

## Updated & Innovations in Essential Conversations for the Health Care Team ECHO Series

### *Taking Serious Illness Conversations Seriously: Unveiling South Asian Perspectives on Advance Care Planning*

**Presenters:** **Dr. Amrish Joshi**, Palliative Physician, Vancouver Coastal Health, Richmond Integrated Hospice-Palliative Care Program; **Monica Kelly**, Lead, Goals of Care Support Team, Vancouver Coastal Health; **Dr. Sukaina Kara**, Palliative Physician, Fraser Health; **Lara Musa**, Regional Clinical Educator, Vancouver Coastal Health Richmond Professional Practice

**Tues Jan 20<sup>th</sup>, 12pm-1pm**

Item	Discussion
<b>Key Takeaways</b>	<ul style="list-style-type: none"> <li>• South Asian perspectives on Serious Illness Conversations (SIC) reveal cultural differences in how these conversations are received and understood</li> <li>• Three main themes emerged from research: generational differences, family structure importance, and power differential between patients and healthcare providers</li> <li>• Cultural adaptations to the SIC Guide are needed when working with South Asian families, particularly recognizing relational autonomy versus individual autonomy</li> <li>• Family-centric decision making is common in South Asian cultures, with protection of loved ones often prioritized over individual autonomy</li> <li>• Healthcare providers should be flexible in their approach, adapting questions to be culturally sensitive rather than following a rigid script</li> </ul>
<b>Research study on South Asian perspectives of Serious Illness Conversation Guide</b>	<p>The presenters shared their qualitative research study examining how South Asian individuals respond to the Serious Illness Conversation Guide (SICG).</p> <ul style="list-style-type: none"> <li>• South Asians are the largest visible minority in BC (28% as per 2021 census) and gap identified that the SICG is widely used but yet to be validated for cultural appropriateness in South Asian communities</li> <li>• Study was conducted in 2019 using an older version of the guide. Study methodology - 18 participants from South Asian backgrounds who spoke English participated in focus groups and been in Canada more than 10 years.</li> <li>• Role-play demonstrations of the SIC Guide with focus groups to gather feedback and how they might respond and how they think elders in their community would respond</li> <li>• Many on research team from South Asian background themselves</li> <li>• Research identified cultural nuances that affect how the SIC Guide is received by South Asian patients and families</li> <li>• The study was published in the British Columbia Medical Journal with culturally representative artwork</li> </ul>
<b>Key themes identified in the research</b>	<p>Theme 1: Generational differences in willingness to engage in discussions</p> <ul style="list-style-type: none"> <li>• older generations expect family to make decisions while younger generations understand the importance of advance care planning</li> </ul>

	<ul style="list-style-type: none"> <li>younger South Asians raised in Western culture are more accepting of individual autonomy principles</li> </ul> <p>Theme 2: The family structure during discussions</p> <ul style="list-style-type: none"> <li>family involvement is essential and decision-making is collective rather than individual</li> <li>Western medical ethics prioritizes autonomy, which conflicts with Eastern collective values</li> <li>"relational autonomy" where decisions are made in context of relationships rather than individually</li> </ul> <p>Theme 3: Power differential between patients and health care providers</p> <ul style="list-style-type: none"> <li>older South Asians often defer to healthcare providers and expect direction rather than shared decision-making</li> <li>Cultural differences create tensions between Western medical approaches that prioritize individual autonomy and South Asian approaches that prioritize family-centered decision making</li> </ul> <p>Healthcare providers need to recognize these differences to effectively communicate with South Asian patients</p>
<b>Recommended adaptations to the SICG</b>	<ul style="list-style-type: none"> <li>Asking permission seemed confusing to elderly South Asians who expect doctors to lead conversations</li> <li>Questions about illness understanding were perceived as strange since patients expect doctors to be the experts</li> <li>Questions about goals, fears, and strengths were often taken literally rather than in medical context</li> <li>Monica highlighted that her team adapted the guide by changing "illness" to "health" which was better received</li> <li>The SIC Guide requires cultural adaptations rather than rigid application</li> <li>Understanding cultural context helps clinicians phrase questions in ways that resonate with patients</li> </ul>
<b>Case Study Discussions</b>	<p>Two case studies were presented to demonstrate the application of cultural considerations in serious illness conversations.</p> <ul style="list-style-type: none"> <li>first case: 56-year-old South Asian woman with breast cancer who was born in Canada but married to a man from India. Married 15 years with 2 teenage children. Has relatives in same house and relatives in India. All medical conversations primarily with patient directly.             <ul style="list-style-type: none"> <li>Participants identified potential barriers including concerns about being a burden, cultural taboos around discussing illness, and family dynamics, HCP power dynamics</li> </ul> </li> <li>second case: 85-year-old widowed woman with end-stage cancer living with her daughter but with sons involved in decision-making. Bed-bound and in final weeks to month. Exploring options between home with supports or hospice.             <ul style="list-style-type: none"> <li>"filial paradox" where family members protect each other by not discussing serious illness directly</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>○ common scenario where "the daughter is doing all the work, and son is the one making all the decisions"</li> <li>• Cultural considerations significantly impact how SICs should be approached</li> <li>• No single approach works for all patients - clinicians need to be flexible and responsive to individual family dynamics</li> </ul>
<b>Practical applications for healthcare providers</b>	<ul style="list-style-type: none"> <li>• Research is not prescriptive but encourages clinicians to adapt their approach</li> <li>• Presenter shared that sometime their own South Asian background helps establish rapport but can also create expectations</li> <li>• Awareness of cultural nuances can help build trust even if the clinician is from a different background</li> <li>• Importance of person-centered care that considers cultural context</li> </ul>
<b>Resources</b>	Article: <a href="https://bcmj.org/articles/taking-serious-illness-conversations-seriously-unveiling-south-asian-perspectives-advance">https://bcmj.org/articles/taking-serious-illness-conversations-seriously-unveiling-south-asian-perspectives-advance</a>