

Building a Research Agenda for the Inclusion of People with Disabilities in End-of-Life Decisions: Literature Identifies Key Issues

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As persons with disabilities experience increased longevity, there is a need for unbiased, ethical, compassionate, inclusive and timely decisions regarding their end-of-life (EOL) care.

Literature: Ethics & Decision Making

Purpose

- Identify research gaps and agenda
- Identify ethical issues regarding consent to treatment and decision-making capacity
- Support individuals and those who provide care

Search Methods

- Articles from 1992-2010 (N=42)
- Databases: PubMed, PsychInfo, CINAHL, and Web of Science
- Respective thesaurus for databases (exception: Web of Science) used to determine the MeSH or vocabulary terms
- Terms combined with controlled vocabulary terms for EOL care
- "Related articles" feature (PubMed) facilitated discovery of new articles in iterative fashion
- Web of Science used to discover most prolific authors
- Culled "Articles and Academic Papers" section of Dr. Tuffrey-Wijne's website, *Palliative Care for People with Learning Disabilities* <http://www.pcpld.org>
- Reviewed references from 2010 book *End-of-Life Care for Children and Adults with Intellectual and Developmental Disabilities*

Journals

Disability
Legal
Medical (nursing, hospice, palliative care)
Policy
Religion



Research Methods

Case studies, nominal group technique, record reviews, ethnographic observation, policy and legal analysis, surveys, interviews, personal stories, and literature review.

Central Themes and Issues

- Clear communication of terminal diagnosis
- Consent and concepts of quality of life
- Inclusion in decision-making about treatment or no treatment
- Determination of decision making capacity and comprehension
- Treatment decisions by health care providers based on disability and incorrect assumptions
- Surrogate decision making
- Paradoxes faced by decision makers
- Need for staff and health care provider training

Future Directions for Research

- Needs and experiences of individuals with terminal illness
- Palliative care needs, pain & symptom assessment
- Strategies to document individual's preferences
- Preparation & training of residential care providers, other staff, health care professionals, families
- Communication strategies for consent and decision making

