

# Cultural Conceptualization of Palliative Care: A Literature Synthesis

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## 'Palliative Care in the Cross-Cultural Context': A New Emerging Team (NET) for Equitable and Quality Care for Culturally Diverse Populations

### BACKGROUND

- ❖ In a recent assessment completed by Senator Carstairs titled "Still Not There: Quality End of Life Care: A Progress Report" (2005), it was stated that only 15% of Canadians currently have access to Hospice Palliative Care (HPC). This is in large part due to disparities across Canadian jurisdictions in access, scope and quality of care.
- ❖ While various factors account for these differences, a primary goal of the Cross Cultural NET is to specifically investigate the intersection of culture and palliative care, and to advance understanding of its influence on health outcomes.
- ❖ Therefore, the NET investigators initiated an in-depth literature synthesis that would review the relationship between culture and end of life health care.
- ❖ Although the philosophy and practice norms of mainstream HPC have been well described in Canada by the Canadian Hospice Palliative Care Association (2002), there is no conceptual clarity regarding the meaning of HPC, or access to and utilization of it, among culturally diverse populations.
- ❖ Various cultural definitions of all these concepts do exist, but there is limited understanding of the range and scope of these meanings, or their implications for end of life care goals and expectations.

### RESEARCH QUESTION

- ❖ To collect, critically appraise and synthesize all current relevant literature regarding the conceptualization and utilization of HPC among culturally diverse populations.

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### SEARCH STRATEGY

- ❖ A systematic literature search was conducted to identify key literature published from 2001-2006 regarding cultural dimensions of palliative care.

- ❖ Eleven electronic databases were searched.

Ageline	Anthropology Plus
CINAHL	EBM
Embase	Medline
PsycARTICLES	PsychINFO
Social Work Abstracts	SocIndex
Sociological Abstracts	

- ❖ Medical Subject Headings (MeSH) such as Palliative Care, Terminal Care, Hospice Care, and Cultural Diversity were combined with keywords such as cultural competence, social and cultural barriers, and social and cultural exclusion.
- ❖ This search did not include gray literature.
- ❖ This search identified about 550 abstracts.

### APPRAISAL

- ❖ Two reviewers applied pre-determined inclusion and exclusion criteria to the abstracts.

Criteria	
Inclusion	Exclusion
English or French	Opinion or editorial pieces
Concept, theory or data papers	Policy analyses

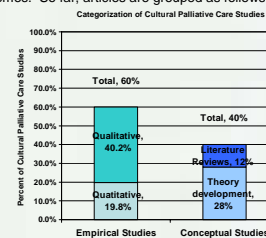
- ❖ Differences were resolved by discussion between the reviewers, and when necessary, in consultation with a 3rd reviewer, who is a NET investigator.
- ❖ About 100 articles met the inclusion criteria and were retrieved in full-text form. These articles are now being critically appraised by the same 2 reviewers.

#### Additional Criteria for Articles

- Primary and secondary analysis of empirical data
- Systematic reviews
- Specific to western countries

### FINDINGS

- ❖ Articles are currently being analyzed and collapsed into themes. So far, articles are grouped as follows:



- Empirical studies pertaining to:
    - utilization of hospice services by different cultural/ethnic/racial groups
    - barriers to access and utilization of mainstream palliative care services
    - advance care planning by different cultural/ethnic/racial groups and influence on EOL care outcomes (mostly in the U.S. literature).
  - Concept papers about cultural perspectives and practices:
    - cultural competence: knowledge acquisition and skill development
    - decision making styles: individual vs familial approaches
    - communication: patterns between patients, families and health care providers
    - biomedical ethics and EOL care: significance of autonomy, beneficence, non-maleficence, and justice
- ❖ While some articles have attempted to define HPC from essentialized cultural perspectives, they tend to caution against the establishment of uniform cultural meanings of HPC in light of diversity within specific cultural and ethnic groups. Accordingly, cultural definitions of HPC within these studies range in their scope and conceptual clarity."

### DISCUSSION

- ❖ The findings of this literature synthesis will provide a conceptual framework that can be used to inform research questions and hypotheses about HPC access and service utilization among individuals and families of culturally diverse backgrounds.
- ❖ The results can be used to develop robust quantitative and qualitative measures of these phenomena.
- ❖ These findings will be helpful not only to the Cross-cultural NET investigators, but will be relevant to other multi-disciplinary researchers, educators, and practitioners involved at micro, meso, and macro levels of HPC.
- ❖ Ultimately, these findings can be used to facilitate the larger goal of promoting quality and equitable access to, and utilization of, culturally appropriate palliative and end of life care.

The New Emerging Team (NET) 'Palliative Care in the Cross-Cultural Context' is a 5-year project funded by the Canadian Institutes for Health Research to develop research and training capacity in the area of culture and cancer palliative care.

The NET supports research in the streams of Access, Caregivers, and Complementary and Alternative Therapies.

The NET is multi-centre and multi-disciplinary.

