

**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)

ETHICS OF HEALTH CARE

Lived
experience

Interpretative
dialogue

Normative
standard

Starting point

Means

Purpose

DIGNITY-ENHANCING CARE

Care

VULNERABILITY

DIGNITY

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

- C. Gastmans & J. De Lepeleire. Living to the Bitter End? A Personalist Approach to Euthanasia in Persons With Severe Dementia. *Bioethics* 24 (2010) 78-86.
- C. Gastmans & Y. Denier. What If Patients With Dementia Use Decision Aids to Make an Advance Euthanasia Request? *American Journal of Bioethics* 10 (2010) nr. 4, 25-26.
- C. Gastmans. Dignity Enhancing Care for Persons with Dementia and its Application to Advance Euthanasia Directives. In: Y. Denier, C. Gastmans & T. Vandeveld (eds.) *Justice, Luck and Responsibility in Health Care: Philosophical Background and Ethical Implications*. Springer: Dordrecht, 2013, 145-165.
- C. Gastmans. Dignity Enhancing Nursing Care. A Foundational Ethical Framework. *Nursing Ethics* 20 (2013) 142-149.