Dignity-Enhancing Care for Persons with Dementia

Advance Directives as a Case

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Introduction

• Number of older people continues to increase worldwide

• Population with dementia will double every 20 years

• Demographic evolutions result in new responsibilities:
  - Opinions on vulnerability, care, dignity
  - ‘Preparing the future’
  - Legal regulations regarding ‘end-of-life care’
Dementia care ethics approach

- Specific ethical approach to deal with ethical issues in dementia care
- Application to advance directives
Dementia care ethics approach

• Three characteristics:
  - The lived experience aspect
  - The dialogical-interpretative (process-oriented) aspect
  - The normative aspect
Dementia care ethics approach

• Lived experience:
  - Lived experiences (inductive approach), not abstract constructions (deductive approach) should be primary guide for development of ethical approach
  - **Vulnerability** as key-concept
Dementia care ethics approach

• **Dialogical-interpretative**
  - Ethical decision-making is based on dialogue between all people involved in ethical problem
  - Viewpoints are never completely clear. Ethics concerns interpretation of viewpoints of people involved in ethical problem
  - **Care** as key-concept
Dementia care ethics approach

• Normative standard:
  - Ethics implies normativity (Why do we feel as if we should care? What counts as good care? ...)
  - These normative questions invoke a certain view of mankind that underlies care, that is, a specific anthropological framework
  - **Dignity** as key-concept
Dementia care ethics approach

• Three key-concepts of dementia care ethics
  - Vulnerability (lived experience)
  - Care (dialogical interpretative)
  - Dignity (normativity)

• Ethical essence of dementia care practices:
  “Providing care in response to the vulnerability of a human being in order to maintain, protect, and promote his dignity as much as possible” (Gastmans 2013)
Dignity-enhancing care

Starting point: Vulnerability of human person
Mean: Care
Purpose: Dignity of human person
Vulnerability (lived experience aspect)

- Human life is characterized by ordinary-human-vulnerability
- Dementia produces more-than-ordinary-vulnerability: vulnerability of persons with dementia is situated in all dimensions of their being: physical, psychological, relational, social, moral, spiritual
- Dignity of these persons is threatened
Vulnerability

• **Moral vulnerability** as a case:
  - Capacity to act responsibly
  - Capacity to make decisions concerning health-related condition and care
  - Advance directives as a solution?
Vulnerability

- Two approaches to AD:
  1. ‘Precedent autonomy’ approach:
     - Competent predementia person (‘then’ self) governs the welfare of noncompetent person with dementia (‘now’ self)
     - Cognitivist approach
  2. ‘Experiential interest’ approach:
     - Predementia person and person with dementia are two different persons;
     - Priority to ‘now’ self
Care (interpretative dialogical aspect)

• Care as interpretative and dialogical phenomenon
  - Care always takes place in a relational context
  - Care originates in concern about the vulnerable state in which a fellow human being finds himself
  - Searching for most adequate and appropriate answer to vulnerability through shared dialogical process of communication and interpretation
Care

• Are **advance directives** adequate and appropriate answers to patient’s vulnerability?

• **Precedent autonomy approach to advance directives**
  - Respect for patient’s autonomy
  - Values of ‘then self’ prevail over ‘now self’
  - Individuals are able to determine their wish concerning end-of-life care cognitively
  - These directives unambiguously tell caregivers what to do
Care

- Experiential interest approach to AD:
  - Patient’s wishes cannot be considered as given whose content is unambiguous clear
  - Patient’s wishes should be constructed through interpretative processes
  - Person’s preferences and values can change: but person with dementia cannot reconsider the decisions outlined in AD; how to balance ‘then’ self and ‘now’ self?
  - Whose autonomy should be respected?
Dignity (normative aspect)

- Dementia care as dignity-enhancing care
  - Vulnerability that affects person with dementia, results in the dignity of the person itself being threatened
  - Goal of care: promotion of dignity of the person by providing good care on the physical as well as the psychological, relational, social, moral, and spiritual levels
  - Dementia care is most meaningful when the patient is respected as a human person in all his dimensions
  - Is advance directive example of dignity-enhancing care?
Dignity

• Advance directives = dignity-enhancing care?

Critique 1: Overemphasis on cognition

- Western world: high value on cognition as integral aspect of individual’s dignity
- Drawing up advance directive as cognitive and solitary activity
- ‘Exclusionary ethics’ (S. Post): value that society places on rationality excludes persons with dementia from the sphere of human dignity
Dignity

**Critique 2: Overemphasis of individual autonomy**

- Advance directives do not guarantee that wishes of person with dementia will be respected
- Unclear whether person had this situation in mind when writing AD
- Dialogue between ‘then’ and ‘now’ self is needed
Dignity

**Critique 3: Underemphasis of dialogue and shared understanding**

- Respect for autonomy should be complemented by dialogue and interpretation (relational phenomena) from the beginning of drafting AD till the moment of implementing AD into clinical decision-making.
Conclusion

• AD can be considered as a dignity-enhancing care instrument if:
  – Continuous dialogue between patient, relatives, and caregivers during process of drafting AD;
  – Wishes of ‘then self’ and ‘now self’ are respected;
  – Legal instrument (AD) never replaces dialogue and interpretation among patient, relatives and caregivers
Further reading


