

# **Palliatieve zorg en onze omgang met het levenseinde: Ethische reflecties die moeilijk moeten blijven**

**Prof. Dr. Sigrid Sterckx**

**Bioethics Institute Ghent, Ugent**

**Consortium Justifiable Digital Healthcare, UZGent**

**End-of-Life Care Research Group, UGent & VUB**

**Centre for Health, Law and Emerging Technologies, University of Oxford**

**Symposium 30 jaar palliatieve zorg in AZ St Lucas – 10 september 2022**



# Overzicht

- 1. “Limitations of this researcher”**
- 2. Leven we in een “palliatieve maatschappij”? (korte filosofische provocatie)**
- 3. De “technologische imperatief” in de geneeskunde als (deel)verklaring voor de onderwaardering van palliatieve zorg**
- 4. Ook een technologische imperatief in de palliatieve zorg?**
- 5. “Technologie-aversie” als alternatieve valkuil ? (persoonlijke anecdote ivm klinische studie)**
- 6. Tot slot : “palliatieve zorg” ver voorbij de WHO definitie ?**

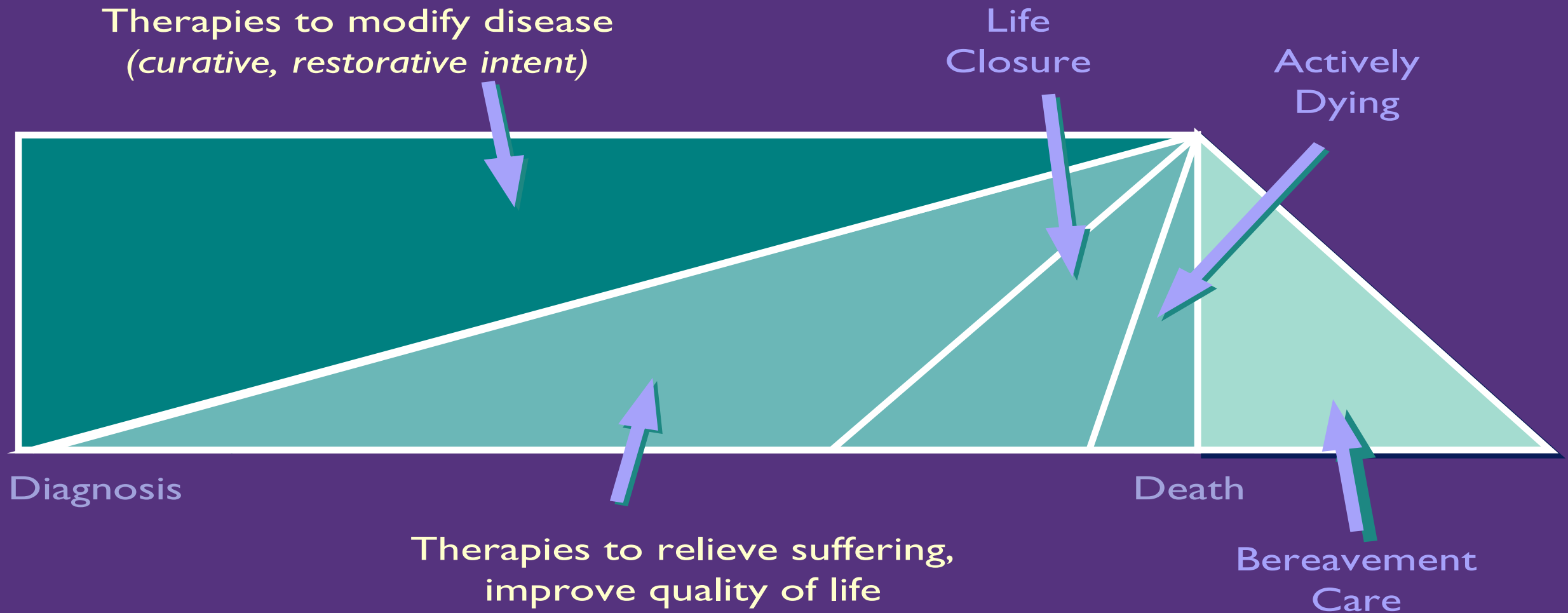
## “Limitations of this researcher”

- **Geen klinische kennis of ervaring**
- **Wel veel ervaring met bioethisch onderzoek over palliatieve zorg, maar de focus daarvan is beperkt in het licht van de extreme breedheid van het domein “palliatieve zorg”:**

*“Unfortunately, palliative care is still misconstrued as end-of-life care only, and is seen as being passive and “not offering hope”, publicly, politically and within health care. Palliative care is active care, with interventions and examinations that address the needs of patients and families during curative, life-prolonging and end-of-life care.”*

Kaasa et al. (2022), Commercial and social determinants in palliative care, *Eurohealth* 28(2): 22-27 (WHO team of the European Observatory on Health Systems and Policies), p. 22

# The continuum of palliative care



# “Abyssal gap” between PC needs and PC provision



**86%**

of people who need  
palliative care do not  
receive it



**83%**

of the world's  
population lack  
access to pain relief



**98%**

of children needing  
palliative care live in  
low and middle  
income countries

Source: WHO infographics on palliative care

# “Limitations of this researcher”

- **Mijn eigen (bioethische) expertise beperkt zich vooral tot continue sedatie aan het levenseinde en euthanasie (over dat laatste zal ik het vandaag niet hebben)**
  - ▶ De Hert M, Loos S, Sterckx S, Thys E, Van Assche K (2022) Improving control over euthanasia of persons with psychiatric illness: Lessons from the first Belgian criminal court case concerning euthanasia. *Frontiers in Psychiatry* 13:933748. doi: 10.3389/fpsy.2022.933748
  - ▶ Raus K, Vanderhaegen B, Sterckx S (2021), “Shortcomings of the application and monitoring of the euthanasia law and practice in Belgium”, *Journal of Medicine and Philosophy*, vol. 46, pp. 80-107.
  - ▶ Verhofstadt M, Audenaert K, Sterckx S, Van Assche K, Chambaere K (2019), “Psychiatric patients requesting euthanasia: Guidelines for sound clinical and ethical decision-making”, *International Journal of Law and Psychiatry*, vol. 64, pp. 150-161.
- **Sterkte: mateloos geïnteresseerd**

# Leven we in een “palliatieve maatschappij” ?

- ▶ “**Algofobie**”: een alomtegenwoordige angst voor pijn
- ▶ “Pijn is een **geheimschrift**. Het bevat de sleutel tot **begrip** van de betreffende maatschappij. ... Wordt pijn alleen aan de **geneeskunde** overgelaten, dan **missen** we zijn karakter als teken.”
- ▶ “Aan de huidige algofobie ligt een **paradigmawisseling** ten grondslag. We leven in een maatschappij van **positiviteit**, die zich van elke vorm van negativiteit tracht te ontdoen. Pijn is negativiteit bij uitstek.”
- ▶ “De palliatieve maatschappij is verder een **maatschappij van ‘het bevalt mij’**. ... Alles wordt net zolang gladgestreken tot het bevalt. **Like** is het symbool, ja het **analgeticum van het heden**.”



# De technologische imperatief als verklaring onderwaardering PZ ??

## Kaasa et al. 2022: Commercial and social determinants in palliative care

### 3. Key CDoHs in PCC

- Commercial interests prevent implementation of PCC due to the dominant focus on antitumor treatment, new drugs and technologies
- Introduction of palliative and symptom-focused care occurs too late in the disease trajectory, due to more anticancer treatment at end-of-life
- Little attention to side effects during and after curative and life prolonging treatment
- Few economic incentives related to symptomatic management and psychosocial support
- Death and dying attract little attention compared to anticancer treatment
- Disproportionate focus, interest and cost allocation between TCC and PCC
- The paradox of the iatrogenic\* opioid-overuse in some high-income countries alongside insufficient pain management and poor availability/accessibility in many middle and low-income countries
- Auxiliary palliative care consultations during pharmaceutical studies are not reimbursed as they are not part of the trials
- Palliative care still has a stigma: this is a CDoH enforced by the tumour-centred focus of cancer care, industry and media, influencing both health care professionals and the public
- The common perception that any physician/oncologist can provide specialist PCC



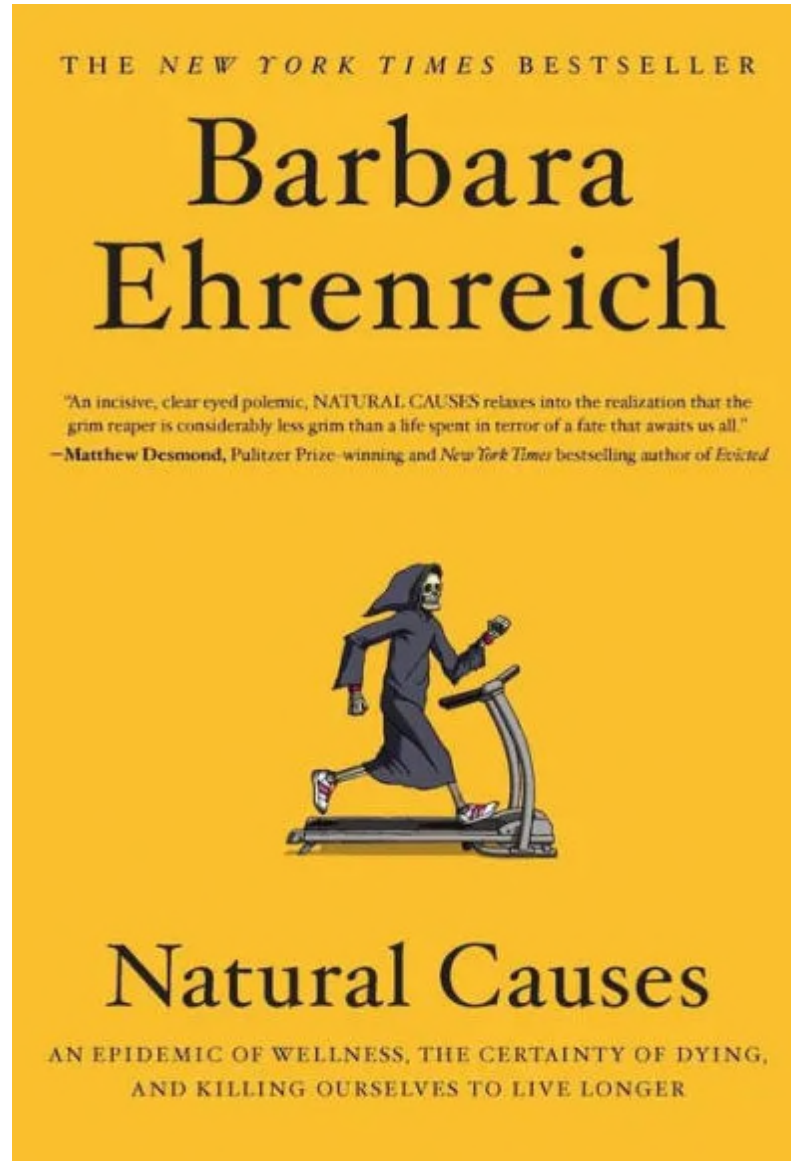
# De technologische imperatief als verklaring onderwaardering PZ ??

## Kaasa et al. 2022: Commercial and social determinants in palliative care

- ▶ “[T]he **clever marketing** of new anticancer treatments as **personalised medicine** given their association with certain biomarkers, promotes the **impression** that the **patient** is in focus. That is not the case: the **tumour** is the target.” (p. 24)
- ▶ “Commercially and societally, it is **easy to sell** the message – *we will cure cancer*. ... All bodies promote **the cure message**, appealing to human nature and emotional states; “*live as long as possible*” ...” (p. 26)
- ▶ “Societal and attitudinal barriers and the **overarching perception** of **palliative** care and [person-centred care] being **synonymous** to **end-of-life** care must be conquered. Palliative care carries a **stigma**, commercially, publicly, and in the press, that is **reinforced by the professional socialisation throughout the medical and nursing education.**” (p. 26)

# De technologische imperatief als verklaring onderwaardering PZ ??

Barbara Ehrenreich (2018)



# De “technologische imperatief”

Dit concept werd “gecoined” door econoom Victor Fuchs (Stanford):

Fuchs V. “The growing demand for medical care. *New England Journal of Medicine* 1983; 309: 607 (reprint of a report he wrote in 1968 for the US National Bureau of Economic Research) :

*“The problem, as I see it, is that the **physician’s approach to medical care and health** is dominated by what may be called a **“technological imperative.”** In other words, medical tradition emphasizes giving the best care that is technically possible: **the only legitimate and explicitly recognized constraint is the state of the art.**”*

# De “technologische imperatief”

There is an **imperative of possibility** : cf. statements such as:

- ▶ *“we have to try everything possible”*
- ▶ *“more choices [of things to try] are better than few”*

There is an **imperative of action** : cf. statements such as:

- ▶ *“do something!”*
- ▶ *“we do not want to be accused of not having tried”*

>> **action** is preferable over no action & ‘**effective**’ action is seen as action that involves **technology**

Hofmann 2002 Internat. J. of Technol. Assess. in Healthcare 18(3): 675

# De “technologische imperatief”

## A variety of drivers:

- ▶ **Institutional** factors
- ▶ **Patient** demand
- ▶ The desire for the “**latest**” technologies
- ▶ Views on the **goals of medicine**
- ▶ Technology constitutes **the very concept of disease**
- ▶ Fear of **uncertainty and ambiguity**
- ▶ Fear of **value judgments**

# De “technologische imperatief”

**Drivers: Institutional factors: e.g. cost control**

Efforts at cost control are diverted away from equipment / technology >> the focus is rather on **reducing personnel expenses**

**Result:** fewer caregivers; **less time for activities that do not involve equipment/technology**; and increasingly less recognition of the importance of **person-to-person care**

Barger-Lux M. & Heaney R. *Soc. Sci. Med.* 1986; 22(12): 1315.

# De “technologische imperatief”

## Drivers: **Patient demand**

- ▶ A rise of **consumerism**
- ▶ Talk about **health** as a **commodity**
- ▶ Health as something money can **guarantee**
- ▶ Health as something determined by felt needs of patients and **delivered on demand by doctors**

Kass L. Regarding the end of medicine and the pursuit of health. *The public interest* 1975; 40.

# De “technologische imperatief”

## Drivers: **Patient demand**

- ▶ Patients are **unhappy** if their physician tells them to change their diet; they **prefer** to be told that they need an MRI / CT / PET scan
- ▶ For patients and families who regard quality of healthcare heavily in terms of technological sophistication, **any reduction in technological intervention** is likely to be unwelcome -- **seen as a sacrifice of quality** or as ‘giving up on’ or ‘abandoning’ the patient.

*“It is **as though** the weakening or neutralization of [a focus on technology] would leave, as the **only alternative, no care at all.**”*

Barger-Lux M. & Heaney R. *Soc. Sci. Med.* 1986; 22(12): 1315.



# De “technologische imperatief”

**Drivers: the desire for the “latest” (technologies)**

Cf. statements such as:

- ▶ *“others (other physicians, other hospitals) use this (version of the) technology”*
- ▶ *“we cannot stop progress”*
- ▶ *“do we have any choice??”*

# De “technologische imperatief”

## Drivers: Views on the goals of medicine

*“In a system dominated by the technological imperative, the prolongation of life – i.e. **death prevention** – is **the de facto purpose or goal** of health care. ...*

*Many **physicians** seem to behave – and the public perceives them to behave – as though they are **locked in combat with death**. The **patient** is both battlefield and prize. ... [A] **single-minded purpose** – to win – stands above all others and **eclipses** them completely. ... [**Winning this war**] becomes a problem that is **essentially technological.**”*

Barger-Lux M. & Heaney R. Soc. Sci. Med. 1986; 22(12): 1316.

# De “technologische imperatief”

## Drivers: **Technology constitutes the very concept of disease**

- 1) Technology **provides** the (physiological, biochemical, and biomolecular) **entities** that are applied in **defining diseases** – all defined by technological measures
- 2) Technology **establishes** the way we **gain knowledge** of disease & the way we **recognize** disease in practice
- 3) Technology **establishes** how we **act** towards disease (diagnosis and treatment technologies)

Hofmann B. “The technological invention of disease” *Medical Humanities* 2001; 27.

# De “technologische imperatief”

Technology constitutes the concept of disease by influencing medical taxonomy

▶ by creating new disease entities:

- ▶ e.g. atrial fibrillation was established by the ECG
- ▶ technology has endorsed a new range of disease entities: asymptomatic diseases --- e.g. the development of molecular biology : various genetic tests can detect diseases where the person tested does not feel ill

**>> the patient is no longer the epistemological basis of the disease concept**

Hofmann B. “The technological invention of disease” *Medical Humanities* 2001; 27

<sup>28</sup> Burch GE. Developments in clinical electrocardiography since Einthoven. *American Heart Journal* 1961; 61: 324.

# De “technologische imperatief”

Technology also constitutes the concept of disease by establishing how we act towards disease (diagnosis and treatment)

Cf. the argument that it is not the concept of disease that decides whether something is treated or not, but rather the treatability that makes something a disease:

*“it is not really the presence of a disease that is crucial, but the fact that some medical intervention may be beneficial and that it is within the physician’s power to help the patient”*

Hesslow G. Do we need a concept of disease. *Theoretical Medicine* 1993; 14: 1-14, 7.

>> the question seems to be: why label something as “disease” if not much can be done ?

# De “technologische imperatief”

## Drivers: **Fear of uncertainty and ambiguity**

The **use of technology compensates** for physicians' fear of ambiguity and uncertainty

*“In medicine [machines] relieve the doctor’s anxiety. ... **the very extension of the senses through machines makes us want to believe they are better than the senses.**”*

>> becomes a problem if machines **pre-empt the clinician’s judgment**

Wolf S. Berle B. *The Technological Imperative in Medicine*. New York: Plenum Press. 1981.

# De “technologische imperatief”

## Drivers: **Fear of uncertainty and ambiguity**

>> becomes a problem if machines **pre-empt** the clinician’s judgment:

*“I know that the minute I see the x-rays of the patient, before looking at the patient or before working on him, I will fit the patient’s story into whatever the x-rays or other images are showing me.”*

Howard M. Spiro, Yale School of Medicine

# De “technologische imperatief”

**Provocatieve vraag:**

Zien we in **palliatieve zorg** iets gelijkaardigs??

Maar dan met ‘**testbatterijen**’ i.p.v.  
**radiografiemachines** ??



## Ook een “technologische imperatief” in palliatieve zorg?

den Hartogh (2017), Suffering and dying well: On the proper aim of palliative care. *Medicine, Healthcare and Philosophy* 20: 413-24:

“[A]lmost all [studies on suffering] refer to Cassell, and one idea that they have all learned from him is that **suffering cannot exhaustively be described in terms of physical symptoms**. But in other respects they are not at all true to his insights. This is particularly true of the **studies that do not only give lists of elements of suffering, but try to measure their importance**. [...] The real **problem** is not only a matter of double counting or of an inaccurate system of classification. It goes **much deeper**. [...]

## Ook een “technologische imperatief” in palliatieve zorg?

den Hartogh (2017), Suffering and dying well: On the proper aim of palliative care. *Medicine, Healthcare and Philosophy* 20: 413-424:

“... Loss of faith [for example, **simply becomes**] **one other item** to be taken into account in determining one’s score on the ‘**distress thermometer**’, **together with indigestion and constipation**. ... The checklists ... are instruments for diagnosis, ideally to be followed by treatment. We could call this **a purely functional approach to suffering**: if we come across any case of suffering, we have a reason to do something about it. This approach **fails to recognize the cognitive aspect of all emotions**, including the negative ones: they are all more or less adequate responses to the situation the person finds herself in.”

# Ook een “technologische imperatief” in palliatieve zorg?

**Voorbeeld: Kissane et al. (2001), Demoralization syndrome – A relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care* 17(1): 12-21.**

**Versus Slavney (1999):**

“A demoralized person is no longer able to bear up under adversity. In demoralization, mood is sad, apprehensive, or irritable; thinking is pessimistic and sometimes suicidal; behavior can be passive, demanding, or uncooperative; and sleep and appetite are often disturbed. Although these phenomena are distressing to the demoralized person and others, they do not constitute a psychiatric disorder. Like grief, which has some of the same manifestations, demoralization is a normal response in certain circumstances.”

Diagnosing demoralization in consultation psychiatry. *Psychosomatics* 40(4): 325-329:

# Ook een “technologische imperatief” in PZ opleidingen?

## VOORBEELD OPLEIDING: MODULE 5: PIJN- & SYMPTOOMCONTROLE

- ▶ Gevorderde pijntherapie - vocht en voeding - gastro-enterologische problemen - respiratoire problemen - urgenties - overige symptomen - palliatieve sedatie - spuit aandrijver - meetinstrumenten
  - De cursist kent de specifieke benaderingen van pijn in de palliatieve zorg en kan de omrekening maken naar de verschillende toedieningswijzen.
  - De cursist kent ook de ernstige, specifieke symptomen toegespitst op de verschillende anatomische organen en stelsels, en het belang van de toediening van vocht en voeding.
  - **De cursist kan verschillende meetinstrumenten hanteren en (h)erkent zo vanaf wanneer patiënten palliatief / terminaal zijn.**
  - **De cursist kent de juiste betekenis van het begrip palliatieve sedatie** en kan de patiënt en zijn omgeving hierin effectief ondersteunen, maar weet ook de urgenties in deze zorg te herkennen.

# Ook een “praktische imperatief” in PZ opleidingen?

## VOORBEELD OPLEIDING:

### MODULE 4: ETHIEK & EMANCIPATORISCH WERKEN

- ▶ Ethisch reflecteren in een palliatieve context - overlegmodellen - casuïstiek - emancipatorisch werken - zorg voor jezelf
  - De cursist is zich bewust van zijn eigen normen en waarden, en deze van de maatschappelijk-culturele omgeving waarin hij functioneert.
  - De cursist kan een ethisch overleg organiseren en begeleiden.
  - De cursist weet ook hoe de zorg voor zichzelf aan te pakken en kent de principes van het emancipatorisch werken naar de eerstelijns werkers toe.

Dit verschilt totaal van de inhoud van modules ethiek & levenseinde !  
(eerder psychologie en praktische organisatie)

# “Technologie-aversie” als alternatieve valkuil ?

## Persoonlijke anekdote i.v.m. klinische studie

*Volume 25, Number 3*

*The Journal of Clinical Ethics* 207

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### **The Ethical and Clinical Importance of Measuring Consciousness in Continuously Sedated Patients**

*Kasper Raus, Martine de Laat, Eric Mortier, and Sigrid Sterckx*



# “Technologie-aversie” als alternatieve valkuil ?

## ABSTRACT

Continuous sedation at the end of life is a practice that has attracted a great deal of attention. An increasing number of guidelines on the proposed correct performance of the practice have been drafted. All of the guidelines stress the importance of using sedation in proportion to the severity of the patient's symptoms, thus to reduce the patient's consciousness no more than is absolutely necessary. As different patients can have different experiences of suffering, the amount of suffering should, ideally, be assessed subjectively; that is, via communication with the patient. Continuously sedated patients are often unable to communicate, however, making subjective methods of pain assessment unusable. For these patients, the degree of consciousness is the sole available measure. It therefore seems important to adequately measure how deeply the patient is sedated, thereby allowing sedation to be increased when it is too light and decreased when it is too

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**Kasper Raus, PhD**, is a Postdoctoral Researcher in the Department of Moral Philosophy and Moral Sciences at Ghent University in Ghent, Belgium, [Kasper.Raus@UGhent.be](mailto:Kasper.Raus@UGhent.be).

**Martine de Laat, MD**, is a Palliative Care Physician at Ghent University Hospital.

**Eric Mortier, MD, PhD**, is Chief Executive Officer at Ghent University Hospital.

**Sigrid Sterckx, PhD**, is Professor of Ethics at Ghent University and is a Professor of Ethics at the Vrije Universiteit Brussel in Brussels, Belgium.

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heavy. This is in accordance with the idea that reducing consciousness is not an ethically neutral act.

Although consciousness measuring techniques are a hot topic in anesthesiology, almost no research exists on the use of such techniques in the context of continuous sedation at the end of life. This article aims to review existing techniques to measure consciousness and to evaluate their applicability, efficiency, and invasiveness for patients who are continuously sedated until death.

Techniques commonly used to assess the depth of sedation in continuously sedated patients are basic clinical assessment and sedation scales, as they are often considered reliable and non-invasive. These techniques might not be very reliable, however, since it is known that some patients are nonresponsive and yet aware. Moreover, sedation scales require stimulation of the patient (for example prodding, shaking, or providing painful stimuli), and can thus be considered invasive of one's bodily integrity or dignity. Other techniques, such as EEG (electroencephalography) derivatives, may score better on reliability and invasiveness. Yet these have so far never been compared to sedation scale scores for patients receiving continuous sedation at the end of life.

Therefore, we conclude that, for both clinical and ethical reasons, research into the efficiency and applicability of other techniques, such as derivatives of EEG, are urgently needed.

## INTRODUCTION

Continuous sedation at the end of life (CS)—the practice whereby a physician uses sedatives to reduce or take away a patient's consciousness continu-

# “Technologie-aversie” als alternatieve valkuil ?

- ▶ Protocol voor klinische studie wordt geschreven, ingediend en goedgekeurd door de Commissie Medische Ethiek
- ▶ De studie raakt niet uitgevoerd...
- ▶ Gelukkig hebben collega's van de VUB daarna dit onderzoek kunnen doen:

Six et al. *BMC Palliative Care* (2018) 17:62  
<https://doi.org/10.1186/s12904-018-0316-2>

BMC Palliative Care

STUDY PROTOCOL

Open Access

Comfort in palliative sedation (Compas): a transdisciplinary mixed method study protocol for linking objective assessments to subjective experiences





# “Technologie-aversie” als alternatieve valkuil ?


- ▶ **Gelukkig hebben collega’s van de VUB daarna dit onderzoek kunnen doen:**

Pain Ther (2021) 10:377–390  
<https://doi.org/10.1007/s40122-020-00214-z>



ORIGINAL RESEARCH

## Neurophysiological Assessments During Continuous Sedation Until Death Put Validity of Observational Assessments Into Question: A Prospective Observational Study

Stefaan Six  · Steven Laureys · Jan Poelaert · Olivier Maïresse ·  
Peter Theuns · Johan Bilsen · Reginald Deschepper

# “Technologie-aversie” als alternatieve valkuil ?

- ▶ **Gelukkig hebben collega’s van de VUB daarna dit onderzoek kunnen doen:**

*Methods:* In this prospective observational study, we observed patients from the start of palliative sedation until death. Subjective caregiver assessments of level of consciousness and pain based on behavioral observations were compared with objective measures from neurophysiological monitoring devices.

*Results:* We collected and analyzed 108 subjective caregiver assessments in a sample of 12 patients and 32 assessments by traditionally used observational scales. We compared these with objective neurophysiological measures. Sensitivity and specificity of caregivers’ subjective assessments of consciousness was 23.6 and 91.1% respectively, with an accuracy of 54.0% and interrater reliability ( $\kappa$ ) of 0.13. For pain, this was 0 and 94.79%, respectively, an accuracy of 88%, and an inter-rater reliability ( $\kappa$ ) of  $-0.063$ . Agreement between caregivers’ subjective assessments and objective neurophysiological measures of consciousness and pain was very poor.

*Conclusions:* Caregivers’ subjective assessment of level of consciousness and pain during CSD is unreliable compared with objective neurophysiological monitoring. Our results suggest that assessments of patient comfort during CSD could have been improved substantially by including objective monitoring of level of consciousness and pain.

**Tot slot :**  
**“palliatieve zorg” ver voorbij**  
**de WHO definitie?**



# Tot slot: “palliatieve zorg” ver voorbij de WHO definitie?

## Guidance Note: Operation London Bridge

There is an official protocol in place in the event of the death of Her Majesty the Queen, officially known as ‘Operation London Bridge. It covers the activities for each day from when the Royal death is announced (Day 0) through to Day+10 when the state funeral will take place.

This guidance sets out the how bell ringing plays its part throughout the process and has been formulated in consultation with The Royal Household and Lambeth Palace. Town and city councils will already have an OLB plan in place and this will consist of what to do on the day on the announcement and the following days, in accordance with Royal protocol.

As with most national/international bell ringing requests, local arrangements with church, council and public plans should be consulted and ringing should take place whenever is most appropriate for a local arrangement.

A lot will depend on the timing of announcements and where we are in the Church liturgical calendar.

The following sets out some guidelines that the bell ringing community might find helpful. **It is recommended that bell ringers liaise with church authorities ahead of time to avoid any confusion at what will be a very sad and difficult time.**

# Tot slot: “palliatieve zorg” ver voorbij de WHO definitie?

## **On the day of announcement of the death of Monarch:**

Bells should be rung half or fully muffled depending on how many muffles you have. If you have enough muffles it would be appropriate to ring fully muffled with the tenor backstroke open. The Royal Household have advised the following times that ringing should take place based on the timing of the official announcement:

Provided that ringing has been approved by the church authorities and does not conflict with other guidance, longer lengths of ringing may be appropriate.

## **Following days:**

Bells should remain half or fully muffled until the day that the Palace proclaims the new Monarch. At that point bells should be rung open in celebration of the accession at a practicable time (again, with the agreement of the church) following the announcement.

Bells should then revert to being rung half or fully muffled until the day of the state funeral (10 days after the announcement of the death).

On the day of the funeral bells should be tolled for the hour immediately prior to the time of the Funeral Service. This may afford those an opportunity to ring a quarter peal, but general ringing or tolling would be acceptable.

# Tot slot: “palliatieve zorg” ver voorbij de WHO definitie?

het lijkt erop neer te komen dat er niet voor alle aspecten precieze instructies kunnen worden gegeven ...

... maar dat men gaat moeten oordelen én aanvoelen wat "appropriate" is ...

... en dat dat soms van “lokale” (subjectieve) en soms van “algemene” (objectieve) criteria gaat afhangen... (een beetje zoals bij inschattingen van bewustzijn)

# Tot slot: “palliatieve zorg” ver voorbij de WHO definitie?

“No man is an island,  
Entire of itself.

Each is a piece of the continent,  
A part of the main.

If a clod be washed away by the sea,  
Europe is the less.

As well as if a promontory were.  
As well as if a manor of thine own  
Or of thine friend's were.

**Each man's death diminishes me,  
For I am involved in mankind.  
Therefore, send not to know  
For whom the bell tolls,  
It tolls for thee.”**

**John Donne (1572 - 1631) – For whom the bell tolls**

**Veel dank voor uw aandacht !**

**sigrid.sterckx@ugent.be**

