

# Cross-Cultural Considerations in Promoting Advance Care Planning in Canada

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Although the Health Canada, Secretariat on Palliative and End-of-Life Care, as well as, the working groups within the Secretariat have ceased to exist (March, 2006) they will leave a legacy of knowledge and useful tools for the public and health professionals in promoting the value of both advance care planning (ACP) and end-of-life care (EOL).

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### HIGHLIGHTS

- Key informants viewed advance care planning (ACP) as important and valuable, however, few Canadians have participated in the ACP conversation or have an advance directive (document).
- Promoting the discussion of death and dying was unappealing but the majority of key informants thought it was necessary.
- Culture is a critical issue in palliative and end-of-life (EOL) care, especially in our ever-expanding diverse country. Despite temptation to have distinct cultural descriptors that fit neatly into a box, these stereotypes and assumptions were not only inappropriate but also inaccurate. All cultures felt that if health care professionals could take the time to understand the individual, this would be the most respectful way to provide a dignified death.
- Although key informants were speaking from their own ethnic background, they consistently expressed that the beliefs, values and traditions were not necessarily shared by all in their cultural group. For example, a Chinese person from mainland China may not necessarily hold the same cultural perspectives as a Chinese person from Hong Kong or Taiwan.
- It is possible to deal with the language barrier but this costs increased time and human resources. Translating materials, providing interpreters and involving community leaders is one way to help break down the communication difficulties.
- ACP may be culturally incongruent for some patients, therefore, health care professionals should identify appropriate alternatives for health planning and decision-making.
- Health care professionals need to consider individual patient/family preferences and society goals in developing specific strategies to overcome barriers to achieving end-of-life care that conforms to the patient's and the physician's values and ideals.
- Although patients and health care professionals generally agree on the value of ACP as the most effective method of preserving patient autonomy and limiting unwanted, futile care at the end-of-life, completion rates of advance directives remain very low.
- The need for professional ACP education across disciplines, especially for nurses and physicians, have been well-documented by many studies conducted during the 1990s yet this area has shown little improvement.
- The literature supports physicians (particularly family physicians) initiating and conducting the ACP conversation, however, this view was not echoed by the key informants we spoke with. Additionally, there was no consensus as to who would be the best person to introduce or facilitate the ACP discussion.
- Creating viable solutions to put ACP into practice in conjunction with normalizing death and dying are the next steps in helping ACP evolve.



## EXECUTIVE SUMMARY

The purpose of this report is to provide insight into how diverse cultural and Aboriginal groups in Canada might respond to advance care planning (ACP) becoming a part of the health care system. We know that the largest and most prevalent cultural and Aboriginal groups may have different perspectives about participating in a conversation that concerns terminal illness, suffering, death, and dying. Our aim is to increase understanding of the diverse perspectives so that we can ensure ACP practices are respectful, sensitive, and not offensive to individuals and their families from various cultural and Aboriginal groups.

We defined culture as **the complex interplay of meanings that represent and shape individual and collective lives of people**. When referring to cultural groups, we are trying to be as inclusive as possible; for example, “cultural” may refer to people of different ethnic backgrounds, persons with disabilities, people sharing the same chronic disease, people living in rural/remote communities, people who share a working environment (e.g., health care professionals), and the Deaf, deafened and hard of hearing.

We gathered information from a number of sources including published research materials, Internet searches and grey literature. We conducted 125 telephone interviews with individuals representing minority groups, Aboriginal groups, health care professionals and organizations. In addition, four focus groups were held which provided insight into the views of Chinese and South Asian cultures.

In general, key informants were positive about ACP and were hopeful that it would be implemented in some fashion so that all Canadians had access to discussing their end-of-life (EOL) wishes. However, although the concept of ACP has been around for the last few decades, the process of having the conversation is still in its infancy. The steps needed to make it a reality were seen as barriers to its success. For example, it was not clear how we could get past bringing up the topic of death. Many key informants commented that we are a death-denying society and were unsure how we could make people more comfortable talking about death and dying, let alone ACP. Moreover, *when* to bring up ACP was also a concern. Should it be done when one is sick or healthy? Young or old?

There were some key themes that emerged that applied to all the ethnic cultural groups. For example, despite speaking from their own ethnic background, the key informants would qualify their remarks, making it clear that there were variations within the culture (except for the Francophone group). The key informants found that communication, including language barriers, was a commonly encountered problem. Regarding ACP, the cultural groups suggested that community leaders or advocates who could not only speak the language but also came from the same ethnic background would be the best person to introduce ACP to the group and help it become more readily accepted. Specific themes for particular ethnic groups were also found.

Key informants from the Aboriginal group discussed specific rituals that they practiced when a loved one was dying and talked about how they valued dying at home. They expressed how the process of having the ACP discussion was strange for them because death was seen as a natural progression of life, and planning for something that was going to happen was incongruent with their beliefs. Key informants who lived in rural communities expressed the hardships

related to having limited access to palliative and EOL care services.

Black Canadians emphasized how important the community was and what an influence the community could have. They reported that ACP was not practiced in their culture because planning for their death would mean that there was no more hope for the person. Black Canadians expressed that lack of communication with health care professionals made them feel left out of the medical system. For example, they were not familiar with medical terminology, especially EOL terms such as “palliative” or “ACP”. Due to these communication barriers some Black Canadians felt that they could not fully participate in their medical care/decisions.

Chinese Canadian informants reported that the topic of death was seen as “unlucky” and a word that they avoided using. When it came to choosing quality or quantity of life, longevity was said to be more important. They mentioned that Chinese patients may find the concept of ACP odd because normally the family would make all the EOL decisions, not the individual/patient. Our Chinese key informants also talked about wanting to protect the family member and not tell them their prognosis which is one of the many issues raised surrounding the value of ‘truth-telling’ in the Western biomedical system.

Filipino key informants emphasized the importance of having a relationship with God and how their Catholic religion played a role in their decision-making at the EOL. They said it was important for the family to care for their loved-ones at the EOL and for family members to die at home with family providing their own brand of palliative care. Because the family plays such a large role at the EOL, Filipino people felt that the ACP conversation should be brought up by and discussed within the family.

South Asian informants viewed dying as the wish of God, therefore planning for one’s death was seen as unnecessary. Like the Chinese informants, they did not like talking about death and the extended family played a large role in patient care. When choosing who would make their medical-decisions should they become incapacitated, gender roles were an important factor.

The Deaf key informants said that ACP was not a concept that Deaf persons were aware of and that knowledge about palliative and EOL services was desired. They expressed a need for health care professionals to gain a greater understanding about suffering in the context of being Deaf and for Deaf people to have access to sign language interpreters at medical appointments and in hospital settings. At the EOL, the ability to sign decreases as the dying person weakens; this makes alternative options necessary to ensure sure the Deaf person’s voice is heard.

We interviewed a number of key informants who were health care professionals (HCP) including: physicians, nurses, social workers, chaplains, and bioethicists. HCP talked about how uncomfortable their colleagues were with the “death discussion” regardless of discipline. They expressed a desire to have adequate training and to evaluate what that training would involve. There was no consensus regarding who should conduct ACP. As it currently stands, it does not appear to fall onto any one person directly and often it is hoped that someone on the team will deal with it. HCP in general preferred to have the ACP conversation early in the disease process and believed it was important to have multiple discussions. That being said, on-going conversations were difficult due to lack of time and resources. Communication was identified as a key issue and in order to overcome the language barrier, HCP were increasingly incorporating interpreters when needed.

Key informants from national and provincial organizations reported that ACP was increasingly being discussed in many palliative care and hospice organizations. Not all organizations have policies regarding ACP; most recognize that it is important but are unclear on the best way to integrate it into practice. Organizations emphasized that flexibility and ongoing communication was integral to effective ACP but the need for flexibility may conflict with institutional

realities. Cost and resources were also highlighted as issues. The organizational key informants were unable to provide us with specific recommendations for cultural groups.

The minority group focus groups were at ease and comfortable in discussing death and dying. We were unsure how the healthy seniors' groups would receive us given the topic of our meeting. However the groups were forthcoming in expressing their thoughts around culture and dying. In addition to commenting on the language barrier, the focus group participants said that they were not familiar with the word "palliative" and due to inadequate translation, the term is difficult to explain. When discussing cultural practices, the Chinese focus group participants mentioned how they would like to see complementary and alternative therapies offered at the EOL.

Recommendations that allow for the further development of ACP in Canada include:

- Public education to help normalize death.
- Clarify what ACP is and offer it as an opportunity.
- Be respectful of all people, regardless of culture.
- Offer training both at the undergraduate level and professional level in palliative and EOL care.
- Conduct research in palliative care/ACP.
- Provide more time and resources for health care professionals to discuss ACP with their patients.

Advance care planning can play an important role in EOL care and the advantages can be seen on the health system, health care professional, and patient/family level. In addition to saving resources for the health care system, it assists health care professionals to know how best to serve their patients during this vulnerable and crucial time. For patients, it offers them the peace of mind of knowing that they will be heard and their wishes respected, while families are not wrought with guilt and anxiety wondering if they are making/made the right decisions. Because ACP can ease the stress and burden at the EOL, it is imperative we make every effort to afford Canadians the opportunity of advance care planning.



## INTRODUCTION

Canada in the 21st century is facing demographic change in the aging of the baby-boomer generation combined with declining birthrates among the Canadian born. An adaptive measure has been encouraging new immigrants to settle in Canada, adding economic stability and greater diversity in language and culture. Advances in health care and technology have increased the longevity of Canadians, but also increased the numbers of people dealing with chronic illnesses and frailty in aging. Thus although medical care and technology can prolong life, they do not necessarily restore health, nor provide quality of life. As a result, the health system is struggling to meet demands while providing accessible, equitable, and quality care. Patients, families, and health care professionals are faced with difficult choices regarding the kind of care and the place of care we want when approaching the end-of-life (EOL).

Since 2000, Health Canada has demonstrated concern for the aging population through strategies such as the development of the Secretariat on Palliative and End-of-Life (EOL) Care. Under this umbrella five committees were established: Best Practice and Quality Care, Education, Research, Surveillance and the Public Information and Awareness Working Group (PIAWG), to deal with various components of palliative and EOL care, policy, planning, education, and standards. Two of these committees were mandated to work specifically in increasing public awareness of palliative and EOL care, as well as promoting advance care planning: the PIAWG and the Advance Care Planning Task Group (ACPTG).

In 2004, the Canadian Institutes of Health Research made palliative and EOL care a priority for funding resulting in ten new and emerging teams across Canada, each of which specified particular areas of research. The Palliative Care in Cross-Cultural Context: A NET for Equitable and Quality Cancer Care for Ethnically Diverse Populations (CIHR Cross-Cultural Palliative NET) was one of the NETs funded in BC. As a multi-disciplinary and multi-provincial team of researchers, its aim is to increase our understanding of the physical, psychosocial, mental, emotional, and spiritual needs of diverse patients and families requiring palliative and EOL care. One of the areas of research interest that developed through collaboration with two BC health authorities was that of advance care planning (ACP). At the request of Health Canada our NET, situated in the Sociobehavioural Research Centre of the BC Cancer Agency, was asked to study ACP from a cross-cultural perspective.

This research paper addresses cultural considerations in promoting ACP in Canada, and builds upon previous work commissioned by Health Canada and the Secretariat on Palliative and End-of-Life Care. ACP was identified as an issue in the Senate report, *Of Life and Death* (The Special Senate Committee on Euthanasia and Assisted Suicide, 1995), and *Quality End-of-Life Care: The Right over Every Canadian* (Subcommittee to update “Of Life and Death” & Standing Senate Committee on Social Affairs, Science and Technology, 2000), and in Health Canada’s *National Action Planning Workshop on End-of-Life Care. Workshop Report* (Tomlinson, 2002). *Health Canada Synthesis Research Project: Integrated End-of-Life Care* (Wilson et al., 2003a), *Still Not There* (Carstairs, 2005), Health Canada’s *Advance Care Planning: The Glossary Project* (Dunbrack, 2006), and the Canadian Strategy on Palliative and End-of-Life Care’s *Advance Care Planning – An Environmental Scan* (Barry Ashpole and Associates, Inc., 2005) are just four more recent reports to identify gaps, trends, and issues in this emerging field.

Advance care planning is one of several initiatives that have grown out of the controversial questions that have emerged as EOL care is practiced. When death is imminent, is life sustaining treatment necessary? Should we prolong cancer patient's lives via artificial or mechanical means despite a patient's inevitable suffering with invasive procedures? What characterizes quality EOL? Canada is a country of diversity and the growing interest in implementing ACP and consideration of the questions just mentioned with respect to EOL have reinforced the need to increase our understanding of how various cultures and Aboriginal peoples will interact with ACP.

The overall objective of this paper is to identify and define cross-cultural issues in ACP and the factors that may influence the responsiveness of cultural and Aboriginal communities to ACP. Various cultural understandings, beliefs, and interpretations of terminal illness, suffering, dying, and death will also be presented.

Specific objectives include:

1. provide a working definition of culture;
2. identify and map the most prevalent and largest cultural and Aboriginal groups for each province and territory;
3. conduct a literature review (published, non-published, grey literature, other sources) related to culture and dying, ACP, and EOL care; and,
4. conduct interviews with Canadians across the provinces and territories to understand who engages in ACP, how and when it is offered, and the barriers and facilitators to ACP.

### 1.1. Advance Care Planning (ACP)

Advance care planning is not clearly understood by many members of the public, health professionals, or health systems' policy and decision-makers. In simplest terms, ACP is a decision-making tool that is meant to ultimately assist individuals in experiencing a "good death". The Institute of Medicine defines a "good death" as "...one that is free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural and ethical standards" (Institute of Medicine, 1997, p. 4). It is a process in which an individual creates instructions and guidelines about their medical care in the event that they are too ill or injured to make decisions or communicate. Often, an individual is named to be a substitute decision-maker during this time.

Health Canada commissioned a report in 2005 in order to bring some clarity to the definition of ACP. In *Advance Care Planning: The Glossary Project* (Dunbrack, 2006), ACP is defined as "a process of reflection and communication in which a capable person makes decisions with respect to future health and/or personal care in the event that they become incapable of giving informed consent. The process may involve discussions with health care providers and significant others with whom the person has a relationship. Advance care planning may result in the creation of an advance directive" (p. 25). Terms including 'living will', 'proxy', 'mandate', 'power of attorney', 'substitute decision-maker', and 'do not resuscitate orders' (DNRs) were often used interchangeably in both the literature and by those we interviewed. In this paper we will translate and adapt such terms to ensure that the meaning is clear while still providing some consistency regarding ACP conversations and directives.



## BACKGROUND

In Canada during the past decade, there have been national, provincial, and association reports identifying the need for palliative care to include ACP as a tool to alleviate prolonged patient pain and suffering at the EOL (Canadian Hospice Palliative Care Association, 2005; Ferris et al., 2002; Lomas, Culyer, McCutcheon, McAuley, & Law, 2005; Quality End-of-life Care Coalition & Kort Consulting Services, 2004). The five committees established by Health Canada working from 2002 through to March 2007 identified areas of interest that required further examination. On their behalf, Health Canada commissioned several reports that speak specifically to Canadian issues regarding EOL care and ACP.

The company, Barry Ashpole and Associates, Inc. was asked in the spring of 2005 by the PIAWG to complete an environmental scan to assess the current activity in ACP in Canada, Australia, and the United States. The report concluded that there was little reliable evidence in Canada that the implementation of ACP ensured that individual's preferences, whether indicated in a conversation, or documented were heeded. A review of provincial and territorial legislation and regulation demonstrated inconsistency in terminology and a lack of clarity in understanding the meaning of various terms and legalities for both health professionals and the general public. While a number of ACP or Advance Directive initiatives were undertaken in several provinces, the integration of this type of tool was fragmented and in the very early stages of any kind of evaluation (Barry Ashpole and Associates, Inc., 2005).

Donna Wilson in her 2003 synthesis of Canadian EOL programs and policies indicates "there is a great deal of disparity in end-of-life care available across Canada" (Wilson et al, 2003b, p.10). She identifies that differing levels of program development exist across regions, provinces, and the country; that mature programs are a result of visionary pioneers and individuals who have lobbied health systems for support; there is need for more supportive action on the part of governments at all levels; that palliative care services are not readily available for non-cancer patients; and that there are too few educated health professionals in the palliative and EOL care field (Wilson et al., 2003b).

In 2006-2007, Health Canada provided funding to the Educating Future Physicians in Palliative and End-of-Life Care (EFPPEC) Project Team for development of an interprofessional education program about ACP. The project created educational competencies in ACP, an ACP facilitator's guide, and is currently completing the curriculum content. Since there are differences in the laws, legislation and regulations across Canada it has been difficult to complete a legal framework that satisfies everyone involved. However, it is hoped that the curriculum will be integrated into the educational programs at several universities in 2008. Although the cultural considerations of ACP have not yet been incorporated into the curriculum, the CIHR Cross-Cultural Palliative NET has submitted a grant that would provide knowledge translation funding intended to facilitate integration of this material.

### 2.1. Culture Definition

Understanding diversity in the EOL is a challenge and one of the difficulties lies in semantics. Concepts such as race, ethnicity and culture are referred to in research, but definitions of these concepts are vast, complex and

often overlapping (Koffman, 2006). As well, recent research suggests that those same terms that have been used interchangeably may be outmoded (Crawley, 2005; Srivastava, 2007). From the section on Statistics Canada's website defining concepts and variables:

*The concept of ethnicity is somewhat multidimensional as it includes aspects such as race, origin or ancestry, identity, language and religion. It may also include more subtle dimensions such as culture, the arts, customs and beliefs and even practices such as dress and food preparation. It is also dynamic and in a constant state of flux. It will change as a result of new immigration flows, blending and intermarriage, and new identities may be formed. There are fundamental three ways of measuring ethnicity: origin or ancestry, race and identity" (Statistics Canada, 2006a, para. 1).*

While terms like race, ethnicity, and visible minority have been used in the past as population terms based on biology, or common nationality, or physical characteristics such as skin colour, hair type, and body structure to distinguish categories of persons, in the present day some of these terms have become laden with historical and pejorative meanings and stereotypes that are perceived as discriminatory and disrespectful.

Culture is comprised of various elements, layers, and implicit and explicit assumptions with numerous definitions. It is a term that is contested in anthropology and the definition that any anthropologist uses is largely informed by their own theoretical orientation. "Culture" as a term can apply to any group of people who share common values and ways of thinking and acting that differ from another group. The working definition that we will use for culture is: **Culture is the complex interplay of meanings that represent and shape individual and collective lives of people.** This definition is guided by the work of anthropologists James Clifford (Clifford, 1988), Clifford Geertz (Geertz, 1973), George Marcus (Marcus, 1992), and Margaret Lock (Lock & Gordon, 1988), amongst others. Using this definition we can draw from the scientific and social literature that can be quantifiable in terms of ethnicity, minority, gender, socio-economic status and geography, as well as in social dynamics and shared experiences that make meaning in people's daily lives.

In order to orient the use of culture, we used the same framework as the CIHR Cross-Cultural Palliative NET. Based on research findings, the framework identifies three levels of cultural influence: micro, meso, and macro levels. These levels are known to affect the patient and family experiences of palliative and EOL care.

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#### Micro Culture

Culture of palliative patients and family caregivers & beliefs and practices about health and illness that they bring to their health care experience (Kagawa-Singer & Blackhall, 2001; Werth, Blevins, & Toussaint, 2002).

#### Meso Culture

Cultural values & practices of the health professionals providing palliative and EOL care (Fan, 1997; Feser & Bernard, 2003; Surbone, 2003; Werth et al., 2002).

#### Macro Culture

System capacity for cultural competency as it relates to palliative and EOL care & factors that may affect competency such as: socio-economic gradient, systemic and institutional discrimination, and gaps in understanding the interface between culture and health (Diver, Molassiotis, & Weeks, 2003; Smaje, 1995).

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In this study our purpose was to focus on the cultural groups that were the most prevalent in each province and territory (as determined by information obtained from Statistics Canada Census publications). We also focused on the Deaf culture because of the expertise of a member on our Steering Committee.

## 2.2. Minority Cultural Group Maps

In order to map the largest and most prevalent minority cultural and Aboriginal groups across Canada we used the Canada Census Statistics from the 2001 Census. This was the most up-to-date version as the 2006 Census data will not be available until 2008, though there are some statistics that we can provide from Statistics Canada's *Report on the Demographic Situation in Canada 2003 and 2004* (Statistics Canada, 2006b). The following information from the Report's Highlights provides a glance of various aspects of the Canadian population:

- As of January 1st, 2005, Canada's population was estimated at 32,107,000, an increase of 301,300 from January 1st, 2004.
- Approximately two-thirds of Canada's population growth was due to migratory increase, a situation that has been observed for a number of years.
- The number of immigrants admitted to Canada in 2004 reached 235,800. The immigration level in 2002, 2003, and 2004 remained close to the average of 224,600 during the 1990-2004 periods.
- The majority of immigrants who came to Canada between 2002 and 2004 were from Asia, even if the percentage of Asian immigration to Canada has decreased recently, from 62% in 2001-2002 to 57% in 2004.
- 80% of immigrants who chose to settle in Ontario in 2004 did so in the Toronto census metropolitan area. This represented some 100,000 people. As well, the majority (86% and 88% respectively) of Quebec and British Columbia immigrants chose to live in the province's largest cities, namely Montréal and Vancouver (Statistics Canada, 2006b, pp. 1 & 3).

As of 2001 the three largest visible minority groups in Toronto were: South Asian, Chinese, and Black; in Montréal the groups were: Black, Arab/West, and South Asian; and in Vancouver the three largest groups were: Chinese, South Asian, and Filipino. Please refer to Appendix D to view the 1981-2001 within-group exposure index for the three largest visible minority groups in Toronto, Montréal, and Vancouver (Hou, 2004). Please see Appendix E for 2001 counts on visible minority groups. Population minority maps for Chinese, South Asian, Black and Filipino can be found online at <http://atlas.nrcan.gc.ca> (National Resources Canada, 2005).



### 2.3. Aboriginal Peoples Maps

Aboriginal peoples were defined by the Constitution Act of 1982 as North American Indian, Inuit, and Métis, each of which have unique heritages, languages, cultural practices, and spiritual beliefs (Statistics Canada, 2007). However, the Aboriginal Self-Government in *Our Government Today* (Government of the Northwest Territories, 1999) provides the following definitions of Aboriginal peoples:

- Aboriginal Peoples - are the descendants of the original peoples of Canada. According to Section 35 (2) of the Constitution Act, 1982 Aboriginal peoples are defined as Indians, Inuit, and Métis.
- Dene - Aboriginal peoples of the Mackenzie Valley, from Inuvik and Aklavik southwards. Dene groups in the NWT include the Gwich'in, Sahtu Dene, Dogrib, Chipewyan, and South Slavey. Dene speak languages that are distinct from one group to another, but which belong to the same general language family.
- Indian – Section 91 (24) of the Constitution Act, 1867 gives the federal government the responsibility “Indians and lands reserved for Indians”. The Indian Act was passed by Parliament under this constitutional authority.
- Inuvialuit – the Inuit of the Mackenzie Delta and the Beaufort Sea Region.
- Métis – Historically, people of both Aboriginal and non-Aboriginal origins mainly located in the Prairie Provinces and the North West Territories. Métis belong to a distinct group and are defined in the Constitution as one of the Aboriginal peoples of Canada (Government of the Northwest Territories, 1999, p. 10-11).

In the 2001 Census, 976,305 people identified themselves as members of at least one of the Aboriginal groups. North American Indians, also called First Nations peoples made up 62% of the Canadian Aboriginal population, 30% were identified as Métis, 5% as Inuit, and 3% unclassified into any one Aboriginal group (Statistics Canada, 2007). Across Canada Aboriginal people in 2001 populated the territories as follows: 85% lived in Nunavut, 51% lived in the North West Territories, and 23% lived in the Yukon. In the south of Canada the largest numbers of Aboriginal people lived in: Ontario (188,000), British Columbia (170,000), Alberta (156,000), Manitoba (150,000), and Saskatchewan (130,000).

In the metropolitan areas the largest Aboriginal population of 51,000 was in Winnipeg, which also claimed the largest population of Métis (31,000), and the largest population of registered Indians (19,000). The Aboriginal birthrate is much higher than other Canadians contributing to a growth rate of 22% from 1996-2001 in comparison to 3% for non-Aboriginal populations. This increase is also due to an increase in the number of Aboriginals who self-identify. It is projected that by 2017 the Aboriginal population could reach 1.4 million through natural growth alone (Statistics Canada, 2007).

The Aboriginal population experiences a poorer quality of life than non-Aboriginals, particularly the Inuit living in the Arctic. Despite the concerted efforts of Aboriginal self-governments people are experiencing higher overcrowding in housing, lower employment rates, and fewer people graduating from high school (Statistics Canada, 2007). Please see Appendix F for 2001 counts on the Aboriginal population (see Statistics Canada, 2003a; 2003d; 2003e; and, 2003f for Aboriginal Population Maps).

## 2.4. Deaf Culture

Our earlier definition of ‘culture’ suggesting that it is **the complex interplay of meanings that represent and shape individual and collective lives of people** is demonstrated in the elements of Deaf culture. As one of our key informants noted:

*Deaf (upper case ‘D’) is a term that refers to members of a socio-linguistic and cultural group whose language is sign language. In Canada, there are two main languages: American Sign Language (ASL) and Langue des Signes Quebécoise (LSQ). The culturally Deaf share a common sense of pride in their language and culture. They seek each other out for social interaction and emotional support. Deafness is natural to them, a positive cultural identity NOT a disability.*

It is a personal declaration of identity and a sense of belonging to a community that is characterized by a distinctive language (Canadian Association of the Deaf, 2007a). Unlike ethnicity it is not derived from common ancestry, or necessarily shared traditions and beliefs – but as an identity that is carved from similar experiences of a hearing world. The micro, meso, and macro cultural constructs of palliative and EOL care will intersect with Deaf culture offering an opportunity for cultural sensitivity and competence to ensure quality of care and to bring an increased understanding of how this particular culture responds to ACP.

## 2.5. Professional Meso Cultures

This level relates to the cultural values and practices of the health professionals providing palliative and EOL care and/or those implementing ACP. At this level we have individuals from a micro culture who may have differing religious/spiritual backgrounds, values and beliefs which guide their personal lives. At the same time, the individual may exhibit practices, values, behaviours and ethics that are indicative of a professional culture such as physicians, nurses, and social workers. The ways in which these individuals interact with colleagues, patients, and families are a complex interplay of the micro and meso cultural meanings shaping their experiences, perceptions, and actions.

## 2.6. Systems/Institutional Macro Cultures

At this level we introduce yet another overlaying culture when we consider the institutional culture of a particular hospital/care setting and the systems culture represented in the Western model of medicine and bio-ethics. Often times professionals/individuals working within these macro cultures are largely unaware of the cultural context that is layered in how they making meaning of what choices should be offered, who should make decisions, how and what information should be communicated and to whom. When we are talking about the bio-ethics system that is imbued in Western medicine, the macro culture has guidelines and values reflecting the importance of self determination, autonomy in decision-making, the right to know, and truth-telling. Health professionals make diagnoses from a disease construct and attribute causality to patho-physiology and what science has proven (Solomon, Romer, & Heller 2000).

Consider a terminally ill person whose micro culture values family decision-making, who believes that the cause of illness is due to imbalance of body, mind and soul and whose family has protected them from knowing the prognosis of their illness. How will this person’s values and beliefs assist them to make meaning of the meso and macro cultures they are surrounded by in the health system? How will the health professionals in the system begin to draw out and understand such an individual’s preferences for EOL care (Kleinman, 1978)? Much of the literature suggests that cultural competence, sensitivity, and knowledge are the answers in making meaning of one’s own or another’s culture; the responses from many key informants suggest otherwise. Bridging the cultural gap is addressed later in the report.

The Canadian health system is influenced by other Western systems located in the United States, United Kingdom,

Australia, Northern Europe, and international bodies such as the World Health Organization. The patterns of ACP growth in the United States and Australia, in particular, have had an impact on the evolution of ACP in Canada. The following references identify issues that many of the developed countries are dealing with, as we are in Canada, which are reflective of economic and resource concerns in EOL care.

Robert Blank recently edited a 12 country cross-national study about EOL decision-making (Blank & Merrick, 2007). In the introduction he suggests that decisions about the ending of life are now, in many societies, a matter for public policy and ethical debate, and less about religious and cultural concepts. The advances in medicine, aging of the baby boom generation in many countries, and concepts of euthanasia have added legal and social dimensions to how we look at death. In 1990 the US signed the Patient Self-Determination Act (PSDA) into law; thus giving consideration to patient's preferences and quality of life in relation to clinical decision-making about life sustaining treatments (Prendergast, 2001).

The development of new technologies has allowed us to extend life beyond past boundaries or past cut-off points for care. This situation has led incrementally to the increasing allocation of health resources to EOL care, a phenomenon that will continue due to rapid aging of the population, and the increasing incidence of chronic disease, as people age. Consequently governments at varying levels are faced with policy-making and decision-making about a number of issues. What services are available, what level of care will be equitable and quality care, how will services be paid for, where do people want to die and what supports are there for different settings (e.g., home versus acute care versus hospice palliative care), how do people with chronic diseases fit within the EOL determination and what services should be available, who will determine when services are offered or withheld (Blank & Merrick, 2007)?

In 2000, the Journal of the American Medical Association devoted an entire issue to EOL care illustrating the array of issues that patients, families, clinicians and the health care system must address (Winkler & Flanagan, 2000). Issues cross the age spectrum from infancy to the elderly, for example, EOL decision-making practices in neo-natal care in ten European countries, euthanasia and physician assisted suicide considered from patient and caregiver attitudes, and access to palliative and hospice care (Emanuel, Fairclough, & Emanuel, 2000; Navari, Stocking, & Siegler 2000; Rebagliato, et al., 2000; Zerzan, Stearns, & Hanson, 2000). These are issues that demand evidence relevant to policy and decision-making for the provision of quality palliative and EOL care; and may influence the extent to which ACP preferences are honoured within the health system.



## METHODOLOGY

### 3.1. Scoping Review of the Literature

The purpose of the scoping review was to identify literature that:

1. addressed the responsiveness of various cultural communities to ACP;
2. identified cultural understandings, beliefs and interpretations of terminal illness, suffering, dying, and palliative care; and,
3. provided background on previous Canadian research activities on ACP including how the influences of micro, meso, and macro cultures might affect ACP implementation.

The review was conducted using the following process which was based on methodology described by National Institute for Health and Clinical Excellence (National Institute for Health and Clinical Excellence, 2005):

- A literature search of relevant databases and a search for grey literature.
- Assessing the titles and abstracts of the references found.
- Purposively selecting documents to be screened that match criteria established.

Extracting limited data that is relevant to research questions. The questions addressed in the scoping review included:

- What cultural groups (populations) make up the fabric of Canada?
- How do these groups identify with terminal illness, suffering, dying and death?
- What do we know about how culture influences engagement in ACP?
- What do we need to know about ACP to ensure care that is culturally acceptable?
- What are the considerations and barriers to minority cultures engaging in ACP?
- What are the cross-cultural considerations?

Ten databases (Ageline, Anthropology Plus, CINAHL, Dissertation Abstracts, EBM Reviews, EMBASE, MEDLINE, PsychINFO, Social Work Abstracts, and Social Sciences Index) were searched to find literature on cultural understandings, responses, beliefs and experiences of ACP, terminal illness, dying, and palliative care (see Table 1). Database searching occurred from January-March 2007. To obtain an overview and awareness of the Canadian literature, only MEDLINE was searched as it is the key bibliographic database for the medical literature and this search was done in September 2007. Searches were based on subject headings, keywords, or a combination of both and limited to English language material from 1980-2007. 1830 citations were retrieved, which included primarily journal citations, but also included books, book chapters, abstracts, and dissertations. Additional detail on search terms is listed in Appendix G.

To manage the search results, the retrieved citations were downloaded into a bibliographic management system, EndNote to assist in removing duplicate citations and to keep track of the citations. (Near the end of the project, the

BC Cancer Agency switched to another bibliographic system, RefWorks, and as a result the Endnote records were converted to RefWorks). Citations were reviewed using an Abstract Review Form to indicate which articles were to be retrieved. Abstract selection was conducted between January – May 2007. Of the 1830 citations obtained from the electronic bibliographic databases, 592 full-text articles were obtained (32%). The 592 full-text articles were further assessed for review in this study. Due to the expanse of the literature retrieved, selection criteria were based on a more refined definition of culture. As well, articles chosen for review had to focus on adults and EOL care rather than on after-death cultural practices.

Of the 592 articles, 146 were selected and then divided among two members of the research team who reviewed and rated the articles based on an Article Review Form. Each article was rated on a scale of 1 to 5 on trustworthiness of results; appropriateness of study design; appropriateness of focus (i.e., applicability to the key research questions) and overall weight of evidence. Papers rated 3.5 or higher were then divided into those which used qualitative/quantitative methods to research ACP and culture (23 articles as summarized in Appendix H) and those which were review articles or were relevant general articles on ACP (36 articles as summarized in Appendix I).

Grey literature was also identified by asking the key informants for recommendations; searching palliative and EOL care organization publications; announcements on listservs; reviewing bibliographies of articles read; searching the library catalogue of the BC Cancer Agency and University of British Columbia; and, searching the Internet websites of various professional associations; government agencies and health-related organizations. Grey literature, as defined by the Grey Literature Network in their Sixth International Conference on Grey Literature held in New York in 2004, is “information produced on all levels of government, academics, business and industry in electronic and print formats not controlled by commercial publishing i.e., where publishing is not the primary activity of the producing body” (D. Farace, GreyNet, Grey Literature Network, personal communication, Nov. 13, 2007). The grey literature obtained for

Table 1 - Search Topics for the Scoping Review

Search Topic	Databases Searched	Area of Interest / Purpose
Advance Care Planning and Culture	Ageline, Anthropology Plus, CINAHL, Dissertation Abstracts, EBM Reviews, EMBASE, MEDLINE, PsychINFO, Social Work Abstracts, and Social Sciences Index.	Identify research regarding cultural response to advance care planning.
End-of-Life and Culture	Ageline, Anthropology Plus, CINAHL, Dissertation Abstracts, EBM Reviews, EMBASE, MEDLINE, PsychINFO, Social Work Abstracts, and Social Sciences Index.	Determine the cultural understandings, beliefs, and interpretations of terminal illness, palliative care and dying.
Advance Care Planning and Canada	MEDLINE	Obtain an overview of medical literature discussing advance care planning in a Canadian context.

this report was not reviewed or rated, however they were a valuable source of information for the study and as a result have been included in the Bibliography.

### 3.2. Key Informant Interviews

The study methods were reviewed by the Chair of the UBC/BC Cancer Agency Ethics Review Board with the determination that a full ethics review was unnecessary since the interviews were being conducted for the purposes of public policy and involved key informants representing specific health-related or culturally-related organizations. The usual practices of keeping data in locked cabinets, and on a password protected personal computer drive were followed. Recruitment of key informants involved mailing a letter under the auspices of the BC Cancer Agency and the CIHR Cross-Cultural Palliative NET providing an explanation of the study goals, several options for contact, and mention that the letter would be followed up by a phone call or email to seek permission for the interview and to determine a mutually convenient time and date.

Using qualitative research methods the team developed interview schedules for use in semi-structured interviews that were reviewed by the Advisory Committee. Each specific schedule was then piloted and revised. Interview questions were developed for three categories of key informants:

1. Organizational (e.g. national or provincial organizations; volunteer organizations, health organizations, hospices);
2. Health care professionals (HCP) (e.g. nurses, physicians, social workers, chaplains, health administrators, home/long term care providers); and,
3. Ethnic/cultural/Aboriginal (e.g. someone of a particular cultural or Aboriginal group).

Interviews were conducted between April – August 2007. Telephone interviews were conducted by trained interviewers using the appropriate schedule and lasted from 45 minutes to 90 minutes, with the average interview approximately one hour in length. Interviews were taped with the key informants consent, transcribed, and analyzed. Key informants were also asked to indicate their willingness to be acknowledged as a contributor to the study (Appendix B). Each informant was offered the opportunity to receive a copy of the finished report.

Data was analyzed using **content analysis** which is an iterative process that can be used to:

1. code key informant interview and/or focus group data in relation to the questions asked, and;
2. to code the data based in grounded theory where the coding is an expression of themes that are informant inspired.

The NVivo software program was used to facilitate coding of verbatim transcriptions in two levels utilizing a constant comparative approach to data analysis (Emanuel, 1996). The two levels include similar ideas or themes grouped together to form thematic codes, and second level codes serve to generate patterns amongst the concepts, and illuminate the properties that describe each code. Concepts are compared and contrasted across interviews and similarities and differences are highlighted.

The key informant list began with a list of 67 core individuals or organizations. The individuals were people who had either been involved with Health Canada's Secretariat on Palliative and End-of-Life Care, the Public Information and Awareness Working Group (PIAWG) or the Advance Care Planning Task Group (ACPTG). Subsequently, additional key informants were found through:

1. referrals;
2. searching the Canadian Hospice and Palliative Care Association's Directory of Hospice Palliative Care Services ([http://www.chpca.net/canadian\\_directory\\_of\\_services.htm](http://www.chpca.net/canadian_directory_of_services.htm)) and the Researcher Registry ([http://www.chpca.net/initiatives/researcher\\_registry.htm](http://www.chpca.net/initiatives/researcher_registry.htm));
3. contacting the presidents of the provincial palliative care associations;
4. contacting the regional palliative care offices and provincial/federal/territorial government health departments; and,
5. searching the Internet for researchers/policy makers or health care professionals and academics in Canada with expertise in palliative care or with knowledge of a large and prevalent cultural group.

Table 2 shows the geographic distribution of the key informants. A total of 334 individuals were identified as being potential key informants. Of these, 269 were contacted by telephone, fax or email and invited to participate in an interview for the study. One hundred and twenty-five of the people contacted were interviewed for the study (see Appendix B - Key Informant List). As necessary, interviews were conducted in French or with Punjabi, Mandarin, and sign language interpreters.

Regarding their backgrounds, the majority of key informants (63%) described themselves as Caucasian (Canadian, European descent). Eleven percent of our key informants were Aboriginal (First Nations, Métis, Inuit, Cree), 7% Chinese, 6% South Asian, and the remainder 13% included Black, Deaf, Filipino, Francophone, Iranian, and Latin American.

The Organizational interview schedule was used in 60 interviews, the HCP interview schedule was used in 48 interviews, and the Ethnic interview schedule was used in 29 interviews. Those informants who fit more than one category may have been asked questions from a combination of schedules. Appendices J, K and L contain the three types of schedules used.

**Table 2– Geographic Distribution of Key Informants**

Province/ Territory	Number of Key Informants Interviewed
British Columbia	30
Alberta	6
Saskatchewan	10
Manitoba	6
Ontario	30
Quebec	10
New Brunswick	4
Nova Scotia	4
Prince Edward Island	4
Newfoundland and Labrador	3
Yukon Territory	8
Northwest Territories	3
Nunavut	7
<b>Total Interviewed</b>	<b>125</b>

The key informants were of different religious backgrounds and/or provided service to people of specific religious backgrounds, such as Jewish, Sikh, Hindu, Muslim, Christian, Hutterite and Mennonite. Many of the key informants indicated that their patients were of a specific population group or mixed groups (listed in alphabetical order): Aboriginal (i.e. First Nation, Métis, Inuit); Black (i.e. Caribbean or African); cancer; Chinese; Deaf; Filipino; Francophone; homosexual; homeless; HIV; Japanese; Korean; Portuguese; renal; and, South Asian.

### 3.3. Focus Groups

Focus group participants were recruited as members of a cultural organization who met regularly as participants in a specific group activity within the organization. All of the focus groups were conducted in June-July 2007. Recruitment was conducted by contacting cultural organizations and speaking with group leaders or program staff. An invitation letter explaining the purpose, providing sample questions, and agreement to provide interpreters was shared with participants to seek their consent. Honorariums were paid to all participants, and a donation was made to each of the organizations. Interpreters were used as needed. Focus groups were taped with the consent of the participants and transcribed. Content was analyzed for themes regarding health system experiences, general EOL, and ACP. Four focus groups were conducted by the study team including the following:

- Two focus groups with 11 participants each were conducted with members of the South Asian Women's Wellness Group comprised of South Asian Punjabi speaking seniors who met regularly to discuss health issues.
- The third focus group was conducted with a Chinese Seniors group consisting of 10 women and men from Mainland China, Taiwan and Hong Kong who regularly met for English as a Second Language class.
- The fourth focus group was conducted with 5 interpreters (3 Chinese; 2 South Asians) who shared their experience in interpreting EOL discussion between patients, family and HCP. They met regularly with the Provincial Language Service.

Each focus group was approximately 1.5 hours long. Interpreters were used in the two South Asian focus groups and the Chinese focus group. A total of 37 participants were involved in the focus groups and individual members who agreed to be acknowledged in the report are found in Appendix C.



## RESULTS

### 4.1. Scoping Review of the Literature

The results of the scoping review begin with summaries about the cultural perspectives from the largest minority groups focused on in this study: Aboriginal, Black, Chinese, Filipino, and South Asian. This will be followed by a section looking at the culture of health care professionals, institutions, and the system itself. The final section will look specifically at ACP in Canada.

Studying ethnic differences can promote stereotypes and this can mask the variation that exists within ethnic groups (Turner, 2005). Generalizations about any group always contain inaccuracies when applied to individuals, families, and even the group itself. Although stereotypes may hold some degree of truth, especially for new immigrants, minority groups living in Canada are clearly a diverse population. Diversity is found among people of varying socioeconomic backgrounds, educational and professional backgrounds, and among generations, with some older people living traditional lifestyles, their children moving easily between cultures, and their grandchildren holding many Western values and living Western lifestyles. The following sections present findings that focus on traditional beliefs and practices at the EOL from cultural perspectives that represent the largest minority groups in Canada and are meant in the spirit that “all cultures are heterogeneous” (Michel, 1994).

#### 4.1.1. *Aboriginal*

According to the 2001 Statistics Canada Census, just over 3% of Canada’s total population was Aboriginal (Statistics Canada, 2003a). Ontario had the highest number of people with Aboriginal identity (188,315 or almost 2% of its population), followed by B.C. (170,025 or just over 4% of its population). Census Metropolitan Areas (CMA) with an Aboriginal population of at least 5% of the total CMA population included Montréal, Ottawa/Gatineau, Toronto, Greater Sudbury, Thunder Bay, Winnipeg, Regina, Saskatoon, Calgary, Edmonton, and Vancouver. This represents 80% of the total Aboriginal population living in all CMAs. Please see Appendix F for a table of the Aboriginal identity population for Canada. Maps of Aboriginal, Inuit, Métis, and North American Indian population distributions can be found online (Statistics Canada, 2003b; 2003d; 2003e; 2003f).

In Canada, there are a number of distinct Aboriginal groups each with their own languages, traditions, beliefs, and values. Like all cultural groups, differences exist not only between individual Aboriginal communities and regional organizations but within each group. Aboriginal persons are seen as a disadvantaged group with major health and social issues. Therefore when considering EOL care it is important to identify what preferences would contribute to a culturally appropriate death. The following summary represents key themes noted in the literature.

Currently, many Aboriginal people living in remote communities are transported to large urban centers to die despite most Aboriginal people preferring to die at home surrounded by friends, family and their cultural community (Hotson, Macdonald, & Martin, 2004). Despite these wishes, provisions for palliative care services and programs for remote native populations have been attempted but there are many challenges to face and implementation has been

difficult (Decourtney, Jones, Merriman, Heavener, & Branch, 2003). Another barrier to offering palliative services was communication. Some elders hold the belief that truth-telling, a widely-held Western practice of care is disrespectful and may be dangerous to one's health (Kaufert, Putsch, & Lavalley, 1998).

Research suggests the following guidelines for care-giving in the Aboriginal community (Ellerby, McKenzie, McKay, Gariepy, & Kaufert, 2000):

1. respect the individual;
2. practice conscious communication;
3. use interpreters (Kaufert, Putsch, & Lavalley, 1999);
4. involve the family (extended family);
5. recognize alternatives to truth-telling;
6. practice non-interference; and,
7. allow for traditional medicine.

In regards to ACP, the National Aboriginal Health Organization's *Discussion Paper on End of Life/Palliative Care for Aboriginal Peoples* states:

*Within an Aboriginal context, the process of explaining the ACP process, finding mutual understanding and making decisions may well involve extended family members. The process may have to be designed to ensure consensus and appropriate respect for traditional forms of decision-making (NAHO, 2002, p. 19).*

#### 4.1.2. Black

The Statistics Canada 2001 Census enumerated 662,200 Blacks living in Canada, up 15% from 573,900 in 1996. This third largest visible minority group represented 2.2% of the country's total population and 17% of the visible minority population (Statistics Canada, 2003g). Many Blacks have a history in Canada dating back several centuries and vary extensively in their roots, with some born in the Caribbean, others in Africa, while yet others have been in Canada for many generations (Milan & Tran, 2004). In 2001, 45% of Blacks were born in Canada and they were a proportionally large component of the visible minority population in all Atlantic provinces and in Quebec: Nova Scotia (57%), New Brunswick (41%), Prince Edward Island (31%), Quebec (31%), and Newfoundland and Labrador (22%).

When conducting the literature review, we came across a plethora of articles regarding Black African Americans. For example, according to these articles many African Americans:

1. believe that the health care system controls treatment;
2. had not heard of advanced directives;
3. wanted to wait until very sick to express their wishes;
4. feared completing advance directives because they thought it would lead to less intensive medical treatment;
5. often select aggressive treatment and life-sustaining measure, regardless of likely futility of effort or the expected quality of life; and,
6. were reluctant to "sign anything" out of fear of exploitation (Eleazer et al., 1996; Perkins, Geppert, Gonzales, Cortez, & Hazuda et al., 2002; Phipps, True, & Murray, 2003).

Some of these findings were explained by poor education (Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000) and

by African American history. Wariness regarding completing an advance directive stemmed from African Americans who grew up in the Deep South under conditions of open segregation and oppression and were likely to be aware of a history of negligent treatment by the medical and research communities (Eleazer et al., 1996). It is not possible to generalize these results to Black Canadians as their history and origins are not the same as the African Americans. A large proportion of our Black population is from the Caribbean and not just Africa.

There is a paucity of research with the Black Canadian population, though the CIHR Cross-Cultural Palliative NET has supported pilot research with the Black Nova Scotian community, which has a fairly lengthy and distinctive history in Canada. As well, a policy forum in 2005, held by the Department of Canadian Heritage provided discussion papers related to various multicultural groups, including the Black and Caribbean Canadian Community (Department of Canadian Heritage, 2005). In a collection of reports prepared for Health Canada on the needs of minority and marginalized populations, it included a study undertaken by the Canadian Centre on Minority Affairs Inc. (CCMA) to provide a preliminary view of health care issues and needs in the Black and Caribbean community in Canada (Canadian Centre on Minority Affairs, 2001). Study findings indicated that systemic discrimination within health care institutions and the lack of culturally sensitive services were barriers to access for this community. Economic disadvantages, unfamiliarity with the Canadian health care system, and the community's reliance on home remedies also influenced the engagement of the Black and Caribbean community's utilization of the system.

The literature review indicated that members of the Black and Caribbean community attribute illnesses to both spiritual and physical causes; and that hospitals are a place to die and should be avoided. Communication was identified as another barrier to health care, though it is more a matter of accents, direct and indirect ways of communicating information, and most particularly, private information and body language which health professionals have difficulty interpreting or understanding. A recommendation from a discussion paper was that health care organizations ought to seek and disseminate cultural information about the Black and Caribbean community that would enlighten health professionals about:

- 
- |  |  |
|--|--|
| 1. values;   | 5. ways of interpreting illness;                   |
| 2. lifestyle;                                      | 6. eating habits; and,                             |
| 3. myths, beliefs and taboos;                      | 7. nutritional value of foods in traditional diets |
| 4. terminology in relation to disease and illness; | (Canadian Centre on Minority Affairs, 2001).       |
- 

Research we found that may also be reflective of Canadian Blacks was done in the United Kingdom with Caribbean Blacks. In one study that looked at satisfaction levels of the family caregiver after the patients' death, found that Caribbean Blacks had larger negative satisfaction ratings and that few Caribbean respondents accessed palliative care services (Koffman & Higginson, 2001). Three years later Koffman & Higginson (2004) compared first generation Black Caribbean and native-born White patients in the UK and studied preference for location of death. Although no patients reported wanting to die in hospital, they found that the majority of patients did (61%). Twice as many Caribbean than White patients preferred to die at home, followed by hospice and residential care and nursing homes.

In another paper (Green, 1992) some traditions and beliefs of Caribbean Blacks were noted including:

1. Christianity is the major religion; and inhibited in the hospital; and,
2. prayer is important;
3. families may feel that the doctors are remote and unapproachable and often feel emotionally restricted
4. often have a lot of visitors including extended family, church and community members/leaders.

Research specifically related to EOL care or ACP with Canadian Blacks was not found.

#### 4.1.3. Chinese

In 2001, the Chinese ethnic group was the largest visible minority group in Canada surpassing one million for the first time (Statistics Canada, 2003g). A total of 1,029,400 individuals identified themselves as Chinese from Hong Kong, Taiwan and Mainland China accounting for 3.5% of the total national population and 26% of the visible minority population (Statistics Canada, 2003g; see also Appendix E and H). Although Chinese immigrants from these three geographical regions have much in common, it is important to recognize the diversity between and among these groups and avoid broad-based assumptions.



Anecdotal and research evidence often suggests that Chinese people are fearful of death and reluctant to talk about it (an inauspicious topic), unassertive and unwilling to express views (conformist), and have strong preferences for family information giving and decision-making (Bowman & Hui, 2000). Evidence from the literature has started to challenge these assumptions. For example, a commonly held norm among Chinese patients and their families is that the family withholds information or lies to the patient regarding diagnosis and prognosis. Payne and colleagues (2005) found that Chinese actually do want to be informed of prognosis and found that there was little support for the common stereotypes of Chinese EOL views. Indeed, they found that the Chinese population in Western cultures held views similar to those in the 'host' country (Payne, Chapman, Holloway, Seymour, & Chau, 2005). Also in contrast to the cultural stereotype, a Calgary study looking at educating Chinese people about palliative care found that participants wanted to know about their illness (Feser & Bon Bernard, 2003).

Communication is an important issue regarding Chinese patients' and families' EOL care (Kemp & Chang, 2002). Evidence suggests that ethnic minorities do not access hospice or palliative care. One possible reason is that in terms of language, there is a lack of a suitable or equivalent term for palliative care and hospice (Feser & Bon Bernard, 2003; Payne et al., 2005) in which to express these options to patients and their families. Another barrier includes translating word-for-word from English to Chinese, as the meaning does not translate properly. There is a need for culturally sensitive translation targeting the culture group rather than word-for-word translation (Feser & Bon Bernard, 2003).

We found one Chinese Canadian study where 40 Cantonese speaking adults over the age of 65 were interviewed to learn about their perspectives on EOL decisions (Bowman & Singer, 2001). The authors' initial objective was to create a culturally appropriate advance directive document; however, this was not achieved as the Chinese seniors rejected advanced directives. The two main reasons for the indifference and negativity towards advance directives was related to:

1. the feeling that it was unrealistic to predict hypothetical future situations in the absence of an actual illness; and,

2. the process of choosing a proxy was felt to limit the opinion of all the family members and impede collective family decision-making.

#### 4.1.4. Filipino

Filipinos comprised 8% of Canada's visible minority population in 2001 (Statistics Canada, 2003g). Similar to Black Canadian literature, we were unable to find research with Filipino Canadians regarding EOL and ACP. One cross-sectional study conducted in the USA found that the overall attitude of Filipinos towards advance directives was positive, however, completion rates and knowledge about advance directives were low (McAdam, Stotts, Padilla, & Puntillo, 2005). A second study from the USA based on studies and publications from the Oncology Nursing Society investigated how culture impacts the health care of cancer patients. A theme that emerged from their work is that culturally sensitive care must be a patient-driven process, and an example used to expand this notion was taken from the experiences of Filipino Americans with relevance to advance directives (Nishimoto & Foley, 2001).

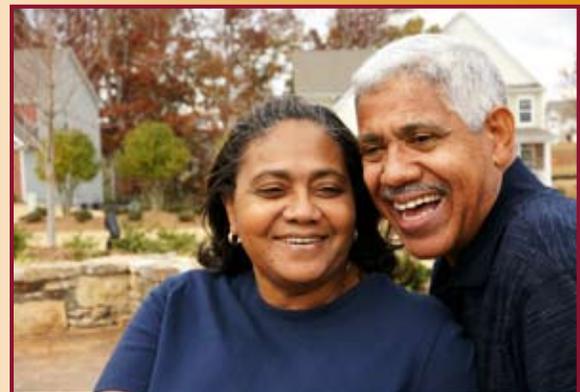
The studies emphasized that the decision to participate in making advance directives can be influenced by the Filipino Americans' belief that the future is in the hands of God and advance directives would be usurping a decision that belongs to God, which is unacceptable. For some Filipino Americans there is a belief that with devout prayer a patient may recover from a terminal illness through a miracle from God, to execute an advance directive would deny the opportunity for God to provide recovery. An interesting comparison made by the authors was that Filipino, Chinese, and Japanese Americans share a belief in the importance of harmony, *pakikisam*. In order to preserve harmony, families might agree with do not resuscitate orders (DNR) to avoid disagreement with a physician, or conversely a patient may change the DNR status in order to preserve harmony if there was disagreement within the family (Nishimoto & Foley, 2001).

Other examples of traditions cherished by Filipino Americans include being respected by health care professionals and asking individuals and families what their cultural needs are before assuming that all people within a culture are alike. Filipino Americans also expressed a desire to die in their homelands, however this was mediated by the presence or absence of extended family members, memories of the homeland and the availability of traditional ritual practices in the USA (Becker, 2002).

#### 4.1.5. South Asian

The South Asian group is the second largest visible minority group in Canada (Statistics Canada, 2003). Between 1996 and 2001, the number of South Asians rose by 37%. According to the 2001 Statistics Canada Census, there were 917,100 South Asians in Canada representing 3.1% of Canada's population and 23% of the visible minority population (Statistics Canada, 2003g; see also Appendix E). They accounted for at least one-quarter of the visible minority populations in Ontario, Newfoundland and Labrador, and British Columbia.

*South Asian (sometimes referred to as East Indian in Canada and Asian Indian in the United States) may be defined as any person who reports an ethnicity associated with the southern part of Asia or who self-identifies as part of the South Asian visible minority group. This definition encompasses people from a great diversity of ethnic backgrounds, including those with Bangladeshi, Bengali, East Indian, Goan, Gujarati, Hindu, Ismaili, Kashmiri, Nepali, Pakistani,*



*Punjabi, Sikh, Sinhalese, South Asian, Sri Lankan and Tamil ancestry. South Asians may have been born in Canada, on the Indian sub-continent, in the Caribbean, in Africa, in Great Britain or elsewhere (Tran, Kaddatz, & Allard, 2005, p. 21).*

A lot of the research on South Asian people was separated by religious faiths: Muslim, Hindu, and Sikh. However, in all practices, both immediate and extended family was a very important aspect to consider at the EOL.

For Muslim patients, the following are some key themes regarding EOL (al-Shahri & al-Khenaizan, 2005; Alibhai & Gordon, 2004; Cheraghi, Payne, & Salsali, 2005; Daar & al Khitamy, 2001; Gatrad & Sheikh, 2002; Randhawa, Owens, Fitches, & Khan, 2003):

- Muslims believe in the afterlife and the Day of Judgment; they regard death as a transition from one phase of existence to the next (Gatrad & Sheikh, 2002).
- Preference is to die at home and care of the dying is a regular and essential responsibility of immediate and extended family life which has historically been managed at home. But with more young Muslims becoming professionals and moving away from their family homes, this is slowly eroding.
- Many families do not wish their dying relative to be informed of the prognosis; aim of EOL care is to reduce anxiety.
- Optimism and hope are regarded as some of the fruits of Faith in Islam.
- Illness & disease is a test from Allah and illness should be received with patience, meditation and prayer.
- Palliative care services were valued and effective but people need to be informed that such services exist.

A study by Doorenbos and Nies in the USA looked specifically at the use of ACP (a living will and/or a durable power of attorney for health care) in a population of Asian Indian Hindus (Doorenbos & Nies, 2003). They were particularly interested in discovering why some ethnic minorities were far less likely to complete at least one form of ACP than Caucasians. The national data showed that only 15% to 20% of the general public completed ACP, despite studies indicating that ACP eased the transition from curative to palliative care and reduced distress for families when the decision to withdraw treatment was made.

Previous studies showed that the law of karma, an important doctrine of Hindu faith, which is related to a belief that life and death are in the hands of God, was a variable in whether ACPs were completed or not (Francis, 1986). Investigating further, Doorenbos and Nies suggested that the Hindu duty to family was another possible variable, particularly if the family wish was for the family member to die at home. In this case, the family was more likely to complete ACPs in order to ensure that the religious rituals could be performed at home, whereas in hospital difficulties often arose concerning their duties to perform in accordance with their religious practices.

Another aspect of the importance of the family decision-making model was that those of the Hindu faith were more likely to use the durable power of attorney part of ACP because it lends itself to proxy decision-making, whereas the living will is based on individual decision-making. If these variables were to hold true in the Canadian context, further research is needed with ethnic minorities to increase our understanding of other factors that might influence the

use of ACP and ultimately the outcomes within the health system.

Sikhism arose from Hinduism and these religions share a culture and world view that include ideas of karma and rebirth, collective versus individual identity, a strong emphasis on purity and a lifestyle based on ayurvedic medicine. These religions affect EOL in a number of ways (Coward & Sidhu, 2000; Gatrad & Sheikh, 2002; Gatrad, Choudhury, Brown, & Sheikh, 2003; Gatrad, Panesar, Brown, Notta, & Sheikh, 2003).

- Talking about death may make it occur so the family is often reluctant to let their loved one know about their terminal illness.
- Preference is to die at home OR hospital. Palliative care units are seen as a place for dying people and may be seen as tainted.
- Withdrawal of food and water at the EOL is not likely to occur because it is believed that both are needed for a good death.
- There is a reluctance to use pain killers as pain must be endured (to help reach a higher state of mind).
- Withdrawal of treatment is OK if it is futile (Gatrad, Choudhury, Brown, & Sheikh, 2003).

#### 4.1.6. Deaf

According to the Canadian Association of the Deaf (2007d, para. 2), “no fully credible census of Deaf, deafened, and hard of hearing people has ever been conducted in Canada” and according to their estimates, in 2006 there are “approximately 310,000 profoundly deaf [*sic*] and deafened Canadians and possibly 2.8 million hard of hearing Canadians” (Canadian Association of the Deaf, 2007d, para. 1).

Regarding ACP, the Canadian Association of the Deaf on Seniors have written a position paper that highlight some relevant information regarding the issue of ACP (Canadian Association of the Deaf, 2007c). In particular, they express concern about Deaf seniors’ wishes being ignored and therefore, their preferences not being respected.

*Well-meaning non-Deaf people, including children and siblings, often take control of the lives of Deaf seniors “in their own best interests”, such as by obtaining power of attorney. It is all too easy for non-Deaf people to do this when the Deaf senior is not provided with interpreters, for example at medical assessments, so as to have the senior labelled incompetent to manage his/her own affairs. They may then place the Deaf senior in a nursing home or retirement residence that suits their own wishes, rather than placing them in a Deaf-aware environment or allowing them to continue living independently (Canadian Association of the Deaf, 2007c, para. 7).*

In the literature search, articles were found that pertained to Deaf people and EOL care. Salladay and San Agustin (1984) provide an overview of the needs and concerns of the Deaf patient. Despite offering checklists of “do’s” and “do not’s” when working with Deaf patients, they stress that communication with Deaf people requires special training from a communications expert skilled in working with the Deaf and/or a member of the patient’s own family. They highlight that it can be doubly difficult for a Deaf dying patient because not only are they handicapped by a physical condition but also by societal attitudes and taboos surrounding both

the handicapped and dying patient.

Allen and colleagues (2002) identified a variety of communication issues that need to be addressed in working with Deaf seniors at the EOL. In their article they overview the unique linguistic and cultural characteristics and provide information for working with Deaf individuals. They emphasize that Deaf individuals are a part of a distinct linguistic and cultural minority group and that their language, the American Sign Language, is not something they choose, rather it is the language of the Deaf community. Moreover, access to information in their language was seen as a barrier and hence, a working alliance between health care professionals, researchers and the deaf community was recommended.

#### 4.1.7. Health Care Professionals

The following three sections summarize the literature regarding specific health care professions: physicians, nurses, and social workers in the context of EOL care and ACP.

##### 4.1.7.1. Physicians

Physicians generally agree that patients should be involved in EOL care decisions. Solomon and colleagues (1993) found that decisions about care at the EOL place a significant emotional burden on health care professionals; about half of the physicians surveyed reported that they had acted against their conscience in providing care to the terminally ill. Four times as many physicians felt that they had provided overly burdensome care as opposed to under treatment at the EOL. Much of the overly burdensome care continues to be delivered, however, and patient preferences are not sought routinely in advance.

There are several reasons why physicians are reluctant to engage in the ACP discussion. Discomfort with EOL discussions is one of the chief reasons (Hudson, 1994). Physicians often report fear of “taking away hope” from patients with a known serious diagnosis, of being the “bad guy” conferring the “death sentence” upon patients. Furthermore, by taking away hope, this may initiate clinical depression or anxiety causing the patient additional distress and hardship. Another major obstacle for many physicians has been a fear of legal repercussions if the advance directive results in limiting care at the EOL. In some cases, this translates into criminal prosecution or malpractice litigation when honouring an advance directive that instructs limiting treatment. For an overview of legislation in the Canadian provinces and territories, see Dunbrack, 2006 Appendix 2 (p. 33).

Physicians also cite time constraints and poor reimbursement (Murphy, 1990) as the chief reasons for failure to implement advance directives more broadly (Hudson, 1994). Physicians recognize the time necessary to complete a meaningful discussion and the fact that the ACP conversation needs to be revisited periodically. This is especially important in light of studies that suggest that many patients who have completed advance directives (ADs) do not understand them (Jacobson, White, Battin, Francis, Green, & Kasworm, 1994; Upadya, Muralidharan, Thorevska, Amoateng-Adjepong, & Manthous, 2002). This implies that physicians need to allow a significant amount of time for a thorough, unhurried conversation. ADs must compete with an overburdened agenda of health maintenance issues, however, as well as the need to address chronic and acute diseases. Physicians must constantly weigh the relative value of the range of possible interventions for each patient. Given the degree of ambivalence and discomfort generally surrounding EOL discussions, it is not surprising that AD conversations frequently are delayed until the eleventh hour.

There are many studies that suggest ACP should be conducted in the primary care setting (e.g., Hallenbeck, 2001; Searight & Gafford, 2005). Aitken (1999) advocates family physicians as being in the ideal position to discuss ACP with their patients. He proposes that family physicians introduce ACP during a routine office visit and at the next visit further discussion can take place including the patient and their proxy. The family physician can be key to facilitating the ACP discussion and many studies offer an approach that will help reduce avoidance of the issues and minimize the

difficulty of discussing issues crucial to patients and their families (e.g., Gallagher, 2006).

Although patients and physicians are both reluctant to broach the topic of ACP (Kohn & Menon, 1988), both groups believe that ACP is valuable (Davidson, Hackler, Caradine, & McCord, 1989; Shmerling, Bedell, Lilienfeld, & Delbanco, 1988). Regarding physicians' own preferences at the EOL, Gallo and colleagues (2003) conducted a study with older physicians to determine if they had discussed their preferences for medical care at the EOL with their physician, whether they had established an advance directive and what life-sustaining treatment they wished in the event of incapacity to make these decisions for themselves. Nearly two thirds of the physicians had completed an advance directive and most physicians believed that their families were aware of their preferences for medical treatment in the event of future incapacity. Most physicians reported that they would not accept CPR or other potentially life-sustaining interventions in the scenario provided, yet less than one-third of physicians believed that their doctors were aware of their treatment preferences. So it appears that physicians do not like talking to their own family doctors about ACP either.

Regarding culture and ACP, the literature acknowledges that discussions with members of minority populations is one area that requires special attention and consideration. For example, in the USA, African-American and Hispanic patients may be more likely to fear that signing an AD will lead to poor care, and this may lead to a desire for more rather than less intervention. Physicians are cautioned to recognize the concerns of minority populations by being particularly careful in emphasizing the intent of the AD to preserve rather than to limit patient autonomy and choice. This may also serve as a valuable opportunity for the physician to gain insight into the patient's health care values, and improving future care. When using this approach, patients report feeling "cared for", not threatened or upset, after a physician-initiated discussion (Caralis, Davis, Wright, & Marcial, 1993).

#### 4.1.7.2. Nurses

The literature regarding nursing and ACP supports the role of nurses in the ACP discussion. For example, the Canadian Association of Critical Care Nurses (1999) issued a position statement regarding advance directives in which they stated, "critical care nurses should act as patient advocates during discussions about advance directives within the health care team or with patients' family members" (p. 11).



Nursing research has found that nurses aid in preserving patients' rights and that their presence was an important factor in helping patients develop advance directives (Brown, 2003; Schrim & Stachel, 1996). Nurses, by their defined role, are educators and advocates in the dissemination of advance directives. Because nurses are more involved in the daily care of terminally ill patients, they are in a position to provide support and information, and make referrals related to EOL decisions (Werner, Carmel, & Ziedenberg, 2004). Further, patients are comfortable with nurses inquiring about ACP (Emanuel, 1993).

Although nurses may perceive it as their role to promote discussion of ACP, in the ETHICUS study (2006), 78.3% of physicians surveyed perceived that nurses were involved in EOL decisions but only 2.1% believed that nurses actually initiated EOL discussions. Not initiating the discussions does not seem to be due to lack of knowledge about advance directives. Grego and Lipp (1998) tested 339 RNs knowledge of ADs. The mean score for knowledge of ADs was 78%. However, 55% indicated that they did not have a good understanding of

ADs. Only 14% had completed ADs for themselves and 92% indicated that further education would increase their understanding of ADs.

There were many reports recommending that nurses need to be given the education, time and institutional support in order to provide the support and information necessary to carry out the ACP discussions. Briggs and Colvin (2002) discuss one organization's educational approach to clarifying the role of the nurse as patient advocate. They highlight how some of the cultural changes required for organizations to build systems that move beyond mere completion of the AD to ACP that affects EOL decision-making.

Regarding working with minority populations, the literature provides suggestions for how nurses can become more culturally competent. Mazanec and Tyler (2003) believe that it is important to define and understand one's own perspective regarding death and dying. They also suggest that barriers to cultural competence are from two sources: those related to HCP and those related to systems. When individual HCP lack knowledge of their patients' cultural practices and beliefs or when HCP beliefs differ from those of their patients, those are HCP barriers. System-related barriers exist because most facilities have not been designed for cultural diversity, favouring instead a one-size-fits-all approach to care. Limitations in personnel or materials may hinder a facility's ability to adjust care to the various ways people approach death and dying. Some settings, such as the ICU, may be unable to accommodate certain needs.

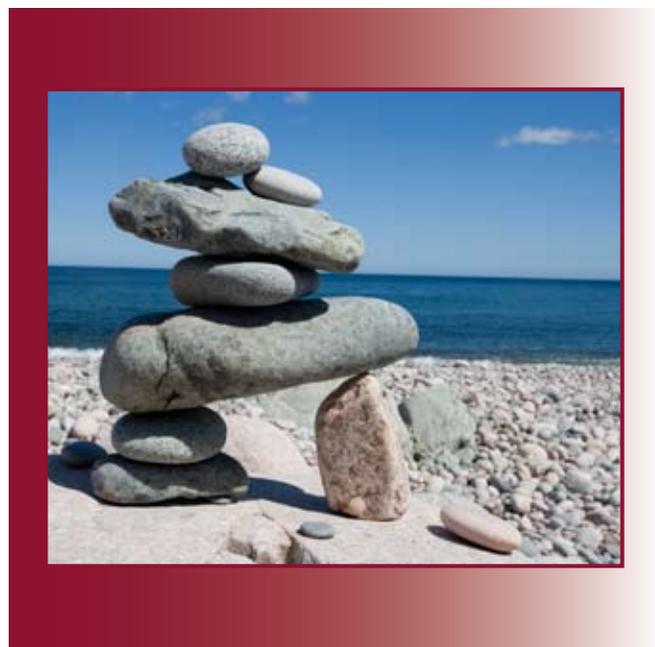
There was also a body of literature that reviewed cultural views on ADs for nurses and models of how to properly assess and provide care for these patients. Giger and colleagues (2006), reviewed cultural views on ADs and provided application of a transcultural nursing assessment model to assess culturally and ethnicity diverse dying patient and the family in an effort to plan culturally appropriate care that recognizes the uniqueness of each client at the EOL. Mitchell and colleagues (2002), found in their study examining criticisms of transcultural nursing theory in EOL care that nurses encounter barriers that impede their ability to provide ideal EOL care in light of the growing cultural diversity of our country, together with the diversification in health care.

#### 4.1.7.3. Social Workers

The literature search revealed a large number of studies in the health care profession and ACP specific to social workers. From the following description of what social work entails, it is easy to see why social workers are a good fit for the task of ACP in general but also with minority populations:

*The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. A historical and defining feature of social work is the profession's focus on individual well-being in a society context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living (National Association of Social Workers, 1999, Preamble, para. 1).*

One distinct message from the literature was that social workers were participating in ACP, playing a very major



role. Black (2004) surveyed 29 social workers and found that social workers frequently and comprehensively address the phases of the advance directive (AD) communication process in their practices with hospitalized patients. Social workers report raising the topic of ADs at a fairly high frequency. In another study that included 213 nurses and 61 social workers, social workers were more involved in discussions with patients and family members compared to nurses (Werner et al., 2004).

Social workers also have a good working knowledge about ADs and a positive attitude regarding ADs. Baker (2000) conducted a cross-sectional investigation with 324 social workers and found that the majority of social workers had high to moderate levels of knowledge about ADs and that they held positive attitudes regarding the AD policy. Social workers with more experience working with the elderly had higher levels of knowledge and those employed in nursing homes and hospice settings had more positive attitudes than did those working in other health care facilities.

Werner and colleagues have looked at social workers' attitudes and beliefs about EOL issues. Werner and Carmel (2001) had 63 Israeli social workers participate in a mailed survey examining social workers' attitudes to life-sustaining treatments and the correlates associated to those attitudes. Findings indicated that social workers' attitudes to the use of life-sustaining treatment were more associated to beliefs regarding life and death than to socio-demographic or professional variables. Similar to the nursing literature, this supports the notion that it is important for HCP who work in this area to examine their own values and beliefs around death and dying. In 2004, Werner et al. found that social workers also expressed stronger beliefs about their involvement in EOL issues compared to nurses. The differences between nurses and social workers reflect professional values and experiences of both groups, and encourage the use of interdisciplinary teams to improve EOL decision-making.

The specific training and skills of social workers are seen as integral to the success of the ACP discussion. A comparative study about interdisciplinary advance directive communication practices with patients found that between physicians, nurses, and social workers, social workers offer distinct skills in their advance directive communication practices and discuss advance directives more frequently than either physicians or nurses (Black, 2005). Social workers' counselling skills enhance individual autonomy and establish patient-provider rapport so that the relationship, along with directed interventions, can be used to foster patient reflection and decision-making. Social work communication skills benefit the HCP teams in discussions about AD. Social work training focuses on developing clear communication practices that translate into clarifying information about ADs. Stein and Sherman (2005) recommend that the next step for social workers' is to be leaders in advocating for changes in policy regarding palliative and EOL care, including ACP.

#### 4.1.8. Advance Care Planning in Canada

As mentioned previously, there have been a number of projects conducted over the last decade to move palliative and EOL care forward on the national agenda. There is no federal law regarding advance directives in Canada, however there are laws in each province and some territories. In June 2000, the Canadian Senate released an update to the *Quality End-of-Life Care: The Right of Every Canadian* report which emphasized a "traditional" view of advance directives including instruction directives, proxy directives and legal documents. They described problems such as interpretation of the instructions, family members disagreeing, not updating the advance directives, and HCP not aware that an advance directive exists. In the update, the committee stated that this "traditional" view (or strictly speaking, production of a document) was the problem with advance directives and suggested moving towards the process of conversation (or ACP) and that advance directions should be seen as part of an overall:

In 2004, the Canadian Hospice and Palliative Care Association and GlaxoSmithKline released the results of an Ipsos-Reid survey of 1055 Canadians (Ipsos-Reid, 2004). Part of this survey assessed attitudes and behaviours relating to ACP. With this sample size the results are considered to accurately reflect, within 3.1 percentage points, the entire adult Canadian population had it been polled. Survey results revealed that:

- 70% of Canadians had not prepared a living will (p. 55).
- The majority of Canadians (eight in ten) agreed that people should start planning for EOL when they are healthy (p.49).
- 47% of Canadians have not designated a surrogate decision-maker (p. 55).
- Fewer than 44% Canadians have discussed EOL care with a family member (p. 53).
- Although Canadians felt that EOL care was an important discussion to have with a physician, only 9% had done so (p. 53).

*...planning and communication process that helps people prepare for death in the context of their loved ones. The preparation of an advance directive can facilitate discussions between people and their family, and provide guidance and support for substitute decision-makers who must make the difficult decisions regarding life-sustaining treatment. If loved ones and medical professionals have engaged in a process of serious communication, the problems associated with the interpretation and application of advance directives are much less likely to occur. The passage to death is eased, the level of comfort rises, and the burden of care is lightened for the substitute decisions-maker (Subcommittee to update "Of Life and Death", & Standing Senate Committee on Social Affairs, Science and Technology, 2000, Part 1, B5 - Advance Directives section, para. 2).*

We found one Canadian article that voiced opposition to advance directives in Canada. Browne and Sullivan (2006) discuss the variety of legislative approaches offered in each province and territory and make suggestions for the best legislation and policies. They express concerns regarding the risks of having an advance directive and are not convinced that most Canadians would be served well by having one. They further state that they are encouraged that no policy exists urging the public to complete them due to the fact that they are not aware of medical costs being saved or quality of life being improved.

One of the premises of ACP is that by allowing patients and their families the opportunity to avoid aggressive therapy or inappropriate prolongation of dying, this may save medical resources. One Canadian study provided support for this. Molloy et al. (2000) conducted a randomized controlled trial to examine the effect of systematically implementing an advance directive program in nursing homes. Using the *Let Me Decide* advance directive program, staff was educated and residents in nursing homes were offered a range of health care choices. The investigators found that the program was able to reduce health care services utilization as there were fewer hospitalizations and less resource use.

Other studies have found that ACP has not had an impact on clinical care nor reduced medical costs and resources (e.g., Teno et al., 1997a; Teno et al., 1997b). Easson (2005) suggests that one of the reasons why we have not been able to see any measurable benefits with ACP lies in our inability to conduct appropriate research. She argues that understanding the complex process of ACP requires medical research to move beyond traditional research methodology

and employ non-quantitative research techniques. By looking at health care professionals, organizations, and health system levels and focusing ACP research on quality improvement rather than as therapeutic research, we can advance and evolve the ACP process.

In the 1990s, Singer conducted a number of studies looking at advance directives in Canada. In a cross-sectional study, he examined the knowledge and attitudes towards advance directives in outpatients (Sam & Singer, 1993). They found that outpatients had positive attitudes towards advance directives but that their knowledge and experience was limited. In a study looking at prevalence of advance directives in long-term care facilities in Canada, less than one third of long-term care facilities had policies on advance directives. These findings lead Singer and colleagues to conclude that despite positive support towards the principle of advance directives, this has not been translated into practice.

As Cohen and colleagues report in their literature review of multiculturalism and palliative care, there were few studies addressing multicultural issues in palliative care with cancer (Cohen, MacNeil, & Mount 1997). Indeed they found one study by Kagawa-Singer (1993) that dealt with Japanese-Americans and Anglo-Americans. Like Cohen et al., we found many editorials and essays about or recommending cultural sensitivity (e.g., Coward & Sidhu, 2000; Ellerby, McKenzie, McKay, Garipey, & Kaufert, 2000) but few studies looking at ACP in Canada.

## 4.2. Key Informant Interviews

The following section discusses themes that emerged from the key informant interviews. The first section will talk about general themes about EOL and ACP that key informants expressed despite cultural membership. This is followed by a section of themes that applied across the minority groups. The third section breaks down the largest minority groups in Canada, health care professionals and the Deaf and hard-of-hearing. Key themes from each group are presented.

### 4.2.1. General Themes

#### 4.2.1.1. Death

One of the barriers most frequently mentioned by key informants impeding the success of ACP was the general unwillingness of people to discuss the topic of death. The majority of key informants reiterated that death was not a popular topic and that whether a person was Caucasian, Aboriginal, Chinese, South Asian or any other minority, the discussion of death was not welcomed, in some cases, even considered taboo. The goals of Western biomedicine are seen to be “cure” and “treat” while patients are encouraged to “fight” and “battle”. Unfortunately none of these are appropriate or even options when patients are at the EOL. This sense of failure has been deemed one of the reasons why health care professionals choose not to talk about death. However, our continued efforts as a society to pretend that death does not exist or will not happen, only further mystifies the EOL process and our understanding of how best to help those in need of palliative care. According to one informant:

*Like in Tim Horton's, you don't see it up on the wall, “We Support the Terminally Ill”. But you see “We Support the Humane Society” or a picture of a little dog or we see “We Support the Children's Wish Foundation” and you'd see a bunch of kids playing. Now I've got nothing against those two groups because they're essential to those organizations and I support them myself but still, when it comes to end-of-life, palliative and end-of-life care, I mean that's going to impact on everyone but it's just something that people don't really care [to see], it's an unpopular subject.*

The key informants were in favour of national campaigns to help normalize and educate all Canadians about death, dying, palliative care, and ACP. By helping to make death a less threatening topic, it would allow people to ask more questions, seek out information and know what options are available when the time comes. Normalizing death and

dying would give people the opportunity to be prepared when health care professionals ask about their wishes for EOL care.

#### 4.2.1.2. Palliative/End of Life Care

There are many specific terms used in EOL care. For example, “hospice”, “palliative care”, and “advance care planning” are just a few that many key informants said were confusing and easily misunderstood. In their experience, patients interpreted these words as “giving up on them”, “taking away treatment”, “sending them away to die”, and “ACP = DNR”. If patients and their families are fortunate enough to be presented with any of these options, the terms are foreign and they do not know what they are being offered. Patients and families are trying to cope with the stressful situation and simultaneously trying to teach them new terminology upon which to make important decisions will only lead to more distress and confusion.

#### 4.2.1.3. ACP

Nearly every key informant expressed a positive attitude towards ACP. Three key points emerged regarding the advantages of ACP. First, the person would have control over their EOL decisions even if they were incapacitated and hence, this would provide peace-of-mind for the patient. Second, ACP also provided peace-of-mind for the family as they would have no guilt or burden in making the decisions and be able to live with knowing that they made the right choices. Lastly, key informants mentioned that ACP could help save resources and medical costs.

To gain a balanced understanding of ACP, we asked key informants what the negative aspects of ACP were. There were no negative comments regarding the concept of ACP, however, two challenges emerged: 1) in order to have a legal document, the cost of a lawyer or notary was seen as a barrier to completing an advanced directive (as a result of having the ACP conversation); and, 2) the need to occasionally review one’s ACP was seen as problematic particularly if this was not done on a regular basis as one’s wishes and preferences can change over time and situation.

In general, most people thought it was not a good idea to wait until the patient was terminal to have the ACP discussion. However, there was no consensus as to how much earlier the conversation should take place. Some suggested introducing the idea as early as high school when one would apply for a driver’s license, while others suggested after the birth of a child, writing of a will, or at their annual physical check-up (which would also be a good time to revisit their ACP).

When asking about ACP, confusion arose as to whether ACP consisted of a conversation, a document or both. Some key informants considered having a signed document with their wishes stated on it a completed ACP while others who had had conversations with patients and their families with no document considered this a completed ACP. Further examination into this difference of opinion revealed that most key informants felt that the conversation was most important. Although the document may be helpful for health care professionals and families not in agreement, some felt that the document could not be trusted depending on when the patient last reviewed it. The process of having multiple ACP discussions with the patient and family produced more confidence in knowing that the patient’s wishes were heard and respected.

#### 4.2.2. General Themes Regarding Cultural Diversity

Although there were themes specific to the largest minority groups in Canada, the following themes were expressed by all ethnic groups:

1. Variation within culture (except for the Francophone group). Although some of the key informants were speaking

from their own ethnic background, they consistently expressed that the beliefs, values and traditions were not necessarily shared by all in their cultural group. For example, a Chinese person from mainland China may not necessarily hold the same cultural perspectives as a Chinese person from Hong Kong or Taiwan.

2. A need for more minority-matched health care professionals to work with these groups. From the point of view of both health care professionals and patients and their families, minority matching was a plus in health care. Patients and families felt that there was an instant bond and understanding, and the language barrier was not an issue. Health care professionals thought they had an easier time “getting their foot in the door” to discuss EOL issues when they were from the same cultural group.
3. Having a community leader or advocate who is trusted and well-respected would help ACP be accepted much faster. Because some of the minority groups would not understand the use or benefit of ACP, key informants were asked who would be best to introduce the idea of ACP so that it would be accepted. Although some suggested physicians or other family members, a well-respected community leader was thought to be the most successful because not only would the community listen to the leader but they would also be more open to hear about ACP.
4. Language was a consistent problem discussed with every minority group. Not only was communication difficult when the patient’s first language was not English but there was also the problem of being able to translate words like “palliative” as that is not a word in many other languages. Particularly for the seniors/elders, it was important to keep the medical jargon to a minimum and explain things in a simple manner.
5. Communication is a fundamental aspect of ACP. Appropriate and inappropriate verbal and non-verbal communication varies and what is acceptable in one culture, is an insult in another. However, despite these differences, key informants reported that the following approach to discussing ACP and EOL issues is all that is needed, regardless of ethnic or cultural background:
  - a. Be respectful and sensitive.
  - b. Prepare for these discussions and make time for them.
  - c. Beliefs are so diverse that it’s important to be comfortable to ask.

The following three sections will provide some of the key themes that emerged from our key informant interviews regarding culture and ACP. The first section includes key themes from ethnic minority groups: Aboriginal, Black, Chinese, Filipino, and South Asian, followed by the Francophone and Deaf cultures. The second section contains results from the health care professional interviews and the final section provides themes for the organizational key informants.

#### 4.2.2.1. Aboriginal

1. Key informants reported that there were common rituals practiced when an Aboriginal person was dying. These examples included: having the community come by and say goodbye to the person for the last time; burning sweet grass; and prayers to name a few.
2. For most Aboriginals, key informants said that they would prefer to die at home and be with family rather than stay alive a little bit longer, alone, in the hospital.
3. The key informants said that Aboriginal people were generally accepting of death because they saw it as a natural progression of life. Therefore, given that death was viewed as a natural process, asking them to plan for it would be odd (i.e., ACP).
4. Key informants told us that in their experience in working with Aboriginal people, many Aboriginal

people valued honesty and knowing the reality of the situation. When dealing with EOL issues (i.e., death and dying), it was suggested to:

*Present the reality, offer choice and show respect.*

5. Interviewees who work with Aboriginal tribes in the North or rural communities reported that Aboriginal people had limited access to palliative care services:

*We don't have the advanced technology that you find in the South [of Canada]. A lot of people have come to accept the fact that we're not going to get the same kind of medical treatment as we are in the South, and for some people, it's a source of frustration that we're not, we don't have the same access to those facilities. So people kind of accept the fact that if something serious does happen there's not always an easy fix to that problem.*

#### 4.2.2.2. Black

1. The key informants said that community was very important because they provided support for each other and the community acted like an extended family.
2. Black key informants reported that ACP was not practiced in their culture because it was an admission that an individual was in a hopeless state:  
  
*In my culture, it [ACP] is never done because it sends a wrong message, both to the sick and the family that you've given up on that individual.*
3. A theme that emerged from the Black key informants was that there was a fear of discussing death and dying among the Black Canadians.

Therefore, trying to bring up EOL issues or ACP was often met with resistance. One key informant said:

*Communication around this topic is tainted with beliefs, suspicion and should only be brought up when there is a relationship built upon trust and rapport.*

4. Some Black key informants expressed concerns about ACP because they were unaware of what it was and what palliative care meant. They said that they did not always feel “welcome” or “accepted to participate” in the medical system. Key informants emphasized that family was very involved with the decision-making process and would be insulted if they were left out.

#### 4.2.2.3. Chinese

1. Many of the key informants reported that talking about death was seen as “unlucky”. As one interviewee said:  
  
*Mentioning death is seen as “taboo” because if you talk about it, you invite it in.*
2. The majority of the key informants said that quantity or longevity was more important than quality of life in Chinese culture.
3. The key informants said that Chinese people valued a “good ending” which was translated to mean being comfortable, peaceful, and surrounded by children/family.
4. It is very important to include the family (“it’s the whole family’s business”); the oldest son would likely be the decision-maker interacting with health care professionals:

*If it’s an elderly person, they would not want to make decisions. They would delegate to the children because number one, they feel uncomfortable that they don’t have as good knowledge to make decisions. And number two, they take it as an honour that the children are making decisions on their behalf.*

5. Interviewees reported that a Chinese family would often want to protect their sick relative and may not tell them their prognosis. As one key informant explains:  
  
*...the family worries that if you tell the sick relative they are going to die, they will give up.*
6. Regarding policy, the Chinese key informants said that Chinese families would find it strange to have an ACP policy because they would have difficulty conceptualizing ACP.

#### 4.2.2.4. Filipino

1. Key informants reported that they had a strong Catholic faith and believed God was responsible when death took place:  
  
*What is very important to me is that in the event I’m already a vegetable just waiting for time, please do not remove it [life support]. I do not like the decision to end my life to be given to a health professional, only God. That’s true, very important to Filipinos because we believe that nothing is impossible. God is the author of life so he is the only one who should know if it is your time. I would like to die naturally and I refuse strongly about removing the life support from somebody who is dying.*
2. Key informants found that Filipino families had

their own “built-in palliative care service” within the family. The Filipino people did not want to put their loved ones in nursing homes or hospitals to die; they preferred to have them be at home where the family would provide the care the patient needed.

3. Because Filipino families liked to look after their own family members at the EOL, ACP should be brought up by the family rather than by health care professionals.
4. The key informants said that discussion of death when people are sick, adds insult to injury. They reported that this discussion could make the patient depressed, and therefore it was better to talk about ACP when people were healthy.

#### 4.2.2.5. South Asian

1. South Asian people viewed terminal illness as “God’s wish”. For that reason, ACP was a foreign concept to them and they did not discuss or plan for their death:  
  
*You can’t plan to die before it is God’s time to take you.*  
  
*You go to death as it happens and as the route unfolds in front of you.*
2. South Asian key informants believed that anticipating one’s future and end, would bring it closer. Therefore in order to conduct ACP, culturally sensitive questions must be asked without telling them that ACP is being done.
3. Like the Chinese key informants, South Asian key informants reported that besides their spouse and children, the extended family played an important role in their EOL care.
4. Key informants said that at the EOL, South Asian people found prayer and connection with God very important.
5. Several of the interviewees reported that South Asian men would not name their spouse as their proxy. South Asian males would name a male relative or male friend whereas South Asian women always named their husband as their proxy.

#### 4.2.2.6. Francophone

1. Most of the key informants reported that there was little to no cultural diversity within the Francophone community. Some interviewees mentioned that there was a cultural difference between generations with older people being less likely to have a mandate (advance directive). However, children watching their aging parents die have been sensitized to the need to prepare their own mandate.
2. Most Quebecois would have their advance directive prepared by a notary rather than a lawyer (more confidence in notaries than in lawyers). With notaries, they discussed the legal aspects of the mandate and suggested to clients to discuss their care wishes with their family and choose a proxy and alternate proxy.

#### 4.2.2.7. Deaf

1. Very few Deaf persons were aware of ACP.
2. The Deaf community said that they needed more knowledge. They suggested adapting information for the needs of the Deaf about illness, death, dying, and palliative care. For instance, educational videotapes in sign language would be a very valuable tool.
3. One key informant said that there was a long standing distrust between people with disabilities and HCP. They believe that:  
  
*Palliative care workers of various disciplines need to gain more knowledge and understanding about suffering in the context of disability.*  
  
They argued that cultural awareness and competence training for HCP was required.
4. Just as ethnic cultures use interpreters, Deaf hospice palliative care workers or volunteers should be used. Also the rights of the Deaf to access sign language interpreting services, when required, must be respected. Efforts must be made to form an

equal partnership between the Deaf and hearing in palliative care.

5. One of the great difficulties for the Deaf was that the ability to sign decreases as the dying person weakens. As one key informant notes:

*At that point, only a close friend could understand what the person is communicating, and not always through sign – perhaps through a gesture or eye motion. Compared to those who can speak (some Deaf persons can), the ability to sign is lost faster than the ability to speak in the dying process.*

6. Key informants commented that Deaf spouses and caregivers need to have more support services. With this support, that they can become an important

#### 4.2.2.8. Health Care Professionals

We interviewed a number of key informants who were health care professionals (HCP) including: physicians, nurses, social workers, chaplains and bioethicists. The following themes were found regarding death, ACP and culture.

1. Health care professionals were surprised that their colleagues were uncomfortable talking about death:

*Dr. XXX was here and did an in-depth study on what state palliative care was in. One of the parts of the study was a questionnaire that he sent around to our physicians and clergy and asked them what their attitude was towards/ what their thoughts were around discussing death with clients/patients/parishioners. There was a large percentage of both groups who were very uncomfortable with it, something that surprised me to no end. I'll be honest with you, because I thought, at least physicians and clergy should be familiar and comfortable talking about death but even those individuals had some reservations about it.*

resource person for Deaf patients.

7. One key informant brought up the fact that there was a seasonal aspect to communication that could improve the effectiveness of workshops for the Deaf community:

*Spring and summer are the best times to raise difficult subjects such as death, dying and ACP because the weather is good, people feel optimistic and strong enough to confront tough subjects. In the fall and winter, people get isolated indoors, a bit depressed and it's harder to bring up difficult subjects.*



Physicians often had the duty to give “bad news” to patients and their families despite not being comfortable or having skills to do so. One possible reason for physicians’ discomfort about talking about death/ACP was that it was in direct conflict with their mandate - that of saving lives.

2. Level of training. Many health care professionals noted that they had not received specific training for palliative care during their education. Most mentioned that they had to look elsewhere for this additional specialized training. A particular component to palliative care training was not just learning about medication but also psychosocial care for patients and families.
3. Key informants suggested that those working in palliative care should take time to reflect on their own thoughts/feelings regarding EOL. Because having the ACP discussion would bring up their own issues about death and dying, HCP should be comfortable and able to cope with their own issues in order to be successful at having these conversations.
4. There was no real consensus on who should conduct ACP whether it was nurses, physicians, social workers, chaplains, but most believe it should be a HCP who was a good communicator or one who had the best rapport with the patients. As one key informant notes:

*I think it should be whoever on the team has the interest and the skill to do so. I think it should be somebody the patient feels comfortable with, and I really think that the patient should be consulted around who they would like to have, and even how you do that matters, you know, how you phrase that questions. It can either be an opportunity or it can cut things off and make patients very frightened by how you approach that.*

The HCP was seen as an expert who could most accurately explain any potential medical situations and help patients with their decision-making.

5. HCP key informants reported that they often felt trapped between a rock and a hard place regarding having ACP conversations because they felt forced into having the ACP conversations. However, they knew that patients/families could not be pushed into having the conversation. As one key informant expressed:

*It would be lovely if there was just a formula [for introducing advance care planning]. For me, I don't think you can ever reduce that, to that kind of formula. I think you get your opportunities, you have to be able to recognize the opportunities as they arise.*

6. HCP felt that ACP was about the conversation and it was an ongoing conversation that takes time. Despite positive attitudes towards ACP and noting the many advantages of ACP, HCP felt that there were not enough resources to conduct ACP in this manner.
7. In addition to having the ACP discussion, HCP felt that having an advance directive or a document at the end of the conversation was important especially from a legal perspective to protect them in the event of disagreement with the family/proxy.
8. The interviewees said that they preferred to deal with ACP as early in the disease process as possible or even when patients were still healthy. In the words of one interviewee:

*Once you just have a diagnosis, people don't want to talk about [ACP] then, because it's like “Wait a minute, I'm fighting this thing and I don't want to talk about that”. Fair enough, because your energy is pretty different and that's a lousy time; it's probably the worst time, you know.*

9. Communication with patient/family/team members was a challenge. Key informants reported that the ACP conversation was difficult to have with patients and their family. They also mentioned that conveying the outcome of the conversation to all members of the care team was hard to accomplish. According to one key informant:

*Somebody has to keep the continuity of that ACP discussion going. So on Monday morning, if I've been involved with a patient from the week before, and we've been having these kinds of conversations with the family, then I will talk with that physician after he's done rounds and say, "Okay, this is what we've been doing with this family". But he should have gotten a report from the physician on Sunday night as well. Not all of them are as good at that as they should be; I think they're pretty good about sharing the medical details but they're not always as good about sharing the advance care planning details.*

And when the patient/family comes from a different ethnic background, this created additional challenges. As another key informant noted:

*There's a belief within Western culture that open conversations, even if they're emotionally difficult, are good for you. And there are many cultures in this world that do not believe that. So overt conversations about death, overt conversations about potential catastrophic and disabling illness, can completely overwhelm people. And the belief that this may be difficult but you will be better off, I think, can almost be an assault if you're not aware of cultural differences when you do these things. You know it's the Western perspective of 'the truth shall set you free'.*

10. In order to help overcome some of the cultural barriers, HCP key informants said that when they were not familiar with another culture, it was important to have an interpreter with the same cultural/health background as their patient; and/or to seek pastoral services.

#### 4.2.2.9. Organizations

There were several similar themes that emerged from speaking to key informants from national and provincial organizations that were congruent with what was found in the health care professional interviews. For example:

1. Many key informants felt that physicians had a potentially critical role to play in addressing ACP with their patients. However, physician-related barriers were often deemed to be a key impediment to ACP. According to one informant, "I think we need to do a lot of work with physicians. I think they need training to have this discussion". Other informants noted that physicians often felt uncomfortable bringing up the issue with patients. Others reported that physicians often did not see the value of ACP. As one informant notes:

*it's like, this is not how these people [physicians] are trained. Death is the enemy and you are a loser if your patient dies.*

2. A key theme running throughout the majority of the interviews was that when ACP takes place, for the most part it often does not happen early enough. As one interviewee succinctly noted "It's a conversation that needs to happen way earlier than it does". In the words of another informant:

*I think there are good services but they haven't been able to deliver them in a coordinated way. So typically... hospice is brought in when, you know, when death is imminent or has already happened, which means those early conversations when advance care planning needs to happen, we're not part of.*

However, consensus did not exist on when the best time to initiate conversations about ACP is. For one informant,

it should ideally happen “...before you're ever diagnosed with any illness. You know ideally it should be a conversation that families are having as part of, you know, just general life planning”. However, another informant expressed the view that:

*...I think that's what so unrealistic to ask people to have advance directives, for everybody to have one, you know. That's what I find so difficult. You know, I think until you're faced with an illness and you then know what the prognosis is, you know, what the probable life expectancy is, and what the options for treatment are, then you can start to make a decision as to what you want.*

3. Communication was seen as another key problem. Specifically, even when those conversations around ACP occur, this information is not necessarily transmitted effectively amongst the various health care professionals connected with the patient in question. As one interviewee noted:

*...everybody and their dog can have an advance care directive, but if nobody at the hospital can find it or knows about it then it doesn't do you any good... So how do you put that information in the hands of the people that need to know, when they need to know? And I think that's as much of the battle as getting people to write them in the first place.*

4. Resources and training were also found to be a challenge with the effective implementation of ACP. Organizations must grapple with whom they are going to employ to conduct conversations about ACP and the resource implications involved. One informant noted that a very good advance care directive takes “at least 30 minutes”. Others emphasized the need for conversations about ACP to take place with “someone specifically trained to be able to have that conversation”. As another informant noted: “...there's such a time constraint, and of course everybody's busy”. For those regions where physicians are expected to play a key role in discussing ACP with their patients, “another [barrier] might be the reimbursement of physicians for the time that it spent – they would have to spend with helping their patients fill out an advance care plan”.

#### The following key themes emerged from an organizational stand point:

1. The interviews with key organizational figures revealed that ACP was increasingly being discussed in many palliative care and hospice organizations. In some cases, ACP policies have been implemented from above and in other cases they have emerged out of the experiences and concerns of clinicians. Although there was regional variation in ACP policies and practices, the overall consensus amongst the key informants appeared to be that ACP is important – although there were a number of concerns about how to integrate it into practice. In the words of one informant:

*Okay, this is a great idea but how do you actually make it work?*

2. The logistics of locating the ACP document were found to be challenging. There was mention about the need for “transferable directives”, pointing out that:



*...very often this difficult discussion has been had with the patient and the family, of what they want, whether they want to be resuscitated, and the decision has been made, and so when the patient moves from one setting to another that discussion should not have to be revisited.*

3. **Making the situation more complicated from an organizational perspective is the fact that people's decisions about ACP change over time.** According to one informant:

*...another thing that's actually come up in discussions with other people in this field is that the social workers that are responsible for doing advance care planning in the extended care facilities are quite frustrated with the process, because what they're finding is, you know, their little old granny will change her mind 84 times and so the advance care directive needs to be changed every time.*

Another informant commented:

*...I think the notion that your advance care directive can change and evolve and needs to be revisited frequently, you know, is important. It's not just a one document you sign one day that then that's it. Because, you know, absolutely things change... so I think it needs to be something that is emerging and not written in stone. And that will lessen the anxiety around doing it.*

However, whilst many informants recognized that flexibility and ongoing communication is integral to effective ACP, in reality this need for flexibility may conflict with institutional realities. As one informant noted:

*...because guidelines and policies are developed that are quite stringent and medicalized at the larger health region level practices that "don't fit the system mould" tend to "ruffle a few feathers".*

4. **Cost came up as an issue.** Several key informants mentioned the cost issues connected with ACP, while others emphasized that cost savings are likely to result long term. As one interviewee noted:

*I'm pretty sure that we would be saving money – that there are people sadly who are in very intensive care situations who really needn't be there, and in fact, don't want to be there.*

Another interviewee emphasized the benefit of ACP in facilitating the responsible use of resources, noting:

*...to waste them futilely, to no benefit I think is unethical, and we've had a hard time coming to that point in health care.*

5. Regarding culture and ACP, the organization key informants were unable to provide us with specific recommendations. In general, there were a number of interviewees working in areas with little cultural diversity so they did not feel the pressure to deal with cultural issues compared to communities with larger diverse populations. Amongst those serving diverse populations there was generally (although not always) a recognition of the importance of having knowledge about cultural diversity and being able to adjust to people's individual needs. Some key informants spoke about the communication issues connected both with the necessity of using interpreters and well as cultural views and traditions in the face of death and dying. However, for some informants, this recognition of the importance of 'culture' was tempered with a sense of the necessity of not generalizing to all people of a particular 'culture.' One informant noted:

*And when I learned about smudging, I thought we could offer that to every Aboriginal. But not every Aboriginal is interested in that. So beside the fact that we have to know what the cultural customs are, we have to keep remembering that every person is an individual and we need to check it out with them whether or not they're interested in pursuing that particular cultural feature.*

Similarly, another interviewee expressed that:

*...to make assumptions about how somebody feels about death and dying based on what you think their culture is, or their ethnicity or their religious beliefs, you know, I think that's really dangerous.*

### 4.3. Focus Groups

The information from the focus groups represents themes that were expressed during the focus group meetings. The South Asian, Chinese and Interpreter focus groups were able to confirm some of the themes found in the key informant interviews (e.g., karma, not talking about or mentioning death, difficulty in translation of “palliative care”, need for community involvement). In addition a few new themes emerged.

The South Asian and Chinese focus groups brought up 4 similar themes:

1. Although the focus group was about death and dying, the participants had many questions about ACP and at the end of the focus group session, wanted more information about it. There was no indication of fear in discussing the topic of death.
2. Focus group participants expressed concerns about the long wait times to see doctors.
3. Extended family has always been considered important in EOL decision-making, however both groups talked about how nowadays, the family is too busy to be able to care for the family member at home.
4. Some members in the focus groups cautioned that care had to be taken when children were made responsible for their parent's EOL decisions because their decision could be influenced by their desire for their inheritance.

#### 4.3.1. South Asian groups

1. As seniors they expressed concern that physicians had little time to spend with them and would only allow them to discuss one issue per visit. They felt that the healthcare system was in decline with physician's having no time to listen, doctors not taking new patients.
2. The participants felt it was important to prepare for death, and therefore, some were open to talking about death.

#### 4.3.2. Chinese group

1. Like the South Asian groups, the Chinese group was forthcoming in their experiences with the healthcare system, death, and dying. They acknowledged that death was a reality and should be something discussed in advance/to prepare for.
2. The participants said that they wished they were able to access complementary and alternative therapies if they were dying.
3. The spiritual well-being of the patient was also important to consider at the EOL.

4. There were a number of questions that the group was interested in discussing suggesting that if an information or educational session was offered, it would be well-attended.
5. The Chinese participants requested to have printed information in Chinese.

#### 4.3.3. Translator group

1. Interpreters for South Asian and Chinese people found that they were often put in a difficult situation when the family did not want them to tell the patient of diagnosis but were simultaneously being pressured to translate what the physician was saying to the patient.
2. Palliative care was often interpreted as “waiting to die” and translators indicated a need to help educate patients and their families that there was still caring in palliative care.



## DISCUSSION

The purpose of this report was to provide insight about how diverse cultural and Aboriginal groups in Canada might respond to advance care planning (ACP) becoming a part of the health care system. By talking to key informants across the country, we were able to determine that ACP is an important and valuable tool that can provide a sense of control, comfort and peace at the EOL. Despite many ethnic groups not knowing what ACP was, they were open to learning more about ACP and how they could participate in their EOL decision-making.

Terminology around ACP was confusing and many people use key terms interchangeably. However, it was clear that whatever one called it, key informants made distinctions regarding the conversation versus the document. Although the document was important for clarification and legal purposes, the process of being able to have the conversation about what one would want in the event that they could not make decisions for themselves was seen as essential from many perspectives:

1. patients felt that their values and beliefs would be respected;
2. families said that they did not have to endure any guilt about having done enough or anxiety about doing the right thing; and,
3. health care professionals reported that it eased their burden of care giving because they knew what was expected of them and that the services they provided were what the patients wanted.

There was fear that signing “a document” was equivalent to signing a DNR order and that patients were essentially consenting to life-limiting treatments without truly understanding what they were signing. Hence, the conversation, although viewed as unpleasant and perhaps depressing, was seen as a key component to go hand-in-hand with the document. In addition, there are few health care systems that have a consistent method of accessing advance directives. Therefore, in the event of not being able to obtain it in a timely manner, having had the conversation with family members or HCP would be pertinent.

HCP also valued the conversation, however, who would be best to initiate this conversation and ensure that ongoing conversations continue was not identified. In Canada there are several different palliative care programs in which a nurse may be responsible; some hospices have volunteers engage in ACP; a few areas have coordinators who are responsible for overseeing ACP; in hospitals it could be social workers, physicians or ICU nurses; in the community ACP may not exist. It was not clear who should lead, especially if there were interdisciplinary teams where everyone was expected to oversee EOL care. However, in primary care, general practitioners were raised as an ideal person to initiate the ACP conversation.

ACP is not the typical medical service that HCP are used to supplying. In a world where time is of the essence and tasks need to be completed “yesterday”, the addition of ACP is not a simple request. Although the merits of ACP may be obvious at first glance, putting ACP into practice and seeing those benefits is a difficult task. Perhaps this is the

reason why much of the research performed in the early 80s and 90s have found little benefit or improvement with the use of ACP. The potential cost-effective implementation of ACP may have been the reason for its apparent failure. The addition of this time- and resource-demanding task to an already overburdened health care system was/is destined for failure. Future research needs to focus on creating systems whereby highly trained clinicians have the time, skills and resources to carry out ACP.

The HCP and organizational key informants were excited to talk about culture and eager for information about how best to serve our diverse nation. Equally excited to have a say about EOL care were key informants from minority groups. This suggests openness on both sides to learning about what the other needs. On an organization level, they were not able to offer specific recommendations to cope with cultural diversity. They did recognize it as an issue and many had global statements such as “respect the individual” that would apply to all cultures and advocated for cultural sensitivity.

The Aboriginal and largest minority groups in Canada, represented by the Black, Chinese, Filipino and South Asian groups provided some specific themes regarding EOL care and ACP. However, in spite of traditions and beliefs that were inherent to particular cultural groups, they carefully framed their remarks by noting that not all people in their culture behave/think/feel/believe as they do. Factors such as generation/age and acculturation played a role in how strongly one held on to traditional beliefs, however, this was not always the case.

Despite the general feeling that people do not like discussing death, the participants in our focus groups were forthcoming in speaking about it and welcomed the opportunity to have this conversation. Many of the focus group participants were seniors and their willingness to participate may be due to the fact that death is a closer event or that they have had more life experience with friends and family who have died. In any event, they were comfortable and had no trouble with the topic or discussion. Focus group members also talked about how the family dynamic was changing as the next generation was too busy to look after aging parents and how staying at home to die was becoming a thing of the past.

### 5.1. Limitations

Some limitations of this study should be noted. First, the sample employed may limit the generalizability of the results. We spoke to people from organizations, particular cultural populations as well as health care professionals across the nation. However, we did not speak to a sufficient number of people in each group to represent every Canadian and the results presented are a snapshot into ACP within those groups. Given unique barriers, whether they are personal, professional or global, how ACP will affect Canadians will differ. Furthermore, stereotyping about specific cultures should always be avoided and the themes in this study speak to the experiences specific to the key informants interviewed.

Second, to fit within our definition of “culture,” we had intended to include key informants who were people with disabilities, however, there were some difficulties finding key informants who represented the disabled community in Canada, as well as in the Caribbean, Haitian, and Filipino community in Central Canada. Although various organizations were contacted requesting recommendations of interviewees for this study or key informants directly, no response was received. Recruitment may have been more successful if there were members of the research team who could make in-person contact with the organizations to discuss the project. Although attempts were made to conduct focus groups across Canada, due to limitations in time, funds and staff, the four focus groups were conducted in British Columbia.

Additionally, there were numerous other cultural groups existing in Canada who fit within our micro, meso, and

macro cultural framework. Certainly the Francophone culture of Quebec and other French speaking communities represent a distinct culture within Canada; however, as they share an equal status with that of the English speaking culture of Canada it did not meet the Health Canada criteria of a visible minority culture. It was important for the purposes of this study to acknowledge other types of culture that do not fit within the notions of ethnicity, geographic origin, or visible minority status. As a result, we focused on the culture of the Deaf, deafened, and hard of hearing, as well as, professional and institutional cultures.

Lastly, as mentioned throughout the report, there was confusion around general medical EOL procedures and terms. We asked all key informants their understanding of ACP and learned that those who work in the area were familiar with the terminology however their patients and the general public were not. “Palliative” was a word that many people did not understand and was thought to involve technology available to prolong one’s life. For example, one key informant’s remark about the inability to access advanced technology in Aboriginal communities appeared to be based on a lack of understanding of hospice palliative care, which is not advanced technology that requires high-tech facilities but rather pain and symptom management and psychosocial support that can be provided at home. Efforts to develop and implement a specialized rural model of palliative care in Canada have recently begun (c.f., MacLean and Kelley, 2001).

## 5.2. Conclusion

Advance care planning is an important process that can ultimately lead to an advance directive. Keeping in mind that some people will never have to use their advance directive, for those that do, it allows them to have a say in their medical care at a time when they may not be able to speak for themselves. As medical technology continues to advance, we are able to prolong life even if it is futile or quality of life is lacking. It brings some comfort to know that there is a choice between being kept alive artificially and having a natural death.

Not all cultural groups will understand or want to participate in ACP because it is not something that fits with their beliefs about death and dying. However, there are minority groups who would benefit from the ACP process but do not have access to it because of location, language, or discrimination. The goal is to be able to offer ACP to everyone so that ultimately, they can have a say in their EOL care. Often this leads to benefits for the family, health care professionals, and the health care system. It is imperative that we pursue this goal to allow every Canadian compassionate EOL care.



## RECOMMENDATIONS

Based on the data we obtained, advance care planning (ACP) has many advantages and is a concept that is supported by Canadians. However, implementation of ACP has been met with resistance and challenges, from lack of training and resources to high reluctance to talk about death. The sustainability of ACP programs has been called into question. In order to have ACP as a routine part of EOL care, the following recommendations are offered as a start to moving ACP forward.

- Public Education - There is a need to organize a national campaign to help Canadians become more comfortable with the topic of death. Death, by all accounts is scary, to be avoided at all costs, and unknown. We do not seek to know about the dying process let alone talk about it until we are forced to. By increasing our understanding of death and dying, it will help to decrease the fear of the unknown and allow people to conceptualize what their “good death” will look like realistically. In order to achieve greater awareness, the following suggestions help to move towards this goal:
  - o Normalization of death and dying.
  - o Increase understanding of death and dying.
  - o Education about what palliative care is.
  - o Information about resources available (e.g. hospice).
  - o Greater understanding of ACP and development of evidence-based practice.
  - o Gauging public response to these campaigns, to gain greater knowledge regarding when is the best time to introduce ACP or who is best to conduct the discussion.
- To implement policy on ACP does not mean that everyone is required to have a document filled out (i.e., an advance directive), but what it does is *offer the opportunity* to every Canadian to have this discussion with their loved ones and/or health care professions so that their voices are heard.
- Participants believed that ACP was essential and had great potential for EOL care. However, making the ACP specific to situation, circumstance, and disease would make the ACP more valid and relevant to each patient/family context.
- Regarding culture, key informants stressed that the beliefs, values and traditions they were expressing were not necessarily shared by all in their cultural group. For example, a Chinese person from mainland China may not necessarily hold the same cultural perspectives as a Chinese person from Hong Kong or Taiwan. Therefore when working with a particular culture, it is critical to keep this in mind.
- Medical schools in Canada should offer Palliative Care, not as an option/elective but a routine part of the

curriculum including ACP, cross-cultural considerations and specific communication/counselling skills needed for EOL care.

- Professional schools should provide incentives for non-mainstream students to complete their studies and establish their practices in high-need communities.
- The Canadian Medical Association or Health Canada should make Palliative Care an official Medical Specialty offered as part of the continuity of care throughout hospitals and care facilities. ACP requires considerable time and resources which a Palliative Care team could be responsible for.
- There is a need for national and provincial funding agencies to provide research dollars for palliative and EOL care research.
- Further research on ACP is also required. ACP is not an exclusive palliative care concept although it is often associated with EOL. For example, it is not clear when ACP would be most effective (i.e., primary care, initial diagnosis, palliative).
- Organizations/health care facilities should create pathways to help guide HCP in their ACP conversations. By providing support and direction, this will assist in dealing with patients who are and are not comfortable with ACP discussions.
- To implement ACP, HCP require training and/or a team (e.g., physician, nurse, social worker, psychologist, chaplain) that not only can handle ACP but is also skilled in dealing with diverse minority groups. Those who open up these types of discussions without training are ill-equipped to deal with the emotional reactions of patients and families and can do more harm than good. Specialized training will also address the concerns of HCP who are not comfortable with conducting the ACP conversation.
- It is important to be respectful of all people, regardless of culture. When a loved one is dying, the situation is particularly emotional and stressful. ACP can be a useful tool to help bring the family together to discuss what is in the best interest of the patient and help make decisions that not only comply with patient wishes but also direct HCP in their care.
- Engage communities to develop outreach programs to ensure that everyone knows about and has access to adequate services.



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## APPENDIX A - STEERING COMMITTEE

**Monica Elaine Campbell** – Member of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care. She has a graduate college certificate in Multidiscipline Palliative Care and is a Palliative Care Volunteer at Friends of Hospice Ottawa, with her work primarily with the Deaf.

**Richard Doll** – Provincial Leader for Cancer Rehabilitation, Director of the Sociobehavioural Research Centre, BC Cancer Agency, and Co-Principal Investigator for the CIHR Cross-Cultural Palliative NET. He is an experienced researcher in a variety of areas including palliative and end-of-life care, supportive cancer care, and knowledge translation.

**Romayne Gallagher** – Palliative Care Physician and the Head, Division of Residential Care and the Physician Program Director for Palliative Care Program, both at Providence Health Care in Vancouver, BC. Dr. Gallagher is also a Clinical Professor in the Division of Palliative Care at the University of British Columbia. She was the Co-Chair of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care.

**Gerard Yetman** –Senior Policy Analyst, Secretariat for Palliative and End-of-Life Care, and the liaison between the project and Health Canada.

## APPENDIX B - KEY INFORMANT LIST<sup>1</sup>

We wish to thank the following key informants who agreed to be interviewed for this study:

1. Zenaida Abanato, Programmer/Statistical Analyst, BC Cancer Agency, Vancouver, BC
2. Ruby Soccoro Arico, Community Member, Vancouver, BC
3. Judith Atkin, Saanich First Nations Adult Care Society, Sidney, BC
4. Dr. Michèle Aubin, Hôpital Laval, Québec, QC
5. Sarb Basra, Renal Social Worker, Kidney Care Centre, Fraser Health Authority, Surrey, BC
6. Sharon Baxter, Executive Director, Canadian Hospice Palliative Care Association, Ottawa, ON and Co-Chair of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care.
7. Dr. Fraser Black, Victoria Hospice, Victoria, BC
8. Roxanne Boekelder, Native Health Consultant, Native Health Services, Pasqua Hospital, Regina, SK
9. Dr. Kerry Bowman, Coordinator, Improving EOL Care Project, University of Toronto, Toronto, ON
10. Lynda Brown, Manager of Community Healthy Living, Pauktuutit Inuit Women of Canada, Ottawa, ON
11. Roxane Brown – Rayner, Palliative Care Coordinator, Sunrise Health Region, Kamsack, SK
12. Jack Cameron, President, Hospice Greater Moncton/du Grand Moncton, Moncton, NB
13. Monica Elaine Campbell, Palliative Care Volunteer, Friends of Hospice Ottawa & Member of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care, Ottawa, ON
14. Donalda Carson, Executive Director, Rotary Hospice House, Prince George, BC
15. The Honourable Sharon Carstairs, Senator, The Senate, Ottawa, ON
16. Jaquie Chambers, Community Care Coordinator, Champagne and Aishihik First Nations, Haines Junction, YT
17. Jas Cheema, Manager, Diversity Services, Surrey Memorial Hospital, Fraser Health Authority, Surrey, BC
18. Gail Chester, Social Worker, Home Care, Yukon Health and Social Services, Whitehorse, YT
19. Alice Choi, Administrator, SUCCESS, Vancouver, BC
20. Glenda Christie, Social Worker, BC Cancer Agency, Vancouver, BC
21. Velda Clark, Director, Palliative Care Program Qu'Appelle Health Region, Regina, SK
22. Linda Cliff, Victoria Hospice, Victoria, BC
23. Tanis Coletti, Manager, Moog and Friends Hospice, Penticton, BC

<sup>1</sup>The key informants listed by name agreed to be acknowledged as a contributor to the study. Those that wished to not to be named in the report have been listed as Anonymous. Details on how key informants were selected and interviewed are described in Section 3.

24. Andrea Conway, Palliative Care Program Coordinator, Queen Elizabeth Hospital, Charlottetown, PE
25. Judy Cutler, Co-Director, Canadian Association of Retired Persons, Toronto, ON
26. Ruth Cyr, Health Promotions Officer - Aboriginal Cancer Care Unit, Cancer Care Ontario, Toronto, ON
27. Janet Dunbrack, Health Policy Consultant, Ottawa, ON
28. Jennifer English, Director of Priority Projects, Home and Community Care and Performance Accountability, Ministry of Health, Victoria, BC
29. Dr. Godwin Eni, Past-President, Vancouver Multicultural Society, Vancouver, BC
30. Professor Lise Fillion, Université Laval, Québec, QC
31. Dr. Marg Fitch, Canadian Strategy for Cancer Control, Toronto, ON
32. Veronica Fobister, Program Manager, Long Term Care Program, Kenora Chiefs Advisory, Kenora, ON
33. Louise Fullerton, Clinical Nurse Specialist, ICU, Montréal General Hospital, McGill University Health Centre, Montréal, QC
34. Dr. Romaine Gallagher, Department of Family and Community Medicine. St. Paul's Hospital, Vancouver, BC and Co-Chair of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care.
35. Graham Gaudet, Executive Director, Hospice Palliative Care Association of Prince Edward Island, Charlottetown, PE
36. Liza Gaudet, Medical Social Worker, Stanton Territorial Health Authority, Yellowknife, NT
37. Jill Gerke, Director of Programs and Services, Hospice Calgary Society, Calgary, AB
38. William Gleberzon, Co-Director, Canadian Association of Retired Persons, Toronto, ON
39. Dr. Judy Globerman, Executive Leader, Care Services, Louis Brier Home and Hospital, Vancouver, BC
40. Amy Go, Executive Director, Ho Lai Oi Wan Centre - Markham, Yee Hong Centre for Geriatric Care, Markham, ON
41. Evelyne Gounetenzi, Canadian Association of the Deaf, Ottawa, ON
42. Sylvie Goyer, Nurse-in-Charge, Igloolik Health Centre, Igloolik, NU
43. Dr. Sydney G. Grant, Director, PCU, Dr. Everett Chalmers Hospital Palliative Care Unit, Fredericton, NB
44. Sue Grant, Project Leader, Advance Care Planning, End of Life Care, Fraser Health, BC
45. Gogi Greeley, Territorial Home and Community Care Coordinator, Population Health, Health and Social Services, NU
46. Nora Hammell, Director, Nursing Policy, Canadian Nurses Association, Ottawa, ON
47. Louise Hanvey, Project Manager, Education Future Physicians in Palliative and EOL Care, Ottawa, ON

48. Dr. Michael Harlos, Medical Director, Winnipeg Regional Health Authority Palliative Care Sub - Program, Winnipeg, MB
49. Karen Henderson, CEO - Long Term Planning Network, Caregiver Network Inc., Toronto, ON
50. Shirley Herron, Retired – Unit Manager, Palliative Care Unit, St. Michael’s Hospital, Toronto, ON
51. Elizabeth Hill, Palliative Care Coordinator, Prairie North Health Region, Meadow Lake, SK
52. Dennie Hycha, Acting Program Director, Capital Health Regional Palliative Care Program in Edmonton, Edmonton, AB
53. Melody Isinger, Ethicist, Canadian Medical Association, Ottawa, ON
54. Pauline James, Manager, Service Redesign and End of Life, Victoria, BC
55. Sandy Johnson, Executive Director, Hospice Greater Saint John, St. John, NB and Member of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care.
56. Rhonda Karliner, Coordinator, St. James Community Service Society (May’s Hospice & St. James Cottage Hospice), Vancouver, BC
57. Sylvia Keall, Palliative Coordinator, Five Hills Health Region, Moose Jaw, SK
58. Dr. Mary Lou Kelley, School of Social Work, Lakehead University, Thunder Bay, ON
59. Donna Kidd, Nurse Practitioner, Queen Elizabeth Hospital, Charlottetown, PE
60. Dr. Malcolm King, Institute of Aboriginal People’s Health, Edmonton, AB
61. Marie-Paule Kirouac, Directrice Générale, La Maison Aube-Lumière, Sherbrooke, QC
62. Karin Kondas, Executive Director, Red Deer Hospice, Red Deer, AB
63. Roy Koshy, Specialty Programs Manager, Community Care, David Thomspson Health Region, Red Deer, AB
64. Linda Kozina, Hospice Manager, Crossroads Inlet Centre Hospice, Port Moody, BC
65. Tina Krieser, Coordinator, Westman Hospice Association, Brandon, MB
66. Johnny Kuluguqtuq, Health Promotion Officer, Dept. of Health and Social Services, Nunavut, Pangnirtung, NU
67. Deborah Kupchanko, Regional Home and Community Care Coordinator, Health Canada, Saskatchewan Regional Office, Regina, SK
68. Suk Han Lai, Medical Social Worker, Toronto Rehabilitation Centre, Toronto, ON
69. Jan Langford, Policy Analyst, Yukon Health and Social Services, Whitehorse, YT
70. Elisa Levi, Public Health Research and Policy Analyst, Assembly of First Nations, Ottawa, ON
71. Marilyn Lundy, Clinical Consultant, Toronto, ON
72. Jade McGinty, Home and Community Care Case Management, Teslin Tlingit Council, Teslin, YT

73. Patty McQuinn, Clinical Nurse Specialist, Tantramar Hospice Palliative Care Organization, Sackville, NB
74. Heny Moise, HIV Clinical Nurse, McGill University Health Centre, St Laurent, QC
75. Dr. David Morrison, Spiritual Care, Queen Elizabeth Hospital, Charlottetown, PE
76. Dr. John Morse, Internist, Stanton Territorial Health Authority , Stanton Medical Centre, Yellowknife, NT
77. Cathy Mosher, Social Worker, Capital District Health Authority, Halifax, NS
78. Dr. Janice Mulder, Executive Director, Hospice & Palliative Care Manitoba, Winnipeg, MB
79. Al-Noor Nenshi Nathoo, Executive Director and Southern Alberta Coordinator, Provincial Health Ethics Network, Calgary, AB
80. Laurie Anne O'Brien, Past President, Newfoundland & Labrador Palliative Care Association, St. John's, NL
81. Dale Orychock, Director, Cape Breton Healthcare Complex Palliative Care Service, Sydney, NS
82. Dr. Fiona O'Shea, Palliative Care Physician, Dr. H. Bliss Murphy Cancer Centre, St. John's, NL
83. Jean-Bernard Parenteau, Notary, Laval, QC
84. Dr. Eileen Peters, Physican, Great Slave Community Health Clinic, Yellowknife, NT
85. Wayne Peterson, Victoria Hospice, Victoria, BC
86. Holly Prince, Research Coordinator, Palliative Care in First Nations Communities, Centre for Education and Research on Aging and Health, Lakehead University, Thunder Bay, ON
87. Shannon Pyziak, Palliative Care Coordinator, Interlake Regional Health Authority, Fisher Branch, MB
88. Monique Raymond, Métis Nation of Ontario, Timmins, ON
89. Gail Redpath, Supervisor, Health Programs, Dept of Health and Social Services, Arctic Bay, NU
90. Dora Replanski, Health Coordinator, AMMSA, Vancouver, BC
91. Patricia Rose, Clinical Nurse Specialist, Royal Victoria Hospital, McGill University Health Centre, Montréal, QC
92. Cathy Routledge, Executive Director, Hospice Yukon, Whitehorse, YT
93. Sita Ram Saroa, Research Assistant, BC Cancer Agency, Vancouver, BC
94. Janice Schnieder, Social Worker, Aboriginal Health and Wellness Centre, Winnipeg, MB
95. Lloyd Searcy, Director of Hospital Services, Baffin Regional Hospital, Iqaluit, NU
96. Hazel Sebastian, Social Worker, Toronto Rehabilitation Centre- Geriatric Rehabilitation, Toronto, ON
97. Ingrid See, Vancouver Home Hospice, Vancouver, BC
98. Elaine Senkpiel, Social Worker, Continuing Care, Yukon Health and Social Services, Whitehorse, YT
99. Kamlesh Sethi, Coordinator, South Asian Senior Women's Wellness, South Vancouver Neighborhood House, Vancouver, BC

100. Sandra Seto, McGill University Health Centre – Montréal General Hospital Site, Montréal, QC
101. Wendy Sherry, Nurse Clinician, Organ and Tissue Donation, Royal Victoria Hospital, McGill University Health Centre, Montréal, QC
102. Rev. Catherine Simpson, Doctoral Candidate, Interdisciplinary PhD Program, Dalhousie University, Halifax, NS and Member of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care.
103. Dr. Rick Singleton, Regional Director, Pastoral Care and Ethics, Eastern Health, St. John's, NL
104. Dr. Joseph H. Springer, Director, Ryerson Caribbean Research Centre, Toronto, ON
105. Rani Srivastava, Deputy Chief of Nursing Practice, Centre for Addiction and Mental Health, Toronto, ON
106. Palmier Stevenson-Young, President, Canadian Caregiver Coalition, Arden, ON and Member of the former Public Information and Awareness Working Group (PIAWG) of the National Strategy on Palliative and End-of-Life Care.
107. Barbara Stewart, Palliative Care Home Nurse Consultant, Capital District Integrated Palliative Care Program, Halifax, NS
108. Karen Svec, Health Programs Manager,, Champagne and Aishihik First Nations, Haines Junction, YT
109. Stella Swertz, President, Saskatchewan Hospice Palliative Care Association, Regina, SK
110. Simin Tabrizi, Operations Leader, Palliative Care Program, Providence Health, Vancouver, BC
111. Jeff Tabvahtah, Research Officer, Ajunniniq Centre, National Aboriginal Health Organization, Ottawa, ON
112. Andrew Tagak, Coordinator of Traditional Inuit Knowledge, Iqaluit, NU
113. Carina Tan-Lucero, Executive Director, Burnaby Hospice Society, Burnaby, BC
114. Michel Turgeon, Executive Director, AIDS Coalition of the Deaf Quebec, Montréal, QC,
115. Ann Vanderbijl, Director, Diversity Services, Providence Health Care, Vancouver, BC
116. Judith Wahl, Executive Director, Advocacy Centre for the Elderly, Toronto, ON
117. Anne Way, Clinical Nurse Leader, Marion's Hospice, Vancouver, BC
118. Kelly Weber, Manager, Home and Community Care, VIHA, Port Alberni, BC
119. Meredith Wild, Manager of Palliative Care Services, Saskatoon Palliative Care Services, Saskatoon, SK
120. May Wong, Client Services Coordinator, Carefirst Seniors & Community Services Association, Scarborough, ON
121. Roberta Wong, Director, Client Care and Community Services, St Paul's L'Amoreaux Centre, Scarborough, ON
122. Laurie Zarazun, Client Care Supervisor, La Ronge Home Care, Mamawetan Churchill River Health Region, La Ronge, SK
123. Anonymous, Health Professional, BC
124. Anonymous, Health Professional, YT
125. Anonymous, Health Professional, SK

## APPENDIX C - FOCUS GROUP PARTICIPANTS

We wish to thank and acknowledge the three organizations who assisted with the focus groups and acknowledge the participants.

### **The Provincial Language Service**

A program of the Provincial Health Services Authority  
Vancouver BC

Manager: Kiran Malli, Quality Assurance and Training Services

### **South Asian Senior Women's Wellness**

South Vancouver Neighborhood House  
Vancouver, BC

Coordinator: Kamlesh Sethi

### **S.U.C.C.E.S.S. (United Chinese Community Enrichment Services Society)**

Senior Quality of Life Project  
Group & Community Services  
Vancouver, BC

Coordinator: Eric Lau

1. Avtar K. Bains
2. Harinder Bedi
3. Shu-Hui Chang
4. G. Cheema
5. Janet Cheng
6. Wei Chia Chia
7. T.L. Chung
8. Amarjit K. Gill
9. Lian Fen Guo
10. Malkiat Kaila
11. Jarina Ladha
12. Shuh Nan Liang
13. S. Manhas
14. Jagjit Kaur Mann
15. Joginder Kaur Mann
16. Rajinder Kaur Ranatua
17. Gurdev Purewal
18. Vimla Sharma
19. Ding Yuan Shen
20. Jagir Kaor Shergil
21. Mohinder Sidhu
22. Pritam K. Singh
23. Chiu-Tung Tam
24. Yin Fun Tam
25. Lily Wei
- 26 - 37. Participants who chose to be Anonymous

APPENDIX D - GROUP EXPOSURE INDEX FOR THE THREE LARGEST VISIBLE MINORITY GROUPS IN TORONTO, MONTRÉAL, AND VANCOUVER, 1981-2001.

		South Asian	Chinese	Black
Toronto	1981	5.8%	9.6%	7.6%
	1991	11.6%	17.4%	10.7%
	2001	20.2%	25.5%	12.8%
		Black	Arab/West Asian	South Asian
Montréal	1981	4.7%	6.4%	2.5%
	1991	7.7%	11.2%	4.2%
	2001	10.2%	7.2%	11.8%
		Chinese	South Asian	Filipino
Vancouver	1981	18.1%	6.8%	2.1%
	1991	24.2%	13.8%	5.4%
	2001	33.4%	24.7%	5.4%

Source: the 20% sample micro-data files from the 1981, 1991 and 2001 Census of Canada

**Table From:** Hou, Feng. 2004. Recent immigration and the formation of visible minority neighbourhoods in Canada's large cities. (Statistics Canada Catalogue No. 11F0019MIE – No. 221). Ottawa. Analytical Studies Branch research paper series. Page 10, Table 2 Retrieved from <http://www.statcan.ca/english/research/11F0019MIE/11F0019MIE2004221.pdf> (accessed October 5, 2007).

## APPENDIX E - VISIBLE MINORITY GROUPS, 2001 COUNTS, FOR CANADA, PROVINCES AND TERRITORIES - 20% SAMPLE DATA

Name	Total population <sup>1</sup>	Total visible minorities <sup>2</sup>	Chinese	South Asian	Black	Filipino
Canada <sup>3</sup>	29,639,030	3,983,845	1,029,395	917,070	662,215	308,575
Ontario <sup>3</sup>	11,285,550	2,153,045	481,505	554,870	411,090	156,515
British Columbia <sup>3</sup>	3,868,875	836,445	365,490	210,290	25,460	64,005
Alberta <sup>3</sup>	2,941,150	329,925	99,100	69,585	31,390	33,940
Quebec <sup>3</sup>	7,125,580	497,975	56,830	59,505	152,195	18,550
Manitoba <sup>3</sup>	1,103,700	87,115	11,930	12,880	12,820	30,490
Saskatchewan <sup>3</sup>	963,150	27,580	8,085	4,090	4,165	3,025
Nova Scotia	897,565	34,525	3,290	2,895	19,670	655
New Brunswick	719,710	9,425	1,530	1,415	3,845	355
Newfoundland and Labrador	508,075	3,850	920	1,005	845	260
Yukon Territory	28,520	1,020	225	205	120	235
Northwest Territories <sup>4</sup>	37,100	1,545	255	190	175	465
Prince Edward Island	133,385	1,180	205	110	370	35
Nunavut <sup>4</sup>	26,665	210	40	25	65	35

<sup>1</sup>Counts for the non-visible minority population are not shown as a separate data column in this table, but are included in the total population data for each geographic area.

<sup>2</sup>Includes population counts for all visible minority groups, including the four groups whose counts are shown separately in this table.

<sup>3</sup>Excludes census data for one or more incompletely enumerated Indian reserves or Indian settlements.

<sup>4</sup>1996 adjusted count; most of these are the result of boundary changes.

**Table From:** Statistics Canada. 2003. Visible Minority Groups, 2001 Counts, for Canada, Provinces and Territories - 20% Sample Data (table). Ethnocultural Portrait of Canada: The Changing Mosaic, 2001 Census. (Statistics Canada Catalogue No. 97F0024XIE2001006). Ottawa. Jan 21. Retrieved from. <http://www12.statcan.ca/english/census01/products/highlight/Ethnicity/Page.cfm?Lang=E&Geo=PR&View=1&Table=1&StartRec=1&Sort=2&B1=Counts> (accessed September 7, 2007).

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## APPENDIX F - ABORIGINAL IDENTITY POPULATION, 2001 COUNTS, FOR CANADA, PROVINCES AND TERRITORIES - 20% SAMPLE DATA

Name	Total population	Aboriginal population <sup>1</sup>	North American Indian	Métis	Inuit	Non-Aboriginal population
Canada <sup>2</sup>	29,639,030	976,305	608,850	292,305	45,070	28,662,725
Newfoundland and Labrador	508,080	18,775	7,040	5,480	4,560	489,300
Prince Edward Island	133,385	1,345	1,035	220	20	132,040
Nova Scotia	897,565	17,010	12,920	3,135	350	880,560
New Brunswick	719,710	16,990	11,495	4,290	155	702,725
Quebec <sup>2</sup>	7,125,580	79,400	51,125	15,855	9,530	7,046,180
Ontario <sup>2</sup>	11,285,545	188,315	131,560	48,340	1,375	11,097,235
Manitoba <sup>2</sup>	1,103,700	150,045	90,340	56,800	340	953,655
Saskatchewan <sup>2</sup>	963,155	130,185	83,745	43,695	235	832,960
Alberta <sup>2</sup>	2,941,150	156,225	84,995	66,060	1,090	2,784,925
British Columbia <sup>2</sup>	3,868,875	170,025	118,295	44,265	800	3,698,850
Yukon Territory	28,520	6,540	5,600	535	140	21,975
Northwest Territories <sup>3</sup>	37,100	18,730	10,615	3,580	3,910	18,370
Nunavut <sup>3</sup>	26,665	22,720	95	55	22,560	3,945

<sup>1</sup>Includes the Aboriginal groups (North American Indian, Métis and Inuit), multiple Aboriginal responses and Aboriginal responses not included elsewhere.

<sup>2</sup>Excludes census data for one or more incompletely enumerated Indian reserves or Indian settlements.

<sup>3</sup>1996 adjusted count; most of these are the result of boundary changes.

**Table From:** Statistics Canada. 2003. Aboriginal Identity Population, 2001 Counts, for Canada, Provinces and Territories - 20% Sample Data (table). Aboriginal Peoples of Canada: Highlight Tables, 2001 Census. (Statistics Canada Catalogue No. 97F0024XIE2001007). Ottawa. Jan 21.  
<http://www12.statcan.ca/english/census01/products/highlight/Aboriginal/Index.cfm?Lang=E> (accessed September 8, 2007).

## APPENDIX G - SEARCH METHODOLOGY

1. For each of the major concepts identified, keywords or related terms were identified as per Table 1.

Table 1 – Concepts and Keywords

Concept	Key Words <sup>1</sup>
Advance care planning	Advance(2w)(directive* or plan or planning) Advance*()care(2w)(directive* or plan or planning) End of life()(plan or planning or care) Substitute decision maker Substituted judgment Express mandate* Representation mandate* or Representation agreement* Personal directive* Instruction directive* Proxy directive* Living will or Living wills (Power of attorney or proxy or directive*) (3w) (health care or personal care or healthcare) Informed consent Do not resuscitate or DNR Withhold* treatment or withdraw* treatment
Culture	Culture or cultural or multicultural* Cross cultural Diversity or disparity or vulnerable Ethnicity or ethnic or ethnology Religion or religious Poverty or impoverished or homeless Disability or disabled or handicap* Race or racial Visible minority Deaf or hearing impaired Blind or visually impaired Sociodemographic* Sociocultural
Dying	Palliative care or Palliative therapy Death or dying Terminally Ill or Terminal Illness or Terminal Care End of Life
<sup>1</sup> Legend *indicates truncation; () indicates adjacency; (#w) indicates words within # word of each other	

When a database was to be searched, the keywords related to each concept were searched in the database's thesaurus to determine the preferred subject heading to be used for the search. If the database did not have an adequate thesaurus; or, the indexing was inconsistent; or, if a multiple databases were being searched at once, then a keyword search was done instead of a subject heading search. Searches were limited to English language articles from 1980-2007.

**Table 2 – Database Search Method & Results**

Database	Search Method	Citations Retrieved <sup>1</sup>
Ageline	Thesaurus terms representing keywords	150
MEDLINE	MESH terms representing keywords	668
CINAHL	Thesaurus terms representing keywords	396
Embase	Keyword	520
PsychINFO	Thesaurus terms representing keywords	248
Social Work Abstracts	Descriptors	50
Social Sciences Index	Descriptors & Keyword	64
EBM Reviews	Keyword	26
Anthropology Plus	Descriptor & keyword	10
Dissertations Abstract	Keyword	48
<sup>1</sup> Total number of citations retrieved also includes duplicate records. Number of unique citations is 1830 as listed in report.		

- Search was done and abstracts downloaded into EndNote bibliographic management software. (The BC Cancer Agency switched to another bibliographic system, RefWorks, and as a result the Endnote records were later converted to RefWorks).

## APPENDIX H- QUALITATIVE OR QUANTITATIVE ARTICLES RESEARCHING ADVANCE CARE PLANNING AND CULTURE<sup>1</sup>

Article <sup>2</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>1</sup>	Topic	Comment
Baker, 2000	Quantitative (mail survey)	324	Health Care	USA	Social Workers	AD	Health care social workers had high to moderate levels of knowledge about ADs & held positive attitudes regarding the AD policy. Social workers with more experience working with elderly had higher levels of knowledge or those working in hospices had more positive attitudes towards ADs.
Black, 2004	Descriptive, questionnaire	29	Hospital	USA	Social Workers	AD	Study showed that social workers played an active role in almost all phases of the AD communication process. Social workers reported a fairly high frequency in raising the topic of ADs & addressing various treatment options. Clear communication skills of social workers helped elicit patient values & identify surrogate decision-makers.
Black, 2005	Comparative, questionnaire	135	Hospital	USA	Social Workers	AD	Focus was social workers interdisciplinary AD communication practices. Results suggested that social workers offer distinct skills in their AD communication practices & discuss ADs more frequently than either physicians or nurses. Only 19% of social workers believed they were spending sufficient time discussing ADs while 55% physicians & 43% nurses believed time spent was sufficient despite spending the least amount of time in AD communication.

<sup>1</sup>As discussed in Section 2, for this research, “culture” is defined as the complex interplay of meanings that represent & shape individual & collective lives of people (i.e. includes people of different ethnic backgrounds; people who share a working environment (like health care professionals, & the Deaf, deafened & hard of hearing).

<sup>2</sup>Articles are listed in the table by author and year (“et al.” is used when there are more than three authors). Full citations to the articles can be found in the bibliography.

**Legend:** ACP=Advance Care Planning; AD=Advance Directive; DNR=Do not resuscitate; EOL=End-of-Life; GP=General Practitioner; HCP=Health Care Professionals; ICU=Intensive Care Unit; LTC=Long-term Care; Pt=Patient; YRS=years

Article <sup>2</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>1</sup>	Topic	Comment
Bowman & Singer, 2001	Qualitative survey	40 (15 male; 25 female; all older than 65)	Toronto Community Centre	Canada (Ontario)	Chinese	ACP & EOL decision-making	Majority of respondents were indifferent or negative towards AD. Some felt it was unnecessary or unwise to predict & anticipate future situations. Naming a proxy was thought to limit the opinions of those who were not named. However, some stated that they would consider ACP if they had a serious illness (i.e. so onset of illness may be best time for HCP to introduce idea of ACP).
Crego & Lipp, 1998	Descriptive, correlational	339	Acute Care Hospital	USA	Nursing	AD knowledge	Assessed nurse's knowledge of ADs. Mean score was 78% correct. 55% indicated did not have good understanding of AD; 14% completed ADs themselves & 92% indicated further education would increase their understanding of ADs. Non-Caucasian nurses had significantly less knowledge about ADs than Caucasian nurses. Suggested that nurses should increase their knowledge & that hospital policy makers need greater awareness of long-term responsibilities for educating persons who convey information about ADs to pts.
Decourtney et al., 2003	Quantitative (cohort study) but mainly narrative		Alaska (34 Alaskan Native villages)	USA	Aboriginal (Alaskan Natives)	Palliative Care program; dying at home; DNR	Described the development & implementation of a palliative care program for remote, native population. Found that program allowed people to remain at home (ie 77% compared to 33% prior to program). Number of DNR orders & out-of-hospital orders also increased after program implementation. Discussed difficulties in developing a program & scientific study in a remote area. Program incorporated contemporary palliative care with traditional customs. Highlighted the importance of developing culturally sensitive program materials.

Article <sup>2</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>1</sup>	Topic	Comment
Ejaz, 2000	Quantitative (cross-sectional survey design)	133 residents (average age 83 yrs old)	13 nursing homes	USA	Jewish, Catholic, Protestant	ACP + DNR	Studied the influence of religion & personal values on life-sustaining treatments. Jewish/Catholic more likely to do an AD. Completion of AD was affected by religion; wanting to make decision or defer to family; personal values; education/knowledge of AD; fear of death/anxiety.
Eleazer et al., 1996	Retrospective chart review	1193	10 Man-aged Care programs	USA	Caucasian, African American, & Hispanic, Asian	AD	Found significant ethnic variations in choice of healthcare wishes (Black, White, Asian).
Kaufert, Pursch, & Lavallee, 1999	Qualitative Interviews	2	Hospital	Canada	Aboriginal	EOL decision-making	Examined problems with interpretation work & cultural mediation. Complex involvement of Aboriginal health workers as pt advocates & cultural mediators.
Koch, Dehaven, & Kellogg-Robinson, 1998	Survey-questionnaire	372	Hospital	USA	African American, Hispanic	AD	Blacks thought they would not be cared for as well & would be treated differently if they had a living will. Blacks & Hispanics wanted to be kept alive regardless of the severity of their illness. Argues ACP on a futility vs. rationing basis & suggests ACP on a community basis.

Article <sup>2</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>1</sup>	Topic	Comment
Lamont & Siegler, 2000	Quantitative (structured interviews)	111	Oncology inpatient service in a tertiary care medical center	USA	African American Cancer pts; White cancer pts	ACP	Studied cancer pts reactions to discussing ACP upon admission & number having AD. Paradoxes revealed: many hospitalized cancer pts had AD but did not want to share ACP preferences with oncologist. However, pts were willing to discuss with admitting staff rather than doctor. Exemplified belief that AD preferences were not seen as part of the scope of oncologist & that preferences were not to be discussed until seriously ill. Belief that ACP discussions interfere with optimism of cure. More than 50% of pts revealed that it was alright to discuss ACP with admitting clerk & this may have been because clerk cannot influence care. Discussed problems with AD: that pt & doctor rarely discuss OR if pt completes a written AD, then doctor is unaware; have found that if there is an AD, it has little influence on care - proxy is often incorrect in substituted judgments.
McAdam et al., 2005	Correlational, cross-sectional	44	Community Hospital	USA	Filipino	AD	Overall attitudes towards ADs were positive although completion rate & knowledge about ADs low. (22 Americans/22 Filipino)
Medvene et al., 2003	Longitudinal	481	17 faith communities	USA	Caucasian, African American, & Hispanic	AD	17 faith-based communities. Developed & evaluated educational project to increase rates of discussion & signing of ADs. African Americans & Hispanics revised/signed ADs at a higher rate than Caucasians.
Mezey et al., 2000	Survey-questionnaire	1016	Tertiary Care Hospitals	USA	Caucasian, African American, & Hispanic	AD	Provided reasons for why people chose or chose not to execute AD. White vs. Hispanic.

Article <sup>2</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>1</sup>	Topic	Comment
Morrison et al., 1998a	Quantitative (survey-questionnaire)	197 subjects over age 65 (65 African American; 65 Hispanic; 67 non-Hispanic White)	Geriatric & internal medicine outpatient clinic in New York City	USA	African American; Hispanic; non-Hispanic White	ACP	Potential barriers to completing health care proxies include: trust in physician; lack of knowledge; availability of health care proxies; belief that it is a burden to the designated proxy; do not have a family member or friend who could act as proxy; comfort level with discussing EOL. Found that religion, educational level & number of yrs in USA did not predict completion rate.
Morrison et al., 1998b	Quantitative (focus groups)	20 (7 African American; 6 Hispanic; 7 non-Hispanic White)	New York Senior Centre	USA	African American; Hispanic; non-Hispanic White	ACP	Barriers identified included: lack of knowledge; discomfort with topic; fear of burdening designated proxy; lack of surrogates.
Morrison et al., 2005	Controlled clinical trial	139	Long term care	USA	Social Workers	ACP	Nursing home social workers were either given an educational session on NY state law regarding ADs (control) or baseline ACP education including workshops, practice sessions, structured ACP discussions, formal structured review of resident's goals, feedback & instruction on charting ADs. Intervention residents were significantly more likely than control to have some of their preferences documented in chart & resulted in a higher concordance between pts prior stated wishes & treatment received.

Article <sup>2</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>1</sup>	Topic	Comment
Perkins et al., 2002	Qualitative (structured, open-ended interviews with blinded content analysis)	58 (26 Mexican American; 18 European American; 14 African American)	2 general medicine wards	USA	Mexican American; European American; African American	ACP	3 Groups shared these themes: had views on life & death that influenced treatment wishes; preferred to have family member as a proxy; liked some aspects of AD; thought AD would improve pt. wishes; that pt/proxy deserved a say in treatment. Identified some shared misconceptions about AD (i.e., was just about making funeral or burial arrangements; were testamentary wills). Lack of use of AD included fear that AD could harm; lack of explanations; fear of obstacles. Outlines differences among the cultures.
Perkins et al., 2004	Qualitative (interviews)	58 (26 Mexican American; 18 European American; 14 African American)	2 general medicine wards	USA	Mexican American; European American; African American	ACP – gender + ethnicity	All groups had a positive attitude toward ACP. Suggest tailoring to ethnic & gender-specific attitudes. Men felt disempowered by the health care system but women felt empowered. Men feared harm from the health care system but women anticipated benefit. Mexican American men preferred death to disability; believed the health care system controls treatment & wanted no “futile life support whereas Mexican American women expressed wishes only about care other than life support (e.g., when & where they wanted to die), believed ADs help staff to know wishes & trusted the system to honour ADs.
Phipps et al., 2003	Qualitative (educational forums for each cultural group & focus groups)	Attendees of forums ranged from 30-61; focus groups ranged from 6-12 participants	Philadelphia	USA	Korean American; African American; Latino	ACP/living will documents	Discusses Community Ethics Program which has an educational initiative to increase knowledge in ACP. All cultures had a fear of discussing death. Advance care documents (e.g. Pennsylvania State Living Will & The Five Wishes) were viewed favorably & seen as useful but found translation needed to be improved.

Article <sup>2</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>1</sup>	Topic	Comment
Romero et al., 1997	Qualitative (structured interview)	883	Bernanillo County	USA (New Mexico)	Hispanic; non-Hispanic White	AD & EOL decisions	New Mexico Elder Health Study. Asked whether participants knew or had a living will/durable power of attorney; asked about life sustaining decisions. Found ethnic differences in responses were significant even after adjusting for the other variables (e.g. sex, age, education etc.).
Shrank et al., 2005	Qualitative - Focus Groups	70	Hospital	USA	Non-Hispanic White, African American	EOL Care	Cultures expressed need for communication about EOL care for a pt. The groups differed broadly in preferences for both content & structure of EOL discussion & values that influence those preferences.
True et al., 2005	Quantitative (interview)	68 (28 male; 40 female)		USA	African American; White	EOL decisions (living wills) & spirituality	Examined differences in using spirituality to cope with EOL decisions. African Americans tended to use spirituality & believed in divine intervention. Those with spiritual coping methods tended to be less likely to have a living will, power of attorney for health care & less likely to want life-sustaining measures.

## APPENDIX I - REVIEW ARTICLES OR SELECTED ARTICLES ON ADVANCE CARE PLANNING

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Aitken, 1999	Review		Family Physician's office	USA	HCP – GP	ACP	Provided overview of ACP & AD. Offered information on how to implement & follow ACP for family physicians. Believed GPs are in the ideal position to discuss ACP.
Arenson et al., 1996	Article		Primary Care	USA	HCP	AD	Overview of beliefs & concerns of pts & physicians regarding ADs. Discussed the AD debate & commented that barriers to ADs include pt & physician discomfort with initiating sensitive discussions as well as financial & time constraints.
Bowman, 2000	Review		ICU	Canada	General culture	EOL Decision-making	Focused on open & balanced communication. Differences can be negotiated. Provided perspectives from both HCP & pt/family.
Briggs, 2003	Review			USA		ACP	Presented new model of implementing ACP using 5 Stages of Representational Approach.
Briggs & Colvin, 2002	Article			USA	Nursing	ACP	Discussed cultural changes required for organizations to build systems that move beyond mere completion of AD to ACP that affects EOL decision-making. Described an organization's approach to clarifying role of nurse as pt advocate. Suggested strategies to help nurse gain necessary competence in EOL decision-making.

<sup>1</sup>As discussed in Section 2, for this research, "culture" is defined as the complex interplay of meanings that represent & shape individual & collective lives of people (i.e. includes people of different ethnic backgrounds; people who share a working environment (like health care professionals, & the Deaf, deafened & hard of hearing).

<sup>2</sup>Articles are listed in the table by author and year ("et al." is used when there are more than three authors). Full citations to the articles can be found in the bibliography.

**Legend:** ACP=Advance Care Planning; AD=Advance Directive; DNR=Do not resuscitate; EOL=End-of-Life; GP=General Practitioner; HCP=Health Care Professionals; ICU=Intensive Care Unit; LTC=Long-term Care; Pt=Patient; YRS=years

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Brown, B.A., 2003	Review			USA	HCP	AD	Reviewed literature on AD & provided USA history of AD. Outlined importance of AD & that it should be part of the clinical process not administrative process. Suggested nurses being the primary educators/advocates & help pts with AD.
Brown, M., 2003	Article			Australia & Canada		AD	Comparison of how ADs used in Australia & Canada. Regarding ACP, recognized that there is a shift towards ACP, especially in Canada but that there was a lack of consistency & clarity about the terminology both within the Provinces & across the nation. Found that living will forms were difficult to design & that the perfect living will was illusory. Also discussed legislative issues remarking that ADs would require both legal & medical counsel which is an additional barrier & expense.
Choudhry, Ma, & Rasooly, 1994	Cross-sectional mailed survey	1021	Long-term care facilities	Canada		Long-term facility policies ADs	One third of LTC facilities had DNR policies & 3% had AD policy. Recommended routine advance discussions, scrutinizing use of utility standard, stipulating procedures for conflict resolution, & explicitly requiring communication of the decision to competent pts or substitute decision makers of incompetent pts.
Cox et al., 2006	Review			UK	General	EOL/AD	Provided a section on international perspectives of ADs (e.g., USA, Germany, Japan & Taiwan).

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Curtis, 2000	Review		ICU, Outpatient clinics & rehabilitation programs	USA		ACP/ EOL care	Suggested communication should not only focus on bad news & in the outpatient setting; should include spectrum of communication about prognosis, treatment options, goals of therapy, values & treatment preferences. HCP needed to improve their skills in this area. No data demonstrating the effectiveness of ACP but such communication was an important part of good quality medical care.
Dirto, 2006	Book chapter			USA		AD	Reviewed the literature surrounding assumptions about ADs & surrogate decision makers. Suggested that more effective methods of improving accuracy of surrogate decision-making; it was necessary to move beyond the idea of simple documents to more comprehensive process of ACP; & more research was needed before specific alternative policies for guiding EOL decision-making could be proposed.
Drought & Koenig, 2002	Review			USA		EOL/ ACP	Found little or no empirical evidence to support the autonomy paradigm of pt "choice" in EOL decision-making. 1) Prognostication at the EOL was problematic & resisted; 2) Shared decision-making was illusory, pts often resist ACP & hold other values more important than autonomy, & system characteristics are more determinative of EOL care than pt preference; & 3) the incommensurability of medical & lay knowledge & values & the multifaceted process of patient & family decision-making were at odds with the current EOL approach toward ACP.

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Emanuel & Emanuel, 1995	Commentary			USA	HCP (Physician)	AD	Discussed the contrast between overwhelming endorsement of ADs from all corners of society & their virtual nonuse. Argued & offered suggestions for physician involvement & reimbursement. "Reimbursement trends carry strong messages about the relative worth of clinical activities & ACP needs to be respected on a level with other interventions."
Ersek et al., 1998	Review			USA	General cultures	ACP	Discussed the fact that some cultures do not agree with the principles of which the Patient Self-Determination Act was based upon (pt autonomy; informed decision-making; truth-telling; control over dying process). Provided recommendations & guidelines for dealing with other cultures: assess individual; try to understand pt; health care provider should understand own beliefs; explain perspectives so that pt can understand; negotiate).
Fins et al., 2005	Structured interview/survey	110	Outpatients	USA		ACP	Looked at the patient-proxy relationship. Stressed that it is important to take into account the exercise of autonomy & the interpretative burdens assumed by the proxy. Found that deviation from pt instruction was not seen as a violation & that proxies were less certain about their decisions than pts about their own. "Do everything" was met with discretionary moral judgment & authors remark that concordance is not the only indicator of successful ACP.

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Fung, 1994	Review					AD	Chinese barriers to AD: death denial; lack of knowledge/literacy; language barrier; Confucius approach of interdependence; Chinese medicine; “respect authority”; filial piety & obligation; refusing treatment can be construed as suicide. Recommended education via small-sized educational forum.
Gallagher, 2006	Article		Family physician office	Canada	HCP (Physician)	ACP Communication	Family physicians can facilitate EOL discussions. Offered approach to help GPs minimize the difficulty of discussing EOL issues.
Giger, Davidhizar, & Fordham, 2006	Review			USA	Korean American, African American, Mexican American, Jewish, Filipino, Aboriginal, Nurses	ACP	ACP based on pt autonomy; informed decision-making; truth-telling; control over the dying process. Cultural differences in these values (e.g. African Americans, longevity is more important than quality of life; e.g. in some cultures, pain is life affirming & body cleanser). Important for HCP to understand their personal values as well as those of pt & family. Need to negotiate for mutually acceptable goals. Suggested a model (Giger & Davidhizar Transcultural Assessment Model) to assess pt & developing culturally competent skills through education.
Gruenewald & White, 2006	Review of qualitative literature	40 articles		USA	Europeans, Korean Americans, African Americans, Mexican Americans, Filipino Americans	Illness Experience at EOL	Observed differences among ethnic groups in attitudes toward autonomy in EOL decision-making, use of life-sustaining treatments, death acceptance, burden & disclosure of info.

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Hague & Moody, 1993	Survey-questionnaire	157	southwestern city in Florida	USA		AD	Sample demonstrated lack of AD knowledge. No real reference to culture (8 Hispanic, 3 African Americans & 139 Caucasian) but reinforced fact that people were not clear what ADs were.
Hallenbeck & Goldstein, 1999	Review			USA	Korean Americans, Mexican Americans, African Americans, Japanese Americans	EOL	Offered different perspectives based on possible cultural values. Advocated for HCP to become culturally competent. Suggested improved communication, mutual understanding & negotiation.
Jordens et al., 2005	Case example			Australia		AD	Discussed the current legal status of ADs. Presented the positive aspects of ADs: 1) easy to count & therefore is attractive as a measure in outcomes research; 2) researchers have an interest in designing forms that entail intellectual property rights; & 3) written forms suit the documentary reality of organizations. Suggested that it should not be assumed that ADs have a place in ACP process. The structure & process of ACP needed to be answered.
Molloy et al., 2000	Randomized controlled trial	1292	6 Nursing Homes	Canada		AD	Systematic implementation of a program increased use of ADs. Found that increased use of ADs reduces health care services utilization without affecting satisfaction or mortality.

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Pacquiao, 2001	Review			USA	Examples of Filipino, African, Korean & Mexican culture	AD	Outlined 3 strategies for culturally congruent care: cultural preservation & maintenance; cultural accommodation/re negotiation; cultural re-patterning. HCP needed to become practitioners of 'biculturalism' (i.e. understanding their own culture as well as the pt's culture). Filipinos accepted suffering, endurance & trust in a supreme being for ones' fate. Advocated for humanistic & holistic approach in discussing AD.
Patel, Sinuff, & Cook, 2004	Systematic review	9 RCTs		Canada		ACP/AD	Systematic review of educational ACP interventions directed at pts without terminal illness to determine their influence on the completion rate of ADs. Odds ratio for completion rate of AD was 3.71. Completion of AD higher among pts receiving direct counselling compared to those who did not. All trials were conducted in USA with predominantly Caucasian & Catholic participants. Concluded that trials of educational interventions were needed that measure whether ADs are a valid representation of pt wishes, whether they influence pt & family satisfaction with EOL care & where & how pts die.
Prendergast, 2001	Review					ACP	Reviewed failure of SUPPORT; Discusses Hammes' Respecting Choices & EOL in ICU. Pitfalls: AD discussions tended to be general rather than specific; often physician did not know pt had AD; even if pt has AD little evidence that it altered treatment outcome. ACP does not necessarily meet pts needs; also needed discussion of pt's values & experiences.

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Pronovost & Angus, 2001	Review					ACP (cost effectiveness)	Discussed the difficulty of putting value on costs at EOL. Small portion of paper discussing costs & AD. SUPPORT intervention did not alter cost; increasing the use of AD was not associated with reducing use of hospital resources. Discussed another study which stated that AD & hospice save 25%-40% in last month but savings decreased in last 6-12 months.
Sam & Singer, 1993	Survey-questionnaire	105	Outpatient clinics	Canada		AD	Discovered a number of perceived barriers to completing AD & that outpatients had positive attitudes towards ADs but knowledge & experience were limited.
Searight & Gafford, 2005	Review		Family Physician's office	USA	General/HCP – GP	AD	Found low rates of AD completion among Asians, Hispanics & Blacks. Provided guidelines for cross-cultural communication.
Siegler & Levin, 2000	Review		Physician EOL care	USA	HCP (physician)	EOL/AD	The section that reviewed ADs included: discussion of AD; patient, physician understanding & interpretation of ADs; physician adherence to patients' preferences & an overview of cultural factors in USA.
Singer, Choudhry, & Armstrong 1993	Cross-sectional survey	1000	General Public	Canada		AD	Assessed public opinion about ADs. 33% said that doctors should withhold information from a pt if asked to do so by pts family; 36% had had advance discussions with their families & 12% had completed a living will; 77% said they would want their wishes followed if they were unable to make medical decisions for themselves; 58% wanted their spouse/partner to make such decisions for them. Remarkd there was a need to consider legislative provisions regarding AD & to target public education programs.

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Singer, Robertson, & Roy, 1996	Review			Canada	HCP (physician)	ACP	ACP cannot avert all conflicts or uncertainties. Programs encouraging ACP increases use. Effect of ACP on health care costs is debatable. Importance of physician to act as educator & provide specific approach to ACP rather than hypothetical. Physician should ensure pt understand information. Provided overview of provincial laws & quotes that 10% Canadians have completed an AD.
Singer et al., 1998	Qualitative	48	Hospital	Canada		ACP	Examined traditional academic assumptions from pt's perspective & found these assumptions were not supported. Pts stated that: 1) the purpose of ACP was not only to prepare for incapacity but that it was also preparing for death; 2) ACP was based on personal relationships & relieving burdens placed on others not just solely on autonomy & the exercise of control; 3) the focus of ACP was not on completing written AD forms but it was also a social process; & 4) ACP does not occur within CHP context but also in relationships with loved ones.
Turner, 2002	Article			Canada & USA	Minority groups	ACP/AD/ EOL	Discussed the cultural dimensions of EOL care in Canada & the USA. In the review of ACP & AD, points out that not all individuals wish to participate in ACP (i.e., inappropriate to engage) & that the detailed frank conversation is not construed as compassionate or beneficent. Suggested that individuals were not prepared to engage in processes of such planning, should not be forced upon people & there was a need to know how to have compassionate, sensitive, respectful conversations. Emphasized bioethics literature which recognizes that cultural models place less emphasis on planning for the future, illness states, communication & anticipatory decision-making.

Article <sup>1</sup>	Type of Study	N (# of participants)	Setting	Country	Culture(s) <sup>2</sup>	Topic	Comment
Volker, 2005	Review			USA		EOL	Focused on fear of abandonment & offered some suggestions of what to say for improved oncologist communication.
von Guntzen, Ferris, & Emanuel, 2000	Article			USA	HCP	EOL	Presented 7-step approach for structuring the communication of important information. Specific to ACP; they recommended: 1) ask the pt how familiar they are with ACP concept & whether they are prepared to engage in ACP discussion; 2) Clinician should explain goals & process they recommend; 3) Offer validated worksheets covering a range of clinical scenarios to facilitate discussion; & 4) make the AD available.
White & Curtis, 2005	Review		ICU	USA		EOL, ADs	North American perspective on recent research & quality improvement initiatives in EOL care.

## APPENDIX J - QUESTIONS FOR ETHNIC REPRESENTATIVES

1. From your cultural perspective, please tell me about health and well-being.
  - From your cultural perspective, please tell me about illness.
  - What may have caused someone to go from being healthy to being ill?
2. When a member of a \_\_\_\_\_ family is dying, who is it important to tell? (*Fill in blank with Chinese, South Asian, Aboriginal etc.*)
  - How did everyone find out?
  - How did members of the family react?
  - How did you know the illness was terminal?
3. How did the family make sense of terminal illness?  
What is your understanding of advance care planning? (*If little, see script about what ACP is: types of procedures, withdrawal of treatment, decision-making etc.*)
  - If a family member is dying, how important is it to discuss advance care planning?
  - What are the positives and negatives of having such plans in place?
4. What kinds of questions would be culturally appropriate in discussing advance care planning?
  - What kinds of questions would not be culturally appropriate?
  - Who would or should be included in this conversation? (*patient, friend, religious leader, sibling, mother/father, child, male/female etc.*)
  - How could it be introduced so that the person would be willing to engage in such a conversation?
  - Who would be the best person to introduce the topic of advance care planning to the family? (*Healthcare professional or family/friend*)
  - Are there topics that would be considered offensive/taboo?
5. If there was a policy on advance care planning, how would that impact people of \_\_\_\_\_ background? (*Fill in blank with Chinese, South Asian, Aboriginal etc.*)
  - Would advance care planning benefit someone at the end of life? Explain.
6. What is most important to remember/consider in end-of-life care?
7. Is there anything else you would like to tell us about advance care planning or end-of-life care?
8. Are there any reports or other literature that you would recommend that would be helpful to this study?
9. Could you suggest anybody who would be helpful in providing us more information on cultural considerations in advance care planning and might be interested in conducting this interview with us?

## APPENDIX K - QUESTIONS FOR HEALTHCARE REPRESENTATIVES

1. What has been your experience in working with various cultural and aboriginal groups?
  - What is the ethnocultural mix of people you serve?
  - What is your understanding of advance care planning? (*If little, see script about what ACP is: types of procedures, withdrawal of treatment, decision-making etc.*)
2. If a patient is dying, how important is it to discuss advance care planning?
3. What has been your experience in discussing advance care planning?
  - Who would or should be included in an advance care planning conversation? (*healthcare professionals, patient, friend, religious leader, sibling, mother/father, child, male/female etc.*)
  - In your experience, or ideally, how could it be introduced so that the person would be willing to engage in such a conversation?
  - Who would be the best person to introduce the topic of advance care planning to the family? (*Healthcare professional or family/friend*)
  - What topics, if any, would be considered inappropriate/offensive/taboo?
  - What observed cultural variations have you seen between different cultures or within cultures?
4. Is there a policy on advance care planning at your organization?
  - How does/would that impact your work/practice? (*nurse, physicians etc.*)
  - Would advance care planning benefit someone at the end of life? Explain.
  - What are the positives and negatives of having such plans? (*in place or not in place*)
5. What is most important to remember/consider in end-of-life care? (*What are the cultural specifics?*)
6. What else you would like to tell us about advance care planning or end-of-life care?
7. Are there any reports or other literature that you would recommend that would be helpful to this study?
8. Could you suggest anybody who would be helpful in providing us more information on cultural considerations in advance care planning and might be interested in conducting this interview with us?

## APPENDIX L - QUESTIONS FOR ORGANIZATIONS/ADVOCACY GROUPS

1. What concerns does your organization have regarding cultural diversity in palliative/end of life care? (*i.e., in addition to ethnicity, rural populations, people with disabilities/chronic illnesses etc.*)
  - What is the ethnocultural mix of people you serve?
2. Please tell me about any discussions/activities on advance care planning.
  - Does your organization advocate for advance care planning?
3. Does your organization have a policy on advance care planning?  
If yes:
  - What kind of policy?
  - What are your organization's goals of advance care planning?
  - Can we obtain a copy of your policy?If no:
  - Are you aware of any issues around integrating ACP?
  - If yes: How do those issues impact cultural groups?
4. What are the cultural considerations (if any) of advance care planning in your organization?
5. Any barriers you might see with the implementation of advance care planning?
6. Any benefits you might see with the implementation of advance care planning?
7. Given that Canada is a multicultural nation and there are concerns about cultural considerations for advance care planning, what would your organization recommend?
8. Can you tell me about your experience with advance care planning?
9. Is there anything else you'd like to add?
10. Are there any reports or other literature that you would recommend that would be helpful to this study?
11. Could you suggest anybody who would be helpful in providing us more information on cultural considerations in advance care planning and might be interested in conducting this interview with us?



### Description of images contained in the document

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The individuals depicted in images do not necessarily endorse the content found within the document *Cross-Cultural Considerations in Promoting Advance Care Planning in Canada*.

