

Wednesday, 12:30 – 2:00, E2

## **Palliative Care and Developmental Disabilities**

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### Objectives:

1. Identify effective methods for the practical application of concepts related to improving the delivery of services for persons with developmental disabilities
2. Identify advances in clinical assessment and management of selected healthcare issues related to persons with developmental disabilities
3. Discuss the ethical issues related to persons with developmental disabilities
4. Identify and emphasize attitudes that enhance the opportunities for persons with DD to achieve their optimal potential
5. Develop strategies to promote community inclusion in meeting the needs of persons with developmental disabilities.

### Notes:

## Palliative Care and Developmental Disabilities

- Anne Cavanagh, MD
- Palliative Care Medical Director  
Bronson Methodist Hospital, Kalamazoo
- Medical Representative Area 16 Special Olympics
- Faculty, KCMS Internal Medicine
- Past board member  
Autism Society Kalamazoo-Battle Creek
- Mother and Grandmother

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## Objectives - INTERACTIVE

- Overview of common medical and social concerns for people who have serious or advanced medical problems and developmental disabilities
- Discuss the roles of palliative care and hospice services, particularly for people with DD
- Review barriers to quality palliative care for people with DD and their families and some strategies for dealing with them
- Dialogue on case studies as time permits

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## Causes of Intellectual Disabilities

- Autism Spectrum Disorders – now the most common cause in US; 90% genetic
- Nutritional deficiencies – most common cause worldwide; particularly inadequate iodine and calories
- Toxic - fetal alcohol, lead
- Chromosomal – Trisomies, Fragile X
- Other genetic – mitochondrial, inborn metabolic, etc.
- Head injury
- Perinatal – twin steal, birth asphyxia
- Infectious – meningitis, measles
- Cerebral palsy – description, not really a cause

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## Societal History

- Pre-industrial
- Institutional
- Effect of antibiotics
- IDEA/movement from large institutions
- Current – life expectancy now within five years of general population, with chronic disease and aging related issues as relatively new but now common challenges

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## Living Situations

- State institutions closed, last in Michigan 2010.
- Family often provide support into their own old age
- Foster care, particularly for high functioning elderly people or in rural areas that lack specialized residences
- Specialized residences – vary greatly
- Community supported living – somewhat independent
- Community nursing homes usually poorly suited

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## Common DD medical concerns

- Suboptimal nutrition, exercise, health screening, mental health care, substance treatment
- Communication barriers can lead to later illness presentation and poor symptom recognition (particularly in lower functioning)
- Lack of patient comprehension of illness, symptoms, treatment, negotiating medical systems (particularly in higher functioning)

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## DD Culture 101

- DD has become a subculture in the U.S.
- History of segregation/exclusion – facilities, schools, etc.
- Patients, families and caregivers frequently experience being devalued by the dominant culture
- Family guilt, “I promised Mother.....”
- Suspicion of medical staff/systems
- Other minority experience can help

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## Caring for People who have Intellectual Disabilities

- Watch your own assumptions about patient/family/caregiver experience and “quality of life.” I avoid the phrase.
- Try to include the legal surrogate AND people who know the patient well
- Understand the situation from the patient point of view, including burdens and benefits
- Try to plan ahead for changes that may be needed in place of residence, home care, etc.

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## Cause of Death Demographic and Social Trends

	Early 1900s	Current
Medicine's Focus	Comfort	Cure
Cause of Death	Infectious Diseases Communicable Diseases	Chronic Illnesses
Death rate	1720 per 100,000 (1900)	800.8 per 100,000 (2004)
Average Life Expectancy	50	77.8
Site of Death	Home	Institutions
Caregiver	Family	Strangers/ Health Care Providers
Disease/Dying Trajectory	Relatively Short	Prolonged

Administration on Aging, 2000; Field & Cassel, 1997; Minino, et al, 2007

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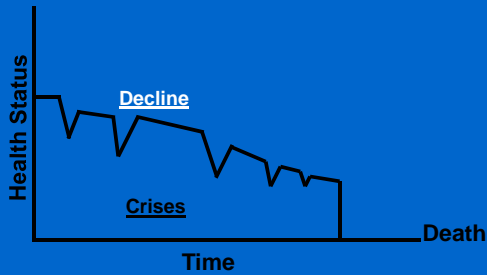
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### Illness/Dying Trajectories Slow Decline, Periodic Crises, Death



Field & Cassel, 1997

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### Death and Dying in America (cont.)

- Disparity between the way people die/the way they want to die
- Patient/family perspective

Egan & Labayak, 2006; Field & Cassel, 1997

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### Barriers to Quality Care at the End of Life

- Failure to acknowledge the limits of medicine
- Lack of training for healthcare providers
- Hospice/palliative care services are poorly understood
- Rules and regulations
- Denial of death

Glare et al., 2003; NHPCO, 2005

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## Palliative Care

- Practice focus is on symptom management, for the patient, family and caregivers.
- Regardless of severity of illness or prognosis
- Symptoms include physical, psychological, social, and spiritual concerns
- Interdisciplinary team practice

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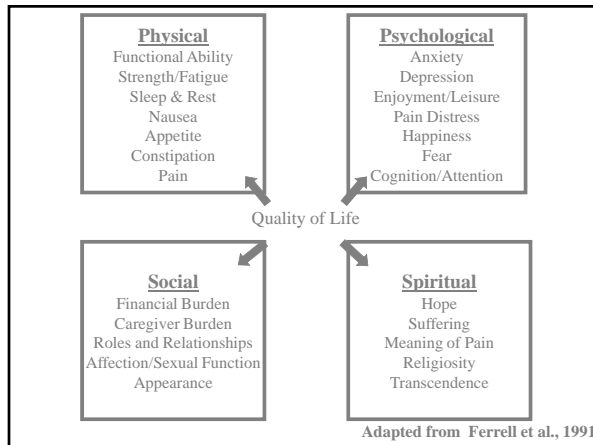
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## Palliative Care Goals

- Teamwork – patient, family and health care professionals working together to achieve common goals
- Increased patient and family satisfaction
- Decreased legal issues through informed consent and increased satisfaction
- Decreased hospital length of stay
- Decreased hospital readmission

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## Palliative Care Roles

- Help with symptom management problems
- Help patient/family understand current disease process and care options
- Assist in placing the current event/hospitalization in the context of overall course
- Support health care professionals and families in situations where they do not agree with each other

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## Hospice vs. Palliative Care

- Palliative care provides symptom management and care coordination, broadly defined for patient and family
- Hospice is a systematic service of palliative care for patients who are likely terminally ill and their caregivers
- One may think of hospice as a subset of palliative care
- Some people think of hospice in terms of insurance benefits

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## Hospice includes:

- Interdisciplinary care
- Medical appliances and supplies
- Drugs for symptom and pain relief
- Short-term inpatient and respite care
- Homemaker/home health aide
- Counseling
- Spiritual care
- Volunteer services
- Bereavement services

<http://www.nhpco.org>

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## Hospice Medicare Benefit Eligibility Criteria:

- The patient's doctor and the hospice medical director use their best clinical judgment to certify that the patient is terminally ill with life expectancy of six months or less, if the disease runs its normal course
- The patient chooses to receive hospice care rather than curative treatments for his/her illness
- The patient enrolls in a Medicare-approved hospice program

<http://www.nhpco.org>

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## Hospice Outcomes

- Better patient and family satisfaction
- Lower cost
- Longer survival – twice as long in end stage heart failure for example

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## Hospice Care for People with DD

- In CAPC referenced studies, 9-18% of people with DD used hospice or palliative care. This compares with 38% in the general population.
- Some hospice agencies don't provide services in specialized residential homes. Concerns include legal issues and staff lack of confidence working with these patients.
- Leadership matters – medical director, etc.

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### Bereavement (Patient)

- Sometimes deprived of knowledge of illness or death of family or caregivers
- May have difficulty understanding death and the grief responses of others
- Usually lack religious connection
- Often excluded from funerals, memorials and other bereavement activities
- Even high functioning people rarely are able to plan for their own end of life

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### Bereavement (Family)

- Caregivers (family or not) experience loss and may be young with little previous experience
- Sometimes complex family structures
- Lack of understanding by the general community
- Lack of religious community connection

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### Complicated Bereavement

- Psychopathology
- Increased suicide risk
- Higher risk for physical illness
- Increased resource use
- Increased by death perceived as sudden or intentional

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## Legal Issues

- Some judges will not permit guardians to approve a DNR order
- State mental institutions are not permitted to have DNR orders. Some jurisdictions interpret this rule to extend to any state related services, including state financed residences
- Some advocates lobby strongly to maintain these state “protections”

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## Additional Cases as Time Allows

- Unrecognized ankle fracture
- Aging man with Trisomy 21 and swallowing difficulty
- Parents with intellectual disabilities
- “Hoarder” having CABG
- Group discussion/concerns

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