Addressing the Cultural, Spiritual and Religious Perspectives of Palliative Care

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Scoping review

• **Objective of scoping review:** Explore attitudes, behaviours and utilization patterns of end-of-life care by culturally- and spiritually-diverse groups and associated gaps in practice, delivery of healthcare services and research

• A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping review, *BMC Geriatrics*
Findings: primary barriers

- Cultural differences between HCP and patients and families
- Under-utilization of culturally-sensitive models designed for improved EOL care
- Lack of awareness of cultural and spiritual diversity issues
- Exclusion of families in decision-making
- Language
- Personal racial and religious discrimination
- Lack of culturally-tailored EOL information to facilitate decision-making and uptake of care
Findings: primary enablers

Active efforts to:

• Engage family members
• Incorporate diverse cultural and spiritual values
• Negotiate with family members the changing needs of the patient to both maintain and release control of the individual’s EoL care
• Improve as well as sustain culturally- and linguistically-effective communication between HCPs and service users
Indigenous Voices:
Stories of serious illness and grief

Video series and print materials based on stories of First Nations, Inuit and Métis about advanced illness, loss and grief.

- Support tool for Indigenous people to understand what quality palliative care is and to advocate for it
- Educative tool for health care providers
Addressing the need

Widespread mistrust of non-Indigenous health systems and authorities and few culturally safe resources and supports specific to EOL

- Addresses myths about advanced illness, PEOLC
- Validates and embraces beliefs, values, traditions
- Supports advocacy for safe, respectful, inclusive care
- Increases involvement in decision-making

All work has been guided OCAP principles
Print materials

What is palliative care?
Compassionate caring
Care at home and away
Helping you feel better
What to expect
Honouring wishes
Making memories
Grief and letting go

Free to download from LivingMyCulture.ca
LivingMyCulture.ca

Video series of personal narratives by members of 11 cultures about living with serious illness, end of life and grief.

- Stories by patients, families, HCP and community leaders
- Tool for patients/families
Cultural groups engaged

First Nations

Inuit

Métis

Chinese

Ethiopian

Filipino

Indian

Iranian

Italian

Pakistani

Somali
Addressing the need

Healthcare services often out of sync with cultural perspectives on illness, death and grieving.

• Support and empower patients and families to advocate for culturally inclusive care
• Promote understanding of how palliative / end-of-life care issues are faced
• Educates health providers on culturally safe and inclusive care
• Improve inclusive and respectful quality care
By the numbers

- 600+ videos in 11 languages
- 11 Cultures
- 64 Storytellers
- 6 Themes
  - Traditions, Rituals and Spirituality
  - Expectations of Care
  - Care for the Patient and Family
  - Emotions and Support
  - Talking About Illness
  - After Death and Ceremonies
Summative Evaluation Results

Users reported:

• Ease of use
• Exceeded expectations
• Useful and of value
• They would recommend the tool
• Engaging and powerful
• Felt personal
How Do Different Cultures Experience Dying in our Health System?
Traditional and Western Medicine
Faith based decisions
Our conflicting beliefs
What do people want providers to know?
Food: an essential ingredient
Talking about death: the etiquette
What Does a Good Death Mean?
Patient dignity question

What do I need to know about you as a person to give you the best care possible?

- Dr. Harvey Chochinov
QUESTIONS

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