Framework for timing of the discussion about forgoing cancer-specific treatment based on a qualitative study with oncologists

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Abstract

Background Many patients with advanced cancer receive aggressive chemotherapy close to death and are referred too late to palliative or hospice care.

Aim The aim of this study was to investigate oncologists’ and oncology nurses’ perceptions of the optimal timing for discussions about forgoing cancer-specific therapy at the End-of-Life (EOL) and the reasons that might hinder them.

Design Qualitative in-depth interviews with oncologists and oncology nurses were carried out. The empirical data were evaluated from a normative perspective.

Setting/participants Twenty-nine physicians and nurses working at the Department of Hematology and Oncology of a German university hospital were interviewed.

Results Health-care professionals differed considerably in their understanding of when to initiate discussions about forgoing cancer-specific therapy at the EOL. However, their views could be consolidated into three approaches: (1) preparing patients gradually throughout the course of disease (anticipatory approach) which is best suited to empower patient self-determination in decision-making, (2) waiting until the patient him/herself starts the discussion about forgoing cancer-specific treatment, and (3) waiting until all tumor-specific therapeutic options are exhausted.

Conclusion The empirically informed ethical analysis clearly favors an approach that prepares patients for forgoing cancer-specific therapy throughout the course of disease. Since the last two approaches often preclude advance care planning, these approaches may be less ethically acceptable. The proposed framework could serve as a starting point for the development of concrete recommendations on the optimal timing for EOL discussions.

Keywords Forgoing cancer-specific therapy · Palliative care · Ethical analysis · Qualitative research

Introduction

Decision-making to forgo cancer-specific chemotherapy is challenging both for patients and for their oncologists [1, 2]. However, when performed well and in a timely fashion, communication about withdrawal of chemotherapy towards the End-of-Life (EOL) is an important prerequisite of high-quality patient-oriented care. Patients who had conversations with oncologists about their preferred care goals were referred earlier to hospices and received less aggressive treatment near death [3].

Nevertheless, clinical evidence shows that oncologists are overwhelmingly reluctant to provide patients with prognostic information, to address the change from curative to palliative goals, and to prepare the patient for dying and death [4]. As a result, increasing numbers of patients with advanced cancer receive chemotherapy close to death [5–7] and are referred too late to palliative care units or hospice settings [6–8].

One important reason for the oncologists’ reluctance is that they feel uneasy about addressing dying and death [9]. However, many studies have shown that communication skills can
be trained to elicit patient preferences and preserve hope while telling the truth about the patient’s prognosis [10–15]. Hence, while we have good concepts and training on how to conduct EOL discussions, it remains uncertain when these discussions should be initiated. Little empirical research is available on physicians’ understanding of the optimal timing of discussions about forgoing cancer-specific therapy and its determinants [16–18]. Literature suggests that such discussions should occur early [6, 19–21], but it is unclear what precisely is meant by “early.” In-depth understanding of the right time to initiate these discussions is lacking from the medical, psychosocial, and ethical points of view [17]. Therefore, we conducted this empirical study to investigate oncologists’ and oncology nurses’ perceptions of the determinants and reasons for timing of EOL conversations with patients with advanced cancer. The aims of this study were first to reconstruct oncology physicians’ and nurses’ understanding of the optimal timing of discussions about forgoing cancer-specific therapy, second, to understand the factors that facilitate or hinder the initiation of such discussions, and, third, to identify potential triggers that are perceived by health-care professionals as most helpful for initiating conversations to forgo cancer-specific therapy. The findings will be discussed against the background of clinically and ethically relevant aspects of treatment decision-making with patients with advanced cancer.

Materials and methods

A grounded theory design with qualitative interviews was chosen because of the exploratory nature of this study. We conducted 29 individual semi-structured in-depth face-to-face interviews with oncology physicians and nurses working at the Department of Hematology and Oncology at the University Hospital of Munich, Germany.

Sample

In order to ensure variability within the data and to include the widest possible range of perspectives and experiences, a purposive sampling method was used in the initial stage of our study to choose physicians and nurses with varied working experience and ages from different hospital units. Then, data collection was guided by theoretical sampling. Theoretical sampling is the process where data collection and analysis are performed simultaneously to allow constant comparative analysis of the data [22]. We continued interviews until data saturation was reached, meaning that during the analysis of the latest interviews (revealed), no new information or themes were emerging (theoretical saturation) [22].

Demographic characteristics of participants are presented in Table 1.

The interview format was open-ended, allowing physicians to speak as much as they wanted. All the interviews were conducted by the principal investigator, who is experienced in qualitative research methods. Most interviews lasted about 40 min (range 25–90 min) and were recorded either by tape (n=27) or through handwritten notes (n=2). Each participant provided written consent in person.

Interview guide

An interview guide was developed through a multistep process that included (1) a review of the current literature on end-of-life decision-making in oncology, discussing interview questions in a research group that consisted of a social scientist (KL), an oncologist and medical ethicist (EW), and an oncologist and psycho-oncologist (PH); (2) pretesting the interview guide through preliminary interviews; and (3) developing a final version of the interview guide during regular interdisciplinary team meetings of the wider research group of the program “Ethics and patient-oriented care in oncology.”

The interview guide included questions about treatment decisions in the context of care for patients with advanced cancer. The leading questions of the interview were the following:

- If you think of treatment limitation in patients with advanced cancer at the EOL—what situations come to your mind?
- What is most challenging for you in such situations?
- Could you recall one of the most difficult situations in your clinical practice with regard to treatment limitation in patients with advanced cancer?

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Table 1 Demographic characteristics of participants
• What is the right moment to start discussions with patients about treatment limitation?
• What can you tell me about patient involvement into decision-making? When is the right time for it?

Probing questions, such as “please tell me more about this” were used to get more detailed responses and reflections of physicians’ and nurses’ experiences.

Data analysis

Interviews were audiotaped, transcribed verbatim, and were analyzed using the grounded theory approach [23]. The aim of this approach is the generation of new concepts and hypotheses that emerged as a result of the iterative process of data analysis and data interpretation [24]. A thematic analysis was performed using constant comparison on the basis of grounded theory. In the first step of open coding, each line or paragraph of the interview data was coded by two researchers (EW and KL). Any emerging discrepancies were discussed within a research team. Subsequently, the codes were used to generate categories and subcategories through the use of comparison analysis. During axial coding, relationships were drawn between the categories against the entire body of interview data. The codes were then grouped according to their properties and types into categories and overarching themes. This process was facilitated by regular interdisciplinary team meetings during which the data categories and subcategories were discussed in relation to the existing literature in order to refine and link them to core themes. The analyses were supported by the qualitative software analysis program MAXQDA.

Results

The interview data showed that the majority of participants stated that discussions about forgoing cancer-specific therapy occur too late in the trajectory of disease and should be initiated much earlier. However, there was little consensus as to what “earlier” should refer. Interviewees mentioned a number of criteria that indicate the appropriate time to address the withdrawal of cancer-specific treatment. It ranged from “at the beginning of systemic therapy” to “when all therapy options have been exhausted,” as (the following) Table 2 shows.

As part of our analysis, we identified three different approaches to determining the optimal time to address this topic: (1) preparing patients gradually throughout the course of disease, (2) waiting until the patient him/herself starts the discussion about forgoing of cancer-specific treatment, and (3) waiting until all tumor-specific therapeutic options are exhausted. Contrary to our expectation, we could not find any relevant differences between nurses and physicians as well as between more and less experienced colleagues.

Prepar ing patients for decisions to forgo cancer-specific treatment gradually over the course of disease (anticipatory approach)

Addressing forgoing cancer-specific therapy was understood as a step-by-step process that continued over time. The physicians emphasized that they should pave the way and “lead” or “prepare” their patients gradually for future discussions and decisions.

I think that one must start the discussion very early and tell the patient that he/she will not become healthy, but that he/she has an incurable illness situation and that any kind of therapy can only buy time. When I see that the patient is weakening, then I start to discuss that he/she has become weaker early, not only because of the treatment but also because of the cancer, as he/she might need to stop therapy in the foreseeable future because of the deterioration of his/her general condition. (Ph. Nr. 22)

Thus, patients are confronted step-by-step with information about the life-threatening aspects of the illness and not overwhelmed by it suddenly:

One day they are told, yes, you are progressing, but we do not have any other options now. Then, they are thunderstruck. (Ph. Nr. 3)

Interviewees said that in prognostically uncertain situations, they would incorporate “hypothetical scenarios” (Ph. Nr. 3) in which diverse disease trajectories that patients might experience in the future are described. However, the participants also emphasized that the right balance between prognostic information and positive outlooks is important and that the physician cannot only talk about a dire prognosis and address EOL themes permanently.

Table 2 Definition of the notion of “early”

“Early” discussion of forgoing cancer-specific treatment at the EOL

<table>
<thead>
<tr>
<th>Criteria</th>
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<td>With the start of systemic therapy for an incurable metastatic disease</td>
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<td>With the start of palliative therapy</td>
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<td>When the patient does not respond to treatment</td>
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<td>With the first diagnosis of incurable metastatic disease</td>
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<tr>
<td>When therapy fails and the patient experiences a recurrence</td>
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<td>When therapy does more harm than benefit</td>
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<tr>
<td>Before there are no more treatment options</td>
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<tr>
<td>When patient’s condition worsens</td>
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(Ph. Nr. 22)
“I think, on the other hand, that you should not address this permanently; otherwise, the patient has the feeling that it is only about this.” (Ph. Nr. 18)

Waiting until the patient him/herself starts discussion about forgoing of cancer-specific treatment

Other interviewees were more reluctant to address forgoing cancer-specific therapy at the outset. One critical point was that if the patient still feels well, it is quite difficult for him/her to imagine and anticipate future situations and decisions:

“It is sometimes difficult to imagine a situation that does not relate to you at the moment. When one is doing very well, it is difficult to decide, ‘What would it be like if…?”’ (Ph. Nr. 15)

They were also worried that early discussions about forgoing cancer-specific therapy could have a negative impact on a trustful patient-physician relationship, causing psychological distress or discouraging the patient from continuing burdensome therapy:

I find that it is also a bit problematic when patients come to us for therapy, and in principle, one does not know certainly in which direction the patient will go; once stabilization is actually likely, then one speaks; however, if the doctor says, ‘Well, it might already be decided that we will limit your therapy at a later time; would you give a thought to it?’ This would be a strange signal for the patient. This is a warning signal… I discuss it with the patient when his/her situation is acute. I find this a little bit better, because if one says to the patient from the beginning, ‘One day, we will speak about the fact that we will discontinue therapy,’ then the patient also asks him/herself, ‘OK, when will this time come, then? How long do I have until we discuss that?’ And this can also be burdensome to the patient. (Ph. Nr. 10)

If the patient him/herself notices that his/her condition always worsens, then over time, the patient and physician can come without addressing the topic explicitly to a “mutual agreement” on forgoing cancer-specific therapy:

They notice that every week or every month, it always becomes worse and worse. Actually, I do not have the problem mentioned in this conversation so often: now it is the end, or now we have to change our treatment goals. However, in general, I believe that this is a process that the doctor and patient develop together. Therefore, I believe that one does not generally say, ‘Now, we will sit together and discuss the change in treatment goals.’ However, I believe that this is a fluent decision, and these people notice very exactly: last year, I could still travel; this year, I am not able to leave the house alone; now, I need oxygen. Further, such people notice very exactly that it will end somewhere, and it is often a mutual agreement with the doctor. (Ph. Nr. 7)

Waiting until all tumor-specific therapeutic options are exhausted

Another group of interviewees would initiate discussions about forgoing cancer-specific therapy only if there is enough certainty that the patient would not benefit from further chemotherapy.

“I do not know exactly when is the right moment. When it simply does not work any more. When you see the patient does not have any chance for curing.” (Nurse Nr. 14)

As soon as the physician has a feeling the therapy does more harm. The longer I postpone this decision, the longer I do something of what I am not convinced or am convinced that it does not help patient, the more harm I do to him, actually. (Ph No. 20)

However, they emphasized that it is quite difficult to prognosticate accurately the future course of a patient’s illness and also to decide whether the health condition of the patient still allows for the continuation of cancer-specific treatment. The participants indicated that if there remains even a slight uncertainty about the likely course and outcome of the disease (i.e., “a spark of hope” of obtaining remission or stabilization), it is quite difficult to start such discussions, and they are likely to be postponed. Some physicians tried to narrow their prognostic uncertainty by waiting until unambiguous progression of the disease and severe symptoms emerge or the patient’s condition becomes acute despite the administration of first-line therapy. Discussions tended to be initiated when all cancer-specific treatments had been exhausted or when therapy failed or brought about severe complications (and thus did more harm than benefit to the patient).

Discussion

This qualitative interview study provides insight into oncologists’ views on potential determinants for optimal timing. Three approaches for the construction of the timeframe could be identified. In the following, we will focus on the medical and ethical implications of these approaches and suggest ways on how they might be integrated into one framework for timing the discussion about limiting tumor-specific therapy. We discuss the normative implications of the different
approaches with reference to a principlist approach to applied ethics. Principlism is a framework for the analysis of ethical encounters in the realm of health-care ethics and focuses on the common ground moral principles of autonomy, beneficence, nonmaleficence, and justice [25].

**Waiting until the patient initiates discussions about limiting cancer-specific therapy**

Oncologists that favor this approach argued that they do not want to harm patients by early confrontation with the situation when tumor-specific therapies are no longer working. However, evidence suggests that the question of prognosis and forgoing tumor-specific therapy can be addressed without destroying the patients’ hope or inflicting psychological harm to (the patient) them [26]. In fact, honest communication can preserve or even help patients to feel more hopeful. Therefore, what at first glance seems to be supported by the ethical principle of nonmaleficence (“first do no harm”) does not apply to most cases, since communicating the limits of therapy must not be harmful if done properly.

One might also argue for this approach based on the principle for respecting patients’ autonomy, meaning that patients themselves should determine the optimal time for discussions about forgoing therapy. However, this would presuppose that patients have all relevant information and a realistic expectation about their therapy. However, empirical evidence shows that patients are oftentimes not well informed and therefore often maintain unrealistic expectations about their prognosis and disease [27, 28]. One reason for this is that physicians still are reluctant to inform patients about prognosis [4]. Therefore, as long as physicians do not empower patient autonomous decision-making by realistic information, the argument from autonomy does not support the approach of waiting for the patients’ initiative. Instead, it would support seeking to find out about the information that the patient needs for making his or her own value choices about treatment goals and intensity. In addition, waiting until the patient initiates the discussion about limiting cancer-specific treatment might lead to overtreatment of the patient so that an early preparation for limiting treatment of questionable benefit is also underpinned by the principle of beneficence.

**Waiting until all tumor-specific therapeutic options are exhausted**

Oncologists describe their difficulties to define the moment at which to initiate discussions about discontinuation of chemotherapy. Hence, waiting until all tumor-specific therapeutic options are exhausted seems a moment that is easier to define. However, if physicians wait until there are no more options from which to choose, patients are confronted suddenly with changes to their therapy and are unprepared for the fact that they now face closely impending death. Patients might also want to engage in advanced care planning. Not being informed ahead of time may forestall a smooth transition to hospice care or best supportive care—and hence, harm can be done by missing timely information.

Furthermore, evidence shows that patients’ preferences vary considerably regarding treatment goals [29, 30]; some choose quality of life over prolonging life and would rather decide against last line marginal effective chemotherapy. For others, gaining live time is paramount and they would search for any new experimental treatment. Therefore, this approach can be viewed as a paternalistic one as the physician defines solely on medical grounds to start a discussion about treatment limitation without taking into account the patient’s value.

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**Fig. 1** Concept of timing advanced care planning: potential triggers for discussing hypothetical scenarios (HS) and then for discussing forgoing cancer-specific treatment (DFT). At each time point, oncologists should consider measures of supportive and palliative care (SPC).

### Diagnosis of incurable cancer

- 1-line Therapy
  - Progression of disease
  - HS/SPC
- 2-line Therapy
  - Progression of disease
  - HS/SPC
- Last-line Therapy
  - Progression of disease
  - DFT/SPC
- Death
  - SPC

### Additional Triggers

- Survival prognosis less than 6 month, or/and
- Worsening of patient’s conditions, or/and
- Patient’s request
systems, wishes, and preferences. Obviously, this approach also does not allow fostering patient autonomous decision-making. To do so, timely information disclosure and eliciting and understanding of patients’ preferences are essential.

**Anticipatory approach integrated into a framework of timeliness**

The anticipatory approach implies helping patients understand that therapy is not curative from the moment that it becomes clear. This approach also involves carving out patient’s preferences at decisive moments throughout their entire disease trajectory. This approach seems best suited to enable patient-oriented EOL decisions, be it a focus on the quality of life or on prolonging a lifetime. For patients who have not indicated that they want others to decide for them, enabling autonomous choices requires informing patients about their condition and all of the treatment options including the best supportive care.

Therefore, timely and appropriate decision-making is more likely to happen if physicians elaborate patients’ preferences in advance.

This approach of addressing treatment goals and choices early on is supported by the literature [16, 31] and a single-center study. In this study, an early integration of palliative care did not only positively impact quality of life and reduce depressive symptoms but also lengthen survival time [22, 31]. With the anticipatory approach to decision-making, the patient’s illness trajectory is divided into much smaller, less-emotionally charged time points. However, oncologist also emphasized that they would be cautious to balance prognostic information with optimistic outlooks.

Oncologists in our study suggested that they would initially mention situations in which forgoing cancer-specific therapy would be sensible, when the patient still feels well, and readdress this point again when only one treatment option is left or when the patient’s condition worsens. We integrated our results and what we learned from the literature into a concept of timing and initiating advanced care planning discussions (Fig. 1). It entails mentioning the hypothetical situation at the outset that one might reach a certain point where chemotherapy is of marginal benefit and might primarily add toxicity and then uses defined trigger points over the course of the disease for readdressing treatment goals and means using hypothetical (best case/worst case) scenarios. We suggest at least the following decisive triggers while not claiming to be exhaustive: mentioning hypothetical (best/worse case) scenarios with every decision to switch to another line of chemotherapy due to progressive disease, explicitly preparing the patient for best supportive care when switching to the last line chemotherapy and also if one expects that the patients’ prognosis (of remaining lifetime?) is quite short (e.g., less than 3 months). Besides, there are several other patient-oriented triggers like the patient’s request or the worsening of the patient’s condition.

**Conclusion**

The results of this empirically based ethical analysis could serve as base for the development of concrete recommendations on the optimal timing for discussions about discontinuation of aggressive chemotherapy. The proposed concept of timing favors an anticipatory approach that prepares patients for such decisions throughout the course of their disease (Fig. 1).

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**References**