Ethical Issues in the Care of Persons With Dementia

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My Goals

- Review perspectives on aging, dementia and personhood
- Identify ethical decision-making over the older life journey
  - competence and capacity
  - advance care planning (ACP)
  - the role of substitute decision-makers
- To identify some challenges
  - for respecting autonomy in community
  - from the legalization of assisted death
Changing Demographics and the Aging of Society

Life expectancy for men is 82; women 85yrs; increased 21 yrs since 1920; fastest growing segment is over 80yrs

- We have an inversion of the traditional “population pyramid”

- Concerns regarding a “tsunami of the elderly”
Traditional Population Pyramid
Developed Nations Pyramid

United States population (2000)

Data source: U.S. Census Bureau, International Data Base (IDB), http://www.census.gov/pope/www/idbnew.html
Attitudes

Toward aging:
“Successful”
Un-successful
  ○ Ageism
    ● Dread/stigma of dementia
    ● A medical condition to be cured

○ Toward older persons:
  ● Dependent, useless
  ● In need of care and resources
  ● Risk of abuse and neglect
Ethically Relevant Features In Aging

- The ‘elderly’ are a diverse population with different trajectories of aging
- Older persons live with a wide range of support from friends and families
- There are different approaches to independence and to decision-making among older persons:
  - Strong need for control
  - The “right to be dependent”
Modern Bioethics: Principles

- Respect for autonomy
  - Recognizes persons’ right to make health choices consistent with their values
  - About more than decisional capacity

- Beneficence
- Non-maleficence
- Justice

- Informed choice is a tool to promote respect for autonomy
Elements of Informed Choice

Information
- Reasonable patient standard
- Ideally shaped to the person’s need

- Capacity (ethics)/competence (law)

- Freedom, voluntariness
  - From coercion
  - From undue fear
  - From guilt
Competence/Capacity

Capacity to indicate a choice; understanding relevant information and consequences; and make a ‘reasonable’ decision

- Not “all or none”
  - Balance criteria with value/risk of the choice

- Can be:
  - Fluctuating
  - Deteriorating
Competence/Capacity

There can be a substantial difference between:
- decisional competence-knowing your wishes and values and
- executional competence-the ability to effect your wishes and values
Ethical Requirements for Substitute Decision-Makers (SDM)

- The gift and duty to speak for those who cannot

- The patient must lack capacity

- The SDM makes an informed choice

- The decision ought to be made as the patient would want using substituted judgment.
Advance Care Planning - A Process

- Clarifying values and hopes for care when not competent
- Conversations with family, friends, health care providers, etc. regarding these values
- Complete an advance directive
  - Instructional (living will)
  - Appointment of a proxy
- May be given written instructions
ACP : Intrinsic Issues in ‘Pre-commitment’

○ The “problem of protecting futures”
  ● Can a prior commitment undermine patient best interest in the present circumstances?

○ Proxies’ task is to judge in these circumstances.
  ● Need to revisit when things change

○ Patient wishes are not the only factor in decisions!
Dementia-The Dreaded Decline

- Society dominated by rational choice, autonomy and productivity

- Personhood focus:
  - Rationality
  - Relational and understood in narrative

- Person-centered Care
Cognitive Capacity and Personhood

• “She’s not the person she was”
Meaning-Making in Aging

- Identity
- Dignity
- Dependence, uncertainty, lack of control *
- Non-abandonment, fidelity to care*
- Dying and death
Ethical Issues Along the Dementia Journey

- At diagnosis
- In day to day decisions
  - Communication and relationships
- Advance care planning
- End of life care
- Balancing empowerment and protection and care
TVN values for frail elderly

**Respect** for the dignity, diversity and autonomy of the frail elderly and their families/caregivers, especially at the end of life.

- **Empowerment** of the frail elderly and their families/caregivers in all levels of care and decision-making.

- **Equity** of access to care that is collaborative, integrated and effective in improving equitable health outcomes for the frail elderly.
TVN values for frail elderly

**Collaboration** in meaningful relationships and projects at all levels of decision-making and care.

- **Innovation** in a cohesive, transformative, solution-driven program of research
Respecting Autonomy in Community: Facility Challenges

- The ‘moral ecology’ of a facility
- Living a private life in a public space
- Autonomy in LTC is not generally about BIG decisions but a series of small ongoing negotiations, acceptances and non-cooperation
The Supreme Court of Canada Decriminalized PAD

- for competent adults with a
  - "grievous" medical condition (including an illness, disease or disability)
  - that is irremediable (cannot be relieved by means acceptable to the individual)
  - causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition."
The Supreme Court of Canada Decriminalized PAD

Special challenges because the main reasons for requests relate to suffering:
- feeling a loss of dignity, being a burden, fear of future care

- PAD for competent persons
  - At the time of the decision
  - At the time of the medical act
  - Can it be in an advance directive?