

Advance Care Planning: Ethical Problems and Recommendations

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Complex Patient Populations

- * **Conditions in which cognitive and physical decline occurs over long periods**
- * **Dementia as prime example**
- * **Growing numbers, common concern**

Dementia Directives

- *To refuse life-sustaining medical interventions**
- *To refuse feeding by mouth**
- *To receive life-ending drugs**

Conflicting Interests

- *Potential discrimination against later self**
- *Respect for individual autonomy vs. protection for people with disabilities**

Reasons to Limit Directives

- * (1) barriers to informed choice;
- * (2) deficiencies in ability to predict quality of life with dementia; and
- * (3) potential harm to people living with dementia.

Informed Choice Problems

- * Too many potential interventions
- * Negative stereotypes about dementia
- * Failure to understand dementia from patients' perspectives

Affective Forecasting Errors

- * **Tendency to overestimate negative impact of illness on subjective well-being**
- * **Perspectives gap between people with disabilities and nondisabled people**
- * **Dementia as transformative experience**

Challenging Advance Directives

- * Changing selves over time**
- * Changing interests over time**
- * Deprivation of opportunity to revise preferences in light of new situations**

Binary View of Capacity and Decision Making

- * **Dissent and Assent: Decisionally Impaired People Have a Role in Medical and Research Choices**
- * **Surrogates Report Consultation with People Affected by Dementia: “Dual Decision Making”**
- * **Supported Decision Making Allows People with Intellectual Disabilities to Make Choices**

Recommendations

- * Promote Better Understanding of Our Potential Futures**
- * Recognize How Stigma Can Shape Individual Preferences, Professional Judgments, and Community Attitudes**
- * Develop Approaches That Recognize Interests and Concerns of People with Dementia and Other Intellectual Disabilities**