



THE UNIVERSITY OF
AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
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Consensus view on assisted dying for dementia: A Delphi study on key issues and concerns

Aida Dekhoda

Dr Phillipa J Malpas

Prof. R Glynn Owens



Dementia

Dementia is:

- A global public health problem.
- One of the most prevalent diseases in older population.
- The leading cause of disability and dependency in older populations worldwide.

Dementia

Common Types of Dementia: Alzheimer's Diseases, Vascular dementia, dementia with Lewy bodies, and Frontotemporal dementia

Dementia's effect:

On the Patients

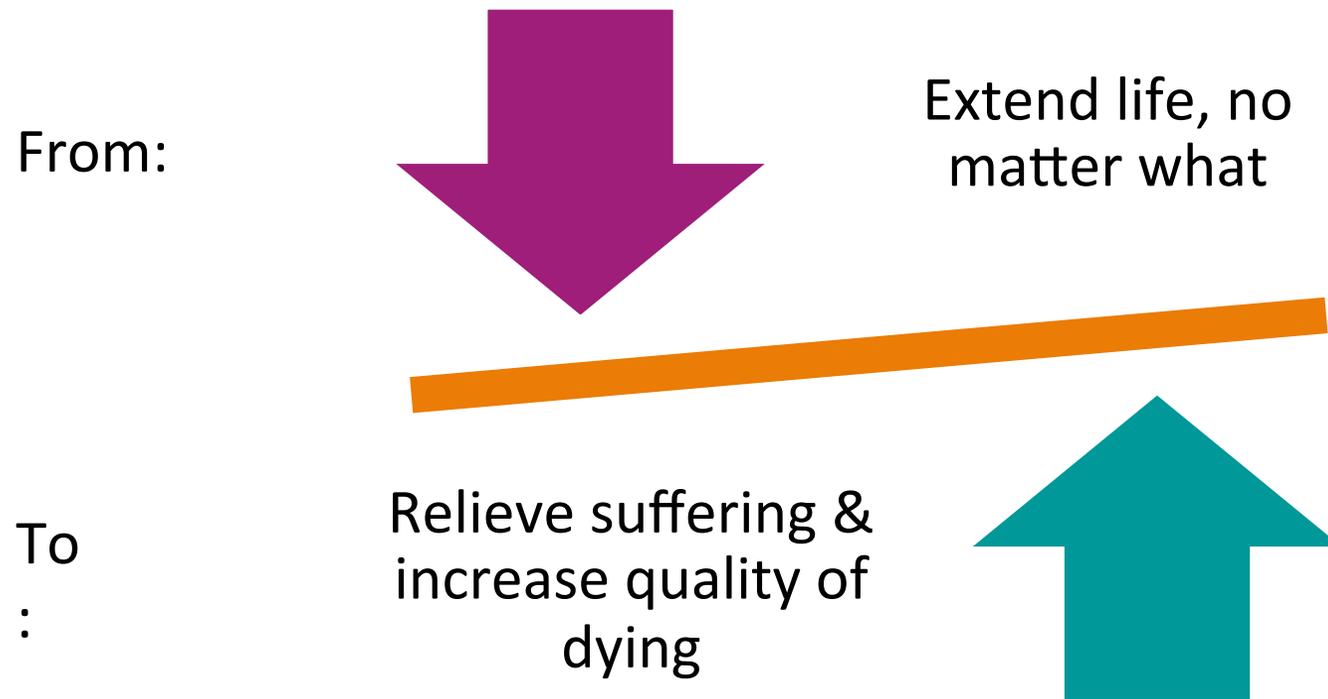
- Cognitive function, Thinking, & Memory
- Comprehension & Judgement
- Learning Capacity & Language
- Emotional Control
- Social Behaviour
- Psychological Wellbeing
- Physical abilities

On the Family & Carers

- Depression & Anxiety
- Poor quality of life
- Reduced income

Request for Assisted Dying (AD)

There is growing recognition of the need to extend the goal of medicine at the end of life:



AD around the world

Euthanasia & PAD:



Netherlands
2002



Belgium
2002



Luxembourg
2009



Colombia
2015



Canada
2015

PAD:



USA

- Oregon – 1997
- Washington – 2009
- Montana – 2009
- Vermont – 2013
- California - 2016



Switzerland

The term **Assisted Dying** in this study refers to:

Euthanasia: A competent person asks for assistance to die and is administered a lethal dose of medication by a doctor or other authorised practitioner with the intent that the patient will die as a result.

Physician assisted dying (PAD): A competent patient asks for assistance to die and is prescribed or supplied with a lethal dose of medication (by a doctor or other authorised practitioner) that they take at a time of their choosing.

Other end-of-life decisions

Illegal practice

- Intentionally hastening death or ending a life WITHOUT an explicit request of the patient

Legal practices

- Intensified alleviation of pain and other symptoms with the use of drugs
- Withholding or withdrawal of potentially life-prolonging treatments
- Terminal/palliative sedation until death

AD's safeguards and limitations

States of America & Canada

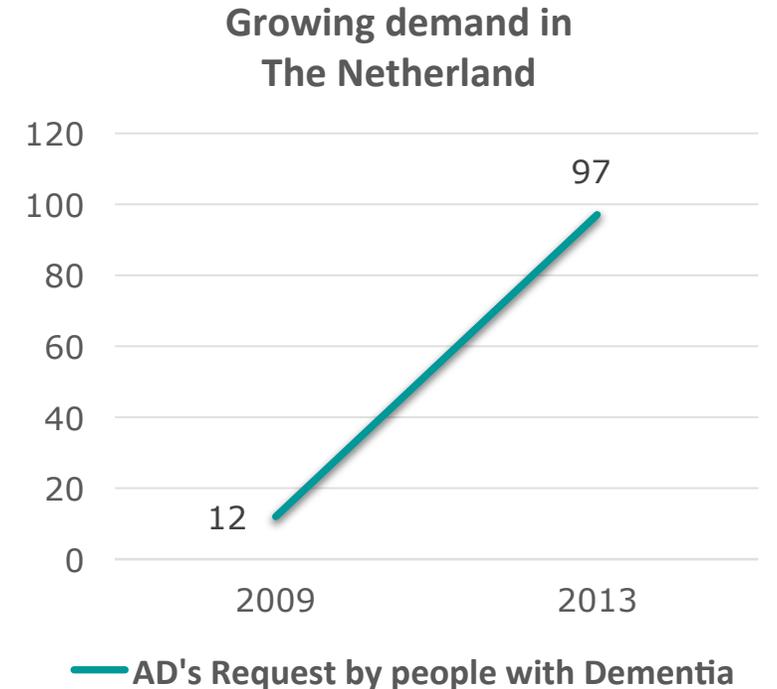
- Be an adult
- **Be competent**
- Have a terminal illness
- No suffering needed
- Be a resident
- Have a life expectancy < 6 months (except Canada)
- Present a consistent request
- Be supported by two independent doctors

Belgium, Luxemburg, and The Netherland

- Be adult (except Belgium)
- **Be competent (except Netherland)**
- Have an incurable disease
- Suffering needed
- Residency not needed
- Life expectancy < 6 months not needed
- Present a consistent request
- Supported by at least one independent doctor

Assisted dying for dementia

- 'The Dutch Termination of Life on Request and Assisted Suicide Act' (2002) includes INCOMPETENT people in the law.
- Advance Euthanasia Directives (AEDs) must precede the loss of competency.
- The vast majority of people who received AD were in the early stage of dementia and were still competent.



**With the prevalence rate of 2% of all
euthanasia or physician-assisted deaths.**

A life terminating act WITHOUT an explicit request

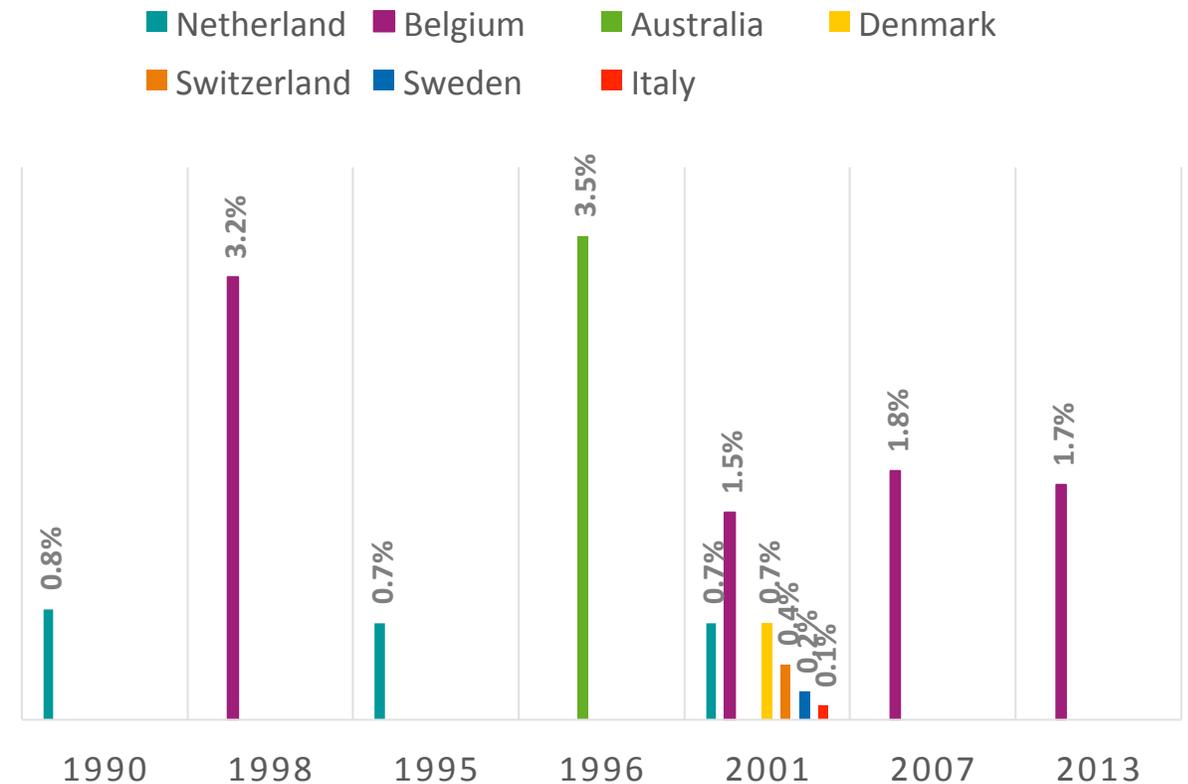
- The requirement to be mentally competent to make an end-of-life decision does NOT always work.
- Dementia was one reason for not discussing the hastening of death with the patients:

Netherland, 18% (2001)

Denmark, 13% (2001)

Switzerland, 21% (2001)

Belgium, 21.1% (2007)



The occurrence rate of the act without patients' request

My research and its challenges

**Isn't it your life? And shouldn't it be your decision?
(regardless of what it might be.)**

How to approach this contentious issue???

Research Questions:

1. Is it possible to devise safeguards which would permit physician-assistance in dying and euthanasia for people with dementia?
2. If so, what form would you expect these safeguards to take?
3. Why do you think this would work well in practice?
4. What you think would be the main concerns and issues regarding the possibility of physician-assisted dying and euthanasia for people with dementia?

Method: The Delphi Study

The methodology: exploring the views of a group of experts with multiple rounds of consultation and structured feedback to achieve consensus, in an anonymous way.

Participants: 12 national & international experts

Area of expertise:

- Dementia care
- Palliative care & Palliative medicine
- Psychology
- Psychiatry
- Neuropsychology
- Gerontology & Geriatric medicine
- Epidemiology
- Aging & Mortality
- Ethics & Spiritual counselling
- Law
- Decision making and end-of-life care
- Activist

Procedures

Round One: 12 experts responded to 5 open-ended questions.

Result: 119 statements were identified using content analysis.

Round Two: 11 experts rated those statements from round one, using a 6-point Likert Scale – Strongly/Moderately/Slightly Agree – Slightly/Moderately/Strongly Disagree

Result: 79 statements reached consensus with **the concordance degree of 70% or more either agreeing or disagreeing.**

Round Three: 40 statements that did not reach consensus presented again + individualized feedback.

Result: ???

Preliminary Findings

Question 1: Is it possible to devise safeguards for Assisted Dying for dementia?

6 YES

“The issue of patients with dementia and EOL options will become more and more relevant to public discussion as the population in most countries is growing older”.

4 NOT SURE

“It is of concern that caregivers and proxies may project their own wishes onto the patient”.

2 NO

“Deciding whether a patient's motivation to request an AD is objective, rather than coerced by internal fears or external worries, is not possible”.

Preliminary Findings

Questions 2&3: What form should these safeguards take? How well would they work in practice?

- Safeguards must consider all the stakeholders

- Patients
- Family/carers
- Health Professionals

- Safeguards must protect all these three groups – especially the patients – from **HARM**.

- Safeguards must include comprehensive procedures

- Safety Procedures
- Legal Procedures
- Ethical Procedures

Preliminary Findings

Questions 2&3: What form should these safeguards take? How well would they work in practice?

Safety Procedures

Coercion: *“Safeguards should prevent patients being persuaded, or encouraged to request PAD/euthanasia by relatives or carers”.*

Projection: *“There is chance that caregivers and proxies project their own fears of dementia into the situation”.*

Ethical Procedures

Autonomy: *“It should be up to patients to decide whether their desire not to be a burden is greater than their desire to live”.*

Contradiction: *“Safeguards are needed to ensure that PAD/euthanasia was not carried out if the person was to indicate that they felt life was still worth living”.*

Preliminary Findings

Questions 2&3: What form should these safeguards take? How well would they work in practice?

Legal Procedures

- Require PATIENTS to make a clear written Advance Directive.

“Patients need to clearly specify in their ADs what types of function must be lost prior to enactment of their end of life directives”

- Advance Directives must be regularly updated and signed by patients and be assessed by health professionals (HPs).
- Require patients to attend a recorded semi-structured interviews with a HP and psychologist to detect any coercion or abuse.

Preliminary Findings

Questions 2&3: What form should these safeguards take? How well would they work in practice?

Legal Procedures:

- Require HPs to regularly and thoroughly assess

- Competency
- Cognitive functions
- Medical conditions
- Quality of care
- Rationality & Judgment
- Suffering & pain

“Safeguards need to include independent assessment for cognitive abilities, pain, medical condition, care environment, and suffering at different points in the person's un-wellness”.

“Safeguards need to include an assessment of the patient's understanding of the typical course of their dementia”.

Preliminary Findings

Question 4: What do you think would be the main concerns and issues in this regard?

- Make a stable long term request
- Possibility of changing mind on AD request
- Difficulty to assess whether the wish is voluntary
- Difficulty to assess suffering
- Difficulty to determine when to enact the AD wish.

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- The Slide 2 picture is taken form the google.

Thank you

Questions?

Comments?