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# The last months of lung cancer patients' lives, in the memory of their relatives. A qualitative study based on in-depth interviews with family members

## Abstract

**Background.** The aim of the study was to assess how family members remember the final months of their loved ones 2–8 years after their death. We focused particularly on their recognition of the patients' physical, psychosocial and spiritual needs.

**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 two researchers, participants were asked to comment freely on the points of the Assessment of Dying in Lung Cancer Patients questionnaire.

**Results.** Almost all the relatives interviewed in our study were able to recognize the beginning of the terminal phase. They connected the beginning of dying with the deterioration of the physical and/or psychological status of patients, such as the exacerbation of weakness and/or other symptoms or with clearly distinguished incidents such as cancer recurrence or hip fracture. The majority were able to define the length of this phase as being several months (median = 3, range 1–11 months). The most common physical symptoms mentioned by the relatives interviewed were, in sequential order: pain (n = 13) and fatigue (n = 13), anorexia (n = 9), dyspnoea (n = 7) and cachexia (n = 7). Of the 20 decedents, 18 regularly received painkillers at least at some period during their final months. Apart from medicines prescribed by the doctors, 9 patients were treated with "anti-cancer" herbs, or homeopathy, or by bioenergotherapy. From the relatives' perspectives, the main approach was focused on the physical aspects of care while there was a lack of psychological and social support, the latter often causing severe financial burden. Most relatives believed that chaplains are the main source of spiritual comfort and there was easy access to such a service both in their parish and in the hospice or hospitals.

**Conclusion.** Our study showed that the families remembered feelings of loneliness and helplessness when confronted with the psychological suffering of their loved ones and the financial burdens caused by the caregivers. Professionals involved in palliative care should acknowledge that holistic care requires sensitivity, not only to the physical but also to the psychosocial and spiritual aspects of end-of-life care.

**Key words:** lung cancer; qualitative study, end of life, spiritual needs, psychosocial support

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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 the percentage of long survivors among lung cancer patients is still unsatisfactory, approximately 13% [4, 5]. Death caused by malignancy is usually preceded by a gradual and progressive debilitation as well as a restriction of the patient's everyday activity. At the end stage of the disease an accelerated deterioration in the patient's condition is usually observed [6]. Apart from typical trajectories of physical decline, Murray and co-workers described the characteristic patterns of social, psychological and spiritual levels of distress for lung cancer patients [7]. The social trajectory mirrored physical decline, while psychological and spiritual well-being decreased together at four key transitions: diagnosis, discharge after treatment, disease progression, and the terminal stage. It was many years ago that Cicely Saunders developed the concept of "total pain" to emphasize the fact that pain can mean social, psychological and spiritual as well as physical suffering. The multi-dimensional nature of suffering in terminal conditions means that, in recognizing patients' needs, physicians should not focus only on somatic problems, as this kind of approach is inefficient and does not bring relief to the dying.

The aim of our study was to assess how family members remember the final months of their loved ones 2–8 years after their death. We focused particularly on their interpretation of the patients' physical, psychosocial and spiritual needs.

## Participants and methods

The first part of this qualitative study, which focused on the dying scenario and the quality of dying, has been published elsewhere [8]. The analysis involved the relatives of patients who had died up to 7 years after radical surgery for 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. The reasons for their declining to participate were recorded.

The study was conducted with the approval of the local Ethics Committee (no KB/200/2005) and all participants signed a 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 final 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 observations from other qualitative studies on lung cancer, heart failure and chronic obstructive pulmonary disease patients [9–11]. 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.

## Results and discussion

### Characteristics of the decedents and their relatives

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. 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 had adenocarcinoma (Table 1). 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 ( $n = 3$ ).

Of the 20 decedents, 9 were visited by a palliative care team at home (Table 2). The spouse was most often the main informal caregiver ( $n = 15$ ), followed by a child ( $n = 11$ , as in some cases more than one was indicated), and the mother ( $n = 1$ ).

Table 1. Patients' characteristics

No.	Initials	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
<b>Total</b>	6 F / 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

### How do the relatives remember the beginning of the terminal phase?

Relatives of only 4 decedents were unable to assess the length of the terminal phase. The others evaluated it in months (median = 3, range 1–11 months). However, all but one of the relatives were able to describe the beginning of the terminal phase. In 5 cases it was a clearly distinguished incident: a recurrence of cancer (n = 4) or a hip fracture (n = 1). In 14 patients the family noticed an exacerbation of symptoms, amongst which severe weakness was underlined as the most common (n = 10).

These observations are in concordance with the studies comparing the terminal phase in malignant and non-malignant diseases. A year prior to death patients with malignant disease are in a better functional state than subjects with chronic obstructive pulmonary disease (COPD), congestive heart failure, diabetes or stroke [6]. For example, only 14% of patients with cancer had difficulty getting out of bed or a chair, while in the case of the other diseases the rate was as high as 35%. However, from the 5<sup>th</sup> month prior to death a substantial acceleration

in the functional decline occurs, so that in the last month of life cancer patients are in a worse condition overall than is the case with other chronic diseases. The rapid process of functional impairment may be a sign for patients and their families that the dying process has begun. In non-malignant diseases the prognosis proves to be much more difficult and so the moment of death is often more unpredictable. The difference has been shown to be quite clear in two qualitative interview studies of patients, their families and physicians, which compare the last year of life in lung cancer patients and in subjects with heart failure [10, 11]. In the latter a gradual functional decline was punctuated by acute episodes of deterioration, one of which proved fatal [10]. The unpredictability of dying and a poorly defined terminal phase made understanding the diagnosis and prognosis difficult for patients. In contrast, in lung cancer both the patients and their families have more chance of realizing the inevitability of death and entering a process of "maturation for death" and an evaluation of their previous as well as present life.

**Table 2. The last months of life recognized as the terminal phase described by the family members interviewed**

Pt	Length of terminal phase	Beginning of terminal phase	Main carer	Hospice home care
ZR	3 months	Hip fracture	Spouse	Yes
JK	1 month	Extreme weakness; need for incontinence pants	Daughter	No
KBE	ND	Even when he was talking, his thoughts were somewhere else; weakness	Spouse, daughter	No
AG	11 months	Weakness	Daughter	No
TP	2 months	Operation of the recurrence in second lung; weakness, dyspnoea	Spouse	No
HK	4 months	Recurrence in brain; weakness, cough, fever	Spouse	Yes
JL	7 months	Syncope, pain exacerbation, anorexia	Spouse, daughter	Yes
TN	4 months	Weakness, vertigo, anorexia	Daughter	Yes
JS	2 months	Recurrence in brain and liver; weakness, dizziness; feeling of cold; pain	Spouse	Yes
KB	3 months	Wheezing, anorexia	Daughter, spouse	No
JR	1 month	Hospital admission due to weakness, dyspnoea, cachexia, sweating, anorexia	Spouse	No
CS	ND	Weakness	Spouse	Yes
ZM	9 months	Weakness, change of mood, anorexia, pain	Daughter	Yes
CB	1 month	Fever, extreme weakness	Spouse, daughter	No
AC	2 months	Dyspnoea and pain	Spouse	No
JD	2 months	Extreme weakness; sedation, dizziness	Spouse, son	Yes
ZME	ND	Until the very end she was able to look after herself (cooking, etc)	Spouse, son	No
SP	ND	Weakness, bedbound, severe pain	Spouse, daughter	No
WK	2 months	Recurrence in the brain (confusion and fever)	Spouse	Yes
RC	3 months	Fever, dyspnoea, cachexia, anorexia, pain	Mother	No

ND — no data, because relatives were unable to assess the length of the terminal phase

### “Pain was never relieved enough”

The most common physical symptoms mentioned by the relatives interviewed were, in sequential order: pain ( $n = 13$ ) and fatigue ( $n = 13$ ), anorexia ( $n = 9$ ), dyspnoea ( $n = 7$ ) and cachexia ( $n = 7$ ), constipation ( $n = 5$ ), vertigo or dizziness ( $n = 4$ ), incontinence of urine ( $n = 4$ ), nausea and/or vomiting ( $n = 4$ ), productive cough ( $n = 2$ ), confusion ( $n = 2$ ), and fever ( $n = 2$ ). Several different symptoms usually appeared in a single patient (tab. 3). The median number of physical symptoms according to the relatives' memory was 3.5 (range 1–7). The most common symptoms of a psychological nature remembered by the family were as follows: anxiety ( $n = 5$ ), irritability ( $n = 5$ ), sadness ( $n = 4$ ), withdrawal into themselves ( $n = 3$ ), changing mood ( $n = 2$ ), insomnia ( $n = 2$ ), apathy ( $n = 1$ ) and suspicion ( $n = 1$ ). In two cases none of these problems were noticed by the relatives (tab. 3).

Of the 20 decedents, 18 regularly received pain-killers at least at some period during the final months before death. Apart from medicines prescribed by the doctors, 9 patients were treated with “anti-cancer” herbs, or homeopathy, or by bioenergotherapy. Three of them continued that management until death (Table 3).

Our observations are in concordance with the prospective studies in lung cancer patients showing that, in the last year of life, they suffer many simultaneous symptoms with increasing intensity during the progression of the disease. The majority of patients complain of fatigue, loss of appetite, cough, dyspnoea and chest pain [12]. The role of symptoms in lung cancer patients is reflected not by their frequency index but by the level of symptom distress generated by them. Several studies have shown that symptom distress is higher in lung cancer patients than it is in other malignancies. They suffer more frightening symptoms, such as dyspnoea and haemoptysis. The intensity of symptom perception in lung cancer patients is determined by several factors, such as co-existing COPD, mood disturbances, current concerns and economic situation [13, 14]. Several studies have shown that the level of symptom distress rises in the more advanced stages of lung carcinoma [14, 15], primarily as a result of progression of the disease and partly due to the fact that debilitated patients have a poorer tolerance of the same symptoms.

We did not ask the families to assess the efficacy of symptomatic treatment, as we did not

**Table 3. Symptoms and their management during the final months of life described by the family member interviewed**

Pt	Physical symptoms	Psychological symptoms	Treatment
ZR	Pain	Anxiety	Analgesia, anti-thrombotic, others, complementary
JK	Fatigue	Irritability	Analgesia
KBE	Incontinence of urine, anorexia, productive cough	Suspicion	Analgesia
AG	Pain, fatigue, nausea/vomiting, diarrhoea, cachexia, dyspnoea	Changing mood	Analgesia, complementary
TP	Fatigue, incontinence of urine, dyspnoea, constipation	Withdrawal, insomnia	Analgesia,
HK	Pain, anorexia	Apathy	Analgesia, palliative radiotherapy, complementary
JL	Pain, fatigue, incontinence of urine, anorexia, confusion, aphasia, syncope	Irritability, sadness	Analgesia, complementary
TN	Pain, fatigue, anorexia, vertigo/dizziness, belching, fever, constipation	Anxiety	Analgesia
JS	Pain, fatigue, anorexia, vertigo/dizziness, vision disturbances, hiccuping, confusion	Withdrawal	Analgesia, sedatives, complementary
KB	Pain, cachexia, dyspnoea, anorexia, wheezing, constipation	Anxiety, insomnia	Analgesia (incl. spinal), palliative radiotherapy, others, complementary
JR	Pain, fatigue, cachexia, dyspnoea, anorexia, sweating	Sadness	Palliative radiotherapy
CS	Cachexia	Irritability	Analgesia, cough suppressants, complementary
ZM	Pain, fatigue, nausea/vomiting, cachexia, anorexia, constipation	Irritability, hanging mood	Analgesia, complementary
CB	Pain, fatigue	Withdrawal	Analgesia
AC	Pain, nausea/vomiting, dyspnoea, anorexia, constipation	None	Analgesia
JD	Fatigue, cachexia, dyspnoea, vertigo/dizziness, productive cough, sedation	Anxiety	Analgesia, palliative radiotherapy
ZME	Fatigue	None	Analgesia
SP	Pain, fatigue, nausea/vomiting, vertigo/dizziness	Anxiety	Analgesia, others
WK	Fatigue, paraplegia	Irritability, sadness	Special nursing procedures, Complementary
RC	Pain, incontinence of urine, cachexia, dyspnoea, anorexia, fever	Sadness	Analgesia, others

want to disrupt the process of bereavement. However, some of the study participants spontaneously commented on the subject, which in some cases suggested very bad clinical practice:

“The pain was never relieved enough” (the daughter of Mrs AG);

“He suffered from dyspnoea” (the wife of Mr TP);

“Morphine in drops decreased the pain, however it evoked hallucinations and visions” (the daughter of Mr JL);

“He spent whole nights in the armchair because of breathlessness” (the wife of Mr JR);

“After she came back home from the Thoracic Surgery Department, she suffered from horrible headaches and pain in her neck” (the daughter of Mrs SP);

“She was conscious only when the drugs stopped working” (the daughter of Mrs SP);

“Once daily the nurse used to visit him at home to give him an intramuscular injection of petidine...” (the mother of Mr RC).

**“At the beginning he wanted very much to fight for life, but later on he was depressed”**

When we asked families about the symptoms of the psychological needs of their loved ones, they usually pointed to one of the following observations:

- the variation of emotions,
- fear of death,
- being withdrawn into themselves, the making of necessary arrangements,
- the telling of their life story (Table 4).

First of all, the relatives tried to describe a wide spectrum of emotions and named them as rang-

**Table 4. Psychological, social and spiritual needs of the patient during the final months of life described by the family member interviewed**

Pt	Psychological needs	Social needs	Spiritual needs
ZR	She was afraid of chemo	It did not compromise their financial situation too much ("to rent a bed was cheap")	"Priest from parish visited her"; she had never talked on "the last issues"; when she heard about metastases, she wrote her Will as she wanted "no problems after her death"
JK	He worried about Christmas (died before); was easily irritated	He was retired; financial situation was no worse because of illness; medicines were from hospital	He was religious during his life; asked for the hospital chaplain; he was fortified with the rites of the Church; and received Holy Sacrament
KBE	He didn't present sadness, but "kept everything inside himself"; he interpreted what the family was discussing after visits in the Oncology Centre; "he observed the family"; he told his wife with whom he wants to meet	He was on a pension; problems with organizing his transport from the village where he lived to the Oncology Centre	He died just after the telephone message from the chaplain confirming that he had been fortified with the rites of the Church and prepared for death
AG	She hoped to be cured	She lived in one room with her daughter and granddaughter; family asked for financial help, but this was rejected due to "too high an income"; despite difficult financial situation, they had nothing against spending more money for mother to be comforted	She was religious and an active Catholic; she very much wanted her small granddaughter to remember her grandmother, which is why she wanted to visit their family with her
TP	He dissimulated and did not accept having physical symptoms; he did not talk about death but said goodbye to his neighbour; he wanted to be cured; he lived day after day; wife planned to organize 50 <sup>th</sup> wedding anniversary but he died before	He had retired but had a good financial situation	He was religious and an active Catholic; he had never discussed the subject of death and "final issues" with the family, however told his wife that he received Holy Sacrament when he was in hospital (from the hospital chaplain)
HK	Very brave; "if it can't be helped, so it has to be like this"; she accepted what had happened; 3 months before death she was the leave from hospital to arrange her documents	She had retired; however she could always rely on her family (also financially)	Without problems; regular visits of the priest; she regularly confessed; she accepted the situation and was preparing for death
JL	Confused (he had problems recognizing his relatives), he was "fastidious in eating"	Good financial situation	He arranged all his documents and business; regular visits of the priest; there was even Holy Mass in his home; during the time the Pope visited Poland

**Table 4. Continuation**

Pt	Psychological needs	Social needs	Spiritual needs
TN	Fear of death (this is his daughter's guess, as he had never mentioned that); he was distressed by leaving his family alone; he wanted to show that he's a strong man; he even insisted on hiding his illness: "I do not want people around knowing about it"; he was withdrawn in himself	Good financial situation	He had never talked about spiritual issues; he did not insist on the priest's visit; it was meaningless for him; he worried about leaving his relatives; he was happy to meet all 9 siblings before death
JS	Withdrawn in himself; sad when he heard about hospice care at home (then he knew he would die); he asked for nothing; he retracted, huddled himself up"	He had retired but had been working part-time before illness; illness caused financial problems (injections cost approx. 120 EUR a month); financial support from hospice (because they gave medicines)	He believed in God; at the beginning did not want to see the hospice Chaplain, but later he accepted him and was fortified with the rites of the Church; it was difficult to accept the priest as for many years he was outside the Church because he joined the Communist Party; he looked at 3 watches checking the time: "his time was escaping"; he worried about financial situation of the wife he left
KB	Fears of death due to suffocation similar to his father (who died because of lung cancer); oxygen made him feel safer; he was afraid to sleep (suffered from insomnia), so daughter was lying on the floor by his bed and holding his hand while he was talking about his life for whole nights (about everyday things); he was very patient	He was on a farmer's pension and they spent more money on good food for him and medications; he liked guests but at the end-of-life period he only wanted to see the family	He seemed to be in a good mood; even told jokes; he was an organist in the church; every Sunday the priest visited him bringing Holy Sacrament; he burst into tears during being fortified with the rites of the Church (he was so moved); he had never discussed the subject of death
JR	He was sad to leave his family; he used to participate in family meetings before terminal phase (even in his granddaughter's wedding)	He was retired; no great financial problems; however medications were expensive and he had to spend a major part of his pension	He was not religious but had a balanced spiritual life; nothing changed during his illness
CS	He did not want to talk about death; He was grateful that family cared for him, his colleagues visited him, and his cousins bought him herbs	He was retired; medications were expensive	He asked for the visit of a priest
ZM	She restrained her emotions after the sudden death of her husband	She did not want to be moved to her children which is why she asked the hospice for help relieving her children of the financial burden. She gave her documents to her daughter and made her the formal representative	Very religious



Table 4. Continuation

Pt	Psychological needs	Social needs	Spiritual needs
CB	He felt embarrassed when his daughter was helping with the toilet; he did not want the grandson to help him either; he was withdrawn in himself and only told his doctor friend about constipation	He was on a pension; difficult financial situation — rental for the flat was not paid for the last 3 months	He did not believe in God, however at the end of his life he visited church regularly; he did not ask the priest to visit him; he was quite without fears; just accepted what life brought him every day; never talked to his daughter about "last issues"
AC	Quiet, patient, aware of his prognosis; he was telling his wife many stories from his childhood	He was retired; good financial situation	Previously very religious; however at the end of life did not want to see the priest; during his last hospitalization he did not want to have confession
JD	"Fear of the bed"; he put on his pyjamas but slept in the armchair; he finished different things like insurance or entitlement to the property of his car; asked his stepson whether he could be buried in the same place as the first husband of his wife and his stepson agreed	He was retired — previously a policeman; good financial support from his wife's family however he was worried that he had bad relations with his sister ;	Accepted he had to die; in hospital asked for the priest and talked to him at length; he was religious; at home he did not ask the priest but listened to Holy Mass on TV; previously he did not visited church as he had a bad relation with the parish priest (he had only a registry marriage) but prepared his children for the sacraments
ZME	She thought everything would be fine	She had retired; however they did not have financial problems	She was religious and an active Catholic
SP	She realized that "something has gone wrong"; she said she could die	Difficult contact due to medications	She did not mention it at all
WK	At the beginning he wanted to fight for life, but later on he was depressed; He wanted his wife to be with him all the time in hospital but she was afraid, both of being in a large hospital room (8 patients) and of taking him home (doctor advised her not to do it)	He had to change jobs because of the illness (sailor); but he died whilst on sick leave	3 days before dying he said he regained an inner peace
RC	He worried about the family he was leaving (mother and wife); asked his wife to look after his mother; asked them both to live in unity; he was aware that he would be dying soon	Difficult financial situation; he died whilst on sick leave	Very religious and believed in life after death



ing from anxiety, irritation, being depressed, to patience or the feeling of acceptance of an unknown future. These emotions often fluctuated in the same patient:

"He wanted to be cured.....but said goodbye to his neighbour.." (the wife of Mr TP);

"At the beginning he wanted to fight for life, but later on he was depressed." (the wife of Mr WK)

Some relatives sensed the patient's fear as the main emotion. Two named it as the fear of dying and death:

"He was afraid to suffocate, as his father who had died from lung cancer had..... oxygen made him feel safer.....he was afraid to sleep..." (the daughter of Mr KB);

"I think he was afraid of death, but he had never mentioned that...he wanted to be remembered as a strong man. He even insisted on hiding his illness". (the daughter of Mr TN).

In one case, the relative remembered the fear of the anti-cancer treatment:

"She was afraid of chemotherapy" (the husband of Mrs ZR).

Another study participant thought that her husband was afraid of the hospice:

"When he heard about hospice care at home, then he knew he would die" (the wife of Mr JS).

The next fear was named as "fear of the bed" and described as follows: "He put on his pyjamas but slept in the armchair" (the wife of Mr JD).

And finally, a fear of being alone:

"He wanted me to be with him all the time in hospital" (the wife of Mr WK).

In contrast to the previous description of the various and fluctuating emotions and fears named by the families, there were also patients who completely withdrew into themselves:

"He kept everything inside himself.....and observed us" (the daughter of Mr KB);

"He asked for nothing....he retracted, huddled himself up" (the wife of Mr JS);

"She restrained her emotions after the sudden death of her husband" (the daughter of Mrs ZM);

"He was withdrawn in himself and only talked to his doctor friend about constipation" (the daughter of Mr CB).

The Study to Understand Patient Prognoses and Preferences for Outcome and Risks of Treatment (SUPPORT), which enrolled several thousands of cancer patients, tried to establish what frightens patients most in the agony phase. Like other patients with malignancies, lung cancer subjects were primarily afraid of the dying phase, when they would not be able to control and decide for themselves

and would pose an additional financial burden to their families [16]. They feared suffocation, "struggling for air", bleeding to death or being confused and, in addition, worrisome and futile procedures which prolonged agony [17]. It was apparent that the suffering that patients are afraid of is multi-dimensional and it is a great pity that our study showed the families to feel lonely and mostly helpless when confronted with the psychological suffering of their loved ones.

Some of the study participants, when asked for the symptoms of the psychological needs of the patients, evoked their behaviour rather than emotions. Firstly, the making of necessary arrangements which were interpreted by the relatives as signs of worry about the families the patient had to leave.

"She accepted what had happened: 'if it can't be helped, so it has to be like this....'.....3 months before death she was on the leave from hospital to arrange her documents" (the husband of Mr HK);

"He finished different things, such as insurance or entitlement to the property of his car....; he asked his stepson whether he could be buried in the same place as my first husband and my son agreed." (the wife of Mr JD);

"He worried about the family he was leaving....He asked his wife to look after his mother; and asked them both to live in unity" (the mother of Mr RC).

Two patients told their life stories:

"I was lying on the floor by his bed and holding his hand while he was talking about his life for whole nights" (the daughter of Mr KB);

"He was telling me many stories from his childhood " (the wife of Mr AC).

Probably by the making of necessary arrangements or the telling of life stories, the families guessed that the patients were trying to cope with the prospect of imminent dying.

#### **"She asked the hospice for help in relieving her children of the financial burden"**

When we asked the families about the social needs of the patients, all but one immediately chose the subject of the financial situation. Of the 19, 8 of them did not recognize caregiving to be an additional economic burden for their families. However, for 11 families the illness compromised their financial status:

"She lived in one room with me and my daughter. We asked for financial support but were rejected due to too high an income" (the daughter of Mrs AG); "

Injections cost approximately 500 PLN (120 EUR) a month" (the wife of Mr JS);

"We spent more money on medications and good food for him" (the daughter of Mr KB);

"She asked the hospice for help in relieving her children of the financial burden" (the daughter of Mrs ZM);

"Rental for the flat was not paid for 3 months" the daughter of Mr CB;

"Every time, we had a problem with organizing transport from the village to the Oncology Centre" (the daughter of Mr KBE);

"She was on a pension but we could always rely financially on the family" (the husband of Mrs HK);

"Medications were expensive" (the wife of Mr JR and the wife of Mr CS); "He had to change jobs because of the illness and he died whilst on sick leave" (the wife of Mr WK);

"It was difficult. He died whilst on sick leave" (the mother of Mr RC).

In the United States, annual family caregiving costs more than 6 billion USD for stroke patients and 65 billion USD for patients with Alzheimer's disease [18, 19]. In Poland, there have been no studies on the scope of the economic disruption to family caregiving. However, in the United States and in Western Europe, surveys have revealed the socio-economic impact of terminal disease on both the particular patient and the caregiver [20]. In the Italian Survey of Dying of Cancer (ISDOC), 44% of interviewed caregivers reported difficulties in their regular employment during the last 3 months of the patient's life [20, 21]. In order to cover the costs of patient care, 26% of families in this Italian survey and 31% in a similar American survey used all or most of their savings [22]. In the United States, 20% of family caregivers must leave work or make major life changes, as for them caregiving is the equivalent of a full-time job [23–25].

Unfortunately, even in developed countries government support for family caregiving is limited. A recent study on the utilization of resources for patients with lung cancer in the United States revealed that only 14% of patients were seen by social workers [26]. In our study, the concerns over the uncompensated financial burden remembered by family members were not addressed at all and none of them received any social support.

**"My father died just after the telephone message from the chaplain confirming that he had been fortified with the rites of the Church and prepared for death"**

Of 20 families interviewed, 17 addressed the spiritual needs of their loved ones in the context of the support from priests and the sacraments. Of those 17, 3 patients did not want to see the priest:

"He did not insist on the priest's visit. It was meaningless for him" (the daughter of Mr TN);

"He did not believe in God, however at the end of life he visited church regularly. He did not ask the priest to visit him....he just accepted what life brought him every day" (the daughter of Mr CB);

"Previously he was very religious, however at the end of life he didn't want to see a priest. And during the last hospitalization he did want to go to confession" (the wife of Mr AC).

However, 14 decedents were visited by priests from the parish or a chaplain from the hospice or in the hospital and received the sacraments. It seemed to be extremely important for them, as the families admitted:

"My father died just after the telephone message from the chaplain confirming that he had been fortified with the rites of the Church and prepared for death" (the daughter of Mr KBE);

"He was an organist in the parish church.....every Sunday the priest visited him bringing the Holy Sacrament..." (the daughter of Mr KB);

"There was even Holy Mass in his home...during the time the Pope visited Poland..." (the daughter of Mr JL).

Apart from the support from the chaplains, only a minority of the families mentioned other aspects of spiritual need:

"When she heard about the metastases, she wrote her Will, as she wanted her relatives to have no problems after her death" (the husband of Mrs ZR);

"She very much wanted her small granddaughter to remember her grandmother, that is why she wanted to visit their family with her" (the daughter of Mrs AG);

"He was happy to meet all 9 siblings before his death" (the daughter of Mr TN);

"He looked at three watches checking the time as his time was escaping" (the wife of Mr JS)

In three cases, the relatives did not address the spiritual needs to any religion at all:

"He was not religious but his spiritual life was regulated and his illness did not cause any change at all" (the wife of Mr JR);

"She did not mention it at all" (the daughter of Mrs SP);

"Three days before dying he said he regained an inner peace and believed there was life after death" (the wife of Mr WK).

In the context of palliative care, spirituality "has come to describe the depth of human life, with individuals seeking significance in their experiences and in the relationships they share with family

and friends, with others who experience illness, and with those engaged in their treatment and support" (p. 954) [27]. Within the religious realm of this broad framework, spirituality aligns itself with a sense of connectedness to a personal God [28]. For almost all of the relatives included in our study, spirituality was seen in the context of religious beliefs. From their perspective, chaplains and the receiving of sacraments were the only source of spiritual comfort for their loved ones. It looks as if no one else was able to recognize and help in the case of existential suffering, if present, especially in the 3 patients who were not practising Catholics. The problem is especially important in more secularized societies. A Swedish national survey of hospital chaplains identified categories of questions posed to them by patients with terminal illness: meaning; death and dying; pain and illness; relationships; and religious issues [29]. Religious issues accounted for only 8% of the questions posed to chaplains. The authors concluded that physicians and other professionals should be able to address many of the questions posed to chaplains. A study of nurses' spiritual interventions found that the majority used the following five "therapies": holding a patient's hand, listening, laughter, prayer, and being present with a patient [30]. The sentence said by many of the family members interviewed, that their loved one "...had never mentioned the final issue", might be a signal that not all patients' expectations were met. Derrickson believes that each member of the hospice team should be able to recognize spiritual work when it is being done and to listen respectfully to patients' individual expressions of their spirituality [31].

## Conclusions

All relatives interviewed in our study were able to describe the beginning of the terminal phase and connected it either with the exacerbation of weakness and other symptoms or with clearly distinguished incidents such as cancer recurrence or hip fracture. The majority were able to define the length of this phase as several months. From their perspective, the main approach focused on the physical aspects of care, such as symptom control or even anti-cancer treatment. Most relatives believed that chaplains are the main source of spiritual comfort and no other people or interventions were considered to be involved. What is more, there was easy access to such a service both in the parish and in the hospice or hospital. Con-

trary to this, the families stated that the psychosocial needs of the patients and the caregivers were not met. Neither social services nor psychologists were engaged in their support. For some families, the lack of economic support in particular caused extreme financial burden. Palliative care is often described in terms of holism. This whole-person care requires sensitivity, not only to the physical but also to the psychosocial and spiritual aspects of end-of-life care. All who are in some way involved in supporting family caregivers should remember what Dame Cicely Saunders wrote many years ago: "How people die remains in the memories of those who live on" [32].

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