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Expectations, end-of-life fears and end-of-life communication among palliative patients with cancer and caregivers: a cross-sectional study

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ABSTRACT

Objectives During serious illness, open communication with caregivers can ensure high-quality care. Without end-of-life communication, caregivers may become surrogates and decision-makers without knowing the patient's preferences. However, expectations and fears may influence the initiation of communication. The present study investigates differences between palliative patients with cancer and caregivers regarding expectations of end-of-life communication, end-of-life fears and experiences with end-of-life communication.

Design A cross-sectional study using a semi-structured interview and a paper-based questionnaire

Setting University Hospital in Germany.

Participants 151 participants: 85 palliative cancer patients (mean age: 62.8 years, 65.9% male) and 66 caregivers (mean age: 56.3 years, 28.8% male).

Primary and secondary outcome measures Expectations, end-of-life fears and experiences of end-of-life discussions.

Results Patients and caregivers wish for the patient to be self-determined. In general, participants reported more positive than negative expectations of end-of-life discussions. Importantly, concerns about emotionally burdening other person was rated much higher in an informal context than a professional context (F(1,149)=316 958, p<0.001, η_p^2=0.680), even though the emotional relief was expected to be higher (F(1,149)=46.115, p<0.001, η_p^2=0.236). Caregivers reported more fears about the last period of life and more fears about end-of-life discussions than palliative patients, whereas palliative patients tended to avoid the topics of death and dying to a greater extent.

Conclusions There seems to exist a 'self-other' asymmetry: palliative patients and their caregivers expect substantial personal relief when openly talking about end-of-life issues, but also expect the other person to be burdened by such communication. Professionals repeatedly need to initiate end-of-life communication.

Strengths and limitations of this study

- ⇒ In contrast to earlier research, expectations and concerns toward end-of-life discussions were investigated quantitatively in palliative patients and caregivers.
- ⇒ Differences between patients and caregivers were analysed using multivariate analysis.
- ⇒ The cross-sectional design cannot analyse causal relations—further longitudinal research is needed.

INTRODUCTION

In palliative care, patients with a life-threating disease and their caregivers are perceived as 'unit of care', meaning that both parts are the focus of a care plan.[1] Caregivers can be relatives or significant others. During the course of illness, there is often a moment when the responsibility for medical decisions shifts from the patient to the caregiver due to patient's poor condition.[2,3] However, research shows that caregivers are often not well prepared for these decisions. In one study, only 21% of the relatives were aware of patients' preferences regarding possible end-of-life (EOL) situations, although 75% rated themselves confident about knowing patients' goals.[4]

Open EOL communication between the patient and the caregiver can improve the quality of EOL care. It can ensure that decisions made are consistent with the patient's values and wishes. EOL communication is defined as 'a clinical interaction, which includes discussion of death and dying as part of the progression of illness or a potential outcome despite treatment efforts'.[5] In a broader sense, EOL communication can include topics around death and dying such as patient's wishes about medical treatment (eg, wished treatment options) but also emotional, spiritual and organisational aspects (eg, funeral, last will or the wished place of dying).[6] Not knowing patients' wishes can lead to emotional burden and distress in surrogates.[7,8] The prevalence of depression and complicated grief was shown to be higher in bereaved families without EOL communication,[9] which highlights the importance of those discussions.

However, patients and their caregivers seem to avoid EOL communication.[10 11] Many challenges are known that discourage them from talking about EOL issues: the patient–caregiver relationship (eg, differences in values or opinions), a lack of communication skills (eg, not knowing how to talk about EOL care) or external circumstances (eg, not having any close person to talk to).[11] Important barriers on a cognitive level can be expectations toward the communication process (eg, talking about death speeds up the process of dying).[11] Expectations are specific and flexible cognitions that (1) are future oriented and (2) concentrate on whether or not an event or an experience will occur.[12] Expectations predict different health-related behaviours such as the intake of medication in patients with breast cancer or the utilisation of psychosocial help.[13–15] The role of caregivers' expectations in healthcare communication was recently investigated in a paediatric setting.[16] In the EOL care context, expectations such as 'speaking about my own death will upset you' may especially deter persons from EOL communication. To the best of our knowledge, there is no study that has analysed and compared the extent of different expectations of EOL communication in palliative patients and their caregivers in a structured and quantitative way to complement existing qualitative research.[11]

Apart from cognitions, emotional factors (eg, protecting others from difficult emotions) and death anxiety prevent persons from EOL communication. Death anxiety (thanatophobia) includes the fear of death and avoidance of news that remind of death.[17] 8.2%–42% of patients with cancer showed moderate levels of death anxiety,[18–21] but it is also prevalent in healthy populations.[22 23] Death anxiety can be a relevant factor in avoiding EOL topics, whereas death acceptance is associated with higher levels of awareness and ability to reflect on death and dying.[24 25] Thus, death anxiety and the tendency to avoid death-related topics are relevant determinants to address in the context of EOL communication.

Therefore, the present study examined (1) who should make decisions about EOL care, (2) the spectrum of expectations toward EOL communication, (3) the level of EOL fears and (4) experiences with EOL communication among palliative patients with cancer and their caregivers. In our research, the term palliative patients with cancer refers to patients with cancer with a life-limiting illness and a life expectancy of less than 12 months. Lastly, the study analysed (5) the correlations between reported expectations, fears and experiences.

METHODS

Setting

All patients who met the inclusion criteria from the outpatient chemotherapy centre of a university hospital were informed about the study by their treating physician. If caregivers accompanied patients to their treatment or consultation, they were additionally briefed on the study. After written informed consent, a separate appointment was made to conduct a structured interview and to complete the paper–pencil questionnaire. Patients and caregivers were interviewed by two psychology master's students and three medical doctoral students under the supervision of CS, YN, MH and PVB. Interviews took place at doctors' consultation room at the outpatient chemotherapy centre. Participants first filled in the questionnaire and were then asked the interview questions. The interviewers were trained through role plays and also prepared for difficult situations. If patients or caregivers felt distressed by the EOL topics, a psycho-oncological consultation was offered. Participants were free to discontinue the interview or the questionnaire at any time.

Participants

Inclusion criteria for all participants were sufficient German language skills and a minimum age of 18 years. For the patient group, a diagnosis of a malignant neoplasm with a limited prognosis judged by the surprise question ('Would I be surprised if this patient died in the next year?') by the attending physician was an additional inclusion criterion. Caregivers had to be a person close to the patient with cancer, taking care of her or him and a potential surrogate (eg, partner, child, parent, close friend, family member chosen by the patient, etc).

Assessment instruments

Sociodemographic and clinical variables were assessed by the treating physician or derived from the medical records.

EOL fears, EOL expectations and the experience with EOL communication were assessed using a structured interview. The interview topic guide was developed by a group of five clinicians and researchers from different professions with expertise in the field. The interview guideline was piloted with 10 palliative patients with cancer from the outpatient chemotherapy centre for comprehensibility and content (pretest). The research group decided to deal with potentially stressful topics in a structured interview instead of a questionnaire, as this was considered a more sensitive approach for the patients and caregivers. All interview questions could be answered on a Likert scale from 0 ('not at all') to 4 ('totally agree' or 'very much'). Three questions addressed self-determination in EOL care (eg, 'It is important to me to be self-determined'); seven questions were about persons who should decide about EOL care (eg, 'I want decisions about my medical EOL care to be taken only by myself'); six questions addressed expectations of EOL care (eg, 'I expect … emotional release/practical support/emotional burden/… '); and five questions were about fears regarding EOL communication (eg, 'I am very afraid of my/my relatives' last period of life' and 'I avoid talking about EOL topics'). Moreover, three questions asked if and whom palliative patients and their caregivers had spoken to (in the informal or professional context; choosing from a list of conversation partners, with the option to add a free text). They were then asked whether they had talked about several prespecified EOL topics such as medical care, nursing care, organisational issues, emotional issues, social issues or religiosity/spirituality. Each of these EOL topics was preceded by a list of examples of what this topic might involve. 'Medical care': for example, treatment of somatic problems like dyspnoea, nausea, pain or maintaining quality of life, living will, life-sustaining treatment, 'emotions': for example, feelings like grief, anger, fear or sadness, 'social aspects': for example, unresolved conflicts, dealing with relatives and friends and saying goodbye, 'nursing care': for example, nursing care while crisis and/or in the last period of life and place of dying, 'organisational aspects': for example, financial and legal issues, life pension, inheritance or funeral, and 'religiosity/spirituality': talking, for example, about religious beliefs or desires, thoughts about death and the hereafter. Finally, three questions related to the experience of EOL communication ('burdening', 'helpful' and 'satisfying').

Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS, German version),[26] which is a commonly used self-administered paper-based questionnaire. Items are rated on a 4-point scale and scored from 0 to 3 with a higher score indicating more anxiety/depression. Therefore, total scores for each subscale range from 0 to 21, with a Cronbach's α of 0.81 for the anxiety scale and α of 0.69 for the depression scale.

Patient and public involvement

During the interview development process, 10 patients were asked in a pretest about the interview schedule (priorities, experience and preferences). Moreover, during the pretest, patients were asked to assess the burden of the interview/questionnaire and time required to participate in the research. Patients and the public were not otherwise involved in the design and planning of the study.

Data analysis

Analyses were performed using SPSS V.26, with statistical significance set at $p<0.05$. The data were screened for univariate outliers, missing data and violations to the assumptions of analysis. Missing data at random (2.1%) were imputed using multiple imputation. To analyse expectations, fears and experiences of EOL communication in palliative patients with cancer and caregivers, and to control for possible influences of demographic and clinical characteristics, (multivariate) analysis of variance (MANOVA), (multivariate) analysis of covariance and univariate analysis of covariance were conducted. For categorical data, χ^2 tests were used. Pearson correlations were used to analyse relationships between variables. Further details are reported in the Results section.

RESULTS

Participants

A total of 165 palliative patients were eligible, of which 76 (46.1%) refused to participate. The most common reasons for refusal were fear of emotional burden (n=32, 42.1%), physical exhaustion (n=15, 19.7%) and the patient not wanting to talk about this topic (n=11, 14.5%). Of the 143 eligible caregivers of these patients, 68 (47.6%) participated. Caregivers refused participation because of a fear of emotional burden (n=25, 32.5%) and effort (n=18, 32.4%). In addition, 4 patients (4.49%) and 2 caregivers (2.94%) discontinued their participation due to problems of a physical (eg, pain) or organisational nature. Thus, the final sample consisted of 85 palliative patients with cancer and 66 caregivers. Demographic and clinical characteristics of the study participants are listed in table 1.

Who should decide about EOL care?

The item 'It is important to me to be self-determined' was agreed to by 95.3% of patients and 92.4% of caregivers. Moreover, 89.3% of patients and 89.1% of caregivers agreed with the item: 'The right to self-determination must be valid beyond death' (V=0.98, F(2,145)=0.143, p=0.869, $\eta_p^2=0.002$). In a MANOVA, there were no significant differences between patients and caregivers regarding self-determination. To specify who should decide about EOL care and to analyse possible differences between patients and caregivers, a MANOVA with the between-subject factor 'status' and seven different degrees of personal involvement in decisions about EOL care (see figure 1) as dependent variables was conducted. No significant effect of status (V=0.97, F(7,143)=0.615, p=0.743, $\eta_p^2=0.029$) was found. Thus, patients and their caregivers reported the same preferences, that patients, their caregivers and physicians should participate in a shared decision-making process about EOL care.

Expectations of EOL discussions

To analyse differences in expectations of EOL communication in the professional vs the informal context among palliative patients with cancer and their caregivers, a MANOVA with the between-subject factor 'status', the within-subject factor 'context' and six different expectations of EOL fears as dependent variables was conducted (figure 2). No significant effect of status (V=0.93, F(6,144)=1.757, p=112, $\eta_p^2=0.068$) was found, but a significant effect of context was seen (V=0.94, F(6,144)=65.806, p<0.001, $\eta_p^2=0.733$). Subsequent univariate analyses showed a higher score for the expectation of emotional relief (F(1,149)=46.115, p<0.001, $\eta_p^2=0.236$) and the expectation of practical support (F(1,149)=38.665, p<0.001, $\eta_p^2=0.206$) in the informal context than in the professional context. Moreover, univariate analyses showed a significant higher score in the expectation of negative emotions (F(1,149)=54.820, p<0.001, $\eta_p^2=0.269$) and in the expectation regarding the emotional burden of the other person (F(1,149)=316 958, p<0.001, $\eta_p^2=0.680$)

Table 1 Sociodemographic and medical data of the study sample

		Patients (N=85)	Caregivers (N=66)	Group differences
Variables		**N (%) / M (SD)**	**N (%) / M (SD)**	**T-test/ χ^2 test value**
Age in years		62.8 (11.4)	56.3 (12.7)	3.24, p=0.002
Gender (male)		56 (65.9%)	19 (28.8%)	20.45, p<0.001
Years of education	9	52 (61.2%)	33 (50%)	
	10	15 (17.9%)	18 (27.3%)	
	12–13	16 (18.8%)	15 (22.7%)	3.442, p=0.328
Working status	Working	4 (4.8 %)	39 (59.1%)	
	Disability pension	16 (18.8 %)	3 (4.7%)	
	Pension	37 (43.5 %)	15 (23.4 %)	
	On sick leave	21 (24.7 %)	1 (1.6 %)	
	Unemployed	1 (1.2 %)	3 (4.7 %)	
	Homemaker	5 (5.9 %)	3 (4.7 %)	64.85, p<0.001
Family status	Married	53 (62.4 %)	48 (72.7%)	
	Divorced	14 (16.5 %)	3 (4.5%)	
	Single	7 (8.2 %)	11 (16.7%)	
	Widowed	11 (12.9 %)	4 (6.1%)	9.278. p=0.026
	Living together with partner (yes)	62 (72.9 %)	55 (83.3%)	2.30, p=0.129
	Children (yes)	73 (85.9 %)	53 (80.3%)	0.837 p=0.360
Religious confession	Catholic	15 (17.6 %)	11 (16.7 %)	
	Protestant	55 (64.7 %)	45 (68.2 %)	
	Other	2 (2.4 %)	3 (4.5 %)	
	None	13 (15.4 %)	7 (10.6 %)	1.244, p=0.742
Relation to patient	Partner		44 (66.7 %)	
	Son/daughter		15 (22.7 %)	
	Parent		1 (1.5 %)	
	Other		6 (9.1 %)	
Tumour group	Lung	25 (29.4 %)		
	Gastrointestinal	14 (16.5 %)		
	Hepatobiliary	3 (3.5 %)		
	Urogenital	8 (9.4 %)		
	Gynaecological	7 (8.2 %)		
	ENT	2 (2.4 %)		
	Brain tumour/medulloblastome	4 (4.7 %)		
	Haematological	10 (11.8 %)		
	Other	12 (14.1 %)		
Treatment	Chemotherapy	72 (84.7 %)	–	
	Radiation	49 (57.6 %)	–	
	Surgery	43 (50.6 %)	–	
HADS Depression		5.64 (3.21)	6.67 (3.09)	–1.971, p=*0.051*
HADS Anxiety		5.83 (3.49)	8.97 (3.63)	–5.368, p<*0.001*

ENT, ear, nose and throat; HADS, Hospital Anxiety and Depression Scale.

in the informal context than in the professional context. There were no context effects on the expectations of refusal (F(1,149)=0.194, p=0.118, η_p^2=0.016) or wishes not being respected (F(1,149)=0.131, p=0.320, η_p^2=0.007).

Thus, palliative patients with cancer and their caregivers reported a higher tendency to expect emotional relief and practical support from communication with their family and friends than from communication with

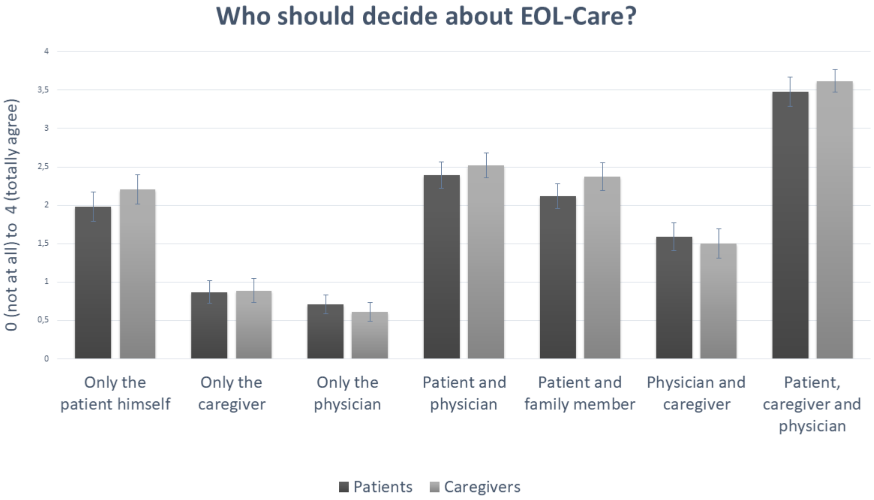

Figure 1 Persons who should decide about EOL care. EOL, end-of-life.

professionals. On the other hand, they reported higher expectations of negative emotions and burdening the other person in informal communication than in communication with professionals. The results remained stable after controlling for possible confounders such as age and gender.

EOL fears

In a MANOVA with the between-subject factor status and 5 different aspects of EOL fears as dependent variables, a significant effect of status (V=0.72, F(5,143)=10.963, $p<0.001$, $\eta_p^2=0.277$) was found. A subsequent univariate analysis showed a generally higher score for the wish to avoid topics of death and dying in patients (F(1,148)=4.623, p=0.033, $\eta_p^2=0.030$) than in caregivers. Moreover, univariate analyses showed a significantly higher score for 'I am very afraid of the last period of my/my relative's life' (F(1,148)=42.279, $p<0.001$, $\eta_p^2=0.223$) and for 'I am afraid to talk about EOL topics' (F(1,148)=7.702, p=0.006, $\eta_p^2=0.050$) in caregivers than in patients. There were no status effects on the reported aspects: 'Thoughts about death and dying are burdening for me' (F(1,148)=1.219, p=0.419, $\eta_p^2=0.004$) or 'I avoid talking about EOL topics' (F(1,148)=0.782, p=0.378, $\eta_p^2=0.005$). Patients reported a higher tendency to avoid topics of death and dying in general, whereas caregivers reported higher anxiety scores (figure 3). The results remained stable after controlling for possible confounders such as age and gender.

Evaluation of EOL communication

Patients and caregivers were asked if they had spoken about EOL topics and with whom. Results showed that the majority of patients and caregivers had talked about the patient's last period of life, but 22.7% of patients and 16.7% of caregivers had not. The results are shown

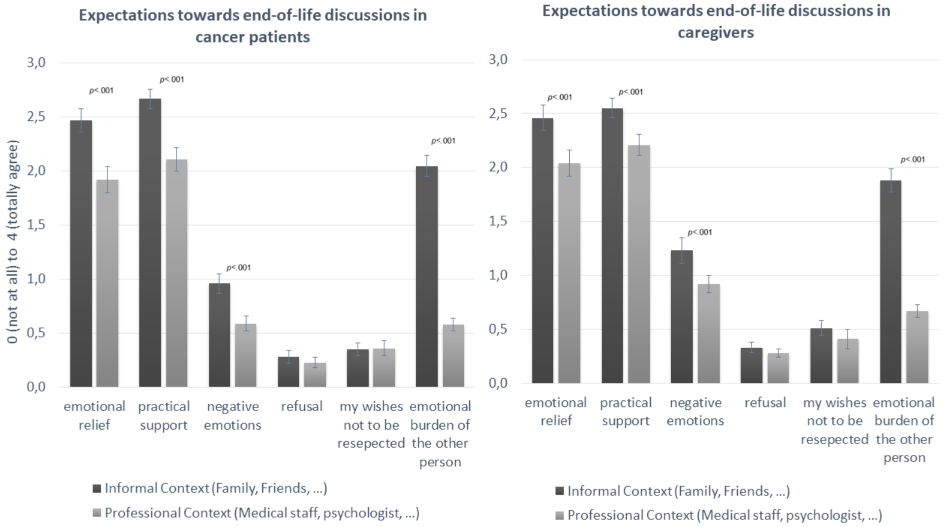

Figure 2 Expectations of EOL discussions among patients with cancer and caregivers in an informal versus a professional context. EOL, end-of-life.

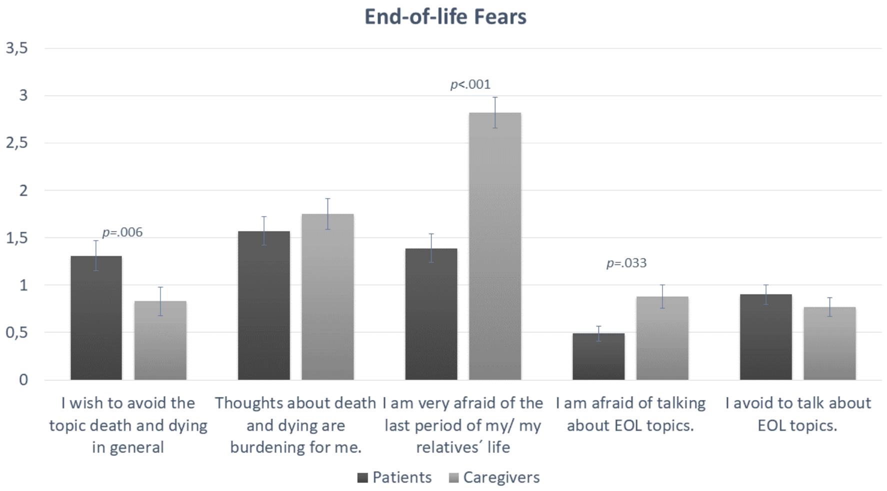

Figure 3 EOL fears among patients with cancer and caregivers. EOL, end-of-life.

in table 2. There were no differences between caregivers and patients in the distribution of EOL communication ($\chi^2(4,1)=6.352$; p=0.174). Most patients and caregivers had talked about these themes in an informal context (55.3% and 71.2%). Main topics were medical care and emotions. Nevertheless, caregivers talked more often about nursing care ($\chi^2(4,1)=7.930$; p=0.005) and social aspects ($\chi^2(1)=11.465$; p<0.001) than patients. Moreover, the majority of patients found the communication helpful or very helpful (51.3%) or more or less helpful (30.3%), and satisfying or very satisfying (49.5%) or more or less satisfying (30.3%). There were no significant differences for caregivers ($\chi^2(4,1)=1.574$; p=0.814) and patients ($\chi^2(4,1)=5.228$; p=0.265). Of the caregivers, 48.4% found the communication helpful or very helpful and 31.8% more or less helpful, while 53.1% found the communication satisfying and 34.8% more or less satisfying. Significant differences were seen in terms of emotional burden of communication ($\chi^2(4,1)=15.160$; p=0.004), with 26.4% of caregivers rating communication as burdening or very

Table 2 Communication partner in EOL communication

EOL communication			Patients (n=84)	Caregivers (n=65)
Have you spoken about (your/his/her) last period of life?	A lot		3 (3.5%)	5 (7.6%)
	Frequently		10 (11.8%)	16 (24.4%)
	From time to time		31 (36.5%)	22 (33.3%)
	Rarely		21 (24.7%)	11 (16.7%)
	Never		19 (22.4%)	11 (16.7%)
In which context did you talk about EOL topics?	Professional	Physician	26 (30.6%)	25 (37.9%)
	Context	Nurse	2 (2.4%)	7 (10.6%)
		Pastor	10 (11.8%)	4 (6.1%)
		Psychologist	4 (4.7%)	5 (7.6%)
	Informal	Family	47 (55.3%)	47 (71.2%)
	Context	Partner	45 (52.9%)	43 (65.2%)
		Friends	30 (35.3%)	30 (55.6%)
		Other patients	5 (5.9%)	10 (15.2%)
		With the patient himself	–	45 (68.2%)
What kind of topics have you spoken about?	Medical care		49 (57.6%)	47 (71.2%)
	Nursing care		34 (40.0%)	42 (63.6%)
	Religiosity/spirituality		23 (27.1%)	27 (40.9%)
	Organisational aspects		54 (23.5%)	46 (69.7%)
	Emotions		42 (49.4%)	46 (69.7%)
	Social aspects		24 (28.2%)	37 (56.1%)

EOL, end-of-life.

burdening, and 34% as more or less burdening, while only 9.1% of the palliative patients with cancer evaluated communication as burdening or very burdening, and 31.8% as more or less burdening.

Associations between expectations, fears and experiences

Table 3 shows the cross-sectional correlations between the expectations, fears and experiences of patients and caregivers. As expected, positive experiences are associated with positive expectations and negative experiences (burden of the conversation) are associated with negative expectations and fears.

DISCUSSION

The study investigated the expectations and concerns of palliative patients with cancer and caregivers regarding EOL communication. A large majority of the participants wish to be self-determined regarding EOL issues and death. Patients and caregivers unanimously wished that they should decide about EOL care together with physicians. Overall, participants reported more positive than negative expectations of EOL communication. Importantly, concerns about emotionally burdening other people with EOL communication was rated much higher in an informal context (eg, with caregivers and/or significant others) than with professionals, even though the emotional relief was expected to be higher in the informal context than in a professional context. Caregivers reported more fears about the last period of life as well as talking about it, whereas palliative patients tended to avoid the topic of death and dying to a greater extent than their caregivers.

In line with earlier research,[27 28] we found that three out of four patients with advanced cancer had talked about the last period of life. We found no significant differences between patients and caregivers. This means they chose to engage or not to engage in EOL discussions similarly. Remarkably, 22.6% of the palliative patients had never spoken to anybody about their end of life; additionally, it is not clear what ‘rarely’ meant in each individual case. Nevertheless, the frequency of EOL communication needed by patients and their carers can be highly individual and variable. For some, repeated conversations about the same existential dilemma or concern are valuable, can support a person’s decision-making process significantly and include parting, grieving and leaving behind. For others, it can be important to clarify issues and make decisions so that they can then focus on matters of life at other times. A helpful framework can be the concept of double awareness.[29] Double awareness is the flexibility of mind between life awareness and death awareness and the possibility of simultaneously switching and tolerating the ambivalence of life and death.[29] Moreover, different EOL topics might be of relevance at different times or situations: in one time, emotions as grieving and leaving behind can be in the front, whereas in other conversations organisational or care-related topics are the ones to look at.

However, a significant proportion of patients had not communicated about EOL decisions and a large proportion of caregivers were not adequately informed. In this light, the difference in expectations between the informal context and the professional context observed in this study is of distinct importance.

The most notable result is that the interviewed persons expected substantial personal relief when openly talking about EOL issues in an informal context but expected the other person to be burdened by such a conversation. Notably, this ‘self-other’ asymmetry applies to both groups, the palliative care patients and the caregivers. This asymmetry was not found in the professional context. On the one hand, persons expect more emotional relief and practical support from communication with loved ones, pointing out the importance and high relevance of informal caregivers in the sense of building a unit of care.[1] On the other hand, concerns about causing negative emotions and burdening the other person were dramatically higher in the informal than in the professional context. Emotion-related factors such as protective buffering can be relevant barriers to EOL communication.[11] The belief that it will hurt the other person to address death and dying seems to be very salient and a relevant barrier to EOL communication. Further research exploring possible interventions involving the dyadic perspective as unit of analysis would be worthwhile.[30] However, in a professional context, this strong barrier seems to be remarkably lower. Consequently, it seems to be almost mandatory for professionals to initiate and foster EOL communication instead of waiting for initiation by the patient. This way the issue can be placed on a professional level, which might be easier to bear.

Overall, patients and their caregivers reported more positive than negative expectations of EOL communication. Given the high psychological burden of emotional stress and uncertainty due to the tense situation, the fact that positive expectations exceeded negative ones seems very promising. Specifically, expected emotional relief and increased support from communication could serve as motivating factors to initiate EOL communication. Moreover, the results show that expectations of experiencing negative emotions are correlated with EOL fears and the tendency to avoid talking. This is not surprising because avoidance is a very common reaction to fear and is part of the classification systems of phobias (eg, thanatophobia).[18] Therefore, another possible explanation for the first observation might be that a decisive proportion of those who had reservations toward communication about death and dying did not participate in this study, resulting in a biased sample. Of the persons who declined to participate, 42.1% did so out of fear of the emotional burden and 14.5% because the person did not want to talk about this topic. The high refusal rate seems to be a common problem in research on EOL topics. In another study with healthy participants, a similar phenomenon

Table 3 Correlations between the expectations, fears and experiences in patients and caregivers

	1	2	3	4	5	6	7	8	9	10	11	12	13
Expectations													
1 emotional relief	–												
2 practical support	**0.777****	–											
3 negative emotions	0.099	−0.008	–										
4 refusal	−0.046	−0.150	**0.344****	–									
5 my wishes not to be respected	−0.072	**−0.175***	**0.173***	**0.645****	–								
6 emotional burden of the other person	0.024	0.039	**0.441****	**0.166***	**0.175***	–							
Fears													
7 avoidance of the topic	−0.066	−0.85	0.090	−0.063	0.017	00.64	–						
8 thoughts are burdening	0.045	−0.044	**0.375****	0.064	0.079	**0.286****	**0.376****	–					
9 very afraid of EOL	0.136	−0.015	**0.383****	0.129	0.036	**0.187***	0.029	**0.387****	–				
10 afraid of talking	0.096	0.040	**0.502****	**0.240****	**0.162***	0.210	0.139	**0.280****	**0.465****	–			
11 avoidance of talking	0.013	0.036	**0.256****	0.138	0.100	**0.222****	**0.374****	**0.348****	**0.168***	**0.516****	–		
Experiences													
12 burdening	−0.005	−0.102	**0.499****	**0.302****	0.177	**0.232***	0.017	**0.382****	**0.478****	**0.438****	**0.209***	–	
13 helpful	**0.362****	**0.320****	−0.104	−0.127	−0.111	0.061	**−0.331****	−0.130	0.012	**−0.232***	**−0.316****	**−0.247****	–
14 satisfied	**0.232***	**0.211***	−0.156	**−0.183***	**−0.203***	−0.049	−0.129	−0.048	−0.048	−0.081	−0.053	**−0.419****	**0.506****

*p<0.05; **p<0.01; (n=118–151).

EOL, end-of-life.

was found: those with higher scores for death anxiety were more likely to drop out.[31] For future research, it would be meaningful to find a way to include those people who are afraid and not open to the topic. Possibly, extremely short and low-threshold questionnaires or interviews and short interventions addressing the person's expectations could be helpful.

The finding of significant correlations between expectations and experiences supports the importance of learning processes in the development of expectations.[32] Thus, if someone experienced positive EOL communication in the past, he/she will probably expect positive communication on these topics in the future. Moreover, a vicious circle can occur, whereby a negative experience entails negative expectations which in turn lead to negative experiences in terms of a nocebo effect.[33] Further research examining the role of expectations in EOL communication in a longitudinal way could address the causal relationship between the two constructs. In a next step, interventions could be developed that aim to optimise expectations.[34 35]

Interestingly, in some areas, caregivers are even more affected than patients such as anxiety levels for both EOL fears and state anxiety. This is congruent with the prior findings of Leroy *et al*[36] showing that caregivers of advanced patients with cancer tend to be more anxious than patients, with prevalences of 32%–72%.[37–39] Caregivers suffer from high levels of distress, emotional burden and unmet needs[31]; thus it is relevant to incorporate dyadic programmes.[40] Alongside communication about death and dying, there are other typical problems faced by families of patients with advanced cancer such as dealing with feelings of separation and loss, role overload, the need to conceal feelings, feelings of isolation, fatigue and exhaustion, and feelings of inadequacy regarding necessary skills.[41] Therefore, as a clinical implication, we suggest that a holistic high-quality EOL care approach should not only focus on patients but also provide as much support as possible for caregivers and close friends .

Some limitations must be considered when interpreting the results of this study. First, the items used in the semi-structured interview in this study were developed by the investigators and were not based on a validated instrument. Nevertheless, most research in this area has been qualitative, so this study can be a helpful addition to the existing research. Second, the study was cross-sectional, showing only correlations but no causal associations between expectations, fears and experiences. It would be worthwhile to evaluate these associations in further longitudinal studies. Third, most of the caregivers were female. Further studies with a balanced gender distribution would be valuable. Finally, due to the high refusal rate, it cannot be excluded that the results are influenced by selection bias. Thus, the results cannot be transferred to other populations. Nevertheless, the fact that many people refused study participation due to fear of emotional burden underlines the importance of the topic and the relevance of expectations.

To conclude, there seems to exist a 'self-other' asymmetry: palliative patients and their caregivers expect substantial personal relief when openly talking about EOL issues, but also expect other people to be burdened by such conversations. Professionals repeatedly need to initiate EOL communication to help families speaking about EOL issues.

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