Heightened vulnerabilities and better care for all: Disability and end-of-life care

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In this presentation I will:

• Give a brief overview of the VP-Net project

• Discuss policy issues regarding palliative care and persons with disabilities

• Share some recommendations regarding Inclusive Palliative Care
Vulnerable Persons and End of Life New Emerging Team (VP-NET)

• Five year team research project to explore the availability and accessibility of end-of-life care for people who experience socially-constructed vulnerability

• Funded by CIHR

• Four key themes: clinical, policy, ethics and social/cultural issues in end of life care

• www.vp-net.ca
Policy theme methods:

• Qualitative research and policy analysis 2005-2007
• 20 key-informant interviews and focus groups (48 participants) in Alberta, Manitoba, Ontario, Newfoundland
• Addressed: decision-making, service provision, symptom management and informal caregivers
• In 2007, researchers returned to present findings to participants and policy makers
Rethinking vulnerability

- Traditional understanding is that some bodies are vulnerable by default – disabled, old, young, seriously ill bodies
- Vulnerability is part of the human condition, thus is constant and universal.
- People made vulnerable through inadequate social, income, physical and emotional supports; physical, psychological or intellectual functional limitations, limited education, wealth or advocacy skills.
Vulnerability and marginalization

• Marginalization has subtle, indirect and systemic effects which we can identify by looking at who was and wasn’t included

• Some populations are treated as outsiders and their experiences and needs are not addressed in policy and design of health care

• We cannot eradicate vulnerability, but can mediate, compensate, and lessen vulnerability through programs, institutions and structures
Marginalization and heightened vulnerability, based on prejudice, bias or faulty assumptions, can find people who are disabled, poor, or disenfranchised further victimized by ever narrowing health care options.
Policy Issues:

• Access and Barriers to palliative care

• Transition to Palliative Care
Access and Barriers to Palliative Care:

• Unpredictable path to end-of-life can lead to barrier in accessing palliative care for people with disabilities

• Chronic poverty/unemployment may lead to lack of income and supports for/during palliative care (ie do they have access to EI, CPP, etc)

• Assumptions about living with a disability may influence decision-making at end of life (ie DNR’s)

• People with disabilities only seen as care recipients, and not as care providers
Transition to Palliative Care:

Transition results in loss of continuity in care

• New physicians

• New personal care providers (home care), loss of relationships with long-term care providers

• Access to assistive devices and technical aids may be discontinued (i.e., Wheelchairs, sign language interpreters)

• Access to alternative treatments for managing impairments may be limited
Addressing vulnerabilities: Location

People with disabilities prefer to choose where they die

Challenges:
• Assumption that must be in an institutional setting to receive ventilators and other assistance
• People who live in transitional housing (hotels, rooming houses)

Policy Measures:
• Access to community-based palliative care,
• Fully accessible, freestanding hospices, including downtown
• Accessibility Audits of existing units
• More accessible housing stock for long-term solution to institutional and transitional housing
Addressing vulnerabilities: Coordination

How to enable coordination between long-standing providers and new care providers?

Challenges:
• Discontinuity in formal care provision

Policy Measures:
• Involve family physicians and home care providers in palliative care plans
• Brief new and old physicians and home care providers
• Involve person with disabilities in determining palliative care plans
• Train palliative care staff in goals and values of self-managed care
• Coordinate between disability supports and palliative care programs
• Review eligibility requirements for disability supports including during transitions to both long-term and palliative care
Addressing vulnerabilities: Informal care

Support and respect for informal care providers

Challenges:
• Support for people with disabilities may come from outside family
• Those who have lived in institutional settings may have fragile relationships with biological families, relying on paid support providers as part of decision-making or support
• Disabled men and women provide care and face attitudinal barriers

Policy Measures:
• Identify chief sources of support and who will advocate on their behalf
• Provide on-going education to address attitudinal barriers
• Recognize impact for disabled care providers on income, access to benefits including compassionate care benefits
Policy Impacts

- Without coordination between disability-related and end-of-life policies, people with disabilities encounter heightened vulnerability as they face end of life.

- With inclusive end-of-life policies, the result is better end-of-life care for all people, including those with disabilities.
Inclusive Palliative Care

• Physical access

• Information and communication access

• Community-based palliative care, including in non-traditional places

• Inclusive attitudes and care practices that respect personhood and dignity
“A good life until the end.”