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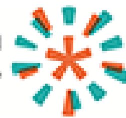

Environmental Scan

Part 1 (South Asian)
Literature review of available published and grey literature related to ACP with South Asian community

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Objective

The objective of this literature review is to:

1) provide insight into how members of the SA community respond to ACP activities;
2) present opportunities to adapt ACP materials to increase culturally appropriate for members of the SA community; and
3) use this information to better inform the development of future ACP activities involving members of the SA community.

Introduction

The South Asian community is the largest visible minority group, and one of the fastest growing immigrant communities in Canada, accounting for just over 25% of the visible minority population.(1) Two-thirds of all South Asian-Canadians in Canada live in Metro Vancouver and Greater Toronto, making up nearly 30% of the combined populations of the two cities. As the South Asian community represents a large proportion of the general population, improving the uptake in Advance Care Planning (ACP), and empowering these communities to advocate for care that is aligned with their values and wishes with this community is a growing priority.

ACP is defined as:(2)

> *"A process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of Advance Care Planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."*

During the process of conducting ACP a person may:

- choose who will make healthcare decisions for them if they are unable to do so (their substitute decision maker, SDM);
- consider their wishes, values and beliefs
- communicate these with their SDM and/or healthcare professionals (HPs)
- document their wishes, values and beliefs in a document such as an advance care plan or Advance Directive (AD)(2).

Completion of ACP has been associated with better care at the end of life, better quality of death and less psychological distress in survivors.(3)

A person's cultural background and ethnicity can shape their attitudes towards end-of-life conversations as well as their willingness to engage in ACP activities.(4,5) This includes the way that people approach ACP conversations, their identification of wishes, values and beliefs, and how they choose to communicate that information with loved ones and healthcare professionals.

Varying Cultural Perspectives

Conflicting Cultural Values

Ethnic minorities express lower levels of satisfaction with the care they receive, reporting that their care providers don't understand their background or values.(6,7) Quite often, South Asian people may prefer to refer to their original cultural beliefs when faced with critical life events such as death and illness(8). Conflict can occur when South Asian people are confronted with the Western concept of ACP, as the value systems and preferences between the two groups differ substantially. Cultural domains where the two groups have conflicting values were around:(9) (see Table 1)

1) attitudes towards death and dying,
2) perspectives surrounding family roles and duties,
3) preferences for disclosure, and
4) decision making.

The failure to acknowledge and respect cultural differences, may lead South Asians to either conceal or fail to disclose their wishes and preferences for care.(10) Some argue that there is a lack of cultural transferability in the Western palliative service model that make it unacceptable to non-western people.(11)

While none of these factors are absolute barriers to a person completing ACP, they do influence the person's response to the concept and how it could be best presented.

Table 1. Conflicting values between South Asian and Western cultures

Western Medical Philosophy	South Asian Philosophy
Open discussion around death and dying	Avoidance of discussions around death and dying.
Individualistic- Strong sense of personal responsibility to take care of self.	Collectivism- Strong sense of duty to take care of the family
Autonomy	Shared decision making

Western Medical Philosophy	South Asian Philosophy
Truth Telling- Full disclosure of diagnostic information	Non-disclosure or withholding of diagnostic information.
Control over dying process	Dying process in God's hands

Diversity within Diversity

Although many members of the South Asian community may have much in common, it is important to recognize that they might not all share the same values, wishes, and preferences, especially when it comes to end-of-life care. There is high diversity between and amongst the different subgroups of the South Asian community.(5,12) Grouping all South Asian people together negates all the different lived experiences and circumstances of the individuals comprising the group.

The South Asian community is a large, heterogenous group of people who may:

- originate from different regions,
- speak different languages and dialects,
- belong to different generations,
- practice different religions,
- be assigned to different class systems,
- experience different levels of acculturation to Western society, and
- engage in different customs and practices

Quite often, research and policy directives tend to combine large groups of people into a single category.(13) Developing research and policies based on broad-based assumptions fails to take into consideration the needs of the individual.

Knowledge and Understanding of ACP

Ethnic disparities in ACP completion rates have been documented and may be attributed to a lack of awareness and knowledge about ACP. South Asian people may be unfamiliar with ACP due to a lack of prior awareness of ACP, and a lack of experience with aging or dying in their adopted country. Spreading awareness of ACP through education and community engagement, has been an effective strategy for increasing ACP engagement levels for South Asian community members.(14)

Lost in Translation

One of the biggest barriers is that there is no literal translation of ACP available in Punjabi, Hindi, or Urdu, making it difficult to understand the meaning.(15) In addition, ACP is also difficult for people from the South Asian community to conceptualize as planning ahead for future medical decisions is an unfamiliar concept, and having open discussions about death and dying is highly unusual in the South Asian culture.(15,16) There is nothing comparable to ACP in the South Asian cultural context that could be used as an example to help describe ACP.(15)

Opening ACP conversations with a story of a personal experience can help illustrate the meaning and importance of ACP, as well as build trust and rapport. Storytelling is an effective way to share experiences and expression, and gain an understanding of South Asian peoples' knowledge of and attitudes towards ACP. Therefore, it is important to take the time to "find the right words" to describe the process of ACP, to develop a shared understanding amongst the SA community.(9)

Meaning is personal

The meaning of ACP is personal to each individual, and largely shaped by cultural assumptions and personal experiences.(9) Furthermore, as ACP is a dynamic process, changes to care preferences and wishes may also change as health status and personal circumstances change. It is important to recognize that although ACP is defined as "a process by which people develop and express their wishes surrounding their future healthcare, for a time when they do not have the capacity to make or communicate decisions themselves", the cultural variability behind the meaning of ACP can be unique to each individual. More specifically, the way in which SA community members choose to engage in ACP activities may present itself differently than what might be "expected" in the Western culture.

Low Health Literacy

A lack of knowledge and misconceptions about ACP can be attributed to low levels of health literacy and a limited understanding of the Western healthcare system.(17) Many South Asians who do not have a reference point for ageing or dying in a Western society are interested in learning about not only the medical aspects of planning for end of life, but also the financial, legal and social aspects related to dying.(18) Incorporating different aspects of life planning into ACP, may increase the attractiveness of ACP to immigrants.

Religious considerations

Religious beliefs have considerable influence on decisions made by patients, their families, and their carers, particularly at the end of life. Religious and spiritual beliefs shape people's attitudes towards end-of-life care, and (see Table 2).(19–23)

Table 2: Religious beliefs about end of life

Muslim	Hindu/Sikh
Believe in afterlife and judgement day, death is the transition from one phase of existence to another	Believe in Karma and rebirth, collective vs individual identity, emphasis on purity and ayurvedic medicine
Prefer to die at home	Prefer to die at home or hospital
Care for dying is the responsibility of immediate and extended family	Care for dying is the responsibility of immediate and extended family
Do not want to inform dying relative of prognosis, with the intention of reducing anxiety	Reluctance to inform dying relative of terminal illness, talking about death and dying avoided.
Optimism and hope	Optimism and hope
Illness is a test from Allah, should be received with patience, meditation and prayer	Life and death is in the hands of God, withdrawal of treatment is acceptable if considered futile.
Palliative care services valued and effective, yet not widely known	Palliative care units were seen as place for dying people, tainted.

External Locus of Control

Prayer and connection with God is considered to be very important for many members of the South Asian community. When confronted with challenges, such as serious illness, many people place their absolute trust in God. Surrendering to “God’s plan” serves as a barrier to ACP conversations for South Asian community members, as planning for their death can be seen as challenging God and attempting to gain personal control over death and dying.(9,14) Furthermore, burdening oneself with worry about things that may or may not happen, or about things that they have no control over may be seen as unnecessary.(9) Therefore ACP can be considered to be irrelevant, as the nature of death is unpredictable and surrounded by so much uncertainty.(16)

- Emphasize that ACP is a dynamic process, and that changes in preferences are likely to occur as health status changes.

Power of Positivity

It is culturally understood that the refusal to engage in end-of-life conversations about death and dying is an attempt at avoiding unnecessary distress and maintaining a positive attitude.(14) Maintaining attitudes of hope and optimism is important for South Asian people. However, thinking positively in later life with the hope that it will enhance longevity might manifest through the avoidance of thoughts related to death, dying, and end of life planning, thus serving as a barrier to ACP.

- Focusing on the positive aspects of planning, and benefits to the individual and the family.

Role of Religious Leaders

Religious leaders are considered to be at the top of the social hierarchy in South Asian culture, and it is not unusual for them to be consulted when discussing important issues.(9) Being highly respected and trusted members of the South Asian community, religious leaders are in a position to raise awareness of important issues in the community. Gaining the support of religious leaders to promote and encourage ACP may serve to facilitate trust and acceptance of ACP within the South Asian community, as well as clarify any religious-based misconceptions around ACP.(15)

- Dissemination of ACP information through religious institutions, eg displaying posters in community places of worship, announcements by leaders at religious ceremonies

The Family Unit

In South Asian culture, both the immediate and extended family is considered to be an important aspect of end-of-life decision making.(16,24,25) South Asians express a strong sense of duty to care for family members, however, very few have actually discussed care preferences and expectations explicitly with their family members. The following section will discuss the barriers and facilitators for ACP conversations with South Asian families.

Cultural Norms

Predetermined roles within families are a naturally understood part of a traditional cultural value. These roles influence the individual's ability to make end-of-life decisions and create a natural dependency on others.

Typical decision making in South Asian Families:(9,24,26–29)

- "Filial Piety" strong sense of duty for children to care for their parents,
- Most caregivers are female,

- Eldest sons often responsible for making all decisions,
- Many South Asian men would not name their spouse as their SDM, preferring to name a male relative or male friend, and
- Many South Asian women name their husband as their SDM.

It is assumed that because many end-of-life care preferences are tied to shared cultural values it is assumed that the family "would know what to do" and "would do what they could" when confronted with death and dying. Therefore, many members of the SA community assume that there is no need to state preferences because many decisions are culturally pre-determined or expected, such as family values of filial piety, or religious rituals such as cremation. Furthermore, individuals in the SA community are not expected to have any involvement in conversations or decisions regarding their own end of life, placing complete reliance on the family unit to make decisions on their behalf, deeming ACP irrelevant.(26,30)

Changing cultural values have been observed within the South Asian family unit. Parents acknowledge that they can no longer expect adult children to fulfill traditional roles due to the adoption of new cultural norms in Western society. Many South Asian parents recognize the need for having ACP conversations with their children, because they can't assume that children are willing, or have the resources to care for them.(15,26,30) Having open conversations about future wishes, can serve to reduce burden on family members in the future.

Avoiding ACP Conversations

Despite many South Asian people recognizing the value of ACP and expressing a willingness to discuss end-of-life care preferences, there is an absence of experiences related to having discussions or making future plans related to death and dying. ACP is dependent on the willingness of a family to discuss difficult subjects. The willingness, or lack there of, to engage in ACP should not be assumed, and the opportunity for discussion should not be denied to this group. Avoidance of ACP can be grouped into two themes: avoidance as cultural norm, and avoidance as protection.(16) The following section outlines cultural norms and assumptions behind initiating and avoiding ACP conversations with others, and provides insight about how to overcome some of these barriers.

Avoidance as a cultural norm

Avoidance as a cultural norm relates to the absence of discussions around death and dying within families.(9,26)

Table 3. Avoidance as a cultural norm

Cultural Value	Impact on ACP Engagement
ACP is culturally unusual	• Unusual to discuss end-of-life preferences or make future plans. • Lack of a cultural reference point to guide ACP conversations.
Living as part of an extended family	• Assumed that ACP is unnecessary. • Trust that family would take responsibility and make necessary decisions on their behalf.
Death and dying taboo topic	• Fear about discussing death and dying. • Belief that thinking about or discussing death and dying will bring death and illness forward. • Prefer not to use words about death and dying at home to protect family from death and illness.
Maintain positive attitude	• Avoid thinking or talking about potentially stressful topics such as death and dying. • In the hopes of living longer. • To shelter oneself or others from emotionally unpleasant topics.
Initiating conversations at the very end of life	• Discussions and decisions relating to end of life take place when health has deteriorated towards the final stage of life. • Assume that there is no need to engage in ACP when healthy.
Role of individual	• Individuals are not expected to have discussions or make decisions about their own dying and dying with family members.

Avoidance as protection

Avoidance as protection relates to the beliefs and experiences of initiating or avoiding ACP with others.(9,17,26)

Table 4. Avoidance as Protection

Behaviour	Reaction
Individual avoids ACP with family	• Want to avoid upsetting family members. • ACP with family members is considered culturally inappropriate. • Respect and understand cultural norms of avoiding conversations of death and dying. • Older South Asian adults do not necessarily expect to initiate or be involved in any end-of-life discussions and related decision making within the family.
Family members avoid ACP with individual	• Want to avoid upsetting the individual by discussing difficult topics such as death and dying. • Families avoid initiating ACP with the individual, because they do not want the individual thinking that caring for them is a burden on others. • Don't want to relay to the sick individual that they are giving up hope by engaging in ACP. • Fear that individual may misinterpret ACP with family attempt at securing assets. • Find it difficult to accept loved one's mortality- coping strategy of denial. • Respect and understand cultural norms of avoiding conversations of death and dying.
Individual initiates ACP with family	• When individuals attempt to initiate ACP conversations with families, family members often refuse to discuss ACP and encourage individual to think positively. • Individuals acknowledge that ACP is unproductive as children refuse to engage. • Prefer to have end-of-life care discussions with friends and people in own age group with similar concerns.

<table>
<tr><th>Behaviour</th><th>Reaction</th></tr>
<tr><td>Individual initiates ACP with Western professionals</td><td>Language barriers hinder ACP discussion with healthcare professionals.
Individuals place trust in families to discuss needs with healthcare professionals on their behalf.</td></tr>
<tr><td>Western professionals initiate ACP with individuals</td><td>South Asian individuals expect professionals to initiate ACP, as they hold the knowledge and information.
Professionals hesitant to initiate ACP discussions due to:
Lack of communication guidelines to communicate with members of the SA community.
Fear of distressing South Asian community members.
Not having enough time to clarify misunderstandings.</td></tr>
</table>

Facilitators for initiating ACP

Although there is an understanding of the different attitudes, cultural barriers and facilitators that impact ACP engagement amongst South Asian people, little is known about how culturally adapt and deliver ACP programs for the South Asian community.

Acknowledge and respect cultural norms

View cultural norms as positive potential to build upon rather than barriers. Cultural and community norms should be considered an asset and powerful facilitator of ACP. To gain a better understanding of the cultural norms consider the following:(31–34)

- Cultural sensitivity training,
- Avoid assumptions about cultural beliefs, categorizing can lead to stereotyping,
- Involve ethnic minorities in planning and outreach activities,
- Recognize that cultural beliefs only form one aspect of end-of-life preferences,
- Training of interpreters and cultural liaisons,
- Recruitment of staff from minority ethnic groups,
- Provide culturally appropriate resources (language, formats), and
- Use culturally appropriate examples and images.

Recognize and build on community capacity

Find ways to capitalize on the community capacities that already exist, such as family networks, community ties and shared norms.(9,31,32,34) Examples of this include:

- Present ACP events in South Asian languages,
- Hold ACP events in community and religious spaces,
- Involve religious political and community leaders in ACP promotion, engagement, and dissemination of ACP,
- Involve family members in ACP discussions, however, be sensitive to cultural needs of disclosure and decision making,
- Build cultural competence by making people more familiar with South Asian cultural values,
- Engage South Asians to help inform ACP decisions and policies, and
- Learn about and understand ACP through storytelling and sharing to bridge differences.

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