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## Letter

### **Supporting Indian and Other South Asians Facing COVID-19 and Other Serious Illnesses**



To the Editor:

India is being ravaged by COVID-19 and even Indians among the diaspora are experiencing its consequences. A close family friend passed away after 42 days on a ventilator. A relative—along with his mother and his sister—died of COVID-19 days before his daughter's wedding. The Indian community is struggling to help friends and families in India navigate shortages of oxygen and medications while providing emotional support and medical advice. Indian healthcare systems are overwhelmed, and patients are denied the presence of loved ones, bedside prayers, rituals, or a dignified death at home.

For the 5.4 million people who identify as South Asian in the United States (US) including many colleagues, these cultural needs have been overlooked. Nearly 2 billion people in the world—a quarter of the world's population—have their roots in one of seven South Asian countries: India, Pakistan, Bangladesh, Bhutan, Nepal, Maldives, and Sri Lanka. These countries have tremendous cultural diversity. In the United States, the majority of South Asians are from India, a country of incredible diversity within its borders. Indians may speak one or more of 419 languages while following all major world religions. Hinduism, the third largest religion in the world and the most common religion among Indians, embraces and has generated countless sects and regional belief systems that add to the diversity of the cultural experience. By contrast, Islam, the second largest religion, transcends geographical boundaries to form a cohesive set of principles for its devotees.

Underlying this rich and diverse tapestry are shared values and practices that can inform COVID-19 and other serious illness care during the pandemic and beyond. Foremost are the typical family structure and caregiving roles. Nuanced data of the South Asian

experience is difficult to find and much of the available data center around the Indian experience. Families with three generations are the norm, since 72% of Indians over the age of 60 live with their sons.<sup>1</sup> Unlike Western nuclear families, these patients may be well supported by cohabitating family despite shelter-in-place.

Caregivers' roles vary based on gender and relationship and communicating with the correct caregiver demonstrates cultural sensitivity and fosters trust. Over 80% of Indian versus 60% of US caregivers are women. Women carry out 85% of meal preparation and household tasks.<sup>1,2</sup> Over 40% of Indian caregivers are daughters-in-law versus less than 10% of US caregivers. Daughters-in-law provide most instrumental and emotional support and coordinate medical care, while finances are handled mainly by men. Women may seek health information, while men may seek financial information about illnesses.

Care teams must acknowledge that caregiver experiences are culturally embedded. For instance, Hinduism and Sikhism champion “seva” (selfless service) towards the vulnerable as service to God. Caring for those in need is to be seen as a privilege, which may protect against negative consequences of caregiving.<sup>3</sup> Conversely, struggling caregivers may feel guilt and shame for not having positive caregiving experiences. South Asians may be helped when providers address both positive and negative caregiving experiences and normalize their coexistence.

Beliefs about physical modesty become relevant when providing clinical care for conditions that affect sexual or reproductive organs. For instance, breast exams may feel invasive, shameful and even threatening for women especially with male providers. Offering the presence of a woman care team member for women patients during sensitive examinations may be an acceptable alternative. In general, there may be cultural and religious reasons why gender-matched providers would be preferred by either men or women, and should be offered whenever possible.

Care teams should also appreciate that major health decisions may be undertaken communally by the

*Table 1*  
**Example Items to Assess Cultural Domains**

Domain	Example Items to Start the Conversation
Language	a. What language(s) do you speak? b. Can I obtain a medical interpreter for you (and/or your companion)?
Religion	a. What religious faith or faiths does your family follow? b. How often do you visit your house of worship? c. How often do you pray or perform religious services at home?
Living Arrangements	a. Who do you live with? b. How are you related to them?
Caregiving	a. Who usually takes care of household tasks? b. Who usually helps you with medical issues? c. Who manages money? d. How many adults and children do you care for? e. How many persons take care of you?
Prognosis and Diagnosis	a. Some people want detailed information about their own health, while others would prefer not to be provided with such information. How about you? b. Who besides you who should receive detailed information? What is your relationship to them?
Modesty	a. I will need to [describe e.g, examine your breast]. How can I make this more comfortable for you? b. Would you prefer that someone who is [the same gender as patient] be present? c. Would you prefer that the rest of the care team [e.g., nurse, resident] leave?
Mental Health	a. Many people who are dealing with a serious illness feel sadness, fear, or worry. How have you been managing your feelings? b. Would you want to talk with a psychologist about this?
Acculturation	a. How old were you when you moved to the US? [if born here] How many generations of your family have lived in the US? b. What language(s) do you speak at home? How often do you eat [Indian, Pakistani, etc] food at home?

family, community, or patriarch. Patients may further seek to consult with religious leaders, gurus, astrologers, or other community leaders to determine the most auspicious time to schedule procedures and milestone events, and providers should work within these constraints, when possible, to put patients at ease. Providers may be contacted by multiple family members and should assess who is critical to decision making, document their information, and develop a communication strategy with them. Clinicians should confirm with patients who they prefer to make decisions on their behalf, and medical interpretation should be offered for those with limited English proficiency.

While typically communities may coalesce around families experiencing illnesses, some serious illnesses including cancer and dementia are stigmatized. Receiving these diagnoses can be shameful and isolating, and the experience of the patient should be assessed and addressed. A third of cancer patients experience emotional distress.<sup>4</sup> Compared to the general population, cancer patients are twice as likely to die by suicide and up to 13 times as likely to die of suicide in the three months following diagnosis.<sup>5</sup> The risk for suicide may be amplified by stoicism valued in South Asian cultures, but screening may be challenging due to the stigma surrounding mental health conditions. Screening for suicide, depression and anxiety should be augmented with conversations to obtain a thorough understanding of patients' mental health.

Further complicating this is the belief that a positive outlook can cure serious illnesses. Patients may prefer not to know about their disease severity and prognosis

to maintain their positivity. For the same reason, their families may filter information received by patients. Care teams should not assume that the patient is aware of —or desire—medical information. Recognizing these individual preferences, discussing the type of information desired, and having separate conversations are needed to elicit and respect these preferences.

The context of death and dying poses particular challenges since rituals and beliefs are embedded in religious and cultural mores. For instance, Hindus consider post-death rituals essential for the soul to ascend to “*svarga lok*,” a transitory place where souls await reincarnation until they attain *Moksha*, that is, freedom from the cycle of death and rebirth. Rituals may include having the body at home until cremation; cremation by a son or another male family member; days of prayers; and feeding the poor. Older Hindus fear the solitary hospital death of COVID-19 because they fear that not performing these rituals will disrupt their soul's journey into the afterlife.

In [Table 1](#), we provide example questions to guide conversations to elicit cultural beliefs, practices, and preferences in relevant domains. While what we have described is broadly true among South Asians, acculturation, education, and age may be associated with significant diversity in personal and family norms, as has been found in other populations.<sup>6</sup> We call for more attention to these nuances and robust, disaggregated data is needed within electronic health records and healthcare systems that celebrates both the inclusivity and diversity present throughout this large and diverse

geographic region. Careful assessment and respect for individuality during communications and clinical decision-making are critical.

Many of our patients and families have suffered catastrophic outcomes from COVID-19. There is much that we can do to support colleagues, friends, patients and families facing these losses in the US and struggling to support loved ones in India, and other South Asian countries where COVID19 continues to wreak damage. Cultural understanding can aid our efforts and is essential to provide high quality care for this rapidly growing population in the US but requires more robust data, validating patients' unique beliefs and experiences, and identifying new tools for the community's continued care and management.

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