

# **A Canadian Perspective on Promoting Advance Care Planning within a Cross-Cultural Context**

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Palliative Care in a Cross-Cultural Context:  
a NET for Equitable and Quality Cancer Care  
for Ethnically Diverse Populations



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# Acknowledgements

- ❖ Health Canada
- ❖ Canadian Institutes of Health Research  
Cross-Cultural Palliative New Emerging  
Team (NET)



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# Background

- ❖ Ipsos-Reid 2003
  - 40% family
  - 10% GP
- ❖ Health Canada Secretariat on Palliative and End-of-Life Care
- ❖ Public Information and Awareness Working Group



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# Objectives

- ❖ Identify and define cross-cultural issues in ACP
- ❖ Determine cultural understandings, beliefs, and interpretations of terminal illness, suffering, dying, and death
- ❖ Identify factors that may influence the responsiveness of cultural communities to ACP



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# What is advance care planning?



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# Defining ACP...

- ❖ “ 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.
- ❖ ACP may result in the creation of an advance directive”

Dunbrack Health Canada Glossary Project 2006



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# ...Defining ACP

- ❖ “In simplest terms, ACP is a *decision making tool* that is meant to ultimately assist individuals in experiencing a “good death”...
- ❖ Institute of Medicine 1997 defines a “good death” as “one that is free from avoidable suffering for patients, families, and caregivers; in general accord with patients’ and families wishes; and reasonably consistent with clinical, cultural, and ethical standards.

Con: *Cross Cultural Considerations in promoting ACP in Canada.*  
Health Canada report Nov 2007 page 3



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# Target Population

## 3 Distinct types of Cultural Groups

- Most prevalent & largest minority cultural groups for each province and territory
  - Montreal – Black, West Asian/Arab, Chinese, South Asian
  - Toronto - South Asian, Chinese, Black
  - Vancouver - Chinese, South Asian, Filipino
- Most prevalent and largest Aboriginal groups for each province and territory
  - 3% of Canada's population
- Number of cultural groups (e.g., deaf, deafened and hard of hearing) whose membership is small but perspectives about ACP may be of interest in policy-making



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# Key Informants...

- ❖ 125 Key Informants
- ❖ Variety of perspectives:
  - Specialized organizations (palliative, hospice and EOL care)
  - Cultural organizations
  - Health systems
  - Government departments



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# ...Key Informants

## ❖ Cultural backgrounds

- 63% Caucasian
- 11% Aboriginal
- 7% Chinese
- 6% South Asian
- 13% Black, Deaf, Filipino, Francophone, Iranian, and Latin American



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# Results: General Themes...

## ❖ Death

- ❖ Unwillingness to discuss
- ❖ Can be considered taboo
- ❖ Seen as sense of failure for HCP



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*Like in Tim Horton's, you don't see it up on the wall, "We Support the Terminally Ill". But you will 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 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.*



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# ...General Themes...

## ❖ Palliative/End-of-Life Care

<b>Term</b>	<b>Interpretation</b>
– “Hospice”	- Sending them away to die
– “Palliative Care”	- Taking away treatment
– “Advance Care Planning”	- ACP = DNR



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# ...General Themes...

## ❖ ACP

- Positive attitude
  - Control over EOL care
  - Peace of mind for family
  - Save resources and medical costs
- Challenges
  - Cost of lawyer/notary
  - Necessary to review on regular basis
- Conversation vs. document



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# ...General Themes

## ❖ Cultural Diversity

- Variation within culture
- Minority matched HCP
- Trusted/well-respected community leader or advocate
- Language
- Communication



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# Aboriginal

- ❖ Common rituals practiced at EOL
- ❖ Prefer to die at home and be with family
- ❖ Generally accepting of death because they see it as a natural progression of life
- ❖ Experience working with Aboriginal people found that:
  - value honesty & the reality of situation
  - North/rural: limited access to palliative care services



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# Black

- ❖ Community important
- ❖ ACP not practiced
- ❖ Fear of discussing death and dying
- ❖ Expressed concerns about ACP
- ❖ Did not feel “welcome” or “accepted to participate” in medical system
- ❖ Family very involved with decision-making process



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# Chinese

- ❖ Talking about death “unlucky”
- ❖ Quantity or longevity more important than quality of life
- ❖ Value “good ending” = being comfortable, peaceful, and surrounded by children/family
- ❖ Important to include the family; oldest son the decision-maker
- ❖ Often want to protect sick relative
- ❖ Regarding policy, Chinese pts would not understand why they would want ACP since their family normally deals with all EOL decisions



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# South Asian

- ❖ View terminal illness as “God’s wish”. ACP foreign concept: do not discuss or plan for their death
- ❖ Anticipating your future and end will bring it closer to you
- ❖ Besides their spouse and children, the extended family play important role in EOL care
- ❖ Prayer and connection with God very important
- ❖ South Asian men will not name their spouse as their proxy



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# Implications

- ❖ Public Education
- ❖ ACP specific to disease
- ❖ Engage communities to develop outreach programs
- ❖ Organizations/health care facilities create pathways to guide HCP in ACP conversation
- ❖ Be respectful of all people, regardless of culture



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