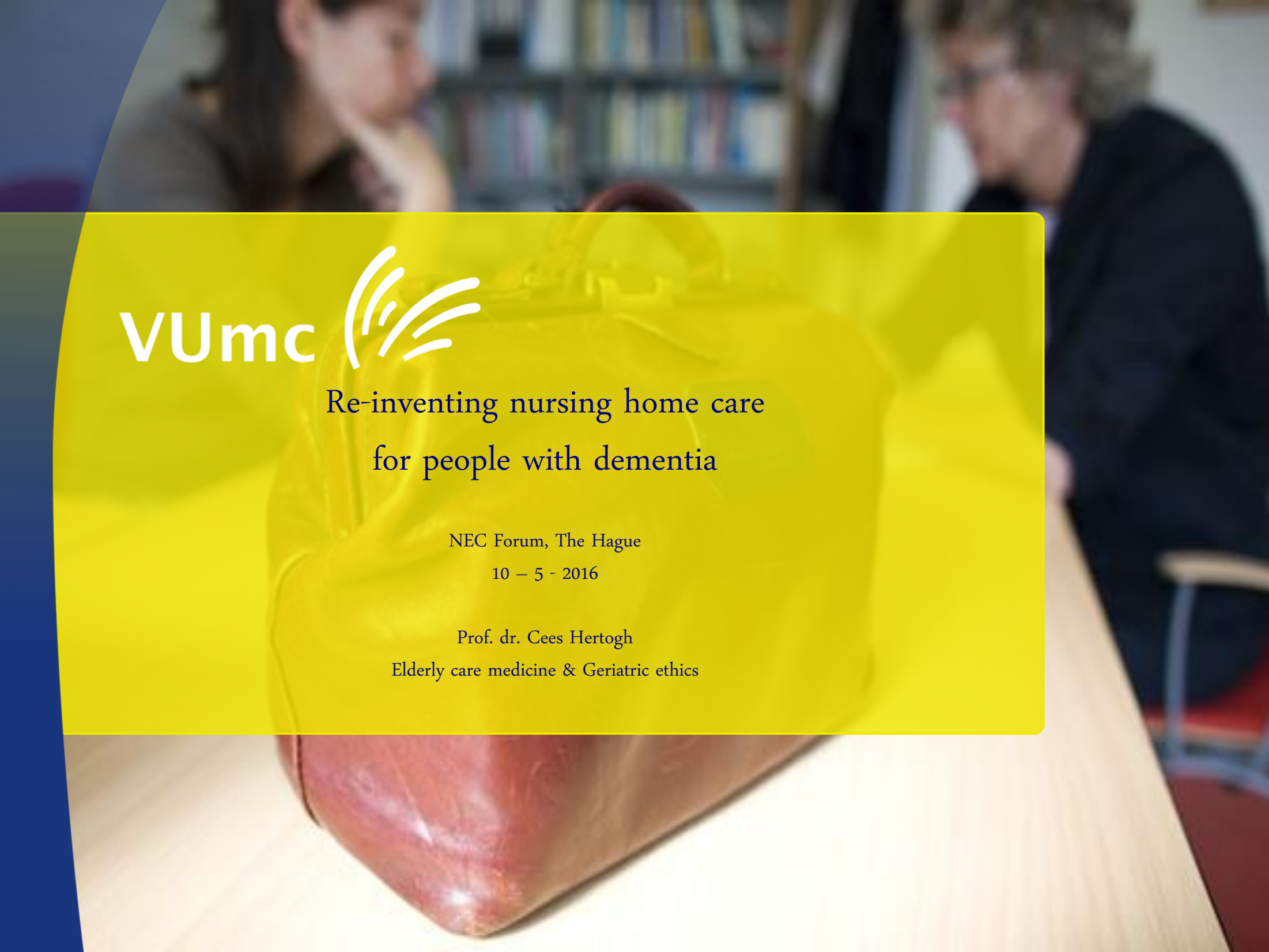


VUmc

Re-inventing nursing home care for people with dementia

NEC Forum, The Hague

10 – 5 - 2016

Prof. dr. Cees Hertogh

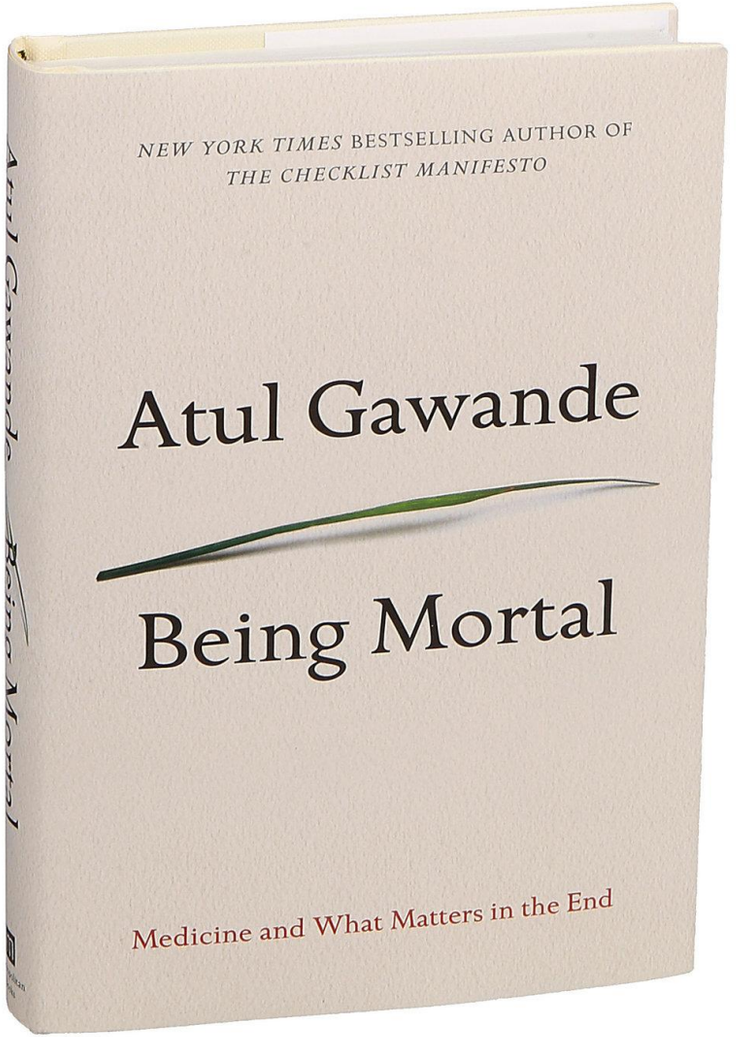
Elderly care medicine & Geriatric ethics

Eos en Thitonos

The ambivalent ideal of aging

Challenges

- 1. Huge Knowledge gap
  - → *older persons with chronic disease and multimorbidity are most excluded in clinical research*
  - → *nosological approach fails*
- 2. Societal challenges



We're good at addressing specific, individual problems: colon cancer, high blood pressure, arthritic knees.
Give us a disease and we can do something about it.
But give us an elderly woman with high blood pressure, arthritic knees, and various other ailments besides – an elderly woman at risk of losing the life she enjoys – and we hardly know what to do and often only make matters worse.

Recent news from gerontology…

- ***The good news: the third age (young old)***
- Increase in life expectancy: more people live longer
- Substantial latent potential for better fittness in old age
- Succesive cohorts show gains in physical and mental fitness
- Evidence of cognitive-emotional reserves of the aging mind
- More and more people age succesfully
- High levels of emotional and personal well-being (self-plasticity)
- Effective strategies to master the gains and losses of late life

Recent news from gerontology…

- ***The not-so-good or bad news: the fourth age (oldest old)***
- Sizeable losses in cognitive potential and ability to learn
- Sizeable prevalence of dementia (about 50% in 90-year-olds)
- High levels of frailty, dysfunctionality and multimorbidity
- Dying at older ages: with human dignity?
- ➔ *prospects for the 21st century: the era of chronic incompleteness of mind and body?*
  - *(Baltes & Smith, BASE)*

Societal challenges:

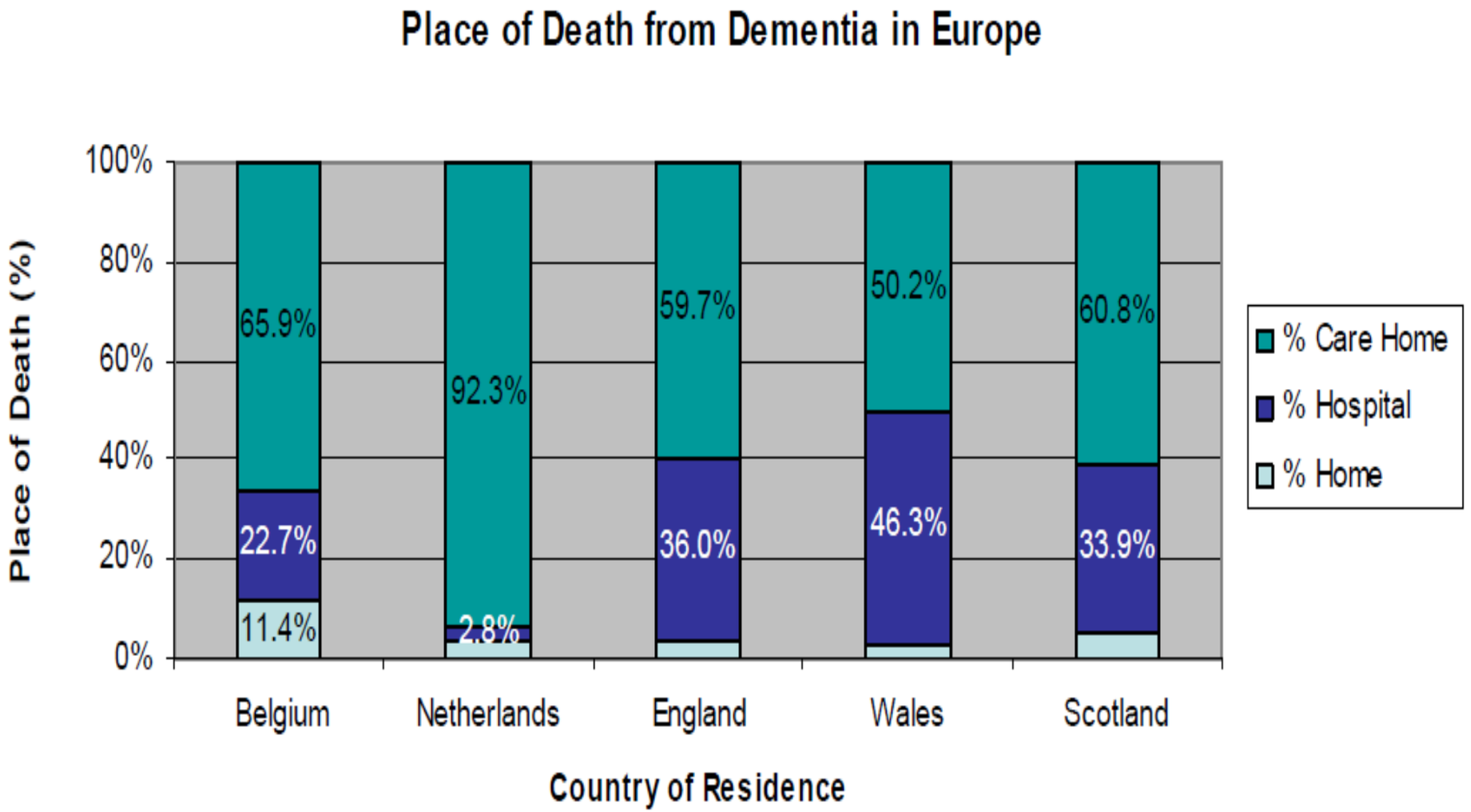
- Pervasive ageism due to focus on ‘successful aging’ and ‘third age script’
- Lack of a positive, acceptable social imaginary of old age
  - → ‘fourth age’ = black hole of aging
  - → demonstrated by institutionalized life and care

Three paradigms of good nursing home care:

- Medicalization: → active treatment
- Psychologization: → person-centred care
- Normalization: → continuation of ordinary life

Re: medicalization: active treatment

- Dementia ≠ normal aging, but a disease
- Boost to research + development professional care
- 1968 Long Term Care Act → Nursing home medicine
- From nurse-led model of custodial care → Active Treatment
- Unique observational studies:
  - → *dementia recognized as life-limiting disease*
  - → *life-sustaining treatment and hospital admission ↓↓*



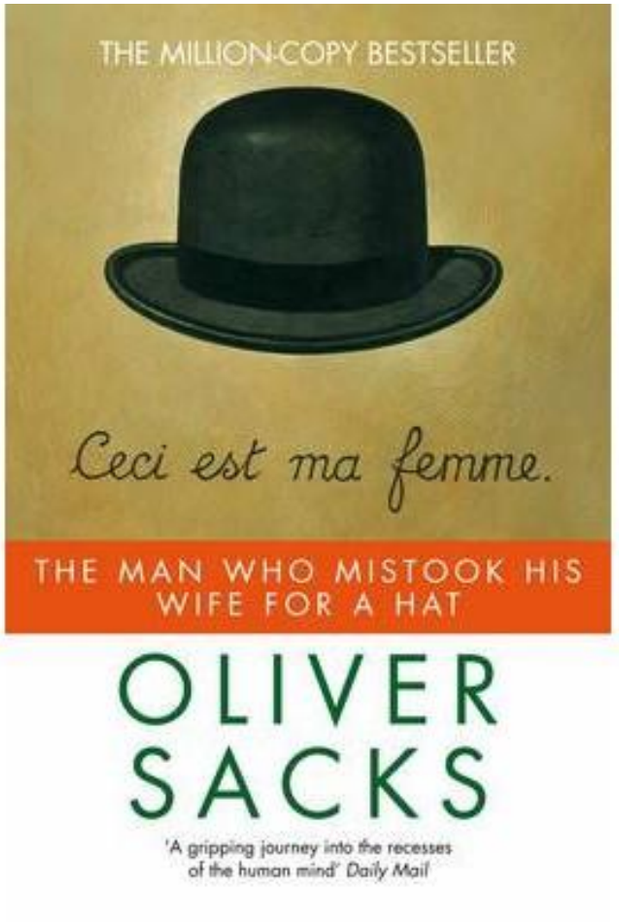
Houtekier et al, 2009

Re: psychologization: person-centred care

- Discovering the perspecive / awareness of the person with dementia
- An alternative way of knowing dementia (…) a shift away from pathology to people (Nolan *et al*, 2002)
- Tom Kitwood: the dialectics of dementia:
  - *“there is still some truth in the old idea that someone can be driven demented”*

memory disorder or disorder of the self?

A neurology of identity



- "…for here the patient's personhood is essentially involved, and the study of disease and of identity cannot be disjoined…"
- "…a disease is never a mere loss or excess, there is always a reaction of the part of the individual to restore and to preserve its identity…"

Holding on to a sense of self…

- ‘identitywork’: balancing between self-maintainance and self-adjustment

- Fundamental psychological dilemma:
  - acknowledge → unbearable awareness
  - block out → losing touch with reality

’staying away from full awareness’

Re: normalization: continuation of daily life

- Accent on built environment:
  - *Small scale living arrangement*
  - *Dementia villages (e.g. Hogeweijk, Weesp)*
- Bachelard / Jung: our house mirrors our soul →
- Home-like environment fosters identity and security
- Whose ‘normality’ is being served here?
- Pitfall: “seeing the world through their eyes!”

Nursing home care beyond the institute….

“The people who can change current nursing home care have the age at which they may have to deal with dementia in their own family. When I ask what they wish for themselves or their loved ones, I invariably get answers that are consistent with the wishes of ordinary living. They outline a secure and trusted environment similar to home, which allows their dear one to do the things they like to do, both in- and outside. Just ordinary life.”

(*J. Spiering, Hogeweijk, 2015*)

“At every thing a man wishes to show of himself we must ask the question: what does he wants to hide?”

(Gaston Bachelard, La formation de l’esprit, 1937)

What's in a name???

Viva!

Vivium

Viventes

Vivantes

Vivre

Vitez

Vivensis

‘long term’ care or palliative care?

- Mean length of stay somatic ward: 1.5 yr
- Mean length of stay dementia unit: 2.4 yr
- Per 100 beds per year: 34 deaths

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journal homepage: www.jamda.com

Original Study

From Admission to Death: Prevalence and Course of Pain, Agitation, and Shortness of Breath, and Treatment of These Symptoms in Nursing Home Residents With Dementia

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Keywords:
Dementia
palliative care
symptoms
pain
behavior
symptom control

A B S T R A C T

Objectives: Burdensome symptoms frequently develop as part of the dementia trajectory and influence quality of life. We explore the course of symptoms and their treatment during nursing home stay to help target adequate symptom management.
Design: Data were collected as part of the Dutch End of Life in Dementia study, a longitudinal observational study with up to 3.5 years of follow-up. Physicians performed assessments at baseline, semi-annually, and shortly after death of pain, agitation, shortness of breath, and treatment provided for these symptoms.
Setting: Long-term care facilities (28) in the Netherlands.
Participants: Newly admitted nursing home residents (372) in variable stages of dementia.

Course of symptoms in patients with dementia

- Pain: 47% - 68 % across assessments, frequently persistent (36% - 41%)
- Agitation: 57% - 71%, decreasing to 35 % in last week
- CONCLUSION:
- → pain and agitation are common and persistent
- → symptom management only intensified near end of life
- → stronger focus on symptom relief is needed in earlier stages

(Hendriks et al, 2015)

JAMDA 13 (2012) 634–639

JAMDA

journal homepage: www.jamda.com

Original Study

Institutionalized Stroke Patients: Status of Functioning of an Under Researched Population

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Keywords:
Stroke
nursing homes
long term care

A B S T R A C T

Objectives: In view of the development of an integrated care and treatment program for institutionalized stroke patients tailored to their needs, we aimed to explore their status of functioning in the physical, cognitive, emotional, communicative and social domains. In addition, we explored the relation between status of functioning and stroke characteristics.
Design: A cross-sectional, observational study.
Setting: Dutch nursing homes (NHs).
Participants: Residents with stroke as main diagnosis for NH-admission, who experienced a stroke ≥3 months ago and stayed ≥1 month in a long term care ward.
Measurements: Attending physicians provided information about stroke subtype, stroke location and time post-stroke. Status of functioning was measured through an observation list comprising the Barthel

Care for stroke in long term care (CASTILON)

- Pain: 58%
- Irritability: 52,9%
- Depressive symptoms: 52,6%
- Apathy: 34,3%
- Low social engagement: 30,3%

- CONCLUSION:

- → high prevalence of burdensome symptoms
- → management of pain and neuropsychiatric symptoms should be key elements of an integrated treatment program

(van Almenkerk et al, 2012)

Adaptive challenges for residents with stroke in LTC
(CASTILON, qualitative interview study, N=)

Three major themes:

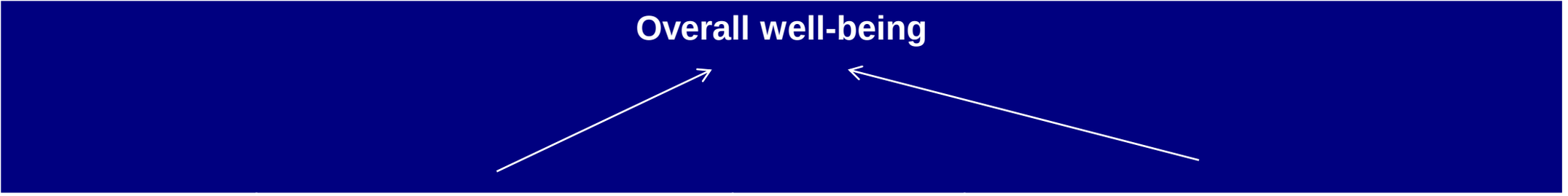
- 1. Identity work: restoring a broken identity
- 2. Maintaining agency and self-esteem
- 3. hope: not loosing hope despite a limited future

No (actively sought or received) support from professional carers!

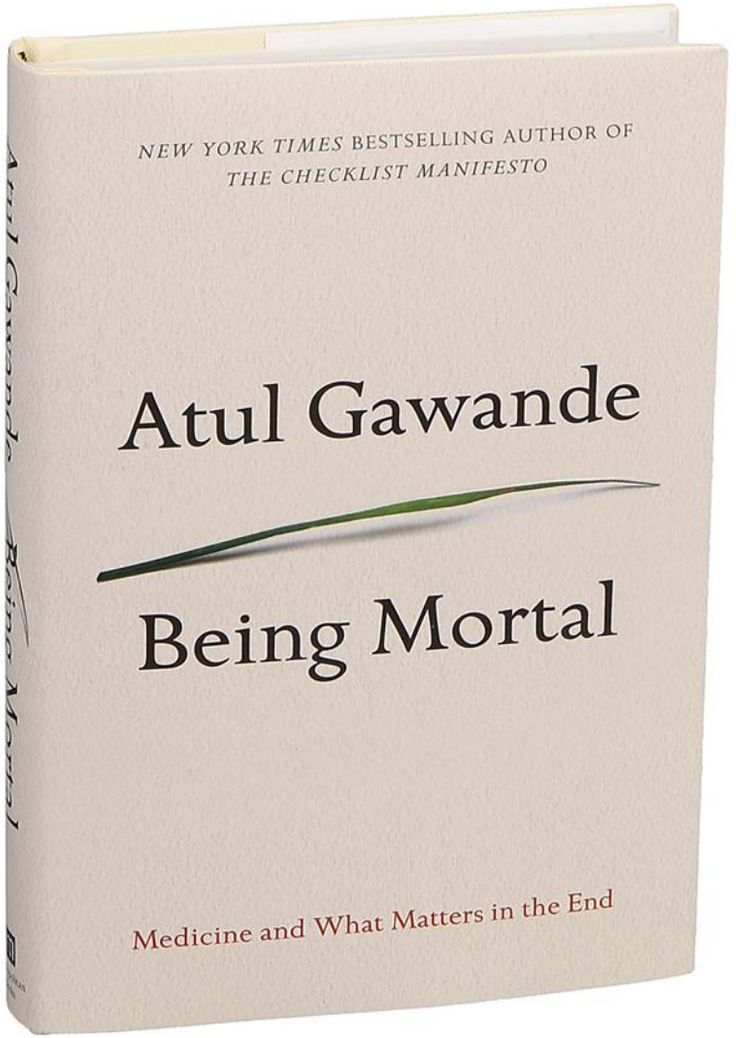
(Van Almenkerk et al, 2016, preliminary data)

Geriatric palliative care (GPC), definition:

An integral multidisciplinary model of care delivery that guides care to patients and families when life prolongation as a goal of care looses it self-evidence. The goal of GPC is to promote both well-being to older patients and their families through interventions that enhance quality of life and reduce suffering.



Universal goals	**Physical well-being**			**Social well-being**	
First order instrumental goals	**comfort**	**stimulation**	**status**	**Behavioural confirmation**	**Affection**
acitivities	safe housing, self care, symptom relief	physically and mentally arousing activities, (re)creative activities	role fulfillment, excelling in a valued role	recognition, behaving according to external and internal roles	exchanging emotional support, spending time together
Resources and endowments	financial means, physical health	physical and mental health, financial means	education, social origin capabilities	social skills, social network, normative environment	attractiveness. empathy, partner, children



Medicine…..and What Matters in the End

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