Wiley
European Journal of Cancer Care
Volume 2024, Article ID 8889981, 8 pages
https://doi.org/10.1155/2024/8889981

WILEY

Research Article

"There is No Alternative." Treatment Decision-Making in Lung Cancer Patients with Limited Prognosis: Results of a Qualitative Interview Study

Laura Unsöld[1,2], **Nicole Deis**[1,2], **Anja Siegle**[1,2], **Michael Thomas**[1,2] and **Matthias Villalobos**[1,2]

[1]*Department of Thoracic Oncology, Thoraxklinik Heidelberg University Hospital, National Center for Tumor Diseases (NCT), NCT Heidelberg, A Partnership between DKFZ and Heidelberg University Hospital, Heidelberg, Germany*
[2]*Translational Lung Research Center Heidelberg (TLRC-H), German Center for Lung Research (DZL), Heidelberg, Germany*

Correspondence should be addressed to Laura Unsöld; laura.unsoeld@med.uni-heidelberg.de

Received 7 March 2023; Revised 27 November 2023; Accepted 5 August 2024

Academic Editor: Mohammad Reza Kalhori

Objective. Decision-making in advanced cancer with a limited prognosis is particularly challenging: constantly evolving therapeutic algorithms with new treatment options that show marginal benefits have to be balanced with end-of-life decision-making. But existing decision support tools for advanced cancer patients are rare, not routinely used in clinical practice and do not sufficiently meet patients' needs. Therefore, our project explores the experienced decision-making process in advanced lung cancer to derive recommendations for the use of shared decision-making in this context. *Methods*. 20 semistructured interviews with lung cancer patients, their relatives, and healthcare professionals were conducted. All data were transcribed verbatim and analyzed with a thematic content analysis. *Results*. The decision-making process of advanced cancer patients is mainly characterized by a lack of perceived options. Physicians do not adequately present palliative care as an alternative or additional support for these patients. Being confronted with limited options that only include active cancer treatment patients tend to choose a more paternalistic decision model leaving the treatment decision to their physicians and accepting aggressive treatments uncritically. *Conclusion*. A paternalistic decision-making model in advanced cancer may neglect individual wishes, values, and preferences of patients and promote a feeling of powerlessness. Empowerment of these patients is needed with context-specific SDM tools and trainings of professionals to avoid overtreatment and facilitate the timely integration of palliative care. This trial is registered in DRKS00023674.

1. Introduction

While in the United States of America (USA), the concept of shared decision-making (SDM) and its implementation exists since the 1970s in many countries in Europe, for example, in Germany, this concept has only increased interest in research and public since the 2000s [1, 2]. Still, the implementation and application are not nearly as pronounced. One possible reason for the broader use of SDM in the US may be the differences in the healthcare systems in who covers the health-related costs for patients [3]. While in the USA, many patients have copayments and out of pocket expenses, and in Europe, patients profit from universal health insurance coverage. Moreover, the treatment (and care) decision-making in advanced and noncurative cancer poses multiple challenges for patients and healthcare professionals (HCPs): time restrictions and workload on the clinicians' side, information overload [4, 5], distress, and anxiety on the patients' side among others [6, 7]. Nonetheless, patients wish to increase their knowledge about the disease and treatment options affecting their quality of life and to participate more actively in the decision-making process [8, 9]. In the German guideline for the treatment of patients with lung cancer, ACP and SDM are

recommended [10]. But the German Healthcare System still lacks standardized, comprehensive, and nationwide implementation of ACP in the hospital setting [11]. Patients with serious illnesses such as advanced lung cancer may use cognitive processing but also intuition, feelings, and trust to make complex decisions [12]. In noncurative treatment, decisions differ substantially from those made in curative settings, as uncertain gains in terms of survival outcomes and quality of life have to be weighed against the potentially severe side effects of treatment regimens [13]. This may leave patients and relatives in limbo between tumor-centered therapy and best supportive care (BSC) in a setting that is characterized by very individualized situations of preference-sensitive treatment decisions. While SDM can improve advanced cancer patients' quality of life and care in the end-of-life [14], it still lacks practical application and quality. Especially, existing decision support tools—such as decision aids (DAs)—for this specific setting are rare, not yet sufficiently confirmed in their positive effect and/or do only insufficiently meet the patients' decision needs [15, 16]. Our study aims to explore the experience of the decision-making process from the perspective of patients with advanced lung cancer, their relatives, and healthcare professionals (HCPs). Hereby, relevant steps and recommendations for the application and implementation of SDM and DAs in advanced cancer should be derived.

2. Materials and Methods

2.1. Design. Semistructured qualitative interviews via face-to-face or telephone were conducted with metastatic lung cancer patients, their relatives, and involved HCPs. A pragmatic worldview guided the study [17]. When considering the decision-making process, we distinguish between the three ideal-typical models of paternalistic, informed, and shared decision-making (SDM) [18–20]. The Standards for Reporting Qualitative Research (SRQR) [21] guided the reporting (see Appendix A).

2.2. Recruitment and Sampling. Staff from the oncological outpatient clinic assisted in identifying potential participants. Eligible patients, who were 18 years or older, had to be diagnosed with advanced metastatic lung cancer (stage IV), showed no indication of mental illnesses or significant cognitive impairment, and had sufficient knowledge of the German language. Patients in poor physical condition were excluded. All potential participants were then contacted by the researcher (N.D.) who introduced the study and addressed questions. Patients (and other participants) who then wished to take part in the study were required to provide written informed consent. Recruitment of relatives was possible through the participating patients. HCPs were identified from the participating outpatient unit and had to have a minimum of two years' experience in oncology. The study was approved by the Research Ethics Committee of the University of Heidelberg (Ethics Committee No.: S-795/2019), registered at the German clinical trials register (No. DRKS00023674) and all procedures followed the regulation of the Declaration of Helsinki [22].

2.3. Data Collection. Interviews were conducted with patients, relatives, and HCPs from the outpatient unit of the Department of Thoracic Oncology at the University Hospital Heidelberg, Germany. This hospital is a certified (German Cancer Society) comprehensive lung cancer center and one of the largest thoracic oncology clinics in Germany providing care for about 600 patients newly diagnosed with metastatic lung cancer per year (about 1% of incident yearly of lung cancer cases in Germany). All interviews were conducted by a female researcher (N.D.) with a background in psychology, communication, and experience in interviewing. The researcher had no relationship with the participants prior to the study (excluding the HCPs). Semistructured qualitative interview topic guides (see Appendix B) were initially piloted and the one for patients modified with patient representatives. The interview guide for relatives included the same topics but was rephrased to the relatives' perspective. The HCPs' interview guide used more generalized questions about the HCPs everyday decision-making processes. This interview guide was extended by the topic of implementation of decision aids. Participants' additional information, e.g., sociodemographic aspects, was collected via a short questionnaire. Field notes and postscripts were recorded after each interview. Interviews were transcribed and analyzed for each participant group separately within eight weeks. Data were collected until no new themes (in the last two interviews conducted) emerged, thus saturation in the patient group (not for relatives or HCPs) was reached.

2.4. Data Processing and Analysis. All interviews were digitally audio-recorded and transcribed verbatim [23]. The qualitative data was coded and analyzed by one author (L.U.) using MAXQDA (version 2020) and thematic data analysis following Kuckartz [24]. The analysis consisted of seven stages: (1) an initial work with the transcripts (repeated reading, highlighting important passages, and case summaries), (2) developing and refining the deductive main topic categories of the code system, (3) first coding process using the main categories, (4) compiling the assigned passages to the main categories, (5) determining the inductive subcategories, (6) second coding process with the elaborated category system, and (7) the category-based analysis and presentations of results. The different stages of the code system as well as the compiling of the interview passages to the codes were discussed with regard to traceability between N.D., A.S., and L.U. To ensure analytical rigor, an investigator agreement was used to enhance the validity and confirmability of the findings. Where disagreement was present, discussion took place between N.D., A.S., and L.U. to reach consensus.

3. Results

3.1. Sample. Twenty participants were recruited and interviewed between July 2020 and March 2021. As shown in Table 1, the participants comprised nine patients, six relatives, and five HCPs. The duration of interviews was on

Table 1: Sample characteristics of participants.

	Patients $n = 9$	Relatives $n = 6$	HCPs $n = 5$
Gender (male/female)	4/5	3/3	3/2
Age (years)			
Mean	61	57	45
Range	42–72	32–70	39–60
Interview duration (minutes)			
Mean	46	34	32
Range	23–110	10–46	20–51
Months since diagnosis			
Median	9	—	—
Range	3–158	—	—
Relationship to patient			
Partner/spouse	—	5	—
Child	—	1	—
Profession			
Nurse	—	—	2
Physician	—	—	3

average 39 minutes (range 10–110 minutes). The cancer patients were on average 61 years old. To get a broader variety of disease experiences, two patients with a longer survival time were included. Relatives were on average 57 years old. Each relative was one relative of one patient and comprised five patients' partners and one child. Healthcare professionals were on average 45 years old and included three male physicians (one with additional training in palliative medicine) and two female nurses (one with additional training in palliative care).

3.2. Main Themes. Three main themes emerged from the data: (1) characteristics of a decision-making process that results in a perceived lack of alternatives (2) different decision-making topics without presentation of palliative care as an option and (3) decision-making influenced by multiple factors (e.g. wish of life-prolongation, social environment, uncertainty). A full coding frame is presented in Appendix C.

3.2.1. Theme 1: Decision-Making Process. The first main theme explores the (conscious and unconscious) nature of the process of treatment decision-making in metastatic lung cancer. It is characterized over the whole disease trajectory by strong emotions related to the life-threatening situation that patients and relatives are exposed to. It starts when confronted with the diagnosis.

> *When I imagine how one gets the diagnosis of lung cancer [. . .] they fall into a very deep hole. And they are afraid because they don't know what's coming. And then the doctors have to explain it precisely, but explain it in such a way that they don't scare them.* (Help001Patient, 81-83)

In this case, treatment decision-making is charged with strong feelings of fear, shock, and worry. These feelings not only occur at the time of diagnosis but also at disease progression and transition to BSC as mentioned by the interviewed patients and relatives. Confronted with all aspects of a life-limiting disease, most patients are too overwhelmed to take part in the process of treatment decision-making, and hand it over to the attending HCPs.

> *At some point I was also mentally and physically, just so down, [. . .], that I was also just glad that others had decided it [note: the treatment] for me.* (Help005Patient, 73)

The choice of a paternalistic decision-making model is stated in context with the emotional state by the patient, and it leads to the second important theme: the patient-physician-relation. This theme highlights aspects (such as chosen decision-making model) and assumptions of the interaction and role expectations of those involved. Even though some interviewees mentioned aspects of shared decision-making, patients seem to choose a paternalistic model more often avoiding actively to participate.

> *You know, when doctors tell me, "Mrs. [patient's name], this is what we recommend," then I never questioned it much. Because I just had the desire to survive somehow if possible. You know? I didn't want to kind of discuss that.* (Help005Patient, 55)

Patients and relatives stated that they were no experts in the field of cancer treatment and therefore needed to have confidence in the abilities and decisions of the treating HCPs. This aspect is connected to the hope of survival when relying on the professionals' decision and also leads to a paternalistic decision-making model. Trustingly, leaving the decision to the professionals, patients want to be guided through the process of treatment.

> *[. . .] someone who takes you by the hand, where you have confidence. That should actually be a doctor.* (Help008Patient, 57)

Patients wish to find in the physician treating them a person "whom they can entrust their life to." Trust is an often-mentioned motive by patients and relatives for the treatment decision-making.

The third theme that characterizes the process of decision-making is the (perceived) lack of alternative treatment options. This theme highlights the patients' and relatives' perspective that there is no further treatment option but the one explained and offered by the treating physician, which is usually tumor-centered.

> *The decision was not difficult at all to say "Yes, I'll do it" [note: the therapy]. Because I had no alternative except chemo. I had no alternative. And the way the doctor explained it to me was very, very conclusive.* (Help003Patient, 31)

Most patients tend to agree on every possible tumor-centered therapy, which in turn leads to the acceptance of side effects and restrictions in quality of life. Not only

patients and relatives but also the treating HCPs perceive a lack of treatment options. However, this is not described by them—especially the physicians—as problematic in relation to first-line therapy.

> *Sometimes there are palliative disease situations and there is no option. Then there are no conflicts in the decision, because there are very clear data in favor of first-line treatment. That is then recommended and accepted by the patient - that fits.* (Help003Professional, 7)

BSC as an alternative is only considered by physicians when factors such as the patient's high age or deterioration in health make it a relevant option:

> *And I always emphasize, especially with stage four patients, perhaps older, frailer ones, that it is also an option to say NO therapy. Because many people also want to hear about several options and not doing anything at all is actually relatively rare. For us doctors, of course, it's always the less favored option.* (HELP004Professional, 9)

The following quote from a nurse shows that even though some of the interviewed HPCs agree that, in theory, patients should be presented with different options and, in practice, they do not explain or offer alternatives.

> *My observation is, that the vast majority of patients, especially at the beginning, when they are newly diagnosed, are not given a choice. They [note: physicians] don´t say "you can now do chemo or nothing at all." They [note: patients] are simply told "this is the therapy, now we'll do the examination and then we'll see which therapy is right for you." And then the patients come to the next meeting and they are told, this therapy fits the tumor and we start then and then.* (Help002Professional, 3)

3.2.2. Theme 2: Decision-Making Topics. This theme comprises—apart from the treatment decision—further possible topics (e.g., about medication and healthcare services; see Appendix C). One decision topic has specific importance in the context of treatment decision-making and perceived lack of alternatives: introducing palliative care. This treatment is often not perceived as a valid option, or even as a treatment option at all, and is usually solely considered as terminal care by patients.

> *I thought about it (note: palliative care) for maybe ten seconds (laughs). But because it is not yet an option for me. And I, for me it's hard whether I stay at home or whether I then, I do think I would get palliative care.* (Help009Patient, 38)

Palliative care has a sensitive character for patients as a decision topic. It is discussed or thought of briefly by patients and then postponed to a later time (when there is nothing else to be done). It is never seen as an alternative option to tumor-centered therapy or as something that could be added. This may also be influenced by the physicians' view on palliative care.

> *The patient is reasonably fit and you could do a therapy, but we know the therapy will not change much - meaning that the tumor becomes small, a little smaller, but nothing changes the patient's life expectancy. This means that you offer the patient a therapy, but you leave everything open. [. . .] That's difficult. I think most of the time it comes from the fact that we doctors ourselves do not want to accept that there is no longer a therapy option for patients who are reasonably fit.* (Help003Professional, 7)

Although the HCP describes the dilemma that an offered therapy may not bring a significant added value for a patient, palliative care as a possible solution to this dilemma is not mentioned or offered to the patient. This physician states that colleagues also tend not to speak about palliative care. One possible explanation for the lack of discussion of palliative care and the associated lack of sufficient thematization of the goals of care is seen by physicians in the widespread—negative—idea and understanding of palliative care among patients.

> *Perhaps they should try to educate people better. Because it's still relatively common, just by mentioning the word "palliative," that many people still think: "Aha, that's the end of the line. Am I already so far gone that they don't want to do anything more with me?"* (HELP004Professional, 31)

Physicians are not only aware of the difficulty for patients in dealing with these issues and can understand them. They are also the ones who find the discussion on palliative care difficult themselves and are unwilling or unable to conduct them at the start of treatment.

> *So this topic, too, is perhaps really difficult for patients who are already at an advanced stage with metastases. Many still find it difficult to deal with issues such as health care proxies and living wills. To be honest, I have to say that even in the metastasized situation, I don't necessarily address this during the first (line) treatment.* (HELP004Professional, 45)

3.2.3. Theme 3: Factors Influencing Decision-Making. In the process of disease-related decision-making, patients are surrounded by a multitude of influencing factors. Important and often stated influences on the decision-making are the themes of survival and life-prolongation:

> *And that's why, in retrospect, I would have decided in favor of chemo and radiation therapy. Because you still have the possibility, even if it is a small one, but that it (note: the cancer) just does NOT come back.* (Help005Patient, 69)

This patient would choose the tumor-centered therapy because the focus lies on survival. This theme is mentioned in connection with the fight against cancer and can also be

found in the context with another important decision influence: relatives and friends.

> *But even then, I have the feeling that patients often want to do everything possible, because they feel that they have somehow not fought enough. Or that they haven't exhausted all the possibilities for their family or relatives.* (Help002Professional, 5)

Patients tend to try everything therapeutically possible to prolong the time together with their relatives. This influencing factor shows that patients' personal decisions are situated in a broader social context apart from individual physical and psychological factors.

When evaluating aspects such as age and comorbidity, the HCPs are also confronted with uncertainty. This often arises due to existing gaps in evidence for cancer treatment in specific settings. This may lead to vague statements and insufficient information in the patient-physician encounter.

> *As a doctor, I don't know whether what I'm saying will reach the patient or not. Does the patient feel afterwards that he/she is well informed or not?* (Help003Professional, 5)

Uncertainty may even have a broader implication in communication as it not only relates to lack of evidence and increasing challenges in prognostication but also includes the insecurity about what the patient may understand or assimilate from the information delivered. It is interesting to note that although the uncertainty is observed by the physician, it persists in the encounter because patients are not asked to which extent they understood or processed the given information.

4. Discussion

Characterized by emotions of shock and fear, advanced lung cancer patients often opt for a paternalistic approach to treatment decision-making, which leads to a fatalistic conclusion, presented by patients and physicians, that there is no alternative. This process results in a seemingly functional system in which patients trustingly place themselves in the hands of the treating physicians and hope that they will act in their best interest. But this system is also characterized by hidden gaps and faulty perceptions. An important but often neglected point is the importance of emotions in the decision-making process. Current research shows that emotions can influence the already complex decision-making process in many ways. Thus, emotions have a strong influence not only during the decision discussion but also before and after. In this context, the influence of emotions is not linear, but complex, because the emotions of all parties—the patients' and physicians'—are interwoven [25, 26]. Not only the patient and relatives but also the physician is an emotional participant in the decision-making with feelings such as uncertainty. Emotions and emotional states influence decision-making on an individual and intraindividual bases. Patients, for example, take a more passive role in obtaining and processing information [27], and decision-making is hindered by intense fear and anxiety [28]. Furthermore, the stress associated with the diagnosis [29] can often not be expressed by the patient and is therefore excluded as a decision criterion in the treatment decision [27]. The paternalistic decision-making model, in conjunction with the charged emotional situation of the serious and life-threatening illness experience, has consequences for the decision-making process [30, 31]. Patients thus do not actively bring themselves and their wishes, needs, and complaints into the decision-making discourse (neither are they invited or assessed by the physicians), which means they cannot be adequately considered [32]. Despite findings that show a positive effect of SDM on patients' quality of life, deficiencies in implementation in the context of advanced cancer are still apparent [33, 34]. By focusing more on the emotional and interpersonal aspects of SDM, it can be used to reestablish patients' personal autonomy and counter the disease-related sense of powerlessness and passivity [35].

Furthermore, it became clear that patients with a limited prognosis perceive a lack of alternatives, which influences the choice of therapy. It cannot be denied that the options for advanced lung cancer patients are limited. However, the perceived lack of alternatives turns out to be a fallacy resulting from the focus on purely tumor-centered therapy and deficits in the use of SDM [34]. Alternative options—such as palliative care or watchful waiting—are not perceived as equal options by those involved. Physicians may even fail to present these possible alternatives for advanced cancer patients in a comprehensible manner during medical encounters [36–38]. The results show that the discussion of palliative care is often still a taboo and is related to the feeling of giving up on the fight against cancer. Tumor-centered treatment seems to be like a maelstrom that is powered by patients', relatives' and HCPs' hope for life prolongation. It appears to work like a self-acting process in clinical practice. To swim in the maelstrom seems easy while stopping it (ending tumor-centered therapy and offering palliative care) is a strenuous effort for those involved. The pressure on patients' decisions is manifold and comprises not only emotional but also social and financial aspects among others. The continuous approval of new cancer treatments constitutes surely an additional factor that stresses decision-making by fueling hope and risking aggressive EOL-care as seen since the introduction of immunotherapies [39, 40]. This pressure influences physicians subjectively and hinders engaging in SDM and even mentioning palliative care [41]. Although the positive effects of early integration of palliative care have already been proven for advanced (lung) cancer [42, 43], the results indicate that the active introduction of this therapy option is still challenging and has to be adapted to the evolving dynamics of cancer treatment [44]. Although ACP has been implemented in Germany since the 2000s and is already firmly established within nursing homes, this has not yet happened in the case of hospital settings [11]. At the same time, ACP is a process and HCPs not always achieve early engagement because of different challenging and hindering factors. This study shows the still prevalent misconceptions about palliative care in several patients and relatives and the reluctance to speak about palliative care in

oncology physicians. These findings show the importance of continuous education on both sides and the necessity of tailored approaches for the complexity of ACP. One intriguing topic that probably explains in part our results is the fact that in the last years (especially since the introduction of immunotherapies), the integration of palliative care is increasingly jeopardized. This is because of inadequate awareness about the prognosis and treatment goals in patients and the negative impact of prognostic uncertainty on discussion between oncologists and their patients [45, 46]. Metastatic lung cancer is paradigmatic for this situation because of rapid changes in therapeutic algorithms. Several studies show that, in general, 20–30% of patients with incurable disease have an inadequate awareness despite honest discussion. Interestingly, in metastatic lung cancer, studies show that patients with targetable mutations and patients receiving immunotherapy may even have worse prognostic awareness. Introducing palliative care can positively support the challenges of physician-patient communication and joint decision-making in advanced cancer by also helping to cope with uncertainty and powerlessness. Patients' and physicians' perceived lack of alternatives also gives an indication of the still insufficient training and implementation of SDM in advanced cancer and shows the necessity of rethinking and differentiating the SDM concept between different types of decisions.

A new perspective on SDM—such as the concept of "purposeful shared decision-making" postulated by Hargraves et al. [47, 48]—could help to solve this problem. The problem-based approach of purposeful shared decision-making considers the uniqueness of each patient's individual situation and experience of illness and shows that decision-making varies between different decision situations and topics which require the use of different methods and approaches of shared decision-making. By this, the concept shows that SDM is more than involving patients in an evidence-based decision situation between equivalent options to choose from. Shifting from a generalized to a purposeful scheme of SDM can help to change the physicians' perception that SDM does not apply to decisional situations for advanced (lung) cancer. Thereby, the active use of SDM concepts in physician-patient-encounters can be improved and important aspects such as the patients' emotions and needs as well as the aspect of timely integration of palliative care can be included.

4.1. Study Limitations. Some limitations of our study have to be noted: all participants have been recruited in a single cancer center from one German region. Specifics in culture and healthcare system have to be considered in respect to the results. Patients have been recruited while being treated at the center which possibly can lead to biased answers. Nonetheless, the strength of this study is the exploration of the complex decision-making process in a real world setting from different participants' perspectives.

4.2. Practice Implications. Decision-making tools, concepts, and trainings to promote SDM in advanced lung cancer have to consider circumstances and context factors of the lived experience of patients, relatives, and HCPs involved. Also, patients' emotional states and needs have to be addressed. Hence, patients, as experts for their own lives [49], have to be empowered to participate in the decision-making by sharing their personal values, preferences, needs, and experiences [50]. In addition, SDM tools and concepts in advanced cancer should introduce the option of early palliative care [51]. The option of maintaining the status quo regarding quality of life (option of exclusive or additional palliative care) should be presented on an equal footing with tumor-centered high-risk and low benefit options in the SDM concept. Especially, interprofessional approaches (including nurse navigators, social workers, and psychologists) may be helpful to improve the facilitation of prognostic awareness and the early introduction of ACP in the context of advanced cancer [52].

5. Conclusions

The treatment decision process for patients with advanced lung cancer is complex and multifaceted. In the hope of life prolongation and accompanied by strong emotions, patients trustingly and passively place themselves in the hands of their treating physicians and rarely reflect on and express their personal needs. At the same time, treating physicians avoid presenting palliative care as a possible alternative to tumor-centered therapy and rarely invite the patient to participate actively in the decision-making process. To countervail these practices, the following prerequisites are necessary: (1) decision awareness, (2) decision enunciation (3) empowerment of the patient to share their emotions and needs, and (4) structured instruments to support SDM. The use of SDM can counteract the powerlessness, hopelessness, and passive decision-making behavior described by patients in the context of diagnosis and disease experience.

Data Availability

The data that support the findings of this study are available from the corresponding author on reasonable request. The data are not publicly available due to privacy or ethical restrictions.

Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this paper.

Acknowledgments

This study was funded by a research grant from the Bristol Myers Squibb Foundation Immune Oncology, Germany. The study is part of the research project "HELP—Heidelberg decision aids for lung cancer patients" (German clinical trials register ID: DRKS00023674; principal investigator: Dr. Matthias Villalobos, University Medical Center Heidelberg, Department of Thoracic Oncology). The foundation provided funding but did not play a role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript. Open access funding was enabled

and organized by Projekt DEAL. We would like to thank all patients, their relatives, and healthcare professionals for participating in this study. We would like to special thank Anastasia Korezelidou and Mara König for transcribing the interviews and Theodore Best for editing the manuscript.

Supplementary Materials

Appendix A of the supplementary material contains the description of the Standards for Reporting Qualitative Research (SRQR) checklist for a clear and transparent presentation of the research. The document gives information on whether the different research procedures have been fulfilled and where they can be found in the manuscript. Appendix B of the supplementary material comprises the used interview guides. According to the three groups of patients, relatives, and HCPs studied, the document contains information on the different interview questions and topics corresponding to each group. Appendix C of the supplementary material shows the full coding frame of the qualitative analysis. Apart from the main results reported in the manuscript, this document gives an overview of all coded (main) themes, their definition, and occurrence in the different groups of participants. (*Supplementary Materials*)

References

[1] F. Scheibler, C. Janssen, and H. Pfaff, "[Shared decision making: an overview of international research literature]," *Sozial- und Präventivmedizin*, vol. 48, no. 1, pp. 11–23, 2003.

[2] A. Coulter, M. Härter, N. Moumjid-Ferdjaoui, L. Perestelo-Perez, and T. vanDerWeijden, "European experience with shared decision making," *International Journal of Person Centered Medicine*, vol. 5, no. 1, pp. 9–14, 2015.

[3] P. M. Carrera, H. M. Kantarjian, and V. S. Blinder, "The financial burden and distress of patients with cancer: understanding and stepping-up action on the financial toxicity of cancer treatment," *CA: A Cancer Journal for Clinicians*, vol. 68, no. 2, pp. 153–165, 2018.

[4] B. J. Russell and A. M. Ward, "Deciding what information is necessary: do patients with advanced cancer want to know all the details?" *Cancer Management and Research*, vol. 3, pp. 191–199, 2011.

[5] L. Josfeld, C. Keinki, C. Pammer, B. Zomorodbakhsch, and J. Hubner, "Cancer patients' perspective on shared decision-making and decision aids in oncology," *Journal of Cancer Research and Clinical Oncology*, vol. 147, no. 6, pp. 1725–1732, 2021.

[6] W. Linden, A. Vodermaier, R. Mackenzie, and D. Greig, "Anxiety and depression after cancer diagnosis: prevalence rates by cancer type, gender, and age," *Journal of Affective Disorders*, vol. 141, no. 2-3, pp. 343–351, 2012.

[7] A. Pitman, S. Suleman, N. Hyde, and A. Hodgkiss, "Depression and anxiety in patients with cancer," *The BMJ*, vol. 361, 2018.

[8] L. Brom, J. C. De Snoo-Trimp, B. D. Onwuteaka-Philipsen, G. A. Widdershoven, A. M. Stiggelbout, and H. R. Pasman, "Challenges in shared decision making in advanced cancer care: a qualitative longitudinal observational and interview study," *Health Expectations*, vol. 20, no. 1, pp. 69–84, 2017.

[9] D. Stacey, F. Legare, K. Lewis et al., "Decision aids for people facing health treatment or screening decisions," *Cochrane Database of Systematic Reviews*, vol. 4, no. 4, Article ID CD001431, 2017.

[10] Guideline program oncology, "German Cancer Society, German Cancer Aid, AWMF: prevention, diagnosis, therapy and aftercare of lung cancer, long version 1.0, AWMF register number: 020/007OL," 2018, http://leitlinienprogramm-onkologie.de/Lungenkarzinom.98.0.html.

[11] K. Gotze, B. Feddersen, J. In der Schmitten, and G. Marckmann, "Advance care planning in Germany," *Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen*, vol. 180, pp. 127–132, 2023.

[12] R. M. Epstein, "Whole mind and shared mind in clinical decision-making," *Patient Education and Counseling*, vol. 90, no. 2, pp. 200–206, 2013.

[13] M. D. Brundage, D. Feldman-Stewart, R. Cosby et al., "Cancer patients' attitudes toward treatment options for advanced non-small cell lung cancer: implications for patient education and decision support," *Patient Education and Counseling*, vol. 45, no. 2, pp. 149–157, 2001.

[14] S. Ozdemir, I. Chaudhry, S. N. G. Tan et al., "Variation in patient-reported decision-making roles in the last year of life among patients with metastatic cancer: a longitudinal study," *Medical Decision Making*, vol. 43, no. 2, pp. 203–213, 2023.

[15] I. Spronk, M. C. Meijers, M. J. Heins et al., "Availability and effectiveness of decision aids for supporting shared decision making in patients with advanced colorectal and lung cancer: results from a systematic review," *European Journal of Cancer Care*, vol. 28, no. 3, Article ID e13079, 2019.

[16] G. Phillips, K. Lifford, A. Edwards, M. Poolman, and N. Joseph-Williams, "Do published patient decision aids for end-of-life care address patients' decision-making needs? A systematic review and critical appraisal," *Palliative Medicine*, vol. 33, no. 8, pp. 985–1002, 2019.

[17] J. Creswell and V. Plano Clark, *Designing and Conducting Mixed Methods Research*, Sage, Thousand Oaks, CA, USA, 2018.

[18] C. Charles, A. Gafni, and T. Whelan, "Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango)," *Social Science and Medicine*, vol. 44, no. 5, pp. 681–692, 1997.

[19] E. J. Emanuel and L. L. Emanuel, "Four models of the physician-patient relationship," *Journal of the American Medical Association*, vol. 267, no. 16, pp. 2221–2226, 1992.

[20] J. Hurley, S. Birch, and J. Eyles, "Information, efficiency and decentralization within health care systems," *CHEPA Working Paper Series*, vol. 21, 1992.

[21] B. C. O'Brien, I. B. Harris, T. J. Beckman, D. A. Reed, and D. A. Cook, "Standards for reporting qualitative research: a synthesis of recommendations," *Academic Medicine*, vol. 89, no. 9, pp. 1245–1251, 2014.

[22] World Medical, "World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects," *Journal of the American Medical Association*, vol. 310, no. 20, pp. 2191–2194, 2013.

[23] T. Dresing and T. Pehl, *[Practical Book Interview, Transcription and Analysis Instructions and Control Systems for Qualitative Researchers]*, Sage Publications Ltd, London, UK, 2015.

[24] U. Kuckartz, *Qualitative Text Analysis: A Guide to Methods, Practice and Using Software*, Sage Publications Ltd, London, UK, 2014.

[25] F. Legare and P. Thompson-Leduc, "Twelve myths about shared decision making," *Patient Education and Counseling*, vol. 96, no. 3, pp. 281–286, 2014.

[26] T. Treffers and P. M. Putora, "Emotions as social information in shared decision-making in oncology," *Oncology*, vol. 98, no. 6, pp. 430–437, 2020.
[27] H. Stanze, N. Schneider, F. Nauck, and G. Marx, "I can't get it into my head that I have cancer.-A qualitative interview study on needs of patients with lung cancer," *PLoS One*, vol. 14, no. 5, Article ID e0216778, 2019.
[28] K. Mazzocco, M. Masiero, M. C. Carriero, and G. Pravettoni, "The role of emotions in cancer patients' decision-making," *Ecancermedical Science*, vol. 13, p. 914, 2019.
[29] D. Arai, T. Sato, I. Nakachi et al., "Longitudinal assessment of prognostic understanding in patients with advanced lung cancer and its association with their psychological distress," *The Oncologist*, vol. 26, no. 12, pp. e2265–e2273, 2021.
[30] M. M. Lowe, P. J. S. Osther, J. Ammentorp, and R. Birkelund, "The balance of patient involvement: patients' and health professionals' perspectives on decision-making in the treatment of advanced prostate cancer," *Qualitative Health Research*, vol. 31, no. 1, pp. 29–40, 2021.
[31] P. Hahlweg, M. Harter, Y. Nestoriuc, and I. Scholl, "How are decisions made in cancer care? A qualitative study using participant observation of current practice," *BMJ Open*, vol. 7, no. 9, Article ID e016360, 2017.
[32] M. M. L. Netsey-Afedo, J. Ammentorp, P. J. S. Osther, and R. Birkelund, "No time for reflection: patient experiences with treatment-related decision-making in advanced prostate cancer," *Scandinavian Journal of Caring Sciences*, vol. 34, no. 4, pp. 880–888, 2020.
[33] S. Ozdemir, Y. Tian, C. Malhotra et al., "Discordance between advanced cancer patients' perceived and preferred roles in decision making and its association with psychological distress and perceived quality of care," *Patient*, vol. 14, no. 5, pp. 581–589, 2021.
[34] G. T. Wasp, K. E. Knutzen, G. F. Murray et al., "Systemic therapy decision making in advanced cancer: a qualitative analysis of patient-oncologist encounters," *JCO Oncology Practice*, vol. 18, no. 8, pp. e1357–e1366, 2022.
[35] P. Gulbrandsen, M. L. Clayman, M. C. Beach et al., "Shared decision-making as an existential journey: aiming for restored autonomous capacity," *Patient Education and Counseling*, vol. 99, no. 9, pp. 1505–1510, 2016.
[36] A. L. Back, "Patient-clinician communication issues in palliative care for patients with advanced cancer," *Journal of Clinical Oncology*, vol. 38, no. 9, pp. 866–876, 2020.
[37] Y. Beaussant, F. Mathieu-Nicot, L. Pazart et al., "Is shared decision-making vanishing at the end-of-life? A descriptive and qualitative study of advanced cancer patients' involvement in specific therapies decision-making," *BMC Palliative Care*, vol. 14, no. 1, p. 61, 2015.
[38] A. Nelson, M. Longo, A. Byrne et al., "Chemotherapy decision-making in advanced lung cancer: a prospective qualitative study," *BMJ Supportive & Palliative Care*, vol. 18, 2020.
[39] J. Auclair, S. Sanchez, J. Chrusciel et al., "Duration of palliative care involvement and immunotherapy treatment near the end of life among patients with cancer who died in-hospital," *Supportive Care in Cancer*, vol. 30, no. 6, pp. 4997–5006, 2022.
[40] R. Matsuyama, S. Reddy, and T. J. Smith, "Why do patients choose chemotherapy near the end of life? A review of the perspective of those facing death from cancer," *Journal of Clinical Oncology*, vol. 24, no. 21, pp. 3490–3496, 2006.
[41] T. A. Pfeil, K. Laryionava, S. Reiter-Theil, W. Hiddemann, and E. C. Winkler, "What keeps oncologists from addressing palliative care early on with incurable cancer patients? An active stance seems key," *The Oncologist*, vol. 20, no. 1, pp. 56–61, 2015.
[42] J. S. Temel, J. A. Greer, S. Admane et al., "Longitudinal perceptions of prognosis and goals of therapy in patients with metastatic non-small-cell lung cancer: results of a randomized study of early palliative care," *Journal of Clinical Oncology*, vol. 29, no. 17, pp. 2319–2326, 2011.
[43] J. A. Greer, W. F. Pirl, V. A. Jackson et al., "Effect of early palliative care on chemotherapy use and end-of-life care in patients with metastatic non-small-cell lung cancer," *Journal of Clinical Oncology*, vol. 30, no. 4, pp. 394–400, 2012.
[44] E. J. Roeland, "Tailoring palliative care to the changing needs of people facing cancer," *Journal of Clinical Oncology*, vol. 35, no. 8, pp. 813–815, 2017.
[45] L. E. McLouth, J. Gabbard, B. J. Levine et al., "Prognostic awareness, palliative care use, and barriers to palliative care in patients undergoing immunotherapy or chemo-immunotherapy for metastatic lung cancer," *Journal of Palliative Medicine*, vol. 26, no. 6, pp. 831–836, 2023.
[46] A. R. Habib, R. Chen, E. S. Magnavita et al., "Prevalence and tolerance of prognostic uncertainty among thoracic oncologists," *The Oncologist*, vol. 26, no. 8, pp. e1480–e1482, 2021.
[47] I. G. Hargraves, V. M. Montori, J. P. Brito et al., "Purposeful SDM: a problem-based approach to caring for patients with shared decision making," *Patient Education and Counseling*, vol. 102, no. 10, pp. 1786–1792, 2019.
[48] I. G. Hargraves, A. K. Fournier, V. M. Montori, and A. S. Bierman, "Generalized shared decision making approaches and patient problems. Adapting AHRQ's SHARE Approach for Purposeful SDM," *Patient Education and Counseling*, vol. 103, no. 10, pp. 2192–2199, 2020.
[49] D. Tuckett, M. Boulton, C. Olson, and A. Williams, *Meetings between Experts*, Tavistock Publications, London, UK, 1985.
[50] D. R. Richardson and K. P. Loh, "Improving personalized treatment decision-making for older adults with cancer: the necessity of eliciting patient preferences," *Journal of Geriatric Oncology*, vol. 13, no. 1, pp. 1–3, 2022.
[51] M. Fliedner, S. Zambrano, J. M. Schols et al., "An early palliative care intervention can be confronting but reassuring: a qualitative study on the experiences of patients with advanced cancer," *Palliative Medicine*, vol. 33, no. 7, pp. 783–792, 2019.
[52] V. A. Jackson, J. Jacobsen, J. A. Greer, W. F. Pirl, J. S. Temel, and A. L. Back, "The cultivation of prognostic awareness through the provision of early palliative care in the ambulatory setting: a communication guide," *Journal of Palliative Medicine*, vol. 16, no. 8, pp. 894–900, 2013.