

Caring for people with “change of self”

Bernard Lo, M.D.
University of California San Francisco
The Greenwall Foundation
February 3, 2012

1

My aunt

- **Multi-infarct dementia**
 - Look at photos of my son
 - Adjust to limitations, find pleasure?
 - “Never keep me alive like that”

2

What change in self?

- **Change in core characteristics**
- **Change in how others regard person**
- **Change in self-concept**
 - May not be able to ascertain in neuro-degenerative diseases

3

Everyday dilemmas in dementia

- **Previous directives to accept interventions did not anticipate current condition**
 - Blood drawing, imaging studies, taking pills are more burdensome and cannot understand why
- **New sexual partner in nursing home**

4

Other brain conditions

- **Major depression**
 - “I’m not myself”
 - No initiative, energy, hope
 - “Medicines make me a different person”
 - “Like fog over my mind”
- **Traumatic brain injury**

5

Common dilemmas in depression

- **Refuse treatment to prevent deterioration, involuntary hospitalization**
 - Should prior approval when competent override current refusal?

6

Change self in non-brain conditions

- **Loss of other core functions**
 - Colectomy
 - Amputation
 - Spinal cord injury

7

Ethical issues

1. **Refusal of treatment that promotes own best interests**
 - Advance directives and values no longer apply to different person?
 - Need action guides for overriding previous directives, values, and choices of person who lacks decision-making capacity

8

Ethical issues

2. **Override previous promises and commitments by different person?**
 - Promise not to place in nursing home
 - Keeping promise impossible
 - No longer repulsed by circumstances
 - Marriage commitment

9

Ethical issues

3. **Distinguish change in self from**
 - Changes in values
 - Affective forecasting
 - Cognitive limitations in anticipating how will adapt to new situation

10

Ethical issues

3. **What are obligations of MDs and society to facilitate continuity of self?**
 - Resources
 - Time, patience
 - Ancillary and in-home services
 - Support for family caregivers
 - Professional and legal standards

11

Suggestions

- Use comparative advantages of Commission
- Recommendations that guide front-line decision-makers

12

- **Aaaa**
 - Aaaa
 - aa
- **Aaaa**
 - Aaaa
 - aa

13

- **Aaaa**
 - Aaaa
 - aa
- **Aaaa**
 - Aaaa
 - aa

14

- **Aaaa**
 - Aaaa
 - aa
- **Aaaa**
 - Aaaa
 - aa

15

Unaddressed ethical questions

- **May override advance directives**
- **Best interests > substituted judgment**
 - Under what circumstances?
 - Using what standards, safeguards?
 - Ethical / legal / clinical disjunctions
 - aa

16

