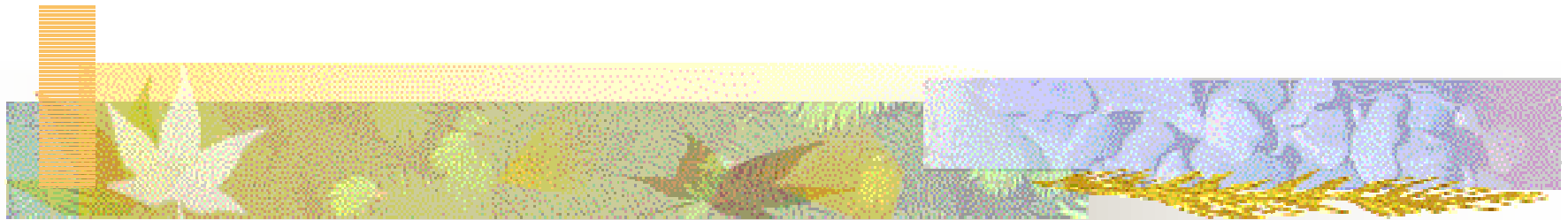


Palliative Care for Adults with Developmental Disabilities



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Introduction

- At the end of this discussion the individual should be able to identify how decision making in palliative care is applied to the general population and specifically to the population of persons with developmental disabilities.



We Will Discuss:

1. Medical Considerations
2. Psychological Considerations
3. Social Considerations
4. Legal Consideration
5. Ethical Considerations



Medical Considerations

- Life expectancy now within 5 years of general population
- Increased frequency of death from age related illnesses
 - Cancer
 - Heart Disease
 - Chronic Lung disease
- Increased need for palliative and hospice services



Psychological considerations

- Decreased Ability
 - Comprehend new or complex information
 - Learn new skills
- Issues are established before adulthood and affect future development
- Examples:
 - Autism
 - Down's Syndrome
 - Cerebral Palsy associated Mental Retardation



Social Considerations

- Impaired Social Functioning
- Persons outlive parents as decision makers
- Decreased institutionalization
- Mainstreaming of ADD to community
- Community housing- possible supervision by individuals with little familiarity



Issues Concerning Medical and Palliative Care for ADD 1

- Lifestyle with potential adverse health effects
 - Suboptimal nutrition
 - Limited exercise
 - Decrease utilization of health screening

- Communication Barriers lead to advanced illness presentation

- Possible lack of clarity of goals of care

- Poorly defined decisionmakers



Issues Concerning Medical and Palliative Care for Add-2

- Lack of comprehension of their illness, symptoms or treatments
 - Interpret illness or treatments as punishment for wrong-doing
 - Not understand death and why their family caregivers are sad
- Symptom Assessment compromised by an inability to communicate
 - Wide Range of behaviors indicating discomfort
 - May only be apparent to people who know them well
 - Unclear what is causing distress: pain, other somatic symptoms, anxiety/fear, Sadness.
- Not allowed Appropriate Bereavement
 - Deprived of the knowledge of death- caregivers and loved ones
 - Excluded from funerals, memorial services, or other bereavement activities



Providing Effective Palliative and Supportive care to ADD

- Maximize time in familiar surroundings
 - Familiar people and objects
 - Routines and activities enjoyable to the patient
 - Offer emotional reassurance
- Communicate about symptoms
 - Understandable to the patient
 - Not about abstract diseases



Advance Care Planning

- Elicit preferences regarding end of life care
 - From ADD directly if possible
 - Guardians
 - Early in the course of a disease
- Early discussions of a disease's likely course
- Concerns such as cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition, spiritual values
- Place and circumstances of death

ETHICAL AND LEGAL



CONSIDERATIONS



Ethical Issues in End of Life

- Autonomy
 - Beneficence
 - Nonmaleficence
 - Justice
 - Informed Consent
 - Decisional Capacity
- Jonsen, A., Siegler, M., & Winslade W. (2002) Clinical Ethics



Autonomy

- Refrain from interference with the right and ability of an individual to pursue their own goals.



Beneficence

- The duty to assist persons in need by considering and asking how a given medical test or treatment will help a patient?
- Will the benefit outweigh the risk?
- Will it restore the individual to his/her usual state of ability



Nonmaleficence

- The duty to refrain from causing harm
- Is this treatment likely to fail, cause more harm than good (Medical futility)?
- Do the risks of this intervention outweigh the benefits?
- Will this intervention prolong suffering?



Social Justice

- Egalitarian: All persons deserve equal access to the benefits and burdens of society.
- Fair and equitable distribution
- The worth of each individual as an individual, not on his ability to contribute



Informed Consent

- How was the diagnosis made?
- Reasons for recommended treatment
- Alternative treatments
- Benefits
- Burdens (side effects)
- Assessment of patient's understanding



Decisional Capacity

- Ability to understand relevant information
- Ability to appreciate the medical condition and its possible consequences
- Ability to communicate a choice
- Ability to engage in rational deliberation about one's own values in relationship to treatment options



Making Decisions For Incompetent Patients

- Extreme vulnerability of incompetent patient
- Patient-Centered theory of decision-making
- Procedural safeguards
 - State has compelling interest in the preservation of human life
 - Clinicians should be aware of local regulations governing such decisions



Standards for Surrogate Decision-Making

Meizel, A. (1993) Kennedy Institute of Ethics Journal V2 #4 309-345

■ Principles

- Respect for individual self-determination and bodily integrity
- Patient's treatment preferences
- Approximate, as closely as possible, the decision about treatment the patient would make if able to do so



Making Decisions for Incompetent Patients How?

- Subjective Standard. Explicit patient choice
 - Instructions given directly, via oral or written statements
 - With the assumption that all tenets of informed consent have been met
- Substituted judgment
 - Through discussions with family/friends, selecting choices that patients themselves would have made, based on the best knowledge of the patient's value system
- Best interests of patient
 - Guided not by patient's *preferences* but by his/her *interests*



The Best Interests Standards

- Determination of the greatest net benefit
- Focuses primarily upon the current and future interests
- Heavy focus on **Quality of Life** issues
- Favorable **balance** of simple pleasure or contentment over pain/discomfort, minimizing pain and suffering
- Prolonging life can effect burdens that are often **disproportionate** to any benefits that the person receives



Quality of Life Judgments

- Social worth or interpersonal judgments
 - Makes comparative value to the life of an individual
 - Ranks worth of individual relative to worth of others
- Intrapersonal or non-comparative judgments
 - According to value or quality of an individual's life to **that individual**
 - Regardless of how society or other calculators of social utility evaluate it



Intrapersonal Quality of Live

- Very Well Circumscribed
 - Not whether QOL is below average
 - Not whether QOL is worse than it used to be
- Only whether quality of patient's life will be so poor as to be not worth living or worse than no further life at all



Conclusion