Ethical dimensions to palliative care for frail older people

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The ambivalent ideal of aging
Older persons?

- healthy
- multimorbidity
- frailty
- Care dependency
Trajectory of aging

healthy → multimorbidity → frailty → Care dependency

• → →

COMPLEXITY
HETEROGENEITY
Older adults ‘beyond frailty’: persistence of ageism

- Complex multimorbidity (frailty + multiple chronic conditions + functional impairment)
  - labeled as ‘the fourth age’ (Lasslet)

- Most excluded in clinical research
  - misbalance in research investment
  - misbalance in treatment

- Most excluded in society
  - shamingly contrasts with dominant values of autonomy and dignity
  - ‘fourth age’: the black hole of aging
  - Poses exceptional adaptive challenges
Older adults ‘beyond frailty’: persistence of ageism

• Complex multimorbidity (frailty + multiple chronic conditions)

• "fourth age"

• Most excluded in clinical research

• Disbalance in research priorities

• Most excluded in society

• Shamefully contrasts with dominant values of sufficiency and productivity

• "fourth age": the black hole of aging

• No script for deep old age

• "Weariness of life" as a motive for (assisted) suicide

→ MORAL PRIORITY FOR PALLIATIVE CARE!
Challenges for research and practice:

• What is the appropriate concept of palliative care for this patient group?

• When to initiate (discussions on) a palliative care approach?

• Who is responsible for initiating (‘ownership’)?

• What is the place of life prolonging treatment?

• How to value and promote autonomy?

• QoL and dignity: adequate outcome measures?
Palliative care according to the WHO:

• Improvement of QoL through relief of pain and other (psychosocial and spiritual) problems

• Focus on life threatening illness

• No intention to hasten or postpone death

• Supports patients and their families

• Applicable early in the course of the disease in conjunction with life prolonging treatments
Conceptual dilemma’s:

Dependent on the ‘oncological’ model

Dependent on nosological paradigm

Defines PC as complementary to curative care

Diagnosis-related start

Predictable illness trajectory
Illness trajectories

Health Status
- Healthy
- Chronic, progressive, eventually fatal illness

The Old Model of Care:
Curative care is the primary focus until the final days or hours of life.

The New Model of Care:
Palliative care is provided at the same time as curative care, maximizing quality of life throughout the course of disease.

Lynn & Adamson, 2003
Not easily applicable because:

• No curative interventions available for (people with) multiple chronic diseases
  – \(\rightarrow\) conjonctive model fails

• No clear demarkable diagnosis-oriented starting point
  – \(\rightarrow\) disease oriented approach fails

• Illness trajectory unpredictable / lack of prognostic guidance
  – \(\rightarrow\) oncological model fails
Geriatric palliative care

• The medical care and management of older patients with health-related problems and progressive, advanced disease for which the prognosis is limited and the focus of care is quality of life
  – (EUGMS, 2007)

• A philosophical stance and a structured, interdisciplinary model of care delivery that guides care to patients and families during the last 5 years of life, irrespective of disease. The goal of geropalliative care is to promote well-being to older patients and their families through interventions that reduce suffering and enhance quality of life
  – (Lee & Coakley, 2011)
Starting point and ‘ownership’/responsibility:

When life prolongation as a(n implicit) goal of care looses its self-evidence / becomes questionable:

• 1. Patient signs: implicit or explicit

• 2. Relevant changes in health condition and care transitions

• 3. Clinical judgment (prognosis?)
Palliative care approach:

- From reactive medical treatment strategies to proactive care planning
- Rooted in collaborative decision-making
- And patient-centered goalsetting
- To be evaluated and revised at a regular basis

How to go the way that will lead us all to the same place?

(Michel Montaigne)
Role of life prolongation
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Role of life prolongation

• 1. Place of chronic and preventive (drug) treatments

• 2. Life prolongation as (co-intended) side effect of palliative care (interventions)
Role of life prolongation

• 1. Place of chronic and preventive (drug) treatments

  → systematic medication review as part of ACP (ACP+)

• 2. Life prolongation as (co-intended) side effect of palliative care (interventions)
Medication appropriateness in late life

• Evidence of safety and effectivity

• Time horizon to benefit i.r.t. remaining life expectancy

• Risk of harm and burden

• Overriding care goal
Role of life prolongation

1. Place of chronic and preventive (drug) treatments

2. Life prolongation as (co-intended) side effect of palliative care (interventions)

- debate on non treatment AD in dementia care
- distinction between (wider) palliative care goal and (more strict) symptomatic / comfort care goal
Role of (respecting) autonomy
Respecting autonomy since the 1970’s

- From paternalism to autonomy
- From independent choice model to various forms of shared decision making
Collaborative decision-making (CDM)

- Focus on the ‘how’ instead of on the ‘who’
- Focus on the process of working together towards a care-plan
- Allows for more participants
- Articulates context of patient values
- Adresses individual strengths
Stepwise practical approach to collaboration in decision-making: ASK ME!

- Step 1 ASSESS strengths and limitations
- Step 2 SIMPLIFY the task
- Step 3 KNOW the person
- Step 4 MAXIMIZE ability to understand
- Step 5 ENABLE participation

– IPA Taskforce on decisional capacity, 2013.
Quality of life and dignity

- QoL important outcome paradigm in PC

- Most instruments lack an explanatory theory of the effect of ill health on QoL that can also guide interventions

- Dignity is viewed as important too; but is it a clear concept?
Dignity

• A useless concept?

• Dominant view: dignity-without-need

• Experiences of older adults:

  – *Dignity of respect and recognition*
  – *Identitywork: maintaining a sense of self in the face of its erosion by disability and care dependency*
  – ‘*Keeping up appearances*’