“I don´t want to make you sad…” Expectations, end-of-life fears and end-of-life communication among palliative cancer patients and their family members

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Title: "I don´t want to make you sad..." Expectations, end-of-life fears and end-of-life communication among palliative cancer patients and their family members

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Strengths and limitations of this study

- The study investigated expectations and concerns of cancer patients and family members regarding end-of-life discussions quantitatively
- Differences between patients and family members were analysed in a multivariate analysis
- As common in this research topic and study population, the refusal rate was high and most of the family members were female.

ABSTRACT

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

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 relatives (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 families wish for the patient to be self-determined. In general, participants reported more positive than negative expectations of end-of-life discussions. Importantly, concern about emotionally burdening the other person was rated much higher in a family context than a professional context ($F(1,149)=316,958, p<.001, \eta p^2=.680$), even though the emotional relief was expected to be higher ($F(1,149)=46.115, p<.001, \eta p^2=.236$). Family members 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 higher degree.

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

INTRODUCTION

During serious illness, open communication can improve the quality of end-of-life care. These conversations should include caregivers and family members, because the responsibility of making medical decisions often shifts to a surrogate due to patients´ bad condition [1, 2]. End-of-life (EOL) conversations can ensure that the decisions made are consistent with the values and wishes of the patient. However, patients and their families seem to avoid EOL conversations [3, 4]. In one study, only 21 per cent of the relatives knew patients' preferences regarding possible EOL situations, although 75 per cent rated themselves confident about knowing patients' goals [5]. Nevertheless, not knowing patients´ wishes can lead to emotional burden and distress in surrogates [6]. The prevalence of depression and complicated grief was shown to be higher in bereaved families without EOL communication [7]. Thus, knowing which treatment is consistent with the patient's preferences has the potential to reduce the negative effects on family members [8].

Many difficulties are known that discourage families from talking about EOL issues: the patient-caregiver relationship (e.g. differences in values or opinions), a lack of communication skills (e.g. not knowing how to talk about EOL care) or external circumstances (e.g. not having any close person to talk to) [4]. Moreover, cognitive factors as expectations can prevent families speaking about death and dying (e.g. talking about death speeds up the process of dying) [4]. Expectations are specific and flexible cognitions that 1) are forward-looking and 2) concentrate on whether an event or an experience will occur or not occur [9]. Expectations predict different health-related behaviours such as the intake of medication in breast cancer patients or the utilization of psychosocial help [10–12]. The role of caregivers' expectations in healthcare communication was recently investigated in a paediatric setting [13]. In the EOL care context, expectations such as "Speaking about my own death will upset you" may especially deter persons from EOL communication. To our knowledge, there is no study that has analysed the expectations of EOL communication in palliative patients and their family members.

Next to cognitions, the most prevalent communication barrier is related to emotional factors (e.g. protecting others from difficult emotions). Another emotional barrier that inhibits EOL communication is death anxiety. Death anxiety (thanatophobia) includes the fear of death and avoidance of news that reminds one of death [14]. In oncological samples, 8.2–42 per cent of patients showed moderate levels of death anxiety [15–18], but it is also present in healthy populations [19, 20]. Death anxiety can be a relevant factor in avoiding EOL topics, whereas death acceptance is associated with a higher degree of awareness and ability to reflect on death and dying [21, 22]. Thus, death anxiety and the tendency to avoid death-related topics are relevant determinants to address in this context.

Therefore, the present study investigates a) the degree of participation in EOL care; b) expectations of EOL conversations; c) EOL fears; and d) experiences with EOL conversations among palliative cancer patients and family members. Additionally, the study analyses the correlations between the reported expectations, fears and experiences.

METHODS

Participants and design

Inclusion criteria for all participants were sufficient German language skills and a minimum age of 18. For the patient group, an oncological diagnosis of a malignant neoplasm, a palliative setting, and the identification of a limited prognosis, using the surprise-question ("Would I be surprised if this patient died in the next year?") by the attending physician, were additional inclusion criteria. Family members had to be potential caregivers of the patient (e.g. partner, child, parent). After being informed about the study and having given their written informed consent, patients were interviewed by five psychology Master's students and medical doctoral students under the supervision of CS, YN, MH and PB.

Ethics

The study was approved by the institutional review board of the Medical School, University of Marburg (AZ:47/12). Before participation, subjects gave written informed consent.

Assessment instruments

Sociodemographic and clinical variables were assessed by the treating doctor. Then, patients were interviewed in a semi-structured interview. All questions in the semi-structured interview 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 (e.g. “It is important to me to be self-determined.”); seven questions were about persons who should decide about EOL care (e.g. “I want decisions about my medical EOL care to be taken only by myself”); six questions addressed expectations of EOL care (e.g. “I expect… emotional release/ practical support/ emotional burden/…); and five questions were about fears regarding EOL conversations (e.g. “I am very afraid of my/ my relatives´ last period of life”, “I avoid talking about EOL topics”). Moreover, three questions addressed the experience of EOL conversations (burdening, helpful, satisfying) and one question asked whom palliative patients and their family members had spoken to (in the informal or professional context). Moreover, anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS, German-Version) [23], which is a commonly used self-administered questionnaire. Items are rated on a four-point scale and scored from 0 to 3, where a higher score indicates more anxiety/depression. Therefore, total scores for each subscale range from 0 to 21, with a Cronbach’s alpha of α=.81 for the anxiety-scale and α=.69 for the depression scale.

Patient and public involvement

Cancer patients were involved to see if the semi-structured interview was understandable and comprehensive. Otherwise, there was no direct patient or public involvement.

Data analysis

Analyses were performed using SPSS 26 (SPSS Inc. IBM, Chicago, Illinois, USA), with statistical significance set at p <.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 conversations in cancer patients and family members, and to control for possible influences of demographic and clinical characteristics, (multivariate) analysis of covariance (MANOVA and MANCOVA) and univariate analysis of covariance (ANOVA) were conducted. For categorical data, chi-square 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, but 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 family members of these patients, 68 (47.6%) participated. Family members refused participation because of a fear of emotional burden (*n*=25, 32.5%) and effort (*n*=18, 32.4%). In addition, four patients (4.49%) and two relatives (2.94%) discontinued their participation because of physical problems (e.g. pain) or organizational aspects. Thus, the final sample consisted of 85 palliative cancer patients and 66 family members. Demographic and clinical characteristics of the study participants are listed in Table 1.

Table 1

Who should decide about end-of-life care?

The item "It is important to me to be self-determined" was agreed with by 95.3 per cent of patients and 92.4 per cent of family members. Moreover, 89.3 per cent of patients and 89.1 per cent of family members agreed with the item: "The right to self-determination must be valid beyond death" (V=.98, $F(2,145)=0.143$, p=.869, η_p^2=.002). In a MANOVA, there were no significant differences between patients and family members regarding self-determination. To concretize who should decide about EOL care and to analyse possible differences between patients and family members, 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=.97, $F(7,143)=0.615$, p=.743, η_p^2=.029) was found. Thus, cancer patients and their family members reported the same preferences, namely that the patients, their family members and the physician should participate in a shared decision-making process about EOL care.

Figure 1

Expectations of end-of-life discussions

To analyse differences in expectations of EOL communication in the professional versus the informal context among cancer patients and their family members, 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. No significant effect of status (V=.93, $F(6,144)=1.757$, p=112, η_p^2=.068) was found, but a significant effect of context was seen (V=.94, $F(6,144)=65.806$, $p<.001$, η_p^2=.733). Subsequent univariate analyses showed a higher score for the expectation of emotional relief ($F(1,149)=46.115$, $p<.001$, η_p^2=.236) and the expectation of practical support ($F(1,149)=38.665$, $p<.001$, η_p^2=.206) in the informal context than in the professional context. Moreover, univariate analyses showed a significant higher score in the expectation of negative emotions

($F(1,149)=54.820$, $p<.001$, $\eta_p^2=.269$) and in the expectation regarding the emotional burden of the other person ($F(1,149)=316,958$, $p<.001$, $\eta_p^2=.680$) in the informal context than in the professional context. There were no context effects on the expectations of refusal ($F(1,149)=0.194$, $p=.118$, $\eta_p^2=.016$) or wishes not being respected ($F(1,149)=0.131$, $p=.320$, $\eta_p^2=.007$).

Thus, cancer patients and their family members reported a higher tendency to expect emotional relief and practical support from conversations with their family and friends than from conversations with professionals. On the other hand, they reported higher expectations of negative emotions and burdening the other person in informal conversations than in conversations with professionals. The results remained stable after controlling for possible confounders such as age and gender.

Figure 2

End-of-life fears

In a MANOVA with the between-subject factor status and five different aspects of EOL fears as dependent variables, a significant effect of status ($V=.72$, $F(5,143)=10.963$, $p<.001$, $\eta_p^2=.277$) was found. A subsequent univariate analysis showed a generally higher score for the wish to avoid topics of death and dying in patients ($F(1,148)=4.623$, $p=.033$, $\eta_p^2=.030$) than in family members. Moreover, univariate analyses showed a significantly higher score for “I am very afraid of the last period of my/my relative’s life” ($F(1,148)=42.279$, $p<.001$, $\eta_p^2=.223$) and for “I am afraid to talk about EOL topics” ($F(1,148)=7.702$, $p=.006$, $\eta_p^2=.050$) in family members than in patients. There were no status effects on the reported aspects “Thoughts about death and dying are burdening for me” ($F(1,148)=1.219$, $p=.419$, $\eta_p^2=.004$) or “I avoid talking about EOL topics” ($F(1,148)=.782$, $p=.378$, $\eta_p^2=.005$). Thus, cancer patients reported a higher tendency to avoid topics of death and dying in general, whereas family members reported higher anxiety scores. The results remained stable after controlling for possible confounders such as age and gender.

Evaluation of end-of-life discussions

Patients and family members were asked if they had spoken about EOL topics and with whom. Results showed that the majority of patients and family members had talked about the last period of life of the patient, but 22.7 per cent of patients 16.7 per cent of family members had not. There were no differences between family members and patients in the distribution of EOL conversations

($\chi^2(4,1)$=6.352; *p*=.174). Most patients and family members had talked about these themes in an informal context (55.3% and 71.2%). The results are shown in Table 2. Moreover, the majority of patients found the conversations 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 family members ($\chi^2(4,1)$=1.574; *p*=.814) and ($\chi^2(4,1)$=5.228; *p*=.265). Of the family members, 48.4 per cent found the conversations helpful or very helpful and 31.8 per cent more or less helpful, while 53.1 per cent found the conversations satisfying and 34.8 per cent more or less satisfying. Significant differences were shown regarding the emotional burden of the conversations ($\chi^2(4,1)$=15.160; *p*=.004), where 26.4 per cent of the family members evaluated the conversations as burdening or very burdening, and 34 per cent as more or less burdening, while only 9.1 per cent of the cancer patients evaluated the conversations as burdening or very burdening, and 31.8 per cent as more or less burdening.

Table 2

Table 3

Associations between expectations, fears and experiences

Table 3 shows the cross-sectional correlations between the expectations, fears and experiences of patients and family members. 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 cancer patients and family members regarding end-of-life discussions. A large majority of the participants wish to be self-determined regarding EOL issues and death. Patients and family members corresponded in their wish that they should decide about EOL care together with physicians. In total, participants reported more positive than negative expectations of EOL discussions. Importantly, concern about emotionally burdening the other person with EOL conversations was rated much higher in a family context than with professionals, even though the emotional relief was expected to be higher in the family context than in a professional context. Family members 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 higher degree than their family members.

Similar to the results of other studies [24, 25], we found that three out of four had talked about the last period of life. We found no significant differences between patients and family members. This means they engage or fail to engage in EOL talk similarly. Remarkably, 22.6 per cent 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, it is not the frequency of EOL conversations that is most important, but whether important issues are clarified and decisions made. Maybe it is helpful for seriously ill persons and their caregivers not to engage all the time in existential topics in the manner of double awareness [26]. Double awareness is the flexibility of mind between life awareness and death awareness and the possibility of switching and tolerating the ambivalence of life and death at the same time [26]. In further research, it would be interesting to investigate whether persons who discussed death and dying frequently show higher levels of death awareness and persons who have never had EOL discussions show lower levels of death awareness.

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 conversion. Notably, this ‘self-other’ paradox is true for both groups, the palliative care patients and the relatives. This paradox was not found in the professional context. On the one hand, persons expect more emotional relief and practical support from conversations with loved ones, pointing out the importance and high relevance of informal caregivers in the sense of building a unit of care [27]. On the other hand, concerns about causing negative emotions and burdening the other person are dramatically higher in the informal than in the professional context. Emotion-related factors such as protective buffering can be relevant barriers to EOL communication [4]. The belief that it will hurt the other person to address death and dying seems to be very salient and a relevant obstacle to EOL conversations. 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 discussions instead of waiting for initiation by the patient. This way the topic can be placed on a professional level, which might be easier to endure.

In total, patients and their family members reported more positive than negative expectations of EOL discussions. In the light of the high psychological burden of emotional stress and uncertainty due to the loaded situation, the fact that positive expectations exceeded negative ones seems very promising. Specifically, expected emotional relief and increased support from these conversations could serve as motivating factors to initiate EOL conversations. 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 (e.g. thanatophobia) [15]. Therefore, another possible explanation for the first observation might be that the majority of those who had reservations towards communication about death and dying did not participate in this study, resulting in a selective sample. Of the persons who declined to participate, 42.1 per cent did so out of fear of the emotional burden and 14.5 per cent because the person did not want to talk about this topic. The high refusal rate seems to be a problem in research on EOL topics. In another study with healthy participants, a similar phenomenon was found: those with higher scores for death anxiety were more likely to drop out [28]. In further research, it would be worthwhile finding a way to include those persons who are afraid and not open to the topic. Maybe extremely short and low-threshold questionnaires or interviews and short interventions addressing the person’s expectations could be helpful.

The result that negative expectations correlated with negative experiences and positive expectations with positive experiences supports the fact that expectations can develop through personal experiences (learning) [29]. It can be assumed that there is a vicious circle consisting of a negative experience leading to negative expectations that again lead to negative experiences in terms of a nocebo effect [30]. Further research examining the role of expectations in EOL communication in a longitudinal way might want to address the causal relationship between the two constructs. In a next step, interventions could be developed that address the optimization of expectations [31, 32].

Interestingly, family members are in some areas even more affected than patients in terms of higher anxiety levels for both EOL fears and state anxiety. This is in line with the prior findings of Leroy et al. [33] which show that family members of advanced cancer patients tend to be more anxious than patients, with prevalence levels around 32–72 per cent [34–36]. Family caregivers suffer from high levels of distress (and emotional burden) and a high level of unmet needs [31]; thus it is relevant to incorporate dyadic programmes [37]. Alongside the communication about death and dying, other typical problems experienced by families of advanced cancer patients can include 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 [38]. Therefore, as a clinical implication, we suggest that a holistic quality EOL care approach should not only focus on patients but also provide as much support as possible for family members and close friends .

Some limitations must be considered when interpreting the results of this study. Firstly, 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. Secondly, 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 studies in a longitudinal way. Thirdly, most of the family members 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 may cannot be generalised to other populations. Nevertheless, the fact that many persons refuse the study 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’ paradox: palliative patients and their relatives expect substantial personal relief when openly talking about end-of-life issues, but also expect the other person to be burdened by such a conversion. Professionals repeatedly need to initiate end-of-life conversations to help families speaking about end-of-life issues.

Availability of data and materials

The datasets generated and analysed during the current study are available from the corresponding author upon reasonable request.

Ethical approval

The study was approved by the institutional review board of the Medical School, Philipps-University of Marburg (AZ:47/12). This study was performed in line with the principles of the Declaration of Helsinki.

Consent to participate

Written informed consent was obtained from all individual participants included in the study.

Consent for publication

Participants signed informed consent regarding publishing their data in an anonymous form.

Contributors

All authors have made a substantial contribution to the work through data acquisition, data collection, analysis, interpretation of data, drafting the article, and approving the final version to be published.

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Competing interests

The authors have no conflicts of interest to declare that are relevant to the content of this article.

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Figure legends

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

Figure 2. Expectations of end-of-life discussions among cancer patients and family members in an informal versus a professional context

Figure 3. End-of-life fears among cancer patients and family members

Table 1. Sociodemographic and medical data of the study sample

		Patients (*N*=85)	**Family Members (*N*=66)**	**Group Differences**
Variables		*N* (%) / *M* (*SD*)	*N* (%) / *M* (*SD*)	*t*- / χ^2- Value
Age in years		62.8 (11.4)	56.3 (12.7)	3.24, *p*=.002
Gender (male)		56 (65.9%)	19 (28.8%)	20.45, *p*<.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*=.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 %)	
	Housewife/man	5 (5.9 %)	3 (4.7 %)	64.85, *p*<.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*=.026
	Living together with partner (yes)	62 (72.9 %)	55 (83.3%)	2.30, *p*=.129
	Children (yes)	73 (85.9 %)	53 (80.3%)	0.837 *p*=.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*=.742
Relation to Patient	Partner		44 (66.7 %)	
	Son/ Daughter		15 (22.7 %)	
	Parent		1 (1.5 %)	
	Other		6 (9.1 %)	
Tumor group	Lungs	25 (29.4 %)		
	Gastro-intestinal	14 (16.5 %)		
	Hepatobiliary	3 (3.5 %)		
	Urogenital	8 (9.4 %)		
	Gynecological	7 (8.2 %)		
	ENT (ear, nose, throat)	2 (2.4 %)		

	Brain tumor/ 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*=.051
HADS Anxiety		5.83 (3.49)	8.97 (3.63)	-5.368, *p*<.001

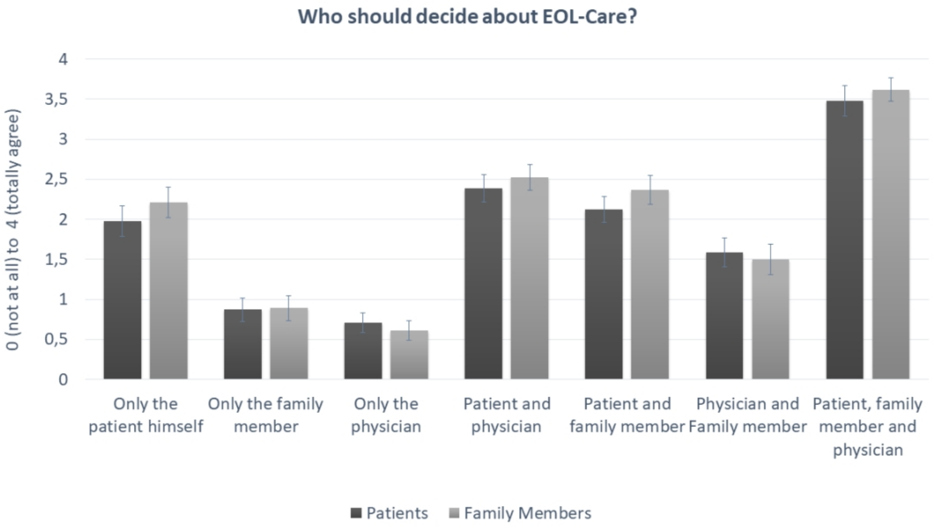
Table 2. Conversational partner in end-of-life discussions

End-of-life communication		**Patients (n=84)**	**Family members (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%)
Professional Context	Physician	26 (30.6%)	25 (37.9%)
	Nurse	2 (2.4%)	7 (10.6%)
	Pastor	10 (11.8%)	4 (6.1%)
	Psychologist	4 (4.7%)	5 (7.6%)
Informal Context	Family	47 (55.3%)	47 (71.2%)
	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%)

Table 3. Correlations between the expectations, fears and experiences in patients and family members

	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
EXPECTATIONS													
1 Emotional relief	-												
2 Practical support	**.777****	-											
3 Negative emotions	.099	-.008	-										
4 Refusal	-.046	-.150	**.344****	-									
5 My wishes not to be respected	-.072	**-.175***	**.173***	**.645****	-								
6 Emotional burden of the other person	.024	.039	**.441****	**.166***	**.175***	-							
FEARS													
7 Avoidance of the topic	-.066	-.85	.090	-.063	.017	0.64	-						
8 Thoughts are burdening	.045	-.044	**.375****	.064	.079	**.286****	**.376****	-					
9 Very afraid of EOL	.136	-.015	**.383****	.129	.036	**.187***	.029	**.387****	**-**				
10 Afraid of Talking	.096	.040	**.502****	**.240****	.162*	.210	.139	**.280****	**.465****	**-**			
11 Avoidance of Talking	.013	.036	**.256****	.138	.100	**.222****	**.374****	**.348****	**.168***	**.516****	-		
EXPERIENCES													
12 burdening	-.005	-.102	**.499****	**.302****	.177	**.232***	.017	**.382****	**.478****	**.438****	**.209***	-	
13 helpful	**.362****	**.320****	-.104	-.127	-.111	.061	**-.331****	-.130	.012	**-.232***	**-.316****	**-.247****	-
14 satisfied	**.232***	**.211***	-.156	**-.183***	**-.203***	-.049	-.129	-.048	-.048	-.081	-.053	**-.419****	**.506****

Note. *p<.05, **p<.01, (n=118-151)



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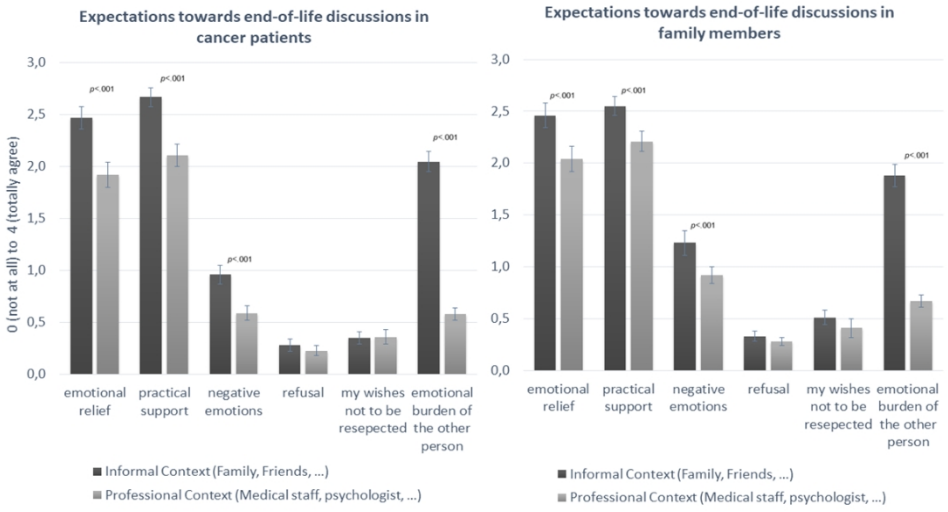

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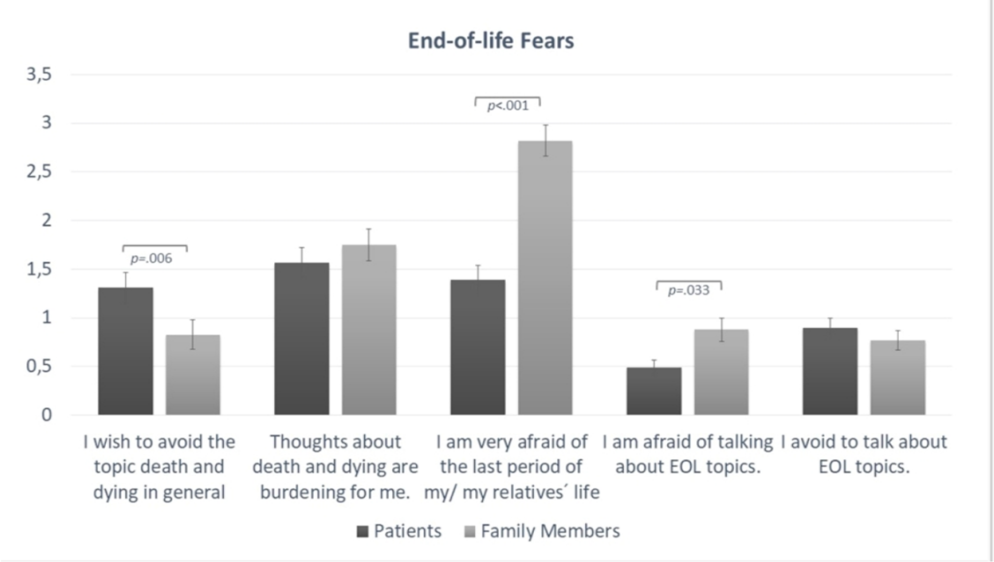

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STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	3
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4f
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (*b*) For matched studies, give matching criteria and number of exposed and unexposed	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5f
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (*b*) Describe any methods used to examine subgroups and interactions (*c*) Explain how missing data were addressed (*d*) If applicable, explain how loss to follow-up was addressed (*e*) Describe any sensitivity analyses	6
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	6
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	Table 1
Outcome data	15*	Report numbers of outcome events or summary measures over time	7ff

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*b*) Report category boundaries when continuous variables were categorized (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	6-9, Table 2, and Figures
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Table 3
Discussion			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	9-12
Generalisability	21	Discuss the generalisability (external validity) of the study results	12
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	13

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.

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

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

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Keywords: end of life, communication, caregiver, palliative care

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Strengths and limitations of this study

- In contrast to earlier research, expectations and concerns towards 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.

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 cancer patients 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 ($F(1,149)=316,958, p<.001, \eta p^2=.680$), even though the emotional relief was expected to be higher ($F(1,149)=46.115, p<.001, \eta p^2=.236$). 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.

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 percent of the relatives were aware of patients’ preferences regarding possible EOL situations, although 75 percent rated themselves confident about knowing patients’ goals [4].

Open end-of-life (EOL) communication between the patient and the caregiver can improve the quality of end-of-life 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 (e.g. wished treatment options), but also emotional, spiritual and organizational aspects (e.g. 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 (e.g. differences in values or opinions), a lack of communication skills (e.g. not knowing how to talk about EOL care) or external circumstances (e.g. not having any close person to talk to) [11]. Important barriers on a cognitive level can be expectations towards the communication process (e.g. 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 breast cancer patients or the utilization 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 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 (e.g. 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 percent of cancer patients 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 a) who should make decisions about EOL care; b) the spectrum of expectations towards EOL communication; c) the level of EOL fears; and d) experiences with EOL communication among palliative cancer patients and their caregivers. In our research, the term palliative cancer patients refers to cancer patients with a life-limiting illness and a life expectancy of less than 12 months. Lastly, the study analysed e) 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 there 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 PB. 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. 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 cancer patient, taking care of her or him and a potential surrogate (e.g. partner, child, parent, close friend, family member chosen by the patient etc).

Ethics

The study was approved by the institutional review board of the Medical School, University of Marburg (AZ:47/12). Before participation, subjects gave written informed consent.

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 ten palliative cancer patients 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 (e.g. “It is important to me to be self-determined.”); seven questions were about persons who should decide about EOL care (e.g. “I want decisions about my medical EOL care to be taken only by myself”); six questions addressed expectations of EOL care (e.g. “I expect… emotional release/ practical support/ emotional burden/…); and five questions were about fears regarding EOL communication (e.g. “I am very afraid of my/ my relatives´ last period of life”, “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": e.g. treatment of somatic problems like dyspnoea, nausea, pain or maintaining quality of life, living will, life-sustaining treatment, “emotions”: e.g. feelings like grief, anger, fear or sadness”, “social aspects”: e.g. unresolved conflicts, dealing with relatives and friends, saying goodbye, “nursing care”: e.g. nursing care while crisis and/or in the last period of life, place of dying, “organisational aspects”: e.g. financial and legal issues, life pension, inheritance, or funeral, and “religiosity/spirituality”: “talking e.g. about religious beliefs or desires, thoughts about death and the hereafter”. Finally, three questions related to the experience of EOL communication (“burdening”, “helpful”, “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 four-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 alpha of α=.81 for the anxiety-scale and α=.69 for the depression scale.

Patient and Public Involvement

During the interview development process, ten 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 26 (SPSS Inc. IBM, Chicago, Illinois, USA), with statistical significance set at p <.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 cancer patients and caregivers, and to control for possible influences of demographic and clinical characteristics, (multivariate) analysis of covariance (MANOVA and MANCOVA) and univariate analysis of covariance (ANOVA) were conducted. For categorical data, chi-square 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, four patients (4.49%) and two caregivers (2.94%) discontinued their participation due to problems of a physical (e.g. pain) or organisational nature. Thus, the final sample consisted of 85 palliative cancer patients and 66 caregivers. Demographic and clinical characteristics of the study participants are listed in Table 1.

Table 1

Who should decide about end-of-life care?

The item "It is important to me to be self-determined" was agreed to by 95.3 percent of patients and 92.4 percent of caregivers. Moreover, 89.3 percent of patients and 89.1 percent of caregivers agreed with the item: "The right to self-determination must be valid beyond death" (V=.98, $F(2,145)=0.143$, p=.869, η_p^2=.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=.97, $F(7,143)=0.615$, p=.743, η_p^2=.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.

Figure 1

Expectations of end-of-life discussions

To analyse differences in expectations of EOL communication in the professional versus the informal context among palliative cancer patients 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=.93, $F(6,144)=1.757$, p=112, η_p^2=.068) was found, but a significant effect of context was seen (V=.94, $F(6,144)=65.806$, $p<.001$, η_p^2=.733). Subsequent univariate analyses showed a higher score for the expectation of emotional relief ($F(1,149)=46.115$, $p<.001$, η_p^2=.236) and the expectation of practical support ($F(1,149)=38.665$, $p<.001$, η_p^2=.206) in the informal context than in the professional context. Moreover, univariate analyses showed a significant higher score in the expectation of negative emotions ($F(1,149)=54.820$, $p<.001$, η_p^2=.269) and in the expectation regarding the emotional burden of the other person ($F(1,149)$=316,958, $p<.001$, η_p^2=.680) 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=.118, η_p^2=.016) or wishes not being respected ($F(1,149)=0.131$, p=.320, η_p^2=.007).

Thus, palliative cancer patients 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 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.

Figure 2

End-of-life fears

In a MANOVA with the between-subject factor status and five different aspects of EOL fears as dependent variables, a significant effect of status (V=.72, $F(5,143)=10.963$, $p<.001$, η_p^2=.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=.033, η_p^2=.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" ($F(1,148)=42.279$, $p<.001$, η_p^2=.223) and for "I am afraid to talk about EOL topics" ($F(1,148)=7.702$, p=.006, η_p^2=.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=.419, η_p^2=.004) or "I avoid talking about EOL topics" ($F(1,148)$=.782, p=.378, η_p^2=.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 end-of-life 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 percent of patients and 16.7 percent of caregivers had not. The results are shown in Table 2. There were no differences between caregivers and patients in the distribution of EOL communication ($\chi^2(4,1)$=6.352; *p*=.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*=.005) and social aspects ($\chi^2(1)$=11.465; *p*<.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*=.814) and patients ($\chi^2(4,1)$=5.228; *p*=.265). Of the caregivers, 48.4 percent found the communication helpful or very helpful and 31.8 percent more or less helpful, while 53.1 percent found the communication satisfying and 34.8 percent more or less satisfying. Significant differences were seen in terms of emotional burden of communication ($\chi^2(4,1)$=15.160; *p*=.004), with 26.4 percent of caregivers rating communication as burdening or very burdening, and 34 percent as more or less burdening, while only 9.1 percent of the palliative cancer patients evaluated communication as burdening or very burdening, and 31.8 percent as more or less burdening.

Table 2

Table 3

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 cancer patients and caregivers regarding end-of-life 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 (e.g. 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 percent 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, repetitive 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 organizational 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 conversion. 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 (e.g. thanatophobia) [18]. Therefore, another possible explanation for the first observation might be that a decisive proportion of those who had reservations towards 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 percent did so out of fear of the emotional burden and 14.5 percent 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 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 end-of-life 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 cancer patients tend to be more anxious than patients, with prevalences of 32–72 percent [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 advanced cancer patients 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. Firstly, 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. Secondly, 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. Thirdly, 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 end-of-life issues, but also expect other people to be burdened by such conversations. Professionals repeatedly need to initiate end-of-life communication to help families speaking about end-of-life issues.

Availability of data and materials

The datasets generated and analysed during the current study are available from the corresponding author upon reasonable request.

Ethical approval

The study was approved by the institutional review board of the Medical School, Philipps-University of Marburg (AZ:47/12). This study was performed in line with the principles of the Declaration of Helsinki.

Consent to participate

Written informed consent was obtained from all individual participants included in the study.

Consent for publication

Participants signed informed consent regarding publishing their data in an anonymous form.

Contributors

CS, WR, YN, US and JRK planned the study and revised the manuscript, HJF accomplished the interviews, MH, PvB and CS supervised the study, PvB conducted the analysis, interpretated the data, drafted the article.

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Competing interests

The authors have no conflicts of interest to declare that are relevant to the content of this article.

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Figure legends

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

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

Figure 3. End-of-life fears among cancer patients and caregivers

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*- / χ^2- Value
Age in years		62.8 (11.4)	56.3 (12.7)	3.24, *p*=.002
Gender (male)		56 (65.9%)	19 (28.8%)	20.45, *p*<.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*=.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 %)	
	Housewife/man	5 (5.9 %)	3 (4.7 %)	64.85, *p*<.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*=.026
	Living together with partner (yes)	62 (72.9 %)	55 (83.3%)	2.30, *p*=.129
	Children (yes)	73 (85.9 %)	53 (80.3%)	0.837 *p*=.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*=.742
Relation to Patient	Partner		44 (66.7 %)	
	Son/ Daughter		15 (22.7 %)	
	Parent		1 (1.5 %)	
	Other		6 (9.1 %)	
Tumor group	Lung	25 (29.4 %)		
	Gastro-intestinal	14 (16.5 %)		
	Hepatobiliary	3 (3.5 %)		
	Urogenital	8 (9.4 %)		
	Gynecological	7 (8.2 %)		
	ENT (ear, nose, throat)	2 (2.4 %)		

	Brain tumor/ 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*=.051
HADS Anxiety		5.83 (3.49)	8.97 (3.63)	-5.368, *p*<.001

Table 2. Communication partner in end-of-life communication

End-of-life 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 end-of-life topics?	Professional Context	Physician	26 (30.6%)	25 (37.9%)
		Nurse	2 (2.4%)	7 (10.6%)
		Pastor	10 (11.8%)	4 (6.1%)
		Psychologist	4 (4.7%)	5 (7.6%)
	Informal Context	Family	47 (55.3%)	47 (71.2%)
		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%)
	Organizational aspects		54 (23.5%)	46 (69.7%)
	Emotions		42 (49.4%)	46 (69.7%)
	Social aspects		24 (28.2%)	37 (56.1%)

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	**.777****	-											
3 negative emotions	.099	-.008	-										
4 refusal	-.046	-.150	**.344****	-									
5 my wishes not to be respected	-.072	**-.175***	**.173***	**.645****	-								
6 emotional burden of the other person	.024	.039	**.441****	**.166***	**.175***	-							
Fears													
7 avoidance of the topic	-.066	-.85	.090	-.063	.017	0.64	-						
8 thoughts are burdening	.045	-.044	**.375****	.064	.079	**.286****	**.376****	-					
9 very afraid of eol	.136	-.015	**.383****	.129	.036	**.187***	.029	**.387****	**-**				
10 afraid of talking	.096	.040	**.502****	**.240****	.162*	.210	.139	**.280****	**.465****	**-**			
11 avoidance of talking	.013	.036	**.256****	.138	.100	**.222****	**.374****	**.348****	**.168***	**.516****	-		
Experiences													
12 burdening	-.005	-.102	**.499****	**.302****	.177	**.232***	.017	**.382****	**.478****	**.438****	**.209***	-	
13 helpful	**.362****	**.320****	-.104	-.127	-.111	.061	**-.331****	-.130	.012	**-.232***	**-.316****	**-.247****	-
14 satisfied	**.232***	**.211***	**-**.156	**-.183***	**-.203***	-.049	-.129	-.048	-.048	-.081	-.053	**-.419****	**.506****

Note. *p<.05, **p<.01, (n=118-151)

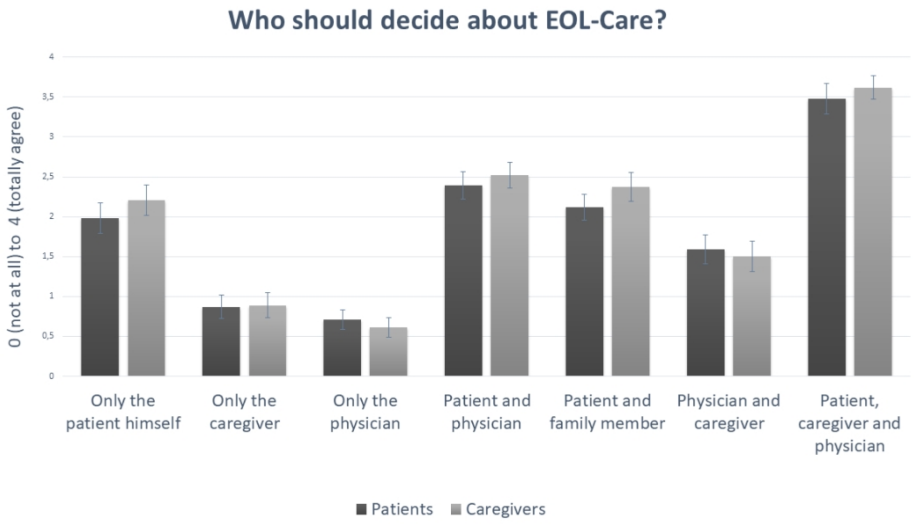

Figure 1. Persons who should decide about end-of-life care

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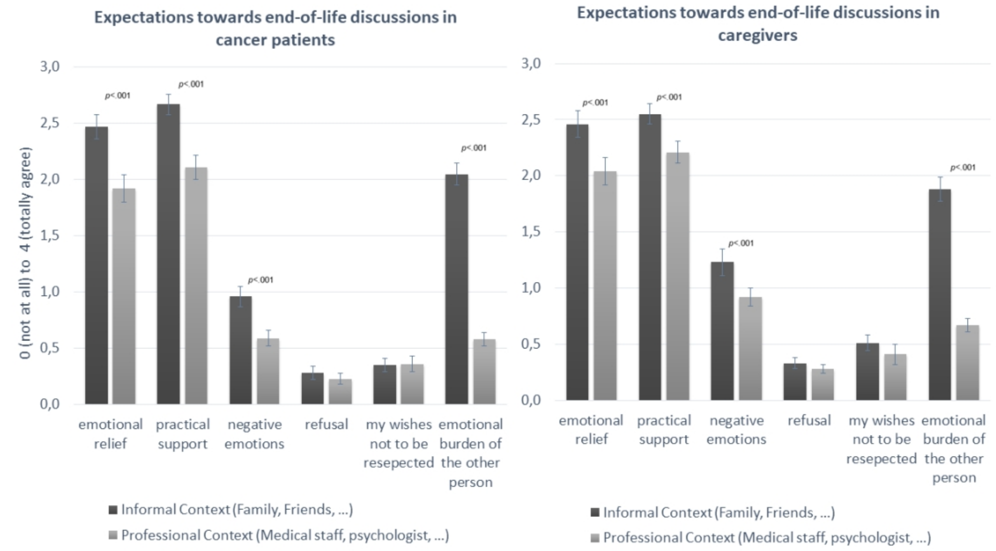

Figure 2. Expectations of end-of-life discussions among cancer patients and caregivers in an informal versus a professional context

855x481mm (38 x 38 DPI)

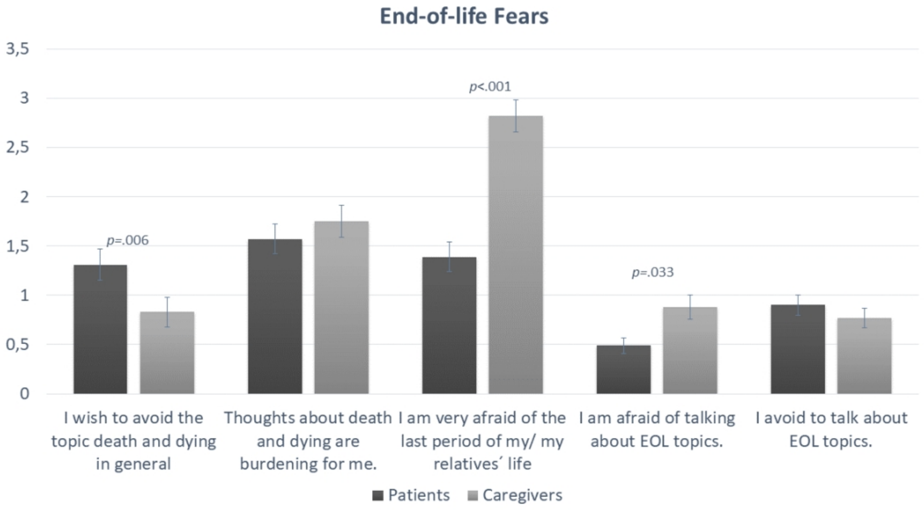

Figure 3. End-of-life fears among cancer patients and caregivers

855x481mm (38 x 38 DPI)

STROBE Statement—Checklist of items that should be included in reports of ***cohort studies***

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract (*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	3 3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4f
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up (*b*) For matched studies, give matching criteria and number of exposed and unexposed	5
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5f
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	6
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding (*b*) Describe any methods used to examine subgroups and interactions (*c*) Explain how missing data were addressed (*d*) If applicable, explain how loss to follow-up was addressed (*e*) Describe any sensitivity analyses	6
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	6
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	Table 1
Outcome data	15*	Report numbers of outcome events or summary measures over time	7ff

Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (*b*) Report category boundaries when continuous variables were categorized (*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	6-9, Table 2, and Figures
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Table 3
Discussion			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	12
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	9-12
Generalisability	21	Discuss the generalisability (external validity) of the study results	12
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	13

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at http://www.strobe-statement.org.