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**End of Life Care for South Asian Immigrants in Halifax, Nova Scotia:
Preliminary Findings**

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End of Life Care for South Asian Immigrants in Halifax, Nova Scotia: Preliminary Findings

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Abstract/Résumé:

Palliative care is an important area of health service that focuses on providing physical, psychological, social and spiritual care to individuals suffering from life-threatening conditions from the time of diagnosis to the end of life and bereavement.

Nearly one out of five immigrants in Canada has arrived from South Asia, and the majority of those who arrived during the third wave of immigration to Canada are now in their late 80s. Cultural belief system and practices strongly influence an Asian Indian's health, wellness and access to health care. When providing end of life care services, health care professionals need to recognize and respect the cultural practices and beliefs of the patient and family. The aim of this research, conducted in Halifax, Nova Scotia, Canada, is to explore familial and professional caregivers' experience in providing care for terminally ill South Asian immigrants. The content analyses of four personal caregivers and one health care professional brought forward four major themes: unwillingness to accept that the illness is terminal; interdependence and bonding; familial and social network support; and communication and cultural responsiveness. Findings of the research provide valuable information for culturally sensitive end of life care program and policy development.

Keywords/Mots-clefs: End of life care, Asian Indian immigrant, personal caregivers and healthcare professional, cultural sensitivity

Background and Context:

Canadian society is becoming increasingly diverse along cultural, ethnic, linguistic and religious lines, and 21.6 % of immigrants to Canada have arrived from South Asia (Statistics Canada 2003). This changing demographic profile has implications for the delivery of health care, and, more specifically, palliative care and oncology services. For example, it is widely recognized that racial and ethnic minority groups have poorer health status and reduced access to health services relative to the health status and access to health services of the mainstream population (Evans, Barer & Marmor, 1994; PHR, 3002; Williams & Warren, 1994). Moreover, it has been documented that racial and ethnic minority patients have reduced access to palliative care services and pain and symptom management (Siriwardena & Clark, 2004).

In general “culture” refers to the collective beliefs and shared practices that people use to make sense of, and guide their interactions with, their surroundings. In this way, culture acts as a set of guidelines – an inherited lens – through which people view society (Helman 2002). Cultural beliefs influence many aspects of people’s lives, including, for example, their family (and hence, decision-making) structure, body image, and attitudes towards health, illness, pain, suffering and death, as well as other life experiences that may involve challenges.

The focus of this paper is on South Asian immigrants who arrived during the early half of the 20th century and make up the largest proportion of immigrants in the Atlantic region. Most South Asians arrived from India, Sri Lanka, Bangladesh and Pakistan. South Asians who arrived during the third wave of immigration to Canada are now in their early to mid-80s. Many of these South Asian immigrants who left their birth country in their mid-30s and then settled in the Atlantic region were professionals: doctors, engineers and teachers.

South Asian culture is patriarchal and thus the males tend to be more educated and, therefore, become the primary breadwinners of the family. Women typically assume the role of homemaker after migration and receive fewer opportunities to be acculturated in Canada; as a result; they are less fluent in English. Asian Indian immigrants’ cultural influences related to sickness and health and access to health care remain strongly tied to religion and language.

One of the most important points to remember when providing end of life care services to the Asian Indian community is that the Asian Indian culture is not homogenous and includes myriad subcultures, languages and religious sects. An immigrant may belong to one or more of these groups. Moreover, individuals vary a great deal in the degree to which they adhere to the traditional practices of their culture or their faith. However, cultural competence in providing end of life health care in the South Asian community has received minimal attention in Canada.

South Asian immigrants bring several religious perspectives to Nova Scotia – Buddhism, several dominations of Christianity, Hinduism, Islam, Sikh, Bahai and Jainism. Also, although English is the second language in most South Asian countries, the native language significantly

differs by country and sub-region. Hindi is the first language in India, Sinhala and Tamil are both considered as first languages among Sri Lankans, people from Bangladesh speak Bengali, and those of Pakistan origin speak Urdu. Nevertheless, the number of South Asian immigrants in Nova Scotia comprising a single cultural grouping (classified by language, religion and culture) is small. This creates challenges when trying to provide culturally competent care at the end of life because significant differences exist among South Asian cultures.

Canada's multicultural policy gives individuals the right to practice the religion, beliefs and customs of their ethno-cultural heritage (Elliott, 1999). These values and beliefs may influence the attitudes of individuals and families faced with terminal illness or death. Hence, when providing end of life care services, health care professionals need to move away from a standard approach of 'one size fits all' to one that recognizes and respects the cultural practices and beliefs of the patient and family. A truly holistic approach to end of life care would be one that not only provides physical and psychological support but also incorporates religious and cultural perspectives.

Palliative care is an important area of health service that focuses on providing physical, psychological, social and spiritual care to individuals suffering from life threatening conditions from the time of diagnosis to the end of life and bereavement. According to WHO, palliative care not only focuses on relieving pain and suffering but also promotes quality of life and helps patients to live as actively as possible until death (Sepúlveda et al., 2002).

Cultural Competence

Health professionals must understand cultural norms and values to facilitate the delivery of culturally competent care. In this sense, "cultural competence" refers to

"...the process of actively developing and practicing appropriate, relevant, and sensitive strategies and skill in interacting with culturally different people...the capacity to respond to the needs of populations whose cultures are different from what might be called dominant or mainstream" (Wells and Black 2000: 278).

Cultural competence begins by understanding one's own culture and biases, trying to understand other cultures, and learning to value the differences (Galanti, 2004). Moreover, cultural competence is based on an increased understanding and not just an increased knowledge of different cultures (Gatrad, Choudhury, Brown, & Sheikh, 2003). According to the document entitled *A Cultural Competence Guide for Primary Health Care Professionals in Nova Scotia* (2005), cultural competence begins with sensitivity followed by awareness and knowledge about different cultures, and then it progresses to the development of skills needed to acquire competence (NSDOH, 2005). Culturally competent health care providers will respect the dignity and uniqueness of every client and try not to impose their own views, values and beliefs on the

patient (Galanti, 2004). Rather, the health professional will strive to develop and practice suitable, pertinent and sensitive strategies and skills when interacting with people from different cultures (Wells & Black, 2000). It is generally accepted that culturally competent care will lead to better clinical outcomes, greater patient satisfaction and greater cost efficiency (Galanti, 2004).

Cultural competence can be understood as the process that enables others to gain knowledge and skills to respond to those unique features of a particular culture. The task of making the health care system culturally competent requires considerable investment by health policy-makers to transmit the cultural knowledge to health care professionals and to the entire health care system. This includes empowerment of the immigrant settlement community to mitigate cultural and language barriers and to make immigrants competent within the dominant western biomedical model of care so that equitable access is promoted.

The importance of considering culture in care settings at the end of life cannot be overemphasized. Terminal illness, dying, death and grief are often perceived within a cultural context, and an understanding of culture and its role in caring is important for professionals providing end of life care (Elliot, 1999). Moreover, this time is surrounded by a number of sensitive issues, and the way individuals deal with them varies significantly across cultures. To make care culturally appropriate, health professionals need to be aware of cultural nuances regarding disclosure of bad news, differences across cultures in the perception and management of pain, patient autonomy and the role of family in decision-making, attitudes towards prolongation of life by artificial means, advanced directives and euthanasia. An understanding of religious values and beliefs and of customs and rituals at the end of life can facilitate the provision of holistic care.

A focus on primary health care models of service delivery promotes a broader vision of health that extends beyond illness treatment and care regimes. Thus, the current understanding of cultural competence needs to include areas of lifestyle behaviours such as dietary practices and physically active living contextualized in conjunction with acculturation. A study conducted by Shea (2007) (not in reference list) provided perspective on immigrant youths living in St. John's, NL. Shea concluded that the changes in food and physical activity habits of St. John's immigrant youths are highly influenced by their cultural backgrounds. In another Newfoundland-based study, this one concerning dietary acculturation among adult Indian immigrants living in St. John's, it was found that 72% of the study participants indicated their food preparation methods had altered somewhat according to Canadian food habits. It was also noted that immigrants became knowledgeable about the Canada food guide (Varghese & Moore-Orr, 2002).

A study conducted among immigrant women living in Prince Edward Island revealed an interconnection to the health of immigrants between food and culture (McKinnon, 2000). In the study, women talked about being accustomed to Canadian values of personal health practices,

such as good nutrition and physically active lifestyles. Based on the research findings, McKinnon (2000) recommended inclusion of cultural contents in clinical practice education for nurses to make them culturally competent. Baker (2007) refers to post 9-11 issues of cultural danger and cultural risk for Muslim women living in New Brunswick as two of the components that emerged from cultural incompetence. Further, research carried out by Weerasinghe (2003) in Halifax, Nova Scotia, pinpointed several areas that need attention to make the health care culturally competent for adult immigrant women. Among them were facilitation of language and communication needs; the curbing of racism and discrimination that exist when they access health care; the accommodation of cultural traditions, rituals and customs in hospice care, such as providing culturally responsive hospital gowns; visitation of clergy from one's own religion during palliative care; and the inclusion of different ethno-racial groups in clinical trials (Weerasinghe, 2003).

Rationale for Research

Specifically, the rationale for this research can be outlined as follows:

1. Very little research has examined the experiences of caregivers and families at the end of life in immigrant populations, in particular members of the South Asian immigrant community in Nova Scotia.
2. The understandings and perspectives of health professionals working in palliative care services regarding providing care for South Asian immigrants need to be examined.
3. The possible cultural or institutional barriers that may prevent South Asian immigrants from utilizing conventional palliative care and end of life care services need to be documented.
4. This research will inform and stimulate dialogue among stakeholders regarding what is occurring – or not occurring – in supporting and facilitating culturally competent end of life care in the South Asian immigrant community;
5. This research will help begin to identify the features that comprise culturally competent palliative and end of life care in the South Asian immigrant community.
6. This research will identify opportunities to educate health professionals working in the palliative care setting regarding cultural competence in care delivery.
7. Conducting the research project may itself stimulate discussion and raise awareness among health professionals about the need to be aware of the health needs of various minority populations in Nova Scotia.

Research Questions

This research will attempt to answer the following questions in the context of culturally competent end of life care:

- (1) What is the experience of South Asian immigrants who currently are fulfilling, or have in the recent past fulfilled, the role of a caregiver for a loved one with a terminal disease?
- (2) What is the experience of health professionals working in the palliative care setting (or other supportive role) who are currently caring for, or have cared for, terminally ill South Asian immigrants?

Study Design and Research Method

This research project used qualitative research methods, specifically a naturalistic approach (Lincoln and Guba, 1985). Features of a naturalistic approach to research include the fundamental belief that realities are multiple, constructed and holistic and that the knower and known are interactive and inseparable. Naturalistic inquiries are characterized by qualitative methods, purposeful sampling, research conducted in a natural setting, inductive data analysis and reflexive reporting (Lincoln and Guba, 1985). In this research, data collection was achieved by in-depth semi-structured interviews and as a result of the field notes of the researchers.

In-depth, in-person, semi-structured interviews with participants explored the end of life experiences of two groups: health professionals working in the palliative care setting and South Asian immigrants who are fulfilling, or have in the recent past fulfilled, the role of caregiver for a loved one with a terminal illness. Interviews focused on their experiences, beliefs, values and practices related to providing end of life care, including, for example, cultural considerations of palliative care (including caregiving roles), preferred place of death (home, hospice or hospital), patient autonomy and decision-making, language and communication issues in the hospice, role of family in caring for the patient, religious and cultural beliefs and practices associated with illness, and issues related to caregiving from the perspective of both professional and family caregivers. [See Appendix One – Interview Guide (Asian Immigrant Caregiver and Health Professional)].

Subject Selection

The two study populations were

- a. health professionals working in the Capital Health Integrated Palliative Care Service, and
- b. the South Asian immigrant community living in Halifax who are currently fulfilling, or have in the recent past fulfilled, the role of caregiver for terminally ill loved one.

Professional Caregivers

The following process was employed to solicit participation from professional caregivers associated with the Capital Health Integrated Palliative Care Service (CHIPCS).

- a. A letter was written to inform the director of the CHIPCS of the research and request a list of professional caregivers, including registered nurses, physicians, Licensed Practical Nurses, home care workers, and volunteers who are affiliated with the CHIPCS.
- b. A letter was forwarded to all staff members inviting their participation. These letters were followed up by a telephone call and e-mails.

The goal was to interview at least 10 health professionals working in this service.

South Asian Immigrant Caregivers

The South Asian immigrant community living in Halifax is relatively small. We used a combination of snowball and purposive sampling to select research participants. Dr. Weerasinghe, principal investigator, and Farhana Kanth, research coordinator, are closely associated with the South Asian immigrant community and initiated the process of seeking research participants. Relevant community associations listed on the Multicultural Association website (<http://www.mans.ns.ca/preslist.html>) were also contacted.

Atkinson and Flint (2001) describe snowball sampling as a technique for finding research subjects in which one identified participant gives the name of another potential participant, who, in turn, provides the name of a third, and so forth. With purposive sampling, research participants are selected because they have some characteristic of interest to the research questions (Silverman, 2000). Silverman (2000) states, "...purposive sampling demands that we think critically about the parameters of the populations we are interested in and choose our sample case carefully on this basis" (p.104). In this research project, we are interested in examining the experience of caregivers who are caring for (or someone who has cared for) a loved one who has/had a terminal illness.

Following the interview with the primary caregiver of the decedent, he/she was asked to identify other significant caregivers (to a maximum of two), including, for example, other family members, neighbours, other health professionals (including alternative or complementary healers, if applicable) and religious or spiritual leaders from the decedent's faith community. Interviews were conducted with other identified caregivers to further explore and build a fuller picture of their experiences and end of life care of the decedent. Our goal was to interview 15 South Asian primary or secondary caregivers in this pilot study.

South Asian immigrant caregiver participants selected fulfilled the following criteria:

- a. They reside in Halifax County;
- b. They are currently, or have been in the recent past (no longer than 10 years), a caregiver for a loved one with a terminal illness;
- c. They immigrated to Canada within the past 25 years;

All interviews with South Asian immigrants were conducted by Farhana Kanth, research coordinator, and/or Swarna Weerasinghe. Before data collection, ethical approval for the study was received from the Capital District Health Authority Research Ethics Board.

Recruitment:

Recruitment of participants – primary caregivers -- was challenging because it was often difficult for them to talk about the details of the decedent's life and because the community of interest is relatively small. We ensured that potential participants were approached by someone known to them. Key informant participants were recruited from the cultural communities. It was advantageous that both the principal investigator and research assistant were from the target research community because both used their personal contacts to identify key informants. In addition, the principal investigator has carried out several research projects among immigrants and has built a network of contacts.

Regarding interviews with professional caregivers, one interview has been conducted to date. Additional interviews with professional caregivers are anticipated.

Refusal to participate:

A number of potential participants, after initially expressing interest in taking part in the study, changed their mind and cancelled their appointment for the interview. As expected, death of a loved one is a hard subject to talk about, and some potential participants found the very thought of going over a loved one's suffering and end of life journey to be very painful and distressing. Others cited their own ill health as a reason for not participating. One potential participant, who had lost his wife to a terminal illness, said his children did not want him to share something so personal and private. Still others did not want to relive the emotional trauma by bringing up sad memories. Interestingly, a couple of participants who did participate found talking to someone about their loved one therapeutic.

Interviews:

Interviews were conducted at times and places convenient for the participant, most at the participant's home and only one at a researcher's home. Following informed consent of the participant, all interviews were conducted by the research assistant, with the principal investigator attending several. A semi-structured interview guide was used, and the interviews took approximately 45- 60 minutes to complete. The interviews were tape recorded to assist with data collection and analysis, and interviewees took down field notes during the interview and were used to support the themes.

Profile of participants:

To date, four interviews have been transcribed, and this report summarizes the preliminary findings emerging from them. One interviewee was a female caregiver, who provided care to her husband. The other three caregivers were male: two had been caregivers for their deceased spouses, and the other took care of his wife. All four had passed middle age, have married children living separately, were conversant in English (the interviews were conducted in English) and had completed post-secondary education in their country of origin.

Preliminary findings:

The findings from the first four interviews were related to the culture, feelings and senses of the caregiver, as well as to immigration-related social and cultural barriers. The content analyses brought four major themes forward, and we use plots to explain the contextual understanding.

Expectations and unwillingness to face reality:

All four of the deceased had been terminally ill for six weeks to seven months. Nevertheless, we found that the caregivers had expected their loved ones to live longer. The news of death came to them as a shock, and they found it unbearable.

“After going for radiation treatment, I was 100% sure that he’d be all right. But he was getting worse and worse and worse. If I knew it was going to happen that much, I would never, never have taken him for radiation.”

“Mentally, I was not ready, even now, in the proper sense, that it was a fatal disease that she was suffering from.”

“So Friday he had a stroke in the morning, and Saturday they took him up to emergency and stayed in the ward, and then Sunday... But I was kind of shocked by what happened?”

Health care professionals agree that in some cases, the caregivers find it difficult to accept that their loved one is approaching the end of life. As one health care professional indicated,

“The gentleman himself was quite ill with cancer, and his wife couldn’t accept that he was just dying. She couldn’t accept that he was just, you know, he wasn’t eating, if he didn’t feel like eating. With her, in particular, there was a lot of work on her part to continue to make things seem as normal as they should be but were not. “

Interdependence and bonding:

It was noticeable that immigrants from the Indian subcontinent countries tend to appreciate their practice of interdependence of nuclear family members, even after migration. Cultural clashes occurred when the health care professional was unaware of the strength of this interdependence. One woman said when her husband was admitted to the hospital,

“Finally we took him to emergency... something wrong, and he [the patient] asked us to go home, and we said “...no, we’re not going home”.

Similarly, a male caregiver expressed bonding to his wife and that he refused palliative care for her.

“And then, that is the time that you are given the choice of either putting her in palliative care at the hospital or keep her home. My decision was no, we will keep her home, because we would not like her to be there alone after spending 37 years of life together. That is basically how we found about the terminal sickness and palliative care.

Interdependence between husband and wife appeared to become stronger during illness. As a result, the woman’s traditional role of caregiver becomes more demanding due to added role and responsibilities of caring for a terminally ill loved one. In one case a female caregiver had major surgery while caring for her terminally ill husband, and at times she was bleeding from the surgical wounds. Nevertheless, even during this period of managing her own illness, she continued her caregiving role. Ultimately, she had to be readmitted, and the hospital had to arrange to have her terminally ill husband with her. Here is how she described the situation:

“Here... so one day a call came and they said ‘we have one room empty right now, you have to go, and be there at 2 o’clock’. I said ‘I can’t do that because my husband takes 1 hour to eat, I have to change him and all that’ they said ‘never mind, we’ll do everything you need, just come’. I said ‘if I come, who is going to look after my husband? I can’t leave him like that.’ She said ‘no, no – we have arranged for your husband also’. So an ambulance came, and we just went.”

Children who have become caregivers of ill parents found it impossible to find a balance between the dual role of a full time worker and a full time caregiver. As a son who took care of his terminally ill mother stated,

“And actually, because we were both working – that was a problem we had – we couldn’t look after her 24 hours a day at home, especially during the daytime.”

Both men and women in the nuclear family had contributed equally to the caregiving roles for their family members: husband, wife, mother and/or father. The South Asian tradition of interdependence among the members of the nuclear family had strengthened the bond between the person dying and the people responsible for providing care. Health care professionals

encountered situations and took measures to accommodate this inseparable bond. As one health professional indicated,

“He [the patient] was a very quiet man, but his wife [the care giver] was always there, to be, sort of, his body guard and make sure that she was controlling everything that was getting to him, by way of medication... and things like that.”

Familial and social network and support:

Canadian literature on health relates the influence of social networks on immigrant health to four socio-demographic characteristics: age, gender, culture, and race/ethnicity, and their interactions with migration-related loss of support networks (Weerasinghe, 2008). Lynam (1985) identified three groups of people that Canadian immigrants drew support from: kin, insiders (local ethnic community) and outsiders (local Canadian community). Female immigrants from cultures such as South Asia that promote closed kinship and family ties tend to rely more on familial networks in making health decisions than do their male counterparts (Grewal, 2005). In the same culture, adults and seniors, i.e., parents and grandparents, borrow knowledge on how to access the health care system and learn about Western medical practices and beliefs from their Canadian-born children and grandchildren. Elderly South Asian immigrants tend to become more vulnerable to emotional distress in the absence of pre-migratory buffering effects they had been accustomed to receiving from the extensive social networks and their interactions (Choudry, 2001). Interestingly, however, interdependence valued in the Indian culture brought emotional rewards to seniors. Choudry (2001) further noted that social networks created in conjunction with religious places and seniors clubs helped the seniors of Indian origin to maintain their ethnic identity and cultural continuity and also strengthened their sense of belonging, acculturation and adjustment to Canada.

One study participant iterated level of dependence of his mother on her husband and then how that dependence fell on his wife after his father passed away.

“No my father did it [gave insulin injections] for her... she was dependent on my father. That’s another thing that happened when my father passed away – she was kind of very lonely, but I didn’t know how we could help in that case...”

He further explained how the extended family came to support his mother.

“Yes, every day. And on top of that, you see, my sister was here, my wife’s sister was here and myself. We would take care of her around the clock. I would take the shift from 1:30 at night and my sister and my wife’s sister would take care for the rest of the time.”

“But one of my nieces on my wife’s side – sorry; my wife’s brother’s daughter – she was with us. Actually, she used to stay at home and she used to look after my parents too. She would go get food for them too. So she was a big help to us too.”

So there were three members in the house [He, his wife and the niece] to support two of them, so that wasn't a problem."

The family members with a medical background provided extensive support, which seems common in all cultures. One participant said

"I had consultations with my daughter, you know her cell phone was always on. I would always consult her and nobody else. Otherwise our family doctor was also very good."

Another participant who was displeased with the health professionals said,

"My brother actually came from xxxxx[mentioned the place where the person works], he's a doctor in xxxxx. He had to tell them to do this and do that."

It was notable that immigrant seniors build their social networks around religious and cultural affiliations, for example, churches, mosques, temples and ethnocultural associations. One participant explained the kind companionship received from a member of the ethnic community.

"And some of her friends [from the ethnic community] were dying to see her. And one of them wanted to see my wife and tried so much. She came to see my wife at 2 o'clock. I told her, she is sleeping now and told her to go and watch TV. And I also went upstairs. At 3 o'clock, she [the deceased] was downstairs talking to her friend there. "

Caregivers' social networks extended to neighbours and even people at work, as one caregiver explained:

"Oh yes, a very nice lady across the street. You call her in the middle of the night – a husband and wife – they would be there, no problem."

He further iterated: "[People at work]...No problem, we're like a family." Immigrant seniors and their caregivers received support from the nuclear family, as well as from the ethnic community, neighbours and people at work.

Health professionals noted a strong sense of family among South Asians during the end of life of their loved ones. As one health professional explained,

"Generally speaking, I can't say out of the ordinary [South Asians were more supportive than the others]. Not really. I find that there is, on an average, there is a better sense of family and a better sense of obligation, so invariably there is family involved. Whereas in other cases, there may be ...like say, the daughter is not bothered or things like that. So there would be a little bit more family involved in this population. South Asian, there is a strong sense of family."

Language and communication:

Language and communication difficulties encountered by caregivers of immigrant seniors can be broken down to two overlapping categories: English illiteracy and culturally unacceptable communication. As a male caregiver put it about his mother,

“We still have old ladies here in our community, some of them don’t speak English, so if they go to the hospital, it’s a problem. My mother used to complain “no one will talk to us, I can’t talk to anybody”, because she didn’t know English that well...”

Although his mother has been in Toronto, Canada, for over 35 years, she never learned English. Because she is illiterate in her own language, therefore to become literate in English would have been a far-reaching goal. Her caregiving son explained communication difficulties that she encountered while in hospital.

“But when she was in the hospital, she had a language problem; a communication problem, because she didn’t know English. So that was bad – it wasn’t a very good thing anyway. She could not communicate properly with the nurses and the doctors, until we’d go to visit her, then they would tell us what’s wrong with her, how she’s doing, things like that. That was the main problem. “

The remedy to the language problem is to provide an interpreter, and two non-governmental organizations provide language interpretation in the province. According to this individual, direct communication is preferred above communicating through an interpreter.

“Language was the main thing. Actually when she was... the last time only they sent somebody there. But if you’re at work then if she goes and visits her doctor, you know. One day we went there and we had an appointment with the doctor, and then we saw somebody that spoke Punjabi, then I don’t know why doctors want to talk to that lady; whoever she was, and they took her into my mother’s room. I don’t know what they talked about. I don’t even know. I don’t know why they called somebody who speaks Punjabi to talk to her privately or something.”

Health professionals found South Asian patients and families to be more conversant in English than other Asians, and there is a general sense of acceptance of family members becoming health interpreters, when needed. As one health care professional stated,

“Yes, I never found language to be a problem. And if ever there is any concern about, you know, perhaps a more complex point being missed, there would be a younger family member in there to clarify, but even then, that has been very rare. It is very straightforward.”

Culturally responsive or not:

In general, study participants did not have major complaints about culturally insensitive medical care. The only ones we came across when analyzing preliminary data gathered from three caregivers were males caring for female patients, hospital garments, and food.

“Mother did not like hospital clothes. It was OK, but the one we took her... “I don’t like that”, we had to take her own clothes. She didn’t want to wear them. That was the way she was.”

“Oh yes, she didn’t have any problems with that. She was ... even until the night before, she went herself to the washroom. A [male] nurse wanted to take her to the washroom, she said no, I’ll go myself. She went with the walker. She didn’t want male nurses.”

“The food also she didn’t like...it wasn’t Indian food, they couldn’t arrange anything like that. We used to take some food from home... homemade chapatis and dhals and stuff like that. She’d always eat that. But she didn’t like hospital food – it was so dull. So food was a problem, too... they wouldn’t get any special food.”

One of the caregivers summed up how happy he was about the care his wife received, saying,

“I would say, even otherwise, the care was good. We have no regrets. We have no complaints.”

Another caregiver found that the health care professionals tried to accommodate cultural food and rituals in the hospice. He stated,

“They did, but it was like old vegetables, things like that. And she didn’t like it; she liked spicy food. That’s the way she was. We used to take her food and leave it there in the fridge and we’d tell the nurses to heat it and give it to her. That was OK. There were no restrictions – you can’t do this, you can’t do that. I didn’t see that. Ritual stuff, they didn’t have any problem with rituals or anything like that. I wouldn’t complain about that... When we came in the beginning we had problems; in the ‘70s there were big problems, not anymore.”

The family caregivers seem to think that things have improved since the 1970’s and that the system is more responsive now.

On the other hand, the health care professional agreed that the cultural needs are met with regards to spirituality, whereas the dietary needs are met by the family. One health care professional illustrated this point by saying:

“I thought family met all of the dietary and other demands, if you will. Certainly there are dietary differences, I found. His wife [mentioned a specific patient] would insist on making him his favourite dishes and forcing it into him, somehow. I don’t think it is unusual, specific to this population or people. You know they were meeting all they needed spiritually. There were a whole bunch of community people, and depending on which faith they had. I always felt that their needs were met.”

Discussion and Conclusion:

Content analyses of the preliminary data gathered from four caregivers’ interviews pointed to four themes. Health professionals’ views confirmed the perceptions of the family caregivers. We found expectations of the South Asian family caregivers were somewhat different from those of the care providers, and this can be confirmed when we analyze the views of care providers as there is no Canadian published data to confirm this finding among South Asian immigrants in Canada. Research carried out by Kwak and Salmon (2007) highlighted Korean

Americans' difficulties in accepting that their loved one has approached the end of life. Tang et.al. (2006) reported substantial discrepancies among caregivers and care providers in accepting the diagnosis of a terminal illness and prognosis of the approach of the end of life. His earlier research--on Taiwanese living in Taiwan--found disagreements among even the patients and their caregivers in accepting that their life was approaching the end (Tang, 2006).

Our preliminary data support the view that interdependence and bonding between couples becomes stronger during hospice and end of life. Health care professionals confirmed the bonding between the family caregiver and the patient. Contrary to the Western cultural practice of promoting independence, elderly men and women from Asian cultures value interdependence among family members (Choudry, 2001). It is customary that the seniors live with their children after retirement age, and taking care of elderly parents is considered as a duty of children. Failing to do so would result in societal backlashes for failing to perform duties. Sin (2006) found that in England, Indian immigrant men and women tend to value interdependence more than White British and Indian immigrants favour family care over state-provided services. Our findings support that females, who face English language barriers, rely on their spouse and children more so than the others because family members act as health interpreters. Although it is customary in the South Asian cultures for the woman be the primary care giver, our study findings support that South Asian men willingly took over the caregiver role during their spouse's illness.

Immigrant caregivers and their terminally ill loved ones drew support from a broad range of social networks of individuals in geographic and relationship proximity. Health care professionals noted a strong sense of family among South Asians. Nuclear and extended family members provide the most supportive care needed to the terminally ill patients, while the ethnic and religious community, neighbours and co-workers support the caregivers. We were unable to find published research findings on social network and support given to terminally ill immigrants and their end of life caregivers. However, a research study conducted in Atlantic Canada among healthy individuals found that immigrants drew support primarily from nuclear family and the ethno-racial and religious community to fulfill health needs, such as finding a doctor or dentist or accompanying them to receive primary care (Weerasinghe, 2008). The preliminary findings of this study confirm that similar supportive care networks exist and operate during the end of life stages of South Asian immigrants.

The language barrier for immigrants in accessing health care is well documented in the scientific literature (Hymann, 2001). Similarly, our research findings uncovered several dimensions of language barriers during end of life care for South Asian immigrants. Language interpretation available during hospice care seems to interfere with patients' and caregivers' solidarity during the last few days remaining in their loved one's life. Since the Atlantic immigrant ethnocultural community defined by a single language, race and ethnicity is small, everyone knows each other, so finding a cultural interpreter to preserve anonymity and privacy is a

daunting task. Health care professionals seem to think that the South Asian community in general is conversant in English, so when interpretation is needed, patients and caregivers seek help from family members.

In general, the four family caregivers had a sense of appreciation for the cultural responsiveness of care providers. Health care professionals confirmed that the religious requirements—and, to a certain extent, dietary requirements -- are met by the family. Minor complaints that arose from the family caregivers were related to culturally inappropriate hospital garments, lack of availability of hospital food to accommodate cultural and religious practices, and female patients being attended by male personal caregivers, all of which were supported by earlier research findings about immigrants' access to health care (Weerasinghe, 2000).

Data gathered from four family caregivers and one health care professional revealed interesting findings. In summary, South Asian immigrants who have fulfilled the role of a caregiver were quite positive about the in-hospice end of life care received by their loved one. Occasional minor complaints were related to the cultural insensitivity of the professional homecare providers. Health professionals working in palliative care settings found that South Asian immigrants' cultural and language needs were met. As the study continues, we are recruiting more people to it to acquire additional data to validate the above-stated findings.

Appendix One Interview Guide

Primary Caregiver(s):

1. Tell me about your loved one and his/her illness.

Prompts:

- a. When did you first find out your love one was ill? How did this affect you?
- b. Can you describe what your loved one's life was like during the illness?
- c. At the time of diagnosis, describe the information that you received about the illness, the likely course of the disease, and treatment options?
- d. Were there any language and communication barriers in receiving and obtaining information?
- e. Would you have wanted the news about the illness conveyed to your loved one any differently than it was (say through a family member indirectly or a community leader).
- f. Describe your cultural ritual and habits that you performed (or have been unable to perform since you migrated) during your loved one's illness.

2. Tell me about your journey as a caregiver.

Prompts:

- a. What kinds of challenges did you face as a caregiver?
- b. How did your journey as a caregiver affect you personally?
- c. How did your journey as a caregiver affect your family?
- d. Describe the social support you received from your family, cultural community, neighbours and friends.
- e. Who else was involved in the care of your loved one?
- f. Who cared for you while you were providing care?
- g. What about bereavement care? After your loved one died, how did you cope?

3. What role did spirituality/religion play in your loved one's illness?

Prompts:

- a. For you, your loved one, your family?

4. Was your loved one cared for at home or in hospital (or both)?

Prompts:

- a. How would you describe the care your loved one received during his/her illness at home/in hospital?
- b. What was your loved one's preference for receiving care? (home, hospital or palliative care unit)?
- c. What kind of decision-making did you and your family use? (Who made significant decisions during your loved one's illness?)
- d. What would have made a difference in the care your loved one received at home or in the hospital?

- e. At any point during your loved one's illness, was he/she admitted to hospital, and, if so, was he/she admitted to a general ward or placed in a palliative care unit?
- f. What was your loved one's preference for place of care/death? In other words, where was the preferred place of death: home or hospital?
- g. If your loved one was cared for in hospital, how would you describe the treatment and care received during his/her illness?
- h. Describe cultural conflicts and language and cultural barriers you experienced. What worked well?
- i. What would have made a difference in the treatment your loved one received at home/ in hospital?
- j. If your loved one was cared for in hospital, what would you have wanted his/her professional caregiver to know (or understand) about your culture or religion, for example, about diet, physical comfort, clothing, religious practices, and pain relief, among others.

5. Describe your interaction with the health care system, for example, with your family doctor ,

- a . at the time of diagnosis
- b. during your loved one's illness
- c. as death approached
- d. when your loved one died.

6. Did your loved one use any kind of alternative or complementary healing practices? List and describe, for example, vitamin therapy, massage, acupuncture, prayer, and herb treatment, or others.

Prompt:

- a. Did your loved one visit any alternative healing practitioners? List them, e.g., a naturopath, massage therapist, acupuncturist, or reflexologist.
- b. Did your loved one use any home remedies during his/her illness? Describe them. Why were these home remedies used? Where did you or loved one learn about these home remedies?

7. What does "palliative care" mean to you?

8. What role did your cultural beliefs play in your loved one's end of life care?

Prompt:

- a. What role did spirituality/religion play in your loved one's end of life care?
- b. What would have made a difference in his/her death if you or he/she had been in the country of birth? Is there anything specific about death and dying rituals (from your cultural and religious view) that you would have wanted your caregiver to know or understand?

9. What is the one story you would like to tell about your loved one during his/her illness/ treatment and end of life?

10. Did you, your loved one or your family have any views on organ donation, advanced directives, or euthanasia?

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