

# "Unbearable suffering and euthanasia". A qualitative study of perceptions of patients, physicians and doctors consulted for a second opinion.

Published: 17-07-2007

Last updated: 08-05-2024

**Purpose**The aim of this study is to gain insight on an empirical basis into the concept of unbearable suffering in situations where a request for EAS is made from the point of view of the patient, the treating physician, and the consulted doctor and...

<b>Ethical review</b>	Approved WMO
<b>Status</b>	Pending
<b>Health condition type</b>	Other condition
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON30580

### Source

ToetsingOnline

### Brief title

"Unbearable suffering and euthanasia".

### Condition

- Other condition

### Synonym

unbearable suffering

### Health condition

uitbehandelde aandoeningen

### Research involving

Human

## Sponsors and support

**Primary sponsor:** Universitair Medisch Centrum Sint Radboud

**Source(s) of monetary or material Support:** KWF

## Intervention

**Keyword:** euthanasia, patients'perspective, Suffering

## Outcome measures

### Primary outcome

There are currently no empirical data available that describe the elements of the concept of unbearable suffering as used by patients, caregivers, treating physicians, and consulted doctors in a request for EAS. As a consequence every physician has to develop his or her own frame of reference. There is no validated checklist referring to unbearable suffering that takes into account the opinions of patients who ask for EAS. The use of a checklist might help physicians and patients to come to a more coherent decision making for decisions with a high impact on the quality of the last phase of life of patients, and on the well-being of their families.

### Secondary outcome

not relevant

## Study description

### Background summary

According to the Dutch Euthanasia Act that came into force in 2002, euthanasia or physician assisted suicide (EAS) performed by a physician is not a criminal act on condition that six specified conditions are adhered to. The second

condition states that the treating physician must be convinced that the patient requesting EAS is in a situation of unbearable and hopeless suffering: hopelessness means that palliative care can offer no possibility of alleviating the symptoms (1). From a medical point of view, hopelessness can be determined reasonably objectively; in 88 percent of cases, the request concerns a patient in a terminal stage of cancer. In lower percentages of cases, the symptoms of other diseases such as HIV, ALS, MS, and a CVA or a spinal cord lesion are the underlying reasons for hopelessness (2). Ascertaining that suffering is unbearable, however, is the greatest dilemma in the performance and assessment of the euthanasia procedure (3, 4). Suffering has served as the focus of much writing by philosophers, theologians, and healthcare professionals and lies at the root of many complex ethical dilemmas. It is the crux in the discussion around EAS(1).

In 1997, Rodgers and Cowles defined suffering as an individualized, subjective, and complex experience that involves the assignment of an intensely negative meaning to an event or a perceived threat (5). Current debates on the suffering that underlies a request for EAS have been based on the perspectives of medical professionals, lawyers, ethicists, politicians, and the general public (1,7, 8, 9). Most studies on euthanasia have been quantitative, focusing on the attitudes of physicians, carers, and patients without giving consideration to an actual request (4.16.17). Qualitative, experiential, and patient-based research is needed to convey a clear idea of the enormous intensity of suffering that underlies a request for EAS. Insight into the perceptions of the suffering of the patient, the carers, the treating physicians, and the consulted doctors is necessary to unravel the factors that influence the complex decision-making involved in a request for EAS.

## **Study objective**

### **Purpose**

The aim of this study is to gain insight on an empirical basis into the concept of unbearable suffering in situations where a request for EAS is made from the point of view of the patient, the treating physician, and the consulted doctor and to develop a checklist as a tool to identify unbearable suffering and to maximize the quality of the support to patients who are making end-of-life decisions

### **Research questions**

1. How do patients, caregivers, treating physicians, and consulted doctors describe unbearable suffering (including somatic, psychological, and spiritual aspects)?
2. What are the differences and similarities in the descriptions of the three persons involved in an EAS request?
3. What are the implications of the differences for professional performance?
4. Which themes and elements of the concept of unbearable suffering can be identified on the basis of the systematic literature review and the interviews with patients, caregivers, treating physicians and consulted doctors, in order

to draw up a draft checklist of unbearable suffering in the case of a request for EAS that incorporates the contexts of a patient's experiences?

5. Is the draft checklist of unbearable suffering valid?

ality of the support to patients who are making end-of-life decisions.

## **Study design**

Prospective in-depth interviews with patients who have asked their treating physician for EAS form the heart of the research. Interviews with the informal caregivers closest to the patient are scheduled to gain insight into their influence on the patient's request. Following these interviews, further semi-structured interviews will take place with the treating physicians and, when relevant, the consulted doctors.

## **Study burden and risks**

the patients interviewed and their closest caregivers are considered to be emotional vulnerable. The interviewer, being an experienced general physician and trained SCEN consultant is aware of this. During the whole procedure she will respect every sign that implicates the wish to end the interview and respect emotions raised by the questions. In her function as SCEN consultant, she experienced the willingness of patients and their closest caregivers to talk about their thoughts and emotions to a passing stranger. Talking about their lives, the illness, the suffering helps them to deal with the approaching death.

## **Contacts**

### **Public**

Universitair Medisch Centrum Sint Radboud

Geert de Grooteplein 21

6525ga Nijmegen

NL

### **Scientific**

Universitair Medisch Centrum Sint Radboud

Geert de Grooteplein 21

6525ga Nijmegen

NL

## Trial sites

### Listed location countries

Netherlands

## Eligibility criteria

### Age

Adults (18-64 years)

Elderly (65 years and older)

### Inclusion criteria

being able to give informed consent, having a non treatable disease, unbearable suffering

### Exclusion criteria

not relevant

## Study design

### Design

**Study type:** Observational non invasive

Masking: Open (masking not used)

Control: Uncontrolled

Primary purpose: Health services research

### Recruitment

NL

Recruitment status: Pending

Start date (anticipated): 01-02-2007

Enrollment: 30

Type: Anticipated

## Ethics review

Approved WMO

Application type:

First submission

Review commission:

CMO regio Arnhem-Nijmegen (Nijmegen)

## Study registrations

### Followed up by the following (possibly more current) registration

No registrations found.

### Other (possibly less up-to-date) registrations in this register

No registrations found.

### In other registers

Register	ID
CCMO	NL16102.091.07