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How do relatives remember the dying of lung cancer patients after 2–8 years? A qualitative study based on in-depth interviews with family members

Abstract

Background. The aim of our study was to assess how relatives remember the dying of lung cancer patients several years after their death.

Methods. The family members of 45 non small-cell lung cancer patients who died up to 7 years after radical surgical treatment were telephoned and asked to meet the research team. Only 20 of them agreed to talk about the dying and death of their relatives; for the rest the issue was still too painful. During the meeting with 2 researchers, participants were asked to comment freely on the points of the Assessment of Dying in Lung Cancer Patients questionnaire and to score the Quality of Dying Apgar.

Results. Family members of 15 of the patients stated recognizing the dying of their loved one. They concluded this on the basis of exacerbation of symptoms, "typical" appearance, change in behaviour or particular words the patient said to them. The median score of the quality of dying was 6.5/10 (range 3–9). Lower scoring was observed for patients who died in hospital, without the family present at the moment of death and with uncontrolled symptoms. Only 5 of the relatives assessed pain and other symptom control as satisfactory. Other family members remembered pain ($n = 9$), dyspnoea ($n = 8$), delirium ($n = 4$) and other symptoms as disturbing the dying in a severe or moderate way. Three relatives assessed that their loved one's dying was not "dignified", mostly due to the severe physical suffering, the nursing being crucially remiss at the hospital and the patient's being alone at the moment of death. All family members were able to describe the healthcare professionals' attitudes and even repeat the statements they heard from them.

Conclusion. We have demonstrated that several years after death many of the words and the behaviour of the dying patients were still alive in their relatives' memories. The family members remember how the healthcare professionals behaved and what they said to them. While caring for dying people, we should bear in mind that the way in which we behave may either give strength to the family or destroy their peace of mind for many years.

Key words: lung cancer, dying scenario, nearing death awareness, qualitative study

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Introduction

In Poland, as in other countries, lung cancer is the leading cause of death related to malignancy [1, 2]. The steady increase in morbidity has been accompanied by a growing mortality rate. Despite adequate therapy, less than 10% of patients survive for 5 years in Poland, mostly as a result of late diagnosis [2, 3]. However, even in the most developed countries this percentage of long survival among lung cancer patients is still very low, approximately 13% [4, 5]. Unfortunately, the literature concerning scenarios for dying in lung cancer patients is scanty. The special concern given to the last weeks and days of life results from the fact that the dying phase is not a mere continuation of the life before. It involves new problems and different reasons for suffering, both for the dying person and his or her relatives (for review see [6]). The way patients die determines the way in which they and their relatives evaluate that person's life. Patients dying a "bad" death are unable to see the meaning and value of the last period of their life and their struggle with the disease. The uncontrolled suffering of a dying person cannot easily be forgotten by the relatives.

The aim of our study was to assess how family members remember this emotional experience after several years.

Participants and methods

This qualitative study involved the relatives of patients who had died up to 7 years after radical surgery of non small-cell lung cancer. The database was prepared for the purpose of another trial (grant number: KBN 3 P05C 0423) and consisted of the records of 240 patients who were operated upon in the Thoracic Surgery Department of the Medical University of Gdansk from 1996–2000. Before May 2005, 163 patients from that group had died, although investigators invited only those relatives who lived nearby (Gdansk and the surrounding area) and for whom actual contact details were available. Family members were identified through the hospital records for next of kin or designated contact and were contacted by telephone a minimum of 2 years after their loved one's death. If no telephone number was available, a letter was sent to their postal address. Reasons for declining participation were recorded.

The study was conducted with the approval of the local Ethics Committee (nr KB/200/2005) and all participants signed the written informed consent form.

For the purpose of this study we developed the Assessment of Dying in Lung Cancer Patients (AOD-LCP) questionnaire to measure important aspects of the last months of life, scenarios for dying and the support of the healthcare professionals from the perspective of family members. The range of issues was wide and related to the observations from other qualitative studies on lung cancer, heart failure and chronic obstructive pulmonary disease patients [7–9]. In addition, family members' perceptions of the quality of dying and death were measured with the Quality of Dying Apgar (QODA) (Table 1). The instrument, based on the paediatric tool for the evaluation of the condition of newborn babies, was primarily developed for and focused on the quality of the dying of patients with end-stage renal disease [10]. However, we employed this tool as it was simple, quick and included the main domains which we recognized as being mandatory for a relative's memory of the good death of a loved one. The five domains (pain, non-pain symptom, advance care planning, peace/dignity and time) were scored from 0–2 and then totalled.

During the meeting with a family member, two trained researchers (two doctors or a doctor and a psychologist) asked questions from the AOD-LCP questionnaire and made notes according to the relative's answers. The study participants were invited to talk freely in their own way. They also attempted to complete the QODA score but were asked to combine scoring with a narrative description of the circumstances.

Results and discussion

General analysis

Family members of 45 of the patients who died 2–7 years after the radical surgical treatment of non small-cell lung cancer were eligible to participate in the study (Figure 1). Of those, relatives of 25 of the patients declined to participate. The most common reasons for not taking part in the study included feeling too emotional, a reluctance to revisit the past and personal health problems such as depression.

Of the 20 decedents, 14 were male, 13 had squamous cell carcinoma and 7 adenocarcinoma (Table 2). Their median age was 57.5 (range 45–71) and the median post-operative survival period was 20.5 months (range 1–85). The most common site of recurrence was the brain ($n = 7$), followed by the bones ($n = 4$) and liver ($n = 3$).

Table 1. The quality of dying Apgar [10]

Parameter	Scale
Pain (during the last week of life)	0 = severe & distressing pain 1 = the pain distressed the patient somewhat 2 = no pain, or the pain did not distress the patient
Other symptoms (during the last week of life)	0 = a severe & distressing symptom 1 = the symptom distressed the patient somewhat 2 = no symptom or the symptom did not distress the patient
Advance care planning During the last week of life to what extent were the patient's wishes followed — regarding a course of treatment that focused on extending life as much as possible, even if it meant more pain and discomfort — or on a plan of care that focused on relieving pain and discomfort as much as possible even if it meant not living as long	0 = formal healthcare proxy or living will had not been completed, documented, or communicated to staff who managed the terminal care 1 = intermediate 2 = formal healthcare proxy or living will had been completed, documented, or communicated to staff who managed the terminal care
Peace/Dignity During the last week of life, did the patient die on his/her own terms? Was the patient lucid, coherent, able to take leave of loved ones or have them say goodbye, complete most of the desired tasks, attend to spiritual matters, die where the patient chose, and leave the family united?	0 = mostly not peaceful/dignified 1 = mostly peaceful/dignified 2 = peaceful/dignified
Time Was dying prolonged?	0 = prolonged 1 = intermediate 2 = not prolonged

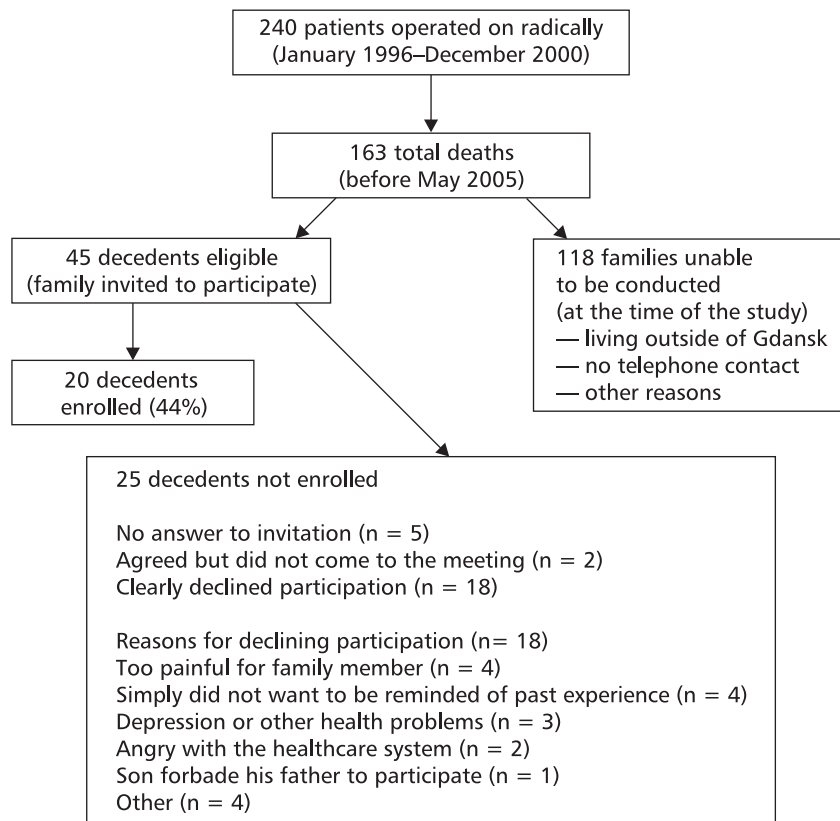


Figure 1. Algorithm of family member participation

Table 2. Patients' characteristics

No.	Initial	Sex	Age	Histopathology	pT	pN	pM	Post-operative survival [months]	Recurrence
1	ZR	F	62	Adenocarcinoma	1	1	0	37	Brain
2	JK	M	70	Adenocarcinoma	2	1	0	1	Brain
3	KBE	M	59	Squamous cell carcinoma	2	1	0	27	Urinary bladder
4	AG	F	45	Adenocarcinoma	2	1	0	12	None
5	TP	M	64	Squamous cell carcinoma	2	0	0	61	Second lung
6	HK	F	70	Squamous cell carcinoma	2	0	0	34	Brain
7	JL	M	71	Squamous cell carcinoma	4	2	0	10	Prostate
8	TN	M	69	Squamous cell carcinoma	2	1	0	18	Liver
9	JS	M	63	Squamous cell carcinoma	2	1	0	5	Brain, liver
10	KB	M	60	Squamous cell carcinoma	2	0	0	8	Bones, abdomen wall
11	JR	M	69	Adenocarcinoma	2	2	0	15	Local
12	CS	M	59	Squamous cell carcinoma	2	1	0	85	Bones, local
13	ZM	F	65	Adenocarcinoma	2	0	0	24	Kidney
14	CB	M	69	Adenocarcinoma	2	1	0	6	Liver
15	AC	M	68	Squamous cell carcinoma	2	1	0	34	None
16	JD	M	49	Squamous cell carcinoma	2	1	0	18	Bones
17	ZME	F	58	Adenocarcinoma	3	2	0	27	Brain
18	SP	F	46	Squamous cell carcinoma	2	0	0	1	Brain
19	WK	M	60	Squamous cell carcinoma	2	0	0	11	Brain, second lung
20	RC	M	53	Squamous cell carcinoma	3	1	0	4	Bones
Total		6F/ /14 M	Median = = 57.5; (range 45–71)	13 squamous cell carcinoma; 7 adenocarcinoma				Median = 20.5; (range 1–85)	Brain — 7; Bones — 4; Liver — 3; Second lung — 2; Local — 2; Other — 4; None — 2

F — female; M — male

According to relatives' assessment, the median of the dying phase length was 8.5 days, with the range from 0 (less than 1 day) to 30 days. Ten patients died at home, 9 in hospital and 1 in a hospice. In 8 cases, no family member was present at the moment of the loved one's death (7 in hospital, 1 in a hospice). The results are presented in Tables 3 and 4.

How does the family remember the dying of their loved one?

Improvement of end-of-life care depends on the proper measurement of the quality of dying. Many investigators underline a limitation of the evaluation made by family members, since their report may be influenced by different emotions [11]. In our study we did not want to measure the quality

of dying but to look at how family members remember this experience several years later. Essentially, we focused on 3 problems:

- Whether and, if yes, how they recognized that their loved one was approaching death;
- How they now assess his/her dying;
- How they remember the relationship, support or other kinds of contact with healthcare professionals during that period.

"He looked to be very close to dying"

Family members of 3 decedents were surprised by the unexpected death of their loved one: "It happened suddenly." (Mr JK's daughter); "The day before he wanted some soup and talked to me by mobile phone." (Mr JR's wife); "She died in her sleep." (Mrs ZME's husband)

Table 3. Dying — described by the interviewed family member

Pt	Days	Symptoms during dying	Presence of family at the moment of death	Place of death	How the family recognized dying
ZR	14	Fatigue, mood depression, tachypnoea	Spouse, mother, children	Home	“She looked at one point and said almost nothing. She had bluish feet and a high fever”
JK	0	Productive cough, fatigue, restlessness, cachexia	Spouse, children	Home	“It was unexpected — it happened suddenly”
KBE	7	Pain, productive cough, fatigue	Spouse, children	Home	“He was weak and was not interested in the surrounding world, either in TV or even the new puppy”; he started “going away”
AG	7	Pain, dyspnoea, productive cough, fatigue, dry mouth, anorexia, nausea/vomiting, mood depression, restlessness, delirium, death rattle, tachypnoea, constipation, cachexia, fever	None	SD	“She had been losing consciousness”
TP	10	Dyspnoea, fatigue, anorexia, mood depression, restlessness, incontinence of urine, constipation, fever	None	ICU	He was unconscious on a respirator for 10 days; “His face was changed with shadows under his eyes. He looked to be very close to dying”
HK	2	Pain, fatigue, anorexia, lack of thirst, sweating, delirium, tachypnoea, incontinence of urine, decubitus, mucositis	Spouse, children	Home	Much worse contact and hallucinations
JL	30	Pain, dyspnoea, fatigue, anorexia, lack of thirst, anxiety, mood depression, restlessness, delirium, incontinence of urine, vomiting, constipation, cachexia	NON	DIM	He slept a lot and was confused (about where he was and what some things were for); very often asked for morphine as he was “full of pain”
TN	7	Pain, fatigue, dry mouth, anorexia, mood depression, delirium, tachypnoea, incontinence of urine, constipation, cachexia, oedema	Spouse, children	Home	He was very weak, anorexic, cachectic; delirious (“lay down on the floor to sleep”) and depressed (“held his head down”)
JS	14	Fatigue, anorexia, lack of thirst, anxiety, mood depression, hiccupping, sweating, productive cough, delirium, death rattle, incontinence of urine, vomiting, constipation, cachexia, fever	Spouse	Home	“He had glassy eyes.” He had problems recognizing his wife. He could not talk too much; he said: “It is high time for me and I have to go away” — for his wife he looked to be anxious”. On the last day he suddenly stood up and went to the window and wiped the curtains. “He felt “hot everywhere in his body”
KB	1	Fatigue, dry mouth, anorexia, delirium, death rattle, decubitus, constipation, cachexia	Spouse, children	Home	He started to sleep most of the time. There were rattling sounds and “bubbling” in the lungs. He rejected the bronchial toilet and receiving furosemide and the physician from the ambulance service respected his will. Seven hours before death he said: “Close the door as they are all here”
JR	1	Dyspnoea, fatigue, anorexia, anxiety, dry cough, cachexia	None	DIM	It was not expected (“the day before he wanted soup; and talked by mobile phone with his wife”)
CS	14	Dyspnoea, fatigue, dry mouth, anorexia, mood depression, restlessness, tachypnoea, constipation, cachexia	None	Hospice	It was not clear for the family; He was dyspnoic (“he was suffocating”) and restless; he told his wife: “Do not cry, everybody has to die”)

SD — surgery department; DIM — department of internal medicine; ICU — intensive care unit



Table 3. Dying — described by the interviewed family member — continuation

Pt	Days	Symptoms during dying	Presence of family at the moment of death	Place of death	How the family recognized dying
ZM	2	Dyspnoea, fatigue, dry mouth, anorexia, restlessness, delirium, tachypnoea, ulceration, nausea/vomiting, constipation, cachexia	None	SD	It was not clear for the family; she had coffee-grounds vomiting and was taken to hospital with the suspicion of gastrointestinal obstruction; she was not allowed to drink; Twelve hours before death — she asked for the priest; 10 hours before death she lost consciousness; at midnight the head of the Surgery Department ordered the daughter to leave the hospital: "If I had known she was dying, I would not have allowed him to turn me out"
CB	1	Fatigue, dry mouth, anorexia, mood depression, death rattle incontinence of urine, constipation, vertigo	Children, grandchildren	Home	"He had a premonition, that something was going on." He had vertigo and had to go to the toilet very often (asked his daughter to help him); he died much earlier than his doctor warned them, as if "escaping from suffering"
AC	6	Pain, dyspnoea, fatigue, anorexia, lack of thirst, incontinence of urine, constipation, cachexia	None	SD	He was dyspnoic; and his face "was changed"; he told his neighbour that he wants his wife to come again as "I want to look at her while I am able to"
JD	1	Pain, dyspnoea, productive cough, death rattle, cachexia	None	DIM	He was taken to hospital because of dyspnoea and "he behaved as if he knew he would not come back home any more." He told his wife that he said goodbye to their 10-year-old daughter
ZME	0	Cachexia	Spouse	Home	It was sudden: "she died in her sleep"
SP	30	Pain, fatigue, nausea/vomiting anxiety, mood depression, cachexia	Spouse	SD	Rapid increase of headache and weakness; sudden loss of sight and consciousness; then she had a gentle expression on her face
WK	7	Restlessness, delirium, paraplegia, decubitus	Spouse	DIM	3 days before death he said that he had found his inner peace; "He looked at our younger daughter (8) as if he wanted to give her his strength." He asked to be taken home from hospital and promised to take all the drugs, but his wife was afraid and doctors advised her not to do it
RC	3	Pain, dyspnoea, productive cough, fatigue, dry mouth, anorexia, lack of thirst, nausea/vomiting, mood depression, insomnia, death rattle, tachypnoea, incontinence of urine, constipation, haematoptysis, cachexia	Spouse, mother	Home	He said to the family: "Goodbye, I am going away." He held his wife's and his mother's hands while he was dying very peacefully

SD — surgery department; DIM — department of internal medicine; ICU — intensive care unit

Table 4. Assessment of dying by the interviewed relatives based on The Quality of Dying Apgar [10]

Pt	Physical symptom which disturbed dying	Assesment of medical care	Pain in the last days	Other symptoms in the last days	Advanced planning with the patient	Peace and dignity	Was the dying prolonged?	Quality of dying
Scale			[0-2]	[0-2]	[0-2]	[0-2]	[0-2]	[0-10]
ZR	None	Good	2	2	0	2	2	8
JK	None	Very good	2	2	1	2	2	9
KBE	Pain	Good	0	1	1	2	2	6
AG	Dyspnoea	Very good	1	0	1	2	2	6
TP	Unconsciousness	Good	2	0	0	2	2	6
HK	Pain, delirium	Good	0	1	2	2	2	7
JL	Pain, dyspnoea, delirium	Bad	0	0	1	0	2	3
TN	Delirium, pain, existential suffering	Good	1	0	2	2	2	7
JS	Dyspnoea, death rattle, pain	Good	1	0	1	2	2	6
KB	Dyspnoea	Very good	2	1	2	2	2	9
JR	None	Good	2	2	1	2	2	9
CS	Dyspnoea, pain	Very good	1	0	2	2	2	7
ZM	Constipation	Good	2	1	1	2	2	8
CB	Pain	Difficult to say	1	2	1	2	2	8
AC	Dyspnoea and pain	Good	0	0	1	1	2	4
JD	Dyspnoea	Bad	2	0	1	2	2	7
ZME	None	Very good	2	2	0	2	2	8
SP	None	Very good	2	2	1	2	2	9
WK	Delirium	Not sufficient	2	1	1	1	2	7
RC	Dyspnoea, dry cough, pain	Very good	0	0	1	2	2	5

Relatives of 2 patients stated knowing that death was imminent but, against the reality, hoped it would not happen as quickly.

The wife of Mr CS believed in it even when her husband told her: "Do not cry, everybody has to die".

The daughter of Mrs ZM said: "If I had known she was dying, I would not have allowed him to turn me out of the Surgery Department at night".

However, family members of 15 of the patients stated that they recognized the dying of their loved one. They concluded it on the basis of exacerbation of the symptoms, "typical" appearance, change of behaviour or particular words the dying patients said to them.

Twelve out of 15 of the relatives noticed an exacerbation of symptoms (Table 3). Five described a specific appearance: "She had bluish feet and a high fever." (the husband of Mrs ZR); "His face was changed with shadows under his eyes. He looked to be very close to dying." (the wife of Mr TP); "He had

glassy eyes." (the wife of Mr JS); "His face had changed." (the wife of Mr AC); "She had a gentle expression on her face." (the husband of Mrs SP).

Of the 15 relatives, 8 concluded from his or her behaviour that the loved one would be dying very soon: "She looked at one point and said almost nothing." (the husband of Mrs ZR); "He was not interested in the surrounding world, either in TV or even the new puppy." (the wife of Mr KBE); "On the last day he suddenly stood up and went to the window and wiped the curtains." (the wife of Mr JS); "He rejected the bronchial toilet and to receiving furosemide and the physician from the ambulance service respected his will." (the daughter of Mr KB); "He had a premonition that something was going on." (the wife of Mr CB); "He behaved as if he knew not to come back home any more." (the wife of Mr JD); "He looked at our younger daughter as if he wanted to give her his strength. ...He asked us to take him home." (the wife of Mr

WK); "He held our hands while he was dying." (the mother of Mr RC).

Six of the dying patients spoke "special words," remembered by the relatives: "It is high time and I have to go away." (Mr JS); "Close the door as they are all here." (Mr KB); "I want to look at her while I am able to." (Mr AC explained to his neighbour as to why he wanted his wife to visit him); "He told me that he had said goodbye to our daughter." (the wife of Mr JD); "Three days before death he said that he had found his inner peace." (the wife of Mr WK); "Goodbye, I am going away." (Mr RC).

The relatives' reports on the exacerbation of physical symptoms and change in behaviour are in concordance with the previous observation that, in cancer patients entering the dying phase, the following symptoms often occur simultaneously [12–14]: extreme weakness, cachexia, lack of appetite and adiposy, drowsiness or disturbed consciousness and a decreased concern about his or her surroundings. The majority of symptoms develop gradually, most frequently over a period of a few weeks [15]. If they emerge abruptly, one should consider potentially reversible causes of deterioration, such as bleeding, infection or hypercalcaemia.

According to the Liverpool Integrated Care Pathway for the Dying Patient (LCP), the first step to delivering active and appropriate care for the dying is to diagnose dying [16]. The LCP criteria for facilitating the diagnosis of dying include:

- being bedbound;
- semi-comatose;
- only able to take sips of fluid;
- no longer able to take tablets.

In the last hours or days of life the pulse becomes less and less palpable and blood pressure drops gradually [12, 17, 18]. Breathing becomes shallow and slow and of variable amplitude, often of the Cheyne-Stokes pattern. As the patient is no longer able to control bladder and bowels, urinary or bowel incontinence may arise. The patient becomes slowly unconscious, even though he keeps his or her eyes open (due to retraction of the eyeballs and the inability to close the eyelids). The skin becomes colder and sticky, with cyanosis appearing at the patient's extremities and lips. Finally, the circulatory and respiratory systems cease to function and the corneal reflex vanishes. The relatives interviewed by us mentioned many of these symptoms and interpreted them correctly as the objective indicators of dying. However, what was even more interesting was that they also reported some subjective predictors of imminent death, which indicated

that the deceased realized they were dying even though nobody had told them. In the 1990s the term "nearing death awareness" was introduced to encompass various phenomena which convince patients they are going to die [19].

Patients may ask to be discharged sooner so that they can die at home or they say farewell to their doctor, declaring they are seeing one another for the last time. Patients often report that they see people who have already died, usually making them feel comfortable, although some patients may be worried by the fact they are experiencing hallucinations. If a patient trusts the doctor enough to talk about this, they can be reassured that it is normal and that other patients experience the same things and, above all, they should not worry if a loved one is awaiting them.

To live and die with dignity

In 1998 the American Society of Clinical Oncology, along with other American medical associations, introduced core principles for the end-of-life care in order to ensure a good quality of dying [20]. Many parameters for the assessment of dying have been established but those modified by Cohen et al for patients with end-stage renal disease seem particularly valuable [10]. Their quality of dying Apgar (QODA) scale is concise and precise and could also be applied easily to cancer patients. We asked the relatives to score five domains: pain, non-pain symptom, advance care planning, peace/dignity and duration of agony and then to comment on their selection. The general score seemed to be quite satisfactory: median = 6.5/10 (range 3–9). Lower scoring was observed for patients who died in hospital, without family present at the moment of death and with uncontrolled symptoms (Table 4).

Only 5 relatives assessed pain and other symptom control as satisfactory (both scoring equal to 2). In other cases, family members remembered pain (n = 9), dyspnoea (n = 8), delirium (n = 4) and other symptoms as disturbing the process of dying in a severe or moderate way. Nobody described agony as being protracted, even the wife of Mr TP, who was mechanically ventilated in the Intensive Care Unit for 10 days before death. Only in 4 cases was the patient's will known and respected (score = 2). Relatives of 16 of the patients admitted either the lack of such discussion or that their loved ones did not eventually die in the place they wanted. Only the daughter of Mr JL judged that her father died without dignity (score = 0), mostly due to

severe physical suffering, lack of proper care at the hospital and his being alone at the moment of death. Similar reasons were underlined by the wife of Mr AC, who scored dignity at 1. Mr WK's wife also assessed the dignity domain as 1 mostly due to the nursing being crucially remiss in hospital ("he was lying in his faeces for the whole day."). However, 17 relatives described dying as full of peace and dignity unrelated to unsatisfactory symptom relief or some negligence in caring. Does this mean they respect the definition of the dignity of human beings as an objective value; or rather the cultivation of the idea that their loved one's dying with dignity allows them reconciliation and the rebuilding of their life?

"The cardiologist was sitting by his bed"

Relatives of 16 of the patients assessed the medical care as being very good or good, even when the symptom control was not satisfactory. Their comments revealed that the healthcare professionals' attitude and style of communication were especially important.

Family members remembered many positive things: "The cardiologist was sitting by his bed... for quite a long time." (the daughter of Mrs ZM); "They came from the hospice every time we needed them." (the husband of Mrs ZR); "They allowed me to stay at night." (the daughter of Mr JK); "The anaesthesiologist tried hard to explain..." (even representing the patient's reaction to pain — the wife of Mr TP); "The physician from the ambulance service respected his will." (he had rejected the bronchial toilet in his last hours of life — the daughter of Mr KB); "He came every other day to control the epidural analgesia..." (the daughter of Mr KB describing the anaesthesiologist who voluntarily visited them at home). "He did not write him off." (the wife of Mr JD regarding how the thoracic surgeon treated her husband).

However, there were many bad memories of healthcare professionals: "The undertaker arrived much too soon ..." (to take the body from the department — the daughter of Mr JK); "The physician who came to write the death certificate did not bother to see the body." (the daughter of Mr KBE); "He needs a priest more than morphine." (the hospital nurse told the daughter of Mr JL, when she asked why no analgesics were administered to her father); "Hopeless nurses gorging themselves on chocolates." (the daughter of Mr JL about the lack of interest from the hospital nurses); "They took her down on the blanket like a sack of potatoes..." (the

daughter of Mrs ZM commenting on the ambulance service); "The head of the Surgery Department turned me out at night" (the daughter of Mrs ZM, who died 2 hours after her daughter left the hospital); "Nothing will help you anymore..." (the wife of Mr JD remembering the words of the surgeon directed to her husband after the operation); "There were no analgesics in the hospital...The doctor was angry that I stayed with my husband the last night..." (the wife of Mr JD); "Lung cancer patients usually die by suffocation" (the hospital doctor answered Mr AG's daughter, when she asked him how her father would die. After 8 years, she still remembered that sentence).

It is too painful

The relatives of 25 of the decedents declined to participate: 7 of them either did not respond to the invitation or agreed but did not come to the meeting. However, 18 firmly stated that they did not want to participate. The most common reasons for not participating included feeling too emotional ("It is too painful"; "I have been trying hard to come round after my husband's death") or reluctance to revisit the past ("I do not want to recall what happened"; "What we had to experience was so horrible, that I don't want to bring it up"). Three relatives gave their own health problems as the reason for not meeting ("My heart is bad"; "I have been treated with anti-depressants"). Some explanations sounded like straightforward accusations: "Hospices and hospitals are killing people"; "My wife's doctor should not treat human beings"; "I have a grudge against the University Hospital".

It can be assumed that if those relatives had agreed to participate, the results of the study would have been much worse.

Conclusions

We usually imagine a "good death" as being of purpose and meaningful, consistent with clinical, cultural and ethical standards. There should be an absence of avoidable suffering and a minimum of distress on the part of the patient's loved ones and staff. Such a death should also allow for resolution and reconciliation. The achievement of a good death is one of the primary goals of palliative medicine. Here we have shown that several years after death many of the words and the behaviour of the dying patients were still alive in their relatives' memories. What is more, the family members remember how the healthcare professionals behaved and what was

said to them. While caring for the dying, we should bear in mind that the way we do this may either give strength to the family or weaken and even destroy their peace of mind for many years afterwards.

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