

END-OF-LIFE PERSPECTIVES AND EXPERIENCES IN FOUR FIRST NATIONS COMMUNITIES

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Purpose of the Study

- To document First Nation peoples' understandings and experiences in providing palliative care
- To understand community beliefs and values and the preferred place for receiving care
- To identify the perceived barriers and supports within the community
- To understand the service and educational needs of community caregivers

Methodology

Qualitative and quantitative data collected in January 2011 – September 2012 in all four communities.

Data collected from internal & external health care providers, community leaders, Traditional Knowledge Carriers and community members.

Sampling:

- 94 key informant surveys
- 21 focus groups with 120 participants
- 41 interviews with 44 participants

Analysis

Descriptive statistics on the numerical data and thematic analysis of the qualitative data from the surveys.

Focus groups and interviews were transcribed verbatim from audio recordings. Analytic work included line-by-line review to identify themes.

Translation services provided locally by each community where necessary.

Understanding & Experiences in Providing Palliative Care

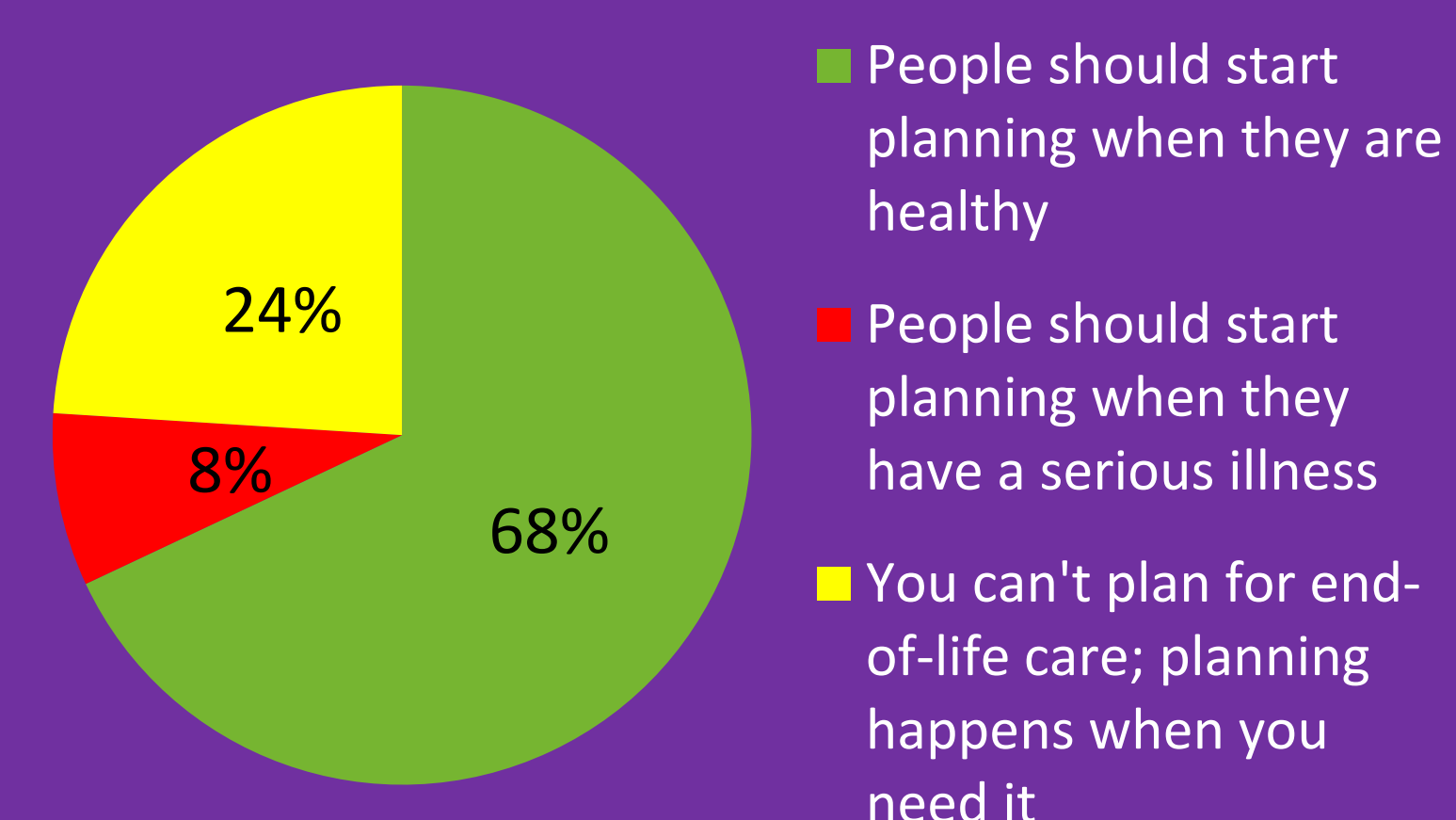
- 91% of survey participants had heard of the term “palliative care”
- 90% of survey participants felt that PC services are intended for everyone at end-of-life regardless of age or illness
- 81% of survey participants had either personally cared for or knew of a family member who cared for a dying loved one



Community Values & Beliefs Related to Dying and the Preferred Place for End-of-Life Care

- 66% of survey respondents felt that talking about death and dying is acceptable in the community
- 17% felt it was unacceptable due to:
 - Traditional & cultural interpretations
 - Death & dying is a difficult topic to discuss
 - Lack of palliative care knowledge
 - No prior experience with death
 - Unresolved grief

Advanced Care Planning:



87% of survey participants felt that, if services were available and adequate, community members would choose to die at home.



Advantages of receiving care in the community:

- Able to remain at home
- Access to community support
- Culturally appropriate care
- Economical advantage
- Familiar and comforting
- Less stress on family
- Transportation is not an issue
- Less exposure to communicable disease

Barriers and Supports within the Community

Barriers:

- Jurisdictional issues
- Lack of services and funding
- Lack of infrastructure
- Communication issues
- Lack of education
- Lack of culturally safe practices
- Health & well-being of community
- Systemic mistrust

Supports:

- Family and community support
- Access to culturally relevant care and cultural practices
- Access to language
- Resource sharing
- Dual-relationships
- Volunteerism

Service & Educational Needs of Community Caregivers

Education and training needs:

- Palliative care training
- Traditional teaching and cultural understanding
- Education about the programs and services currently available
- Increased education for care providers on the provision of care
- Medication and equipment
- Family member training
- Greater education of the dying process
- Education for external health care providers on culturally relevant practices and care



Programming and services needs:

- Formalized palliative care program and funding for palliative care
- Increased support services
- Facilities and equipment
- Community infrastructure
- Grief and bereavement programs
- Traditional practices and cultural understandings
- Training and knowledge-sharing
- Policy and procedures



Next Steps

Each community has developed a leadership team responsible for developing a community based palliative care program.

Interventions will be identified and implemented by each First Nations leadership team over the five years.

These interventions will be documented and evaluated for their effectiveness by the research team.

The interventions will contribute to a “tool kit” of evidence based strategies that will be shared with other First Nations communities across Canada.

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