

# 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying

Marianne K Dees,<sup>1</sup> Myrra J Vernooij-Dassen,<sup>2</sup> Wim J Dekkers,<sup>3</sup> Kris C Vissers,<sup>4</sup> Chris van Weel<sup>1</sup>

<sup>1</sup>Department of Primary and Community Care, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

<sup>2</sup>Department of Primary and Community Care, Radboud University Nijmegen Medical Centre, Scientific Institute for Quality of Healthcare, The Netherlands

<sup>3</sup>Radboud University Nijmegen Medical Centre, Section of Ethics, Philosophy and History of Medicine, Scientific Institute for Quality of Healthcare, The Netherlands

<sup>4</sup>Department of Anesthesiology, Pain and Palliative Medicine, Radboud University Nijmegen Medical Centre, The Netherlands

## Correspondence to

Marianne K Dees, General Practitioner, Radboud University Nijmegen Medical Centre, Department of Primary and Community Care, Internal postal code 117, PO Box 9101, 6500 HB Nijmegen, The Netherlands; m.dees@elg.umcn.nl

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## ABSTRACT

**Background** One of the objectives of medicine is to relieve patients' suffering. As a consequence, it is important to understand patients' perspectives of suffering and their ability to cope. However, there is poor insight into what determines their suffering and their ability to bear it.

**Purpose** To explore the constituent elements of suffering of patients who explicitly request euthanasia or physician-assisted suicide (EAS) and to better understand unbearable suffering from the patients' perspective.

**Patients and methods** A qualitative study using in-depth face-to-face interviews was conducted with 31 patients who had requested EAS. The grounded theory approach was used to analyse the data.

**Results** Medical, psycho-emotional, socio-environmental and existential themes contributed to suffering. Especially fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness and being tired of living were constituent elements of unbearable suffering. Only patients with a psychiatric (co) diagnosis suffered unbearably all the time.

**Conclusions** Unbearable suffering is the outcome of an intensive process that originates in the symptoms of illness and/or ageing. According to patients, hopelessness is an essential element of unbearable suffering. Medical and social elements may cause suffering, but especially when accompanied by psycho-emotional and existential problems suffering will become 'unbearable'. Personality characteristics and biographical aspects greatly influence the burden of suffering. Unbearable suffering can only be understood in the continuum of the patients' perspectives of the past, the present and expectations of the future.

## INTRODUCTION

The main objectives of medicine are to relieve patients' suffering and cure their illness.<sup>1</sup> Once patients can no longer be cured, palliative care is employed to improve the quality of life by prevention and relief of suffering.<sup>2</sup> The availability of palliative care has increased in the past decades.<sup>3-4</sup> Nevertheless 1 in 10 palliative care patients have asked, at some point, a specific question about assistance in dying to alleviate suffering.<sup>5-7</sup> In states and countries where euthanasia or physician-assisted suicide (EAS) has been legalised—Oregon, Washington State, Montana, Switzerland, Belgium, Luxembourg and the Netherlands—unbearable suffering is a major consideration in the professional

assessment of a request for EAS.<sup>6-10</sup> In an integrative literature review we established that unbearable suffering in the context of a request for EAS has a medical, a psychological, a social and an existential dimension.<sup>11</sup> It also made it obvious that despite its essential place in end-of-life decision-making, there is no generally accepted definition of 'unbearable suffering' and there is a lack of knowledge of patients' perceptions of 'unbearable suffering'.<sup>11</sup> In the Netherlands, patients who explicitly request EAS are expected to describe their situation in terms of a lack of hope and an inability to cope with their suffering. This provides a unique opportunity to study unbearable suffering from the patient's perspective. Qualitative research using in-depth interview techniques is best suited to uncover unbearable suffering from the patients' perspectives. Understanding 'suffering' and knowledge of its constituent elements provides a tool that might contribute to an early detection and a proactive approach to prevent suffering becoming unbearable.

We conducted a study to explore what patients who had explicitly requested EAS considered 'suffering' to entail and what made their suffering 'unbearable'.

## METHODS

### Study design

We used a design of qualitative, in-depth, face-to-face interviews.<sup>12-15</sup> Purposeful sampling was used to ensure diversity in diagnosis.

### Recruitment and patient selection

With the assistance of the Support and Consultation on Euthanasia in the Netherlands (SCEN) network, we recruited patients who had explicitly requested EAS. We also approached a hospice, a hospital and a nursing home and placed a notice in the journal *Right to die—NL*. To ensure diversity in the sampling of perceived suffering, we included both patients whose EAS requests had been granted and denied. The treating physician was asked to inform the patient about the study. The interviewer contacted the patient by telephone and written information was sent by mail. Patients who reacted to the notice could directly contact the interviewer by phone. All patients signed an informed consent form.

### Interviews

The interviews took place at the patients' residences and lasted 30–120 min. Patients were interviewed alone to ensure that the caregiver's

presence did not influence the information they gave. We developed an interview guide (box 1) on the basis of the research question and a literature review.<sup>11</sup> Each interview started with a question about the development of the request. Subsequently constituent elements of suffering were explored. All patients were asked about their ability to enjoy things. Finally each patient was asked what made suffering unbearable. The interviewer (MKD), a family physician and SCEN specialist, closely followed the interview line brought forward by the patient.<sup>14</sup> The interviews were audio-taped and transcribed verbatim. Demographics were collected before the interviews and the medical records and SCEN reports were retrieved afterwards.

### Definitions

In accordance with the Dutch law, euthanasia was defined as the termination of life on the explicit request of the patient by a physician with the intention to end hopeless and unbearable suffering. Physician-assisted suicide was defined as assisting in the suicide of a patient by a physician. A request for EAS is called 'explicit' when the patient has specifically asked the physician to (help) end the patient's life.

### Qualitative data analysis

We used the constant comparative method to analyse the data.<sup>15</sup> This method is part of the grounded theory approach in which concepts emerge as theory is formed. We used ATLAS.ti version 5.5 software to process the data. Analysis started as soon as the first data were collected and continued with each additional interview. The first step in the analysis was data reduction; two researchers (MKD and a psychologist) coded the transcript independently to minimise subjectivity. Coding is the interpretive process in which we give conceptual labels to the data. The purpose is to attain new insights by breaking through standard ways of thinking about phenomena reflected in the data.<sup>15</sup> The sequence was as follows: we used codes that were closely related to the text fragments. After five interviews, we compared the analysts' codes and three researchers (MKD, a psychologist and MJV) discussed them until they reached consensus. Then a new coding scheme was developed for further use. New codes could be added. When no more new codes about suffering appeared, we were satisfied that saturation had been reached. We grouped codes referring to the same phenomenon in categories and categories in themes. MKD analysed all transcripts again to come to an understanding of how the different elements of suffering contributed in individual cases to unbearable suffering. Finally, a grounded theory approach was used to derive hypotheses about unbearable suffering from the data. Five researchers reached consensus about the codes, categories and themes in peer-group discussion. This group included two family doctors (CW and MKD), one of whom has experience with EAS (MKD), a sociologist experienced in qualitative end-of-life research (MLV), an ethicist (WJD) and a palliative care specialist (KV). They used an iterative procedure and re-reading to facilitate the discussion.

#### Box 1 Interview guide

- ▶ How did your request for euthanasia or physician-assisted suicide develop?
- ▶ What made your request topical?
- ▶ What is your suffering made up of?
- ▶ What makes your suffering unbearable?

## RESULTS

Between April 2008 and July 2009 45 patients were prepared for interviewing. Twelve were excluded after interviewing because they had not made an explicit request. Two patients died before their interviews could take place. Altogether, 31 patients were included in the study. When data from the last seven interviews were entered, no new codes emerged and we concluded that saturation had been reached.

### Patient characteristics

The participants varied in gender, age, marital status, educational level and residence. They came from rural and urban areas all over the Netherlands. Except those with a psychiatric diagnosis, these patients showed a high degree of self-realisation in social, occupational and economic status. Five patients considered themselves religious. The requests of 11 patients were not granted. In eight cases, this refusal was directly related to the absence of a physical diagnosis (four patients had psychiatric diseases and four patients were tired of living). Two refusals were related to the institutional policies of the places of residence. These patients died as a result of non-treatment of pneumonia and palliative sedation. The request of one patient with cancer was refused because of the coexistence of a depression. He refused treatment and stopped eating and drinking. The request of a second patient with cancer was postponed by successful treatment of her depression. According to the medical records and the reports of SCEN consultants all patients were clinically assessed on depression. The life expectancy of the patients with cancer, at the moment EAS was performed, varied from 2 to 120 days with a mean of 34 days (table 1). <sup>1</sup>

### The patients' perspectives on suffering

The patients described suffering in a multiplicity of very individual ways (table 2). The coding of their statements resulted in 21 categories from which, in accordance with our literature review<sup>11</sup> four themes emerged: medical, psycho-emotional, socio-environmental and existential (table 3).

### The medical context

Suffering always originated in symptoms of illness or ageing. Within the medical theme five categories could be distinguished: physical, cognitive and psychiatric symptoms, side effects of medical treatment and decline.

The physical symptoms varied greatly, depending on the specific course of the illness or ageing. Of the physical symptoms general symptoms such as fatigue, pain, feeling miserable increased suffering more than tract-related symptoms. Decline was often mentioned as an important reason for suffering. Cognitive symptoms caused much suffering. Patients with psychiatric symptoms emphasised the burden of their suffering. The side effects of medical treatment for psychiatric conditions and cancer were named as an additional cause for suffering.

### The psycho-emotional context

The six subcategories in the psycho-emotional theme were loss of self, negative feelings, fear of future suffering, dependency, loss of autonomy and mental exhaustion. With the exception of patients with a psychiatric diagnosis, the patients described themselves as autonomous persons aiming to be significant to others, in favour of communicating with others, preferring an active lifestyle. Loss of self was a great cause of suffering (table 2). Some patients expressed the presence of negative feelings that took centre stage in their minds and thus added to their suffering. The patients mentioned a wide range of fears of

**Table 1** Characteristics of patients explicitly requesting assistance in dying

Patient number	Gender	Age (years)	Diagnosis	Years since diagnosis	Follow-up	Survival after interview (days)	Life expectancy	Residence	Education	Occupation	Marital status	Number of children	Religion
1	Female	53	Lung cancer	4	EAS	61	14 Days	Hospice	Intermediate	Administrator	Married	2	—
2	Male	43	Liver cancer	0.25	EAS	12	20 Days	Hospice	High	Teacher	Single	0	Humanism
3	Male	88	Colon cancer	0.5	EAS	1	14 Days	Hospice	Intermediate	Director	Widower	2	—
4	Male	88	M. Parkinson	4	Pneumonia	122	6 Months	Nursing home	Basic	Farmer	Married	7	Catholic
5	Male	54	Gastric cancer	0.25	EAS	5	1 Month	Home	High	Manager	Married	2	—
6	Female	71	Gall bladder cancer	1	EAS	34	2 Months	Home	Basic	Housewife	Widow	3	—
7	Male	43	Depression	19	Alive	—	—	Home	High	Housewife	Single	0	Buddhism
8	Female	92	Tired of life	2	Alive	—	—	Home	Intermediate	Administrator	Widow	0	—
9	Female	57	Sigmoid cancer	4	EAS	3	1 Month	Home	High	Lawyer	Divorced	2	—
10	Male	65	Depression	6	Alive (ECT)	—	—	Home	High	Director	Divorced	2	—
11	Female	49	Breast cancer	3	EAS	15	2 Months	Home	High	Manager	Married	2	—
12	Male	80	Parotid cancer	2	Not eating or drinking	10	4 Months	Home	High	Teacher	Widower	2	Agnostic
13	Female	70	Parkinson's disease	2	EAS	164	Unknown	Home	High	Teacher	Married	2	Humanist
14	Male	32	Schizophrenia	9	Alive	—	—	Home	Basic	Housewife	Single	0	—
15	Female	65	Breast cancer	9	EAS	29	2 Days	Home	Intermediate	Home care	Divorced	2	There is more
16	Female	55	Nasopharyngeal cancer	1	EAS	195	2 Weeks	Home	Intermediate	Accountant	Married	3	Protestant
17	Female	80	Tired of life	2	Alive	—	—	Home	Intermediate	Café owner	Widow	3	My own
18	Female	55	Ovarian cancer	3	Palliative sedation	10	2 Weeks	Hospital	Intermediate	Secretary	Married	3	—
19	Female	89	Completed life	8	Alive	—	—	Home	Intermediate	Nun	Single	0	—
20	Female	62	Anxiety disorder	48	Alive	—	—	Home	Basic	Author	Single	0	Atheist
21	Male	62	Kidney cancer	9	EAS	60	1 Month	Home	High	Manager	Married	0	Secular
22	Male	83	Lung cancer	0.25	EAS	5	1 Month	Home	High	Businessman	Married	4	—
23	Female	80	Pain syndrome	8	EAS	2	Unknown	Nursing home	Intermediate	Housewife	Married	4	—
24	Male	75	Motor neuron disease	1	EAS	80	4 Days	Home	Basic	Manager	Married	5	—
25	Female	77	Pain syndrome	3	EAS	54	Unknown	Home	High	Psychotherapist	Widow	3	Humanist
26	Female	94	Tired of life	0.5	Alive	—	—	Nursing home	Basic	Needlewoman	Widow	1	Catholic
27	Male	77	Bladder cancer	0.5	EAS	8	2 Weeks	Home	Intermediate	Salesman	Married	2	—
28	Female	65	Pain syndrome	2	EAS	24	1 Month	Hospice	Basic	Housewife	Widow	2	—
29	Male	61	Alzheimer's disease	3	EAS	172	Unknown	Home	High	Director	Married	2	—
30	Male	65	Motor neuron disease	1	EAS	86	1 Month	Home	Intermediate	Real estate agent	Married	3	Catholic
31	Female	76	Motor neuron disease	2	EAS	8	Unknown	Nursing home	Intermediate	Housewife	Widow	2	Protestant

EAS, euthanasia or physician-assisted suicide.

**Table 2** Remarks about unbearable suffering made by patients who explicitly requested assistance in dying

Theme	Patient	Remarks
1. Medical		
1.1a Illness-related physical symptoms	31	I have fecal incontinence. I can no longer swallow and in hot weather I really envy people who can drink
1.1b Fatigue	12	The way to my bed is endless and finally I get there. It takes a lot of energy, but once I'm in bed, it takes an hour just to gather my strength again
1.1c Pain	28	I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could take away half my pain I wouldn't be thinking about euthanasia
1.2 Cognitive symptoms	9	The past few days even the news doesn't interest me anymore, I have less interest in the outside world. My brain no longer works and to me that is a part of human dignity and of unbearable suffering. I want to function normally and if I can't do that...
1.3 Psychiatric symptoms	7	I suffer so much that I can't recall when life was lovely and happy. My life is hell. My life is inhuman. I have such deep pain inside
1.4 Misery due to medical treatment	11	I was simply nauseous and my energy was just running out. And I said that I wished that, just for a short period of time, I could eat normally and not have to fight to keep it down and that I wanted to have a little more energy. Then I stopped the chemo and indeed I had that improvement
1.5 Decline	29	I can no longer bear the undermining nature of my disease; there are moments when I can't find a single word in my brain
2. Psycho-emotional		
2.1 Loss of sense of self	13	I want to present myself as being as normal as possible, but everybody notices it: I stumble and I am slow and that is just not me because I always was a nimble girl
2.2 Negatively coloured feelings	17	I am tired of life and that has to do with my marriage, which was difficult. Not every day, but regularly and that was not so pleasant. I was going to write it all down, but I am so very tired
2.3 Fear of future suffering	21	Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won't belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that's suitable for me
2.4 Dependency	26	I can't do anything anymore, they leave me lying here until 10 o'clock and they only wash me when they feel like it
2.5 Autonomy	27	I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that year ago: if this were to overcome me, then that's what I would choose
2.6 Mental exhaustion	2	Mentally I am completely exhausted. I can't fight it anymore.
3. Socio-environmental		
3.1 Loss of being socially significant	3	I was a very handy man: there were all kinds of odd jobs to be done in the home for the elderly and I enjoyed doing them. Then I felt useful to this society. I can't do it anymore, I can't do anything anymore, but I lived a worthy life...
3.2 Communication problems	30	When he is with his friends, he can't say anything and that's just the difficulty. He likes me to be there because when he can't manage to communicate he feels so unhappy. The conversation flags and with, um, such a device, most conversation is almost impossible. Just talking to him, I notice that you really must never ask him anything, you must just tell him things and only ask questions that he can answer with yes or no
3.3 Discontent about residential circumstances and quality of care	24	I will decide for myself as long as I can. I don't want to go to a nursing home, we have agreed on that. It would be the end of me
3.4 Being a burden	28	I have become so weak because of the pain. I can't walk anymore, I can't eat anymore. My children have suffered enough. I don't want them to go through this again. Everybody has to lose their parents some day anyway
3.5 Loneliness	8	The home help comes once a month. Even though I look healthy, I have so much grief because I have lost everybody, your parents, your husband and your sisters and my brother was shot dead by the Germans. Everything is gone
3.6 Biography	10	...claustrophobia of my existence. To put it simply, it is insight without perspective. Never in my life have I felt any love. If there had been some warmth and love and safety, I could have grown
4. Existential		
4.1 Limitation of activities	25	I can't drive anymore. I loved to paint and draw, but I can't do that either anymore. Everything I enjoyed is gone. And then, my sight became worse...
4.2 Hopelessness	16	You lie in bed and none of the normal functions come back. They will never come back and it will only get worse
4.3 Pointlessness	5	I'm not interested at all anymore, I just lie here and what's the point? There isn't any. I no longer read. Not books, not newspapers. I have CDs and the Walkman right here. Well, I've listened to, um, two CDs and that's enough. And yet I really loved music, but it's all over. I'm just not interested anymore
4.4 Being tired of life	19	I think that my life is absolutely completed. I don't know what else I could want

future suffering. These fears were related to the course of illnesses, physical symptoms, the process of dying, decline, loss of self-determination or anxiety. Sometimes loss of autonomy was experienced as a threat to personality. Being treated as a patient especially when others had to take over everyday tasks or when being bedridden was described as suffering. The wish to have a say about their death was another expression of the desire for autonomy. Many patients suffered from mental exhaustion.

### The socio-environmental context

The six subcategories in the socio-environmental theme were loss of social significance, communicative problems, discontent

with residential circumstances and quality of care, being a burden, loneliness and biographical aspects. The patients mentioned loss of social significance often. Exclusively patients with motor neuron disease or dementia mentioned communication problems, but such problems were of minor importance compared with other symptoms of these diseases. A prospect of a possible transfer to a nursing home added to suffering.

Patients who had high-quality informal care and strong family connections and who had been the central figures in their families were particularly concerned about being a burden.

Those who were widowed, patients with psychiatric problems and patients forced to live separately from their partners

**Table 3** Themes, categories and codes of suffering named by patients explicitly requesting assistance in dying

Themes	Categories	Codes	
Medical	Physical symptoms	General symptoms: pain, fatigue, general malaise, feeling miserable, physical deterioration, changed appearance	
		Gastrointestinal symptoms: eating and drinking problems, anorexia, nausea, vomiting, loss of weight, defecation problems	
		Nervous and locomotor symptoms: deterioration of locomotor function, mobility and coordination; loss of balance; dizziness	
	Cognitive symptoms	Dyspnoea	
		Incontinence	
		Confrontations with cognitive deterioration, deterioration of ready knowledge, inability to concentrate, inability to participate in conversations, slow-wittedness, loss of memory	
	Psychiatric symptoms	Loss of emotional control, loss of emotions, insomnia, de-realisation, depersonalisation, suicidal ideation, depression, identity crisis, fear, addiction	
		Effects of medical treatment	Side effects of chemotherapy, radiotherapy, psycho-pharmaceuticals and morphine. Complications of operations
		Decline	Physical, cognitive and emotional
	Psycho-emotional	Loss of self	Loss of the following:
			<ul style="list-style-type: none"> <li>▶ Autonomy: independence and being in control Expression of personal traits: social-mindedness, readiness to help others, being of significance, caring, pride in achievements</li> <li>▶ Communication style: considerate of the views of others, open</li> <li>▶ Specific personality descriptors: modest, honest, loyal, consistent, interested, rational, humorous, relativistic, optimistic, uncomplaining, not overly emotional</li> <li>▶ Favourite activities: active outdoor events and 'enjoying life'—for example, going out for dinner, etc</li> </ul>
			Impotence, bitterness, misery, emptiness, suffering, emotional pain, disappointment, sadness
		Negative feelings	The course of the illness and dying: getting worse, uncontrollable symptoms, a horrible death
Cognitive decline: deterioration, loss of control of the mind, loss of community, becoming insane with fear, being unable to recognise surroundings			
Consequences of palliation: side effects of treatment, including morphine			
Fears of future suffering		Physical decline: deterioration, dullness, urinary incontinence, mechanical ventilation	
		Physical symptoms: nausea, pain, choking, dyspnoea	
		Loss of self-determination: being totally unable to do anything, loss of control, vegetative state, being bedridden.	
Socio-environmental		Dependency	Emotional aspects: suffering, anxiety
			Being dependent, loss of physical functions of everyday living, being bedridden
			The way others treat you: patient role, being treated as a hothouse plant, not being seen as a human being, being pressured to make decisions
		Loss of autonomy	Loss of self-determination: loss of direction, loss of making your own decisions, loss of independence, impaired daily functioning
	Desire to control death: not wanting to experience the end stage of the disease, not wanting to suffer to the end, desire to have a say about your own dying, wanting your preferred way of dying, wanting to die with dignity, wanting no prolonged dying, desire to die at home, wishing to have some influence on the memories left behind		
	Not being able to stand it anymore, demoralisation, being so tired, exhausted by the treatments, tired of fighting the illness		
	Being worn out	Not being significant for society or loved ones, Loss of social, occupational and family roles, status	
		Inability to participate in conversation, inability to communicate	
		Residential: being unable to go home, nursing home as a prospect, unsuitable living conditions	
		Quality of care: poor quality of professional care, disappointment in informal care	
		Being a psychological or physical burden to the next of kin and the formal and informal caregivers	
		Loss of loved ones, withdrawal, isolation, being left alone	
		Family history, occupational history, autobiography, social background, bad marriage, sexual abuse, family trauma (eg, war)	
Being unable to participate			
Existential	Loss of important and pleasurable activities	Absence of any hope of improvement, absence or degrading future prospects, nature and progress of the disease, unsuccessful suicide attempts	
	Hopelessness	Loss of joie de vivre, loss of purpose in life, loss of the will to live	
	Pointlessness	Being tired of life or weary of living, a feeling that your life is completed	
	Life is over		

were lonely. Aspects of the patients' past, such as sexual abuse, a bad marriage, or childhood in a war camp had a very individual influence on their suffering.

### The existential context

All patients experienced existential suffering. There were four categories within this theme: loss of important and pleasurable activities, hopelessness, pointlessness and being tired of life. Loss

of important and pleasurable activities comprised a long list of activities, which included managing the household, looking after the grandchildren, gardening, going out for dinner, companionship, reading, playing tennis, travelling abroad, listening to music and singing in a choir, being significant to others and having a wonderful job. All patients mentioned hopelessness. Hopelessness inevitably gave rise to feelings of pointlessness that resulted in being tired of life.

### The patients' perspectives on unbearable suffering

Patients who, in contrast with the other patients, emphasised continuous feelings of unbearable suffering, saying it was impossible "to be unable to enjoy anything anymore", had a psychiatric diagnosis. Subcategories of existential and psycho-emotional themes contributed greatly to the perception of suffering becoming unbearable (table 4). As an 80-year-old man, a former mathematics teacher and musician put it: "I can't do anything anymore, I used to play music, participated in various clubs, all so very companionable, I had to say farewell to all of it. It feels so awful just waiting to become bedridden and then waiting to die". All patients considered hopelessness to be a main factor in the perception of unbearable suffering. This is illustrated by a 55-year-old woman with nasopharyngeal cancer: "You lie on a bed and none of the normal functions come back. They will never come back and it will only get worse".

In addition, patients placed unbearable suffering in the broader context of their personality characteristics. They explained how the irreversible consequences of disease or ageing resulted in loss of self, loss of autonomy and mental exhaustion until they felt themselves no longer the persons they used to be. This is exemplified by a 53-year-old woman with lung cancer: "I lost my dignity, lying in bed in diapers, I am no longer the independent person I used to be". In the medical theme,

untreatable neurological pain, fatigue, decline and particularly psychiatric symptoms made the suffering unbearable. A 65-year-old woman with neuropathic pain, on maximum analgesic treatment, expressed this as: "I am in pain all the time, I am in pain at night, I wake up with pain and I go to bed with pain. If they could only take away half my pain I wouldn't be thinking about euthanasia". In the socio-environmental theme, loneliness and being a burden often contributed to unbearable suffering, but these elements mostly were of minor importance.

Most patients, when asked about unbearable suffering, made up a balance of their past, their present and their expectations of the future. When this balance gave rise to feelings of hopelessness (often combined with feelings of pointlessness and being tired of life), they considered their suffering unbearable. As a 48-year-old woman put it: "It is such an aggressive form of cancer. I saw all my energy going down the drain—what I could still do last week I can't do at all now. I really enjoyed my life, but now I have just to wait and see how things go and what death will look like". This was in great contrast with one 94-year-old woman, who was in excellent psycho-emotional condition and had no classifiable disease. She was living in a caring environment, communicating in a lively way and e-mailing with her extensive international network. She requested assistance in dying for reasons of being ready to quit life without any suffering at all.

**Table 4.** Occurrence in themes and subcategories of unbearable suffering among patients

Theme	<i>n</i> *	Subcategory	<i>n</i>	Code	<i>n</i>
Medical	29	Physical symptoms	29	Fatigue	10
				Pain	6
				Feeling miserable	1
				Nausea	1
				Vomiting	1
				Eating or drinking problems	4
				Dyspnea	3
				Locomotor function	5
				Incontinence	2
				Psychiatric symptoms	5
				Complications of treatment	6
				Decline	20
				Psycho-emotional	29
Cognitive	10				
Emotional	1				
Negative emotions	17				
Biographical aspects	1				
Fear of future suffering	5				
Dependency	12				
Socio-environmental	20	Loss of social significance	1	Loss of autonomy	18
				Being worn out	16
				Communication problems	3
				Discontent with residential situation or quality of care	5
				Loneliness	8
Existential	31	Hopelessness	30	Being a burden	13
				Limitation of activities	23
				Pointlessness	17
				Tired of life	17
				Loneliness	8

\**n* = number of patients who mentioned the theme, category, or code

## DISCUSSION

This study has brought to light the fact that unbearable suffering, from the perspective of patients who explicitly request EAS, is the outcome of an intensive process that originates in the symptoms of illness or ageing. The same elements from the medical, psycho-emotional, socio-environmental and existential themes, as we identified earlier in a literature review,<sup>11</sup> appeared to cause suffering. Especially elements from the existential and psycho-emotional themes contributed to unbearable suffering and hopelessness was at the centre. Patients considered physical suffering less important, as earlier studies also demonstrate.<sup>13 16–22</sup> This may suggest that physical suffering had been palliated before the experience of unbearable suffering and the request for EAS came about. It became evident that uncontrollable physical symptoms, such as fatigue and neurological pain, contributed considerably to unbearable suffering through its negative effects on the motivations for living. For most patients who request EAS, time is limited; this affects the possible treatment of elements of unbearable suffering. It strengthens the importance of an early detection and treatment of symptoms like negative feelings, fears of future suffering, being worn out, loss of autonomy, loss of social significance, loss of activities, pointlessness and being tired of life to prevent suffering becoming unbearable.

Our study made obvious that the patient's request for EAS does not exclusively originate in feelings of unbearable suffering. In agreement with earlier findings, most patients did not experience unbearable suffering continuously.<sup>13</sup> In addition, we found that patients who emphasised continuous feelings of unbearable suffering were diagnosed with a depression. Patients without a depression held the opinion that they were in an unbearable situation and named reasons to ask for assistance in dying in terms of unbearable suffering. Earlier research showed that a depressed mood is associated with a four times higher risk of a request for EAS.<sup>23</sup> This underlines the importance of ruling out a depression before agreeing to a request. In agreement with earlier studies, physicians were unwilling to cooperate in requests with psychiatric (co)diagnosis.<sup>24 25</sup>

We found that patients evaluated their suffering in the context of personality characteristics, life history and existential motivations. The moment this evaluation evoked strong feelings of hopelessness, they perceived their suffering as unbearable. This progression of suffering to the point of hopelessness is compatible with a theoretical model of unbearable suffering,<sup>26</sup> which implies that the outcome of unbearable suffering can only be fully understood from the *individual patient's* perspective and not so much from the *burden* of physical signs and symptoms. Individual patients emphasised the loss of all that life made worth living, felt that they were no longer the persons they used to be—Cassell's disintegration of the person<sup>1</sup>—and had no hope of improvement.

Our study underlines that it is possible to carry out research with patients in end-of-life situations. Researchers and practitioners have long been concerned about burdening vulnerable patients in the last phase of their lives with research. Only in the past decade has such research become acceptable.<sup>27 28</sup> We found physicians prepared to ask terminally ill patients to participate in research. Patients found it useful to know that others would benefit from their experiences.

The study has some limitations. The findings should be placed in the context that unbearable suffering is among the criteria of lawful EAS in the Netherlands. Consequently, patients might feel urged to express the reasons for their request in terms of 'unbearable suffering'. It is unclear how this legal aspect affects

the patients' phrasing of their request. It is unknown whether the participating physicians selected patients in view of specific elements of suffering or unbearable suffering. We do not know what kind of patients refused participation and whether refusal was related to the nature of suffering.

We hypothesise that, while suffering is rooted in the symptoms of illness or ageing, the existential and psycho-emotional themes determine how much hope there is and whether the patient is able to bear the suffering. Unbearable suffering can only be understood in the continuum of the patient's perspectives on the past, the present and expectations of the future. Without hopelessness, there is no perception of unbearable suffering.

These findings have implications well beyond decisions about EAS. Physicians, nurses and other healthcare professionals who practice palliative care should be able to understand patients' existential and psycho-emotional suffering (including the hopelessness) in an early stage to prevent suffering from becoming unbearable.

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