challenges that some Asian Indians in the US face when dealing with end-of-life care because of a complex interplay among traditional expectations, cultural values, exposure to US care practices, varying levels of acculturation, and social realities. While providers should not, of course, apply cultural stereotypes to individual patients, awareness of certain cultural values and perspectives may be helpful. For example, factors that influence patient preferences and communication styles, such as specific conceptions of family duty and gender roles or attitudes toward death and suffering, can help facilitate culturally appropriate clinician-patient communication. When eliciting Asian Indian patient preferences for end-of-life care, clinicians should consider explicitly asking about preferences related to family involvement in care, decision control, and communication; and explore the role of traditional expectations and specific social realities for each patient. By assessing each of these topics and respecting the patient's choice for individual or family-centered decision making, clinicians caring for Asian Indian patients can maintain respect for patient autonomy while also respecting the patient's cultural values. Clinicians should also be aware that highly educated, English-speaking, more acculturated-appearing Asian Indian patients and family members may still retain traditional conceptions of family duty, which can influence decision making and caregiving preferences. While this study highlights the way in which certain cultural values drive end-of-life care preferences for a select group of South Asians in the US, additional research is needed to evaluate how clinicians can best use this information to help support the families of South Asian patients facing the end of life.

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