

To speak, or not to speak – do clinicians speak about dying and death with geriatric patients at the end of life?

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Summary

QUESTIONS UNDER STUDY: Research describing healthcare professionals' conversations about issues of dying and death with chronically ill geriatric patients is rare, especially in Europe. The study reviews the willingness and difficulties of physicians and nurses to speak about dying and death with geriatric patients.

METHOD: Interview study with 14 physicians and 17 nurses.

RESULTS: The majority (21/31) of the interviewed physicians and nurses reported a considerable willingness to speak about dying and death with patients approaching the end of life. Obstacles to addressing this topic included external circumstances such as lack of time and/or privacy (14/31); personal reasons, such as feeling confronted with one's own mortality (12/31); resistance or denial in their patients (12/31); and the cognitive state of the patients (7/31).

CONCLUSIONS: Discussing and preparing (the patient) for an end-of-life decision early enough is a prerequisite of good palliative care. It is an ethical obligation on the side of the healthcare professionals to support openness, respect for autonomy, and dignity by addressing issues of dying and death with the patient in order to help facilitate advance care planning.

Key words: *end-of-life care; communication; ethics; geriatrics*

Introduction

Do clinicians (physicians and nurses) speak with their terminally ill patients about dying and death? End-of-life

Abbreviations

EOL End-of-life
ph physician
nu nurse
n number

(EOL) care is a major challenge in clinical work, often raising ethical uncertainty or conflict about the right course of action [1, 2]. Palliative care supports improved symptom control as well as psychosocial and ethical sensitivity [3]. However, involving patients in EOL decision making remains an often neglected task in clinical practice despite wide agreement that healthcare professionals should assist patients in preparing for their EOL [4]. Legal and ethical stipulations mandate appropriate doctor-patient conversation and information as a requirement for respecting patient autonomy [5]. An on-site study in a major tertiary-care oncology unit revealed that regardless of patient competency, more than 50% of doctor-patient conversations avoided the topic of treatment limitation, a key issue in EOL care [6]. A comparable problem exists in pediatrics, especially in neonatology, where parents of terminally ill patients were insufficiently involved in making decisions to limit treatment [7]. There is ample evidence that in intensive care EOL conversations with patients are not only limited due to patient condition, such conversations with the patient's relatives or guardians are also limited [6, 8]. In geriatrics, a holistic approach is applied as far as possible, instead of focusing on a single physical disorder and in order to respect the psychosocial dimension and the patients' integrity. The main goals include improving or maintaining quality of life and functionality when possible. Due to the multimorbidity of geriatric patients, palliative strategies often prevail and death is respected as a natural final state resulting from progressive chronic incurable diseases [9]. In the training of geriatricians and clinical staff taking care of the elderly, the breaking of bad news and conversations about imminent death remains a major challenge [10, 11]. Physicians are trained to maintain health and fight illness but typically receive little guidance on how to communicate with dying patients and their families [12, 13]. Disappointing results about EOL care in hospitals have been published [14], and the American Medical Association of American Medical Colleges has expressed concern about how physicians relate to patients, especially to those who are seriously ill

[15]. Initiating conversations about dying and death seems to be extremely difficult for clinicians [6, 16].

Nevertheless, there are obvious countertrends. Increasing attention to palliative care, including the education for physicians in EOL care programs was reported by the American Medical Association [17]. Biomedical rhetoric of death as a “medical failure” now competes with the emerging public rhetoric of “death as a part of life” [18]. Humane care is an essential component of the doctor’s role at the EOL. Over the last 20 years, there has been a steady global increase in the extent and variety of medical teaching about the care of dying patients [19].

A survey among more than 1,000 physicians in the U.S., carried out in 1976 and 1996, concluded that the same physicians appeared to be more open than previously to communication with terminally ill patients and their families on issues concerning dying and death [15]. Studies in Great Britain confirmed that doctors’ and nurses’ openness about communicating with terminally ill patients and their families has increased in the past two to three decades [19]. Nevertheless, communication about a patient’s EOL is not yet a routine part of care [14].

Research describing healthcare professionals’ conversations about issues of dying and death with chronically ill geriatric patients is rare, especially in Europe [20–22]. Most studies deal with cancer [6, 20, 23] and examine special issues such as overaggressive treatment of dying patients with life-sustaining technologies [24]. The topic of breaking bad news has gained more attention; recommendations emphasise that breaking bad news requires appropriate communication about imminent death [25] but generally neglects the conversation about dying and death with chronically ill elderly patients.

In this exploratory interview study, we assessed the willingness and difficulties of physicians and nurses regarding the conversation about dying and death with geriatric patients.

Method

Questions on whether and how the topic of dying and death is addressed in conversations with patients at the end of life are insufficiently researched. A qualitative exploratory approach is required to access clinicians’ subjective perspectives and to gain meaningful insight. Semi-structured interview studies with systematic content analysis are most appropriate to explore unknown fields and sensitive issues such as EOL care in patient conversation. This study is part of a larger interdisciplinary investigation on EOL decision making and treatment limitation in geriatric and intensive care.

A semi-structured guidance was elaborated and focused on issues of EOL decision making and related difficulties. Questions were derived from the literature or clinical experience and submitted for internal review. Each question was formulated in the written interview explicitly. The interviewer, however, was free to adjust the questions to the conversation. The interview guide was split into two parts; the first part focused on EOL decision making and treatment limitations (which was published elsewhere [34]); the second part investigated “conversation about dying and

death with patients facing death”. This paper examines the interviews carried out in geriatrics (not those from the ICU) and only the second part of the interviews. The interviews were conducted by two interviewers (a male medical student, first author in the scope of his dissertation and a female psychologist). Before starting, the two interviewers involved were trained by conducting test interviews with feedback. Approval for the whole project by the local ethics committee (Ethikkommission beider Basel) was obtained.

Participants and recruitment

The heads of the departments were informed about the interview study and consented to participate. Physicians and nurses were addressed by a general announcement informing them that they could voluntarily enroll. More experienced physicians and nurses were specifically invited by the head of department. Special invitation to more experienced physicians was deemed essential as they form a much smaller professional group than nurses and some physicians had practiced for only a very limited time and exclusively at these hospitals. Most of them were geriatricians, some were internists, one worked as a psychiatrist in the psychogeriatric ward, one was a general physician, and a few were interns. The response rate was very high in both departments and recruitment was closed when the planned sample size of 30 to 35 interviews was reached. The potential interviewees were then contacted by the interviewers in order to fix an appointment and to explain the aims of the study. Face-to-face interviews were carried out with 35 clinicians (physicians and nurses) in two clinical units: 17 in an acute geriatric department of a university hospital and 18 in a geriatric community hospital both located in Basel, Switzerland. Data reported here are on 31 of 35 interviewees from the geriatric clinical staff. Three interviews were excluded due to very limited clinical experience, and one because of a damaged tape recording. Table 1 shows the characteristics of the interviewees. The number of interviews with physicians and nurses was balanced. Full confidentiality and anonymity was guaranteed. Interviewed participants provided written informed consent. The interviews took place during their working hours in a separate room on the ward.

Clinical setting

The separate geriatric ward of the University Hospital Basel was being restructured while the interviews were taking place. Therefore, the nursing home part (60 beds) was closed whereas the remaining acute geriatric units (32 beds) were moved and integrated into the university hospital’s main building. This new acute geriatric university hospital ward with patients’ average length of stay of 14 days takes care of acutely ill complex geriatric in-patients in need of a specialised university platform. It offers the usual geriatric interdisciplinary approach with early rehabilitation to support and facilitate patients’ dismissal back home or to a specialised geriatric rehabilitation facility. In the geriatric community hospital, approximately 230 beds were provided among acute geriatrics, musculoskeletal rehabilitation, neurorehabilitation, psychogeriatrics, internal medicine follow-up care as well as out-patient and day-care

units. In both hospitals, the typical characteristics of geriatric patients included old age, multimorbidity and chronic illness, falls, restricted mobility, taking multiple medications, dementia, delirium, social problems, etc. Some of these characteristics (e.g., dementia, delirium) clearly make conversations with patients difficult.

As dying and death is often inevitable in geriatrics, one might have expected a familiarity or even routine of talking about these matters on the side of the clinical staff. However, conversation on this topic had not been routine in the two hospitals investigated in this study. Regarding dying and death, the most commonly asked questions were limited to the potential existence of advance directives, the wish to be resuscitated, and potentially to be transferred to an intensive care unit.

Data collection and analysis

The interviews were tape recorded, no field notes were taken. The (second part of the) interviews lasted between five and twenty minutes. The interviews were done on a voluntary basis without remuneration. All interviews were registered and analysed following the methodology of “qualitative content analysis”. A framework of categories was progressively developed from the material using a coding guide [26]. Data were coded by one researcher (first

author) using Microsoft Word. The main themes had been defined in advance for the interview guide.

Results

The interviews generally went smoothly. All interviewees were motivated to participate, and many expressed appreciation of the study. Interviewees showed openness and authenticity when speaking about their shortcomings, although some needed to adjust to the unfamiliar situation of being interviewed. Table 2 gives an overview of the results.

Willingness to talk about dying and death

High willingness to talk

High to rather high willingness to talk with patients about dying and death was defined as taking the initiative, being very open, willing, and perceptive to this topic and/or to look carefully for signs on the part of the patients.

Twenty-one of 31 interviewees (10 physicians, 11 nurses) showed high to rather high willingness to talk about dying and death:

- I am always open to converse about this topic. (nurse, nu)
- Always when it’s appropriate. (nu)

Table 1: Characteristics of the interviewees.

	Physicians n = 14	Nurses n = 17	Total n = 31
Age, mean (range)	46.2 (30–64)	46.6 (23–57)	46.4
Gender			
Male	12	3	15
Female	2	14	16

Table 2: Results.

	Physicians n = 14	Nurses n = 17	Total n = 31
Willingness to talk about dying and death			
High to rather high willingness	10	11	21
Low to rather low willingness	3	4	7
Unclear/not apparent	1	2	3
Content of conversation			
Included mental, emotional, religious/spiritual issues	10	16	26
Only/mainly about medical facts	4	0	4
No information	0	1	1
Specific and repeatedly mentioned contents			
Responsive to wishes and needs	6	9	15
Fear	5	10	15
Whether there are issues to be sorted out	4	4	8
Diagnosis/illness/prognosis	7	1	8
Whether to involve a priest/pastor or not	5	3	8
Palliative care aspects	4	3	7
Religion, faith	3	3	6
Relatives	3	2	5
Patient’s perspective	3	1	4
To explore a patient’s wish to die	1	3	4
Difficulties and barriers to talking about dying and death			
External circumstances (location, time, organisation)	8	6	14
Hindrances (resistance) on the side of physicians/nurses	6	6	12
Resistance/aversion on the side of the patient	6	6	12
Patient’s cognitive or conscious state	4	3	7
Others (e.g., cultural, linguistic)	6	6	12

- I try to do it (,) yes [...] actually I think it is good to talk about it. (physician, ph)
- Overall, I routinely speak about dying and death. On a regular basis, I offer the patient the possibility to talk about it, and keep this option open. (nu)
- I openly discuss it with the patient. (ph)

Low willingness to talk

Low to rather low willingness was defined as talking with patients about dying and death only rarely, without providing reasons, without obvious external circumstances (such as working with severely demented patients), or only when it occurred on the initiative of the patients.

Seven of 31 interviewees (3 physicians, 4 nurses) showed a rather low willingness to talk about this topic.

- Rarely ... well, this is a weak point for me. (ph)
- Not explicitly. It is often delegated to the pastor or someone. [...] When a patient brings it up, then I try to respond, but I don't take the initiative. (nu)
- Rarely [...], I seldom initiate these discussions. (nu)
- Sometimes. It depends mainly on the patient, whether the patient initiates the conversation. (nu)

In three of 31 interviewees, willingness was unclear or not apparent according to the interview.

What is the content of conversations on dying and death?

EOL conversations on dying and death – if they occurred – one main difference regards the question, whether they focused mainly on medical facts or whether they also addressed mental, emotional, and/or religious and spiritual aspects.

Four of 31 interviewees (4 physicians) reported that they mainly or only talked about medical facts during EOL conversations dying and death.

- Particularly the inescapability of this process that has started [...], that's definitely the main topic. [...] The patient has a disease and we actually cannot do anything that would effectively contribute to a cure. (ph) (So besides these medical facts, do you speak about other aspects? interviewer). Actually, no. Most of the time medical facts are in the foreground. (ph)

- [...] I limit my conversations to whether or not to reanimate. (ph)

- Most of the time medical facts predominant. (ph)

The vast majority of interviewees, 26/31 (10 physicians, 16 nurses) emphasised that they included mental, emotional, religious, and/or spiritual issues.

- If the patient is afraid [...] it is necessary for me to know whether we should inform family member. I inquire about the patient's religious attitudes, whether he/she would like to talk with a priest ... these aspects are important for me. (ph)
- Medicine doesn't play any role in this at the moment. Well, I think it doesn't for more than 90% (of the patients). Often pain was a topic [...], and the fear of dying alone. (nu)
- How to take into account his/her wishes, how to plan which persons should be present and what should be done. (nu)

- I like to speak about other aspects [non- medical] [...]. I ask generally if there are any issues that should be resolved. That way the patients can choose the topic themselves; it's better to let them speak freely. (ph)
- According to the personality of the patient, you also refer to religious issues; well, I like to speak about these issues. (ph)

One interviewee was not able to give any information about this specific topic.

Difficulties and barriers to talking about dying and death

Five parameters were found and used for further analysis of the interviews:

1. Location, space, time, and organisational reasons;
2. Doctors and nurses personally holding back;
3. Resistance, aversion, and denial from the patients;
4. Patients' cognitive or mental state;
5. Other reasons (e.g., cultural, linguistic).

14 of 31 interviewees (8 physicians, 6 nurses) brought up issues of location, time, or organisational reasons as obstacles of EOL conversation.

- One important obstacle is definitely ... the surroundings, that's to say rooms with four beds [...] you cannot talk with a patient about death in a room with four patients, that's for sure [...]. There is no intimacy if the patient is not in a single-bed room. (ph)
- I find "time" to be a hindrance... when the phone is ringing or the beeper. (nu)
- Time is often lacking as well, quite frankly. (ph)
- There are many hindrances, some of them have to do with the setting [...]. For example, it is not easy to talk about this topic in rooms with four beds. (ph)

Twelve of 31 interviewees (6 physicians, 6 nurses) mentioned personal reasons keeping them from talking about dying and death with patients.

- I find this very difficult every time. Also, I am always very apologetic... these are very depressing, burdensome conversations, for me too. (ph)
- This is a weak point ... probably not only in my case, but in general. (ph)
- The reality of my own mortality weighs heavily on me. (nu)
- The problem is the existing repression in all professional groups including doctors, and for many it's not easy to talk about this topic, it's difficult, and when possible it is avoided. (ph)
- ... one's own death [...]. You have to confront it yourself. (nu)

Twelve of 31 interviewees (6 physicians, 6 nurses) mentioned resistance, aversion, and denial on the side of the patients as obstacles of dying and death conversation.

- Depending on the patient [...], there are impressive repressing mechanisms. (ph)
- When he [the patient] is totally resistant, then it is difficult. (nu)
- There are people who just don't want to hear about it, and they fight until the end [...] you cannot talk openly. (nu)
- If the patient doesn't want it, if the family doesn't want it; this is a problem we meet again and again. There

are people who respond with much distance to that. (nu)

- My experience is that people don't want to deal with dying. It's a taboo. [...] People have a very distant relationship with something which ultimately happens to all of us. Death is something that people don't like to talk about. (ph)

Seven interviewees (4 physicians, 3 nurses) mentioned the patient's cognitive and mental state when they were asked about difficulties.

- Consciousness of patient or when somebody is in a delirium. (ph)
- One hindrance in geriatrics is the frequency of dementia, that's to say the cognitive limitations. (ph)
- Most patients suffer from dementia here, so it's difficult. (ph)
- The general problem of cognitive impairment makes it considerably more difficult to speak about this topic (ph)

Twelve interviewees (6 nurses, 6 physicians) mentioned other hindrances and difficulties such as cultural and linguistic problems.

- Cultural differences also raise difficulties, e.g., patients from Turkey, southern Italy, or former Yugoslavia. First, the problems may be linguistic, not fully understanding; and second, the patients have totally different customs [...], family members say that the patient must not be told. (ph)
- Other hindrances are certainly our medical education. We don't like to talk about death, although we always want to cure. We have learned to heal and not to care for dying people. (ph)
- Our culture still avoids this topic, you feel this, and it is taboo. (nu)
- In particular cases, there is the family members' strict prohibition or strong wish not to discuss this topic with the patient. This has become very rare, but it still happens. (ph)

Discussion

Our results support the request for better and more in-depth training to prepare for conversations on dying and death. The majority (21 of 31) of the interviewed physicians and nurses reported a considerable willingness to talk about dying and death with patients near the EOL, but 23% (7 of 31) were reluctant to bring up any aspect of this topic. When discussed with patients, the majority of clinical staff preferred to address dying and death in a broader way including the emotional and spiritual dimension, whereas only 4/31 preferred to limit it to medical facts. This is in contrast with a study with Dutch GPs about 252 non-sudden patient's deaths showing that social (51%) and spiritual/existential issues (27%) were discussed least frequently with the dying [35]. Another study using nation-wide data of non-sudden deaths in Belgium about EOL care given by all kind of caregivers (GPs, clinical specialists, nurses, informal caregivers and others) showed clearly that physical care was much more regularly provided than psychosocial and spiritual care [36].

Hindrances and difficulties to addressing this topic are the following: 14/31 interviewees mentioned external circumstances such as lack of time or privacy; 12 interviewees admitted personal reasons such as feeling confronted with their own mortality, and 12 observed resistance or denial in their patients. Seven of 31 reported that the cognitive state of some patients caused difficulties due to dementia or delirium. This is in line with Abarshi et al., who showed that dementia was associated with a reduced frequency of discussing EOL issues with the patient [35].

There is much evidence from studies including the SUPPORT Study [27] that communication with terminally ill patients is often insufficient or lacking. Only 39% of control and 41% of intervention group patients reported having discussed their medical prognosis with a physician. Of those who had not discussed their prognosis, 44% of control and 42% of intervention group patients mentioned that they would have liked to have such a discussion. Our data suggest, however, that if EOL conversations take place, they go beyond these mere medical facts.

Family members were interviewed in a representative sample (n = 461) of older people in the U.S. who died from chronic diseases [28]. Physicians had discussed with less than half of the cognitively competent patients about the use of life-sustaining treatments. The existence of a living will did not affect the likelihood of this discussion. Family members complained about poor communication skills of physicians, and the limited time and attention they devoted to the dying patients.

A study about COPD patients showed that only a small number of patients discussed EOL issues with their physicians [29]. The above mentioned Dutch study with GPs showed that considerably more EOL discussions happened with cancer patients, whereas cardiovascular disease was the major cause of death [35]. Also the nation-wide Belgian study showed that cancer patients received more psychosocial and spiritual care [36]. Another study about the involvement of terminal cancer patients in decision making showed that patients were informed about their diagnosis, treatment options, and the course of the disease in almost all of the cases (90–99%). However, only 47% were involved in the decision-making process concerning the limitation of life-prolonging treatment. If patients were concordant with physicians' treatment goals, they were considerably more often involved in the decision-making process than patients who were not [6]. The communication between physicians and dying patients about EOL care seems infrequent, and when it occurs studies suggest important shortcomings in the quality of this communication [25].

Why these important conversations so often are avoided? What are the difficulties in talking about dying and death? Several authors suggest that one important reason why doctors are reluctant to talk about dying and death is their own anxiety in facing death. This assumption has been confirmed through our data. Doctors are confronted with their own mortality, and patient death is still too often perceived as a physician's failure or personal defeat. Another reason could be the fear of destroying the patient's hope [16, 17, 31, 32] or that the patient will perceive the doctor as "giving up" [16].

In the geriatric setting, one might expect clinical staff to be familiar and confident with this topic, because geriatricians do seem to accept death as a natural state of a progressive process of chronic illnesses. Our results show a considerable willingness of both physicians and nurses to talk about dying and death with terminally ill patients in two-thirds of the interviewees, but for one third it seems to be a particularly difficult topic; previous data confirm that initiating EOL conversation can be very difficult [6, 16]. The majority of the clinical staff (physicians and nurses) not only reported to talk about medical facts, but that their conversations also included emotional, religious, and spiritual aspects. Only some physicians, but no nurses, limited their conversations to medical facts. This finding reflects the fact that it is primarily the physician's task to inform patients about their diagnosis, prognosis, and therapy. Hence, this result is not surprising. At the same time, the role of physicians should definitely include more than just talk about medical facts.

This study analysed the willingness to talk, not whether and how often such conversations take place in reality. It is possible that interviewees portrayed their willingness due to social desirability more favourably than their actual attitudes and behaviours are shown in reality. Some of the studies mentioned before analysed how often EOL conversations took place. No comparison is possible between the existing data and our results. However, many interviewees showed a high willingness through spontaneous and elaborately mentioned examples from their clinical experiences (how they initiate such conversations and what they talk about) and described their special attention for indications on the part of the patient. They mentioned the importance of tuning in (is a terminally ill patient open to have such conversations?) and finding the right moment to talk about it or simply to accept that the dying patient is not (yet) ready for this topic. The examples listed may be seen as an indication that conversations do take place when there is willingness. According to a nurse: *"I try to be sensitive. I think you need to have an "antenna". If somebody doesn't have one then he/she doesn't notice when it might be appropriate to have such a conversation"*. The more open and ready the staff is, the more sensitive they are to patients' needs and the more attuned is their way of talking with them about dying and death. Likewise, the more patients feel the doctor's/nurse's openness, the more confident they may be to express their needs, fears, and insecurities about what dying and death mean to them.

The most often mentioned obstacles to starting a conversation about dying and death were external factors such as lack of time or intimacy (e.g., in four-bed rooms), and distractions (phone calls, being called to other patients). These factors could be changed by organisational measures such as special rooms for conversation without telephones or other interruptions.

It is not surprising that clinical staff also observed difficulties and repressive mechanisms on the side of the patients [31]. Seven of 31 interviewees spontaneously said that death was still a taboo topic – not only in society, but also among colleagues and with patients. This reflects an evident cultural and social perception that death is not accepted as a part of life.

The necessity of more training for this kind of conversations for clinical staff is evident. Previous data about EOL care show that for most patients (and their families) good communication, and emotional and spiritual aspects play a key role in what they consider a "good death" [32]. However, training does not replace the individual adjustment to come to terms with one's own mortality. Yet, even this could be enhanced through open communication among colleagues and by developing a culture of integrating dying and death into clinical practice, as has begun in medical education [33].

This study has several limitations. The sample size is too small to make any general conclusions. Another limitation is the fact that the data were only collected in geriatric hospitals, but not in internal medicine wards or in nursing homes where dying and death is also an important issue. However, the interviewees' openness and authenticity when vividly mentioning examples or admitting their own shortcomings can be seen as a sign of validity; in qualitative research, validity does not depend on sample size alone. Our results show that a considerable willingness exists among clinical staff members of geriatric facilities to talk about dying and death with their patients; this includes an openness to include spiritual and emotional aspects into the conversation and indicates a promising basis for training programmes. The identified conversation barriers such as external factors have to be taken into account in the development of such programmes. Further research will help to evaluate the impact of education programmes, even in other clinical specialties.

A large number of interviewees were very positive that we raised this topic and have confirmed their interest and willingness to contribute to further projects. It seems that a single interview had a positive effect already, signalling that this topic deserves attention and can be handled professionally.

Conclusion

Timely conversation with the patient in preparation for EOL decisions is a prerequisite of good palliative care. There is an ethical obligation on the side of the healthcare professionals to support openness, respect for autonomy, and dignity by addressing issues of dying and death with the patient in order to assist in advance care planning. Initiating such conversations cannot be left to the patient alone, because patients – not only healthcare professionals – often avoid these uncomfortable discussions. More specific training for clinical staff is required. This cannot replace the individual adjustment to come to terms with one's own mortality. We suggest engaging in open communication and developing a culture that integrates the topics of dying and death into clinical practice.

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