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Research Article

Personal Values, Wishes, and Goals of Patients with Advanced Lung Cancer: A Qualitative Study

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Objective. Oncology and palliative care guidelines for patients with incurable cancer recommend supporting patients at the end of life (EOL) by considering their personal values, wishes, and goals to facilitate decision making in advance care planning and patient-centered care. It is unclear, though, how to successfully address and integrate personal values in clinical practice. The aim of this study was to explore values, wishes, and goals from the perspective of patients with advanced lung cancer. *Methods*. Semistructured interviews were conducted with patients with advanced lung cancer and transcribed verbatim. The data were analysed using a structured content analysis. After identification of main categories, values were identified using Schwartz's Theory of Basic Human Values as a theoretical framework. *Results*. Identified main categories were "the individual in medical care," "living now," and "coming to terms." Values in the dimensions "conservation" and "openness to change" were described concerning patient-physician interaction, therapy goals, preparedness for EOL, and life goals. "Self-transcendence" values mainly related to caring for the burden on relatives. In general, patients showed reluctance in expressing information about personal values when communicating with physicians. *Conclusion*. Patients with advanced lung cancer engage in various ways to determine how they want and can influence their life and medical care. Different values and the associated wishes and goals play a crucial role in this context and should be taken into account by healthcare providers. The reluctance to express personal information in medical encounters underscores the need for a proactive attitude in physicians and improved interprofessional collaboration. The study was registered in the German register for clinical trials (DRKS00026993).

1. Introduction

Patients with advanced lung cancer are affected by a high rate of distress compared to other cancers [1]. With the diagnosis, patients may face strong physical symptoms, psychological challenges, and existential questions [2–6]. In addition, most patients (>75%) are diagnosed at an already advanced stage (III/IV) [7] with few therapeutic options and consequently a limited prognosis. Since comorbidities, social involvement, and individual preferences have an impact on prognosis, these patient-specific factors should be considered in treatment planning and decision making [2].

Caring for patients with lung cancer comprises tumor-centered therapies, focusing on life prolonging and often with a curative approach as well as palliative care, with a focus of the latter on quality of life. The nature of palliative care is holistic and therefore also interprofessional [2, 8]. However, the subjective perception of patients is also important for decision making in this context [2]. If patients are lacking prognostic awareness and the level of

communication about personal values and goals in life and care is insufficient, they might tend to choose aggressive therapies at the end of life (EOL) or care that is not congruent with their preferences [9]. Potential indicators for poor quality of care near the EOL are late admissions to hospice, tumor-centered therapies, or emergency admissions in the last four weeks of life and dying in intensive care units [10]. Care for patients with lung cancer that is congruent with patients' goals and values is associated with high quality of care [11]. Patients may not be able to process medical information [12], might not be aware of their guiding values, wishes, and goals [13], and therefore fluctuate in what they hope for in therapy [14]. Therefore, communication about values and associated wishes and goals is important for treatment planning and goal setting as it constitutes the basis for an informed decision by the patient [11].

Advance care planning (ACP) is "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care" [13]. To consider the complexity of decisions concerning medical care in serious illness, focus in ACP has shifted from eliciting preferences for a specific life-sustaining treatment to discussing patients' values and goals [4]. Oncology and palliative care guidelines describe domains in which the preferences and goals of patients should be discussed. This includes the general treatment goal (prolonging life or quality of life (QoL)), preferences, and personal goals in life [2, 15]. ACP can reduce the length and number of hospitalisations [16] and the use of aggressive treatments when the risk-benefit ratio is low [17, 18] and avoid the use of treatment services that do not meet patient preferences [19, 20]. Additionally, ACP is associated with higher QoL [19–22] and satisfaction in medical treatment [19, 20]. While it is clear that ACP should be integrated early in the care process, in clinical practice, these conversations are difficult to initiate and conduct and therefore often do not occur or do so only shortly before death [12, 23–26]. Dealing with patients' hopes as well as systemic barriers to the patient-physician relationship such as time constraints and physician rotation may constitute a further challenge for all involved.

A theoretical framework of basic human values was defined and developed by Shalom H. Schwartz [27]. Schwartz defines values as "trans-situational goals, varying in importance, that serve as guiding principles in the life of a person or group. (. . .) Basic values are organized into a coherent system that underlies and can help to explain individual decision making, attitudes, and behavior" [27]. Therefore, the relative importance of values impacts mostly unconscious attitudes and behavior. But when the considered actions or judgements have conflicting effects on different values that are meaningful to an individual, they enter consciousness [27]. Besides being cherished by the individual, values have to be relevant in a specific context to guide action [27]. Schwartz distinguishes ten basic human values, categorized in four dimensions: conservation (conformity, tradition, and security), openness to change (self-direction, stimulation, and hedonism), self-enhancement (hedonism (Hedonism is assigned to both: openness to change and self-enhancement), achievement, and power), and self-transcendence (benevolence and universalism) [27].

Little research has been done on values as guiding principles from the perspective of patients, compared to studies on specific preferences or on interventions to improve patient-centered communication and ACP, such as communication training [28], question prompt lists [29, 30], or nurse-led communication intervention [12, 31]. Ebenau et al. conducted a structured literature review to describe important personal values of older persons suffering from advanced cancer [32]. The authors identified comfort, continuity, humility, dignity, honesty, optimism, hope, and preparedness as important values. Studies included in this review explored preferences concerning general therapy goals or other aspects of care [33, 34], individual experiences of patients while living with cancer [35, 36], and specific [34, 37] or general values [38]. Further studies explored the following general values of patients with a palliative disease: independence and self-direction [6, 38, 39], benevolence [38], and universalism [38]. Values were not conceptualized in all studies [6, 40]. In qualitative interviews with advanced cancer patients, Cottingham et al. identified that patients often focus on living in the present [6]. Considering the nature of disease, lung cancer patient experiences might differ from patient experiences with other serious illness, e.g., regarding prognosis. Furthermore, individual experience can vary between cultural contexts [41, 42], though to our knowledge, there have been no studies on values of lung cancer patients in Germany. In general, little is known about guiding values in interactions with healthcare practitioners (HCPs) in the context of discussing prognosis and ACP, which is relevant to improve value clarification and thus ACP.

Understanding the relevant values in the context of medical care from the perspective of patients enables their improved integration in ACP conversations. Furthermore, conflicting implications on personal values through medical treatment are of interest for shared decision making and ACP. As part of a mixed-methods study named "Advance care planning: as a patient, how are my values, wishes, and goals taken into account in decision-making?", the aim of this qualitative study was to explore which values, wishes, and goals guide actions and decision making of patients with advanced lung cancer in arranging their care and private life.

2. Methods

2.1. Study Design. The study was conducted at the inpatient department of thoracic oncology at the University Hospital of Heidelberg by an interprofessional team comprised of research associates, physicians, and a psychologist. The presented qualitative study is part of a larger study with a mixed-method design, which includes a quantitative evaluation of patients' values using the human value scale (HVS) [43] and the here presented qualitative patient interviews. Findings of the quantitative evaluation and the integration of mixed-methods results will be reported elsewhere. Ethical approval for both parts of the study was

obtained from the ethics committee of the University Hospital Heidelberg (S-615/2021).

For the qualitative study, semistructured guide-based patient interviews were chosen to explore individual values related to living with cancer and patients' individual experiences of patient-physician interaction, therapies, and disease management.

2.2. Study Sample and Recruitment. Adult patients (>18 years of age) diagnosed with advanced lung cancer (stage IV) with a limited prognosis (median ≤12 months) and capacity to consent were approached for participation in an interview at an inpatient unit at the hospital by a researcher (MK) who was unknown to the patients. Participants were expected to be fluent in German. During recruitment, patients received written information about the goal and process of the study. Patients were preselected for participation in the study by two physicians during their inpatient hospital stay based on the inclusion criteria. Patients were not approached if, according to the physician, their ability to give consent was severely limited, e.g., due to secondary diseases or if their health status did not allow (requesting) participation in the study during the inpatient stay. The recruitment strategy did not include any specific strategies to address heterogeneity in terms of gender and age, as this is a difficult group to reach. Depending on patient preference, the interviews were offered to be conducted at the hospital unit or via telephone (at home). All participants had to give written informed consent prior to the interview.

2.3. Data Collection. From January until May 2022, 39 patients were asked to participate. Eighteen agreed and of these 17 completed the interview (1 dropout due to death before interview appointment). A balanced gender representation with nine women and eight men was reached in the study sample, with and an age range of 49 to 83 years (mean age: 64 years).

All participants provided written informed consent and pseudonymization and confidentiality were ensured. Mean interview duration was 36 minutes (range: 22–65). Table 1 provides detailed information on the sample characteristics. Four patients conducted the interviews via telephone, and 13 in the hospital (including single and shared rooms), based on the wishes of patients.

A semistructured interview guide was developed based on theoretical considerations and a thorough literature review covering aspects regarding values, goals, and experiences (Figure S1, supplementary material). At the beginning of the interview, all participants were asked to fill in the HVS [43]. In this qualitative study, we used participants' responses exclusively as starting points for our interviews. We asked them to share their personal interpretations of values of the HVS which were important to them. The main questions contained aspects regarding (1) what was important in their lives; (2) what was important in medical treatment; and (3) how they experienced conversations about personal values, wishes, and goals with physicians. At the end, participants had the opportunity to address further issues of relevance to them. The interview guide was pilot tested with a representative of the self-help group. Interviews were transcribed (f4 transcription software, Version 7.0.6) using the content semantic transcription rules [44]. Interviews were conducted by the first author who had a bachelor's degree in health promotion and was trained by a psychologist with experience in interviewing patients with advanced cancer. Patient characteristics were collected with a questionnaire, including information on sociodemographic attributes, religion, living situation, and subjective health, and from hospital standard documentation. Religion was collected using a continuum scale between zero and ten, with zero being defined as not religious at all and ten as very religious. Subjective health was collected using a five-point Likert scale from very good to very bad. Interviews were audio recorded. Postscripts were prepared after the interviews. To avoid further strain on participants, transcripts were not returned to them for feedback.

Table 1: Characteristics of participants.

Characteristics	Total ($n = 17$)	Range
Mean age (years)	64	(49–83)
Mean duration of interviews (min.)	36	(22–65)
Median religiosity[1] (scale 0–10)	5	(0–8)
Sex (female/male)	9/8	
Living situation (alone/not alone)	3/14	
Place of living		
Village	8	
City or small town	5	
Suburb/major city	1/3	
Subjective well-being		
Good	2	
Average	5	
Bad/very bad	9/1	
Therapy (tumor-centered/best supportive care)	15/2	
Disease status (last check-up)		
New diagnosis	3	
Progressive disease	7	
Stable disease	7	
Diagnosis (small-cell/non-small-cell tumor)	2/15	
Year of initial diagnosis		
2018 or earlier	3	
2019/2020	2	
2021/2022	12	
Stage at time of study participation		
IIIa/IIIb/IIIc	2	
IVa/IVb	15	

[1]Missing variable: 1.

2.4. Data Analysis. All qualitative data were analysed using the software MAXQDA (VERBI, Version 2020) and according to the structured content analysis of Kuckartz, including the steps: (1) initiating text work; (2) developing thematic main categories; (3) first coding process; (4) inductive determination of subcategories; (5) second coding process; and (6) simple and complex analysis and visualization [45]. These steps were modified in the analysing

process concerning the development of categories. Developing main categories from the research question would result in over ten values as main categories. We therefore decided to inductively explore aspects (main categories) of life from the patients' perspective, in which specific values play a role and may be relevant for the care of patients facing serious illnesses.

Those values were identified in a circular process resolving in inductive and deductive subcategories: subcategories were first identified inductively on a semantic approach [46] and then, if possible, assigned to values according to Schwartz, in consideration of the refining of the theory from 2012 [47]. By "inductive categorization," we refer to deriving categories directly from the data, while "deductive categorization" entails deriving categories from the research question, including theoretical frameworks. We decided to use a theoretical framework to provide a transparent understanding of values and to facilitate comparison with quantitative results of the HVS (this study does not present quantitative results using the HVS but is interested in facilitating the triangulation of quantitative and qualitative results). The epistemological approach chosen was pragmatism, whereby reality results from action and is not universally given but individually perceived [48]. Identified categories were coded by one person, described in a codebook (Table 2, supplementary material), discussed within the research team, and further modified to increase intersubjectivity. After 14 interviews, no more new categories were identified, and after conduction of three more interviews, thematic saturation [45] was assumed.

The study is reported according to the qualitative reporting guideline COREQ [49].

3. Results

The analysis identified three main categories: (1) the individual in medical care, (2) living now, and (3) coming to terms. Within these categories, general values were found and aggregated into subcategories (Table 1, supplementary material). Identified categories are described below (Table 2). Participants' quotations were carefully translated from German into English and are reported with reference to the corresponding transcription position.

3.1. The Individual in Medical Care. Participants described how they navigate their individual values, wishes, and goals in experienced aspects of medical care. Those include their interaction with physicians and sometimes other HCPs, as well as expectations regarding therapy and care at the EOL.

3.1.1. Conformity. Patients detailed their respectful and compliant behavior in interaction with physicians. Acceptance of the therapy proposed was described as reasonable, given the professional expertise of the treating physicians and the lack of alternatives. In this context, relying on the competence of physicians and respect for their medical knowledge was expressed. One patient indicated confidence and trust in physicians to be able to set personal goals or discuss personal treatment preferences. Patients also wished to be encouraged to ask physicians questions.

> "In treatment, yes, I take what comes. (. . .) I rely on that." (I14, pos. 53)

> "(. . .) possible alternatives to what was suggested. (. . .) So, whether there are alternatives and whether I can help decide about them or whether I am presented with something that would also be conceivable or seems sensible, but not quite so advisable, but if I wanted it, I could also have it." (I10, pos. 60)

Some patients mentioned that they searched for information themselves on the Internet because of unsatisfied information needs, while they actually wanted more information from physicians about the possible short-term care process or treatment alternatives. Some interviewed patients wanted their preferences for end-of-life care to be heard by physicians but had perceived it challenging to initiate such conversations or did not have the courage to ask. Therefore, they wished physicians would initiate and guide these conversations. One patient valued having their spouse around during prognostic conversation to prepare the spouse for the EOL of the patient.

> "And in this case, I considered it positive that steps were also addressed where one did not yet have the courage to do so oneself." (I9, pos. 67)

One patient described conformity in following the treatment plan despite the patient having accepted the proposed treatment with all its toxicity. Some patients described their reluctance to express personal values, wishes, and goals, as they perceived them as irrelevant to physicians and their professional duties or as a disturbance in the busy hospital routine. Some did not express the need of talking about personal issues such as values or goals in life or experienced distress with physicians, if these were perceived as not related to treatment.

> "You can only talk to the physicians about treatment. But then there are also psychology departments or something like that (. . .). But the physician himself (. . .), they are nice and make an effort, but I can't babble something to them for half an hour (. . .) which has nothing to do with my illness." (I13, pos. 70)

3.1.2. Autonomy of Action. Patients described their needs and related expectations of physicians. Information on prognosis and treatment options and the risks and chances of therapies were desired.

One patient wished for a general change in patients' and even in their own attitude, away from relying completely on the physician to take responsibility for treatment decisions. Subsequently the patient also described a needed change in physicians' role, from decision maker to expert adviser. The same patient wished to discuss personal therapy goals with physicians, especially regarding QoL. Having options in

Table 2: Identified main categories and subcategories.

Category	Subcategory	Definition of subcategory	Identification	Dimension in framework
The individual in medical care	Conformity	Restraint of actions, compliance with social norms	Deductive	Conservation
	Autonomy of action	Independent action	Deductive	Openness to change
	Security	Safety, stability of self	Deductive	Conservation
	Being treated benevolently	Trusted and caring encounters with HCPs	Inductive	Self-transcendence
	Universalism	Understanding and protection for the welfare of all people	Deductive	Self-transcendence
Living now	Security	Safety, stability of self, and relationships	Deductive	Conservation
	Autonomy of action	Independent action	Deductive	Openness to change
	Hedonism	Pleasure for oneself	Deductive	Openness to change/self-enhancement
	Stimulation	Excitement and novelty in life	Deductive	Openness to change
Coming to terms	Hope	Hoping for the best possible	Inductive	Elements of conservation
	Peace	Striving for inner peace and acceptance	Inductive	Elements of openness to change
	Self-respect	Maintaining self-respect and dignity	Inductive	Elements of conservation
	Autonomy of action	Independent action	Deductive	Openness to change
	Benevolence	Caring for welfare of in-group members	Deductive	Self-transcendence

their daily hospital routine such as deciding freely what to drink and eat or taking a walk in the park was valued by many patients.

3.1.3. Personal Security. Health was described as being cured from cancer or as improved QoL or both. Associated tumor-centered goals were prolongation of life and cure, while not tumor-centered goals concerned QoL and caring for comorbidities. QoL-related goals can also be submitted to self-direction and hedonism, which is described in the main category "living now" as life goals. Being cured or having the tumor controlled was sometimes described by patients themselves as naive wishes. Patients described feeling safe because they chose the hospital with the best chances of reaching their therapy goals.

> "And I think that's the hospital which will keep me alive the longest." (I7, pos. 39)

> "I think this has changed due to the illness. It used to be that security/Nothing is certain in life, the only thing that is certain is that there is no certainty. But when you're ill, it looks a bit different, I think. (. . .). Yes, the need for me, when I go somewhere and get a statement, that it's true, that it's right, that it's helpful for me. That I can just feel safe." (I6, pos. 8–10)

Information concerning the provision of organizational information (e.g., treatment appointments) was associated with reliability for planning. Regarding the care at the end of life, patients reported the goal to die without pain, at home and close to family members.

3.1.4. Being Treated Beneficially. Participants expected HCPs to treat them benevolently, which, in relation to the framework, could indicate the expectation of being treated by HCPs in a self-transcendent way, i.e., focused on the patient's well-being. Therefore, patients wanted their HPCs to consider their living situation, make time to explain and for questions, hear the truth, and respond to their concerns. Some patients described being open and honest to physicians about personal issues only if they know them to be trustworthy.

> "Because if someone is honest with me, I can also be honest with them." (I15, pos. 137)

In the context of conversations about personal issues, patients complained about having to explain their situation repeatedly due to rotation of physicians or in one case nurses. They wished for a permanent contact partner, e.g., by having the same professional caregiver throughout the care process.

3.1.5. Universalism. Patients also experienced situations with HCPs where they did not feel treated benevolently, due to insensitive language or their needs not being met. Patients who described such behavior mostly added an understanding of the challenges of HCPs in the clinical setting. Some reported their sympathy and support for other patients, for example, by comforting another patient or by accompanying a patient in a wheelchair to their destination.

3.2. Living Now. Within the second main category "living now,' patients described personal priorities as they live with cancer.

3.2.1. Security. Stability of relationships, meaning having the family around, knowing friends and family to be loyal in difficult times, feeling their care, and experiencing family bonds, was valued highly by patients. Being visited in hospital was described as feeling cared for by close ones. Having friends or family members who still love and accept the patient even when he behaves in challenging ways was important to several patients. Patients also expressed perceiving changes in social contacts because friends have left them due to discomfort with cancer. While their health is in decline, some patients expressed hope for having a good time with the best health possible as highly relevant.

> "Or still having a pretty good time. In terms of health. That's simply the be-all and end-all." (I16, pos. 73)

One patient wanted to leave something to the family, to preserve oneself or the stories they have shared for the family to remember.

3.2.2. Autonomy of Action. Being independent was reported as a goal and indicator for QoL. QoL was described as related to basic things like cutting bread for oneself. Patients reported their dependence on family members. Loss was also considered to be connected to valued activities, such as playing the piano or sports. Several patients described limits in self-directed use of time due to many appointments in the hospital.

> "The physician's appointments and hospitals I've had in the last year. Already determines your life. Changes a lot." (I2, pos. 104)

3.2.3. Hedonism and Stimulation. Enjoying the small things in life was described as an improvement for QoL and as something regained by one patient. Patients valued quietness, sometimes spending time alone in nature or in the community. Difficulties in finding time for this due to appointments were expressed. Enjoyment was also limited by the side effects of chemotherapy, e.g., in enjoying food.

> "I'm happy when I wake up in the morning, when I sleep well at night. When I can eat something that still tastes good. Chemo makes everything a bit different, the body is different, of course, it reacts differently." (I13, pos. 50)

Having hobbies and doing stimulating activities was perceived as important in everyday life by several patients.

Inactivity was described as negative by some patients, as they searched for stimulation in books, going outside, physical activity, or other personal projects. Patients expressed their wish to be active in life and to see themselves as still evolving people who can learn new things and live a varied life. One patient reported having projects for which he wanted to be fit enough.

> "I want to get a bit fitter again. I know I won't live much longer, but until then I don't want to just vegetate in bed. (. . .) I still have a few projects that I have planned, that I would like to do, (. . .). And I just want to get some vitality and energy." (I7, pos. 29)

3.3. Coming to Terms. In the main category "coming to terms," patients described their process of coming to terms with their diagnosis and prognosis, preparing emotionally and practically for the EOL and describing their former and present view on life. Here, some themes were found, that did not match the value framework of Schwartz, but might refer to the dimensions "openness to change" and "conservation."

3.3.1. Coming to Terms with Prognosis with Hope, Peace, and Self-Respect. Two patients expressed that remaining hopeful was as an important factor to process the diagnosis and prognosis. Hope was based on good news in the past for both patients.

> "So, I was told from the start that it was incurable. That if I'm lucky enough to get it encapsulated, that it will stagnate. I've had the happy news twice now that it's gone down a bit. And that already gives me motivation again." (I6, pos. 100)

Regarding the possible disease trajectory, several patients expressed being realistic regarding prognosis as an inner development step in coming to terms with their disease. Being realistic about prognosis was described in the context of distancing oneself from unrealistic perceived hope, such as hope of healing (see also section "personal security"). Insecurity of the future and the prognosis was dominant in these statements. Realism was therefore connected to not planning and not hoping for specific outcomes.

> "So, at the beginning, when I found out that I had a lung tumor, I just thought: six months, then it's over. It was just spring and (. . .) Yes. So, I thought: will you have another spring? Yes, but then I also dealt with it and read about it and so on. And yes, I knew it could go on for a few more years. Depending on how everything works out. Or maybe not." (I4, pos. 89)

> "Well, my naive wish would be: I would like to get cured quickly. And have it all gone. I'm not at that point anymore." (I10, pos. 66)

Patients considered it important to accept their individual life circumstances and the uncertain future. They described the acceptance of their limited individual influence on their present and future life circumstances but also reflected on possibilities to adapt and influence their life, which can be associated with "openness to change" in Schwartz but with no explicit value.

> "I suffered a lot with the Tagrisso pill. So it would be nice, as I said, it doesn't have to be like it used to be, I've come to terms with that. Of course, it's also been a process where you need a long time, where it took me almost a year, (. . .) I've only been in bed for a year now, which isn't so nice. So of course I get up now and then and have a few better and worse days. But that's all it is. (. . .) actually, you're just waiting for death. And I don't want that yet." (I7, pos. 51)

Patients' realism was sometimes contrasted with unrealistic hopes of family members. A few patients described themselves as brave and as fighters against emotional exhaustion or strong self-pity. They were fine with being sad sometimes but did not want to fall into bitterness. The patients described their willingness to keep their composure because sorrow would not solve problems. This could refer to the dimension of "conservation."

> "I've never let myself go or whined about it. Because it, of course, makes you sad, but what's the point? None of it is of any use." (I4, pos. 89)

The process of coming to terms with the diagnosis and prognosis was often expressed as a timely process (e.g., one year) of internal development starting with shock, resulting in acceptance, realism, and a humble/thankful view on life. Acceptance was described as an important mindset in life, which includes not getting upset about trivialities.

Patients expressed a humble and thankful view on life by describing suffering and death as part of life and describing what they are thankful for, like having a family or when they reflected on their past.

> "Life is not just a candy store, I always say life is a system of coordinates, sometimes it goes up, sometimes it goes down." (I2, pos. 14)

3.3.2. Autonomy of Action. One patient mentioned that they had everything prepared for the EOL as far as possible, including contacting the notary and a hospice center. Being prepared was connected to accepting how it would turn out at the end.

> "So now, I mean, I'm sick and (. . .) actually, I've got everything sorted out (. . .). Now it just comes as it comes. So, I don't have any big ideas now." (I4, pos. 31)

3.3.3. Benevolence. In processing their diagnosis and prognosis, patients described honest and genuine conversations with trusted friends or family members as helpful. But talking with friends was also challenging sometimes as they did not want to burden them. Caring for family

members was also expressed through the patients' concern about family having to deal with the patient's limited prognosis and their own lives after the patient's death. Some patients felt responsible for preparing their end of life as thoroughly as possible to protect family members from difficult decisions, e.g., regarding the funeral. They were also concerned about providing for their family after their death, often involving financial issues.

> "Actually, the only thing is that my brother will take care of everything (. . .) I'm still doing well so far, that I help him a bit so that he doesn't have to do too much. That I maybe (. . .) sell things or make arrangements with the funeral, so that he doesn't have to decide (. . .)". (I4, pos. 35)

Being prepared for the EOL and to have everything organized for the relatives were described as important but also as difficult for some patients. One patient wished for physicians to address these issues, as mentioned in the "individual in medical care."

4. Discussion

The aim of this study was to explore personal values, wishes, and goals of patients with advanced lung cancer from the patients' perspective. Our findings allowed insights into values and associated wishes and goals in the context of patient-physician interactions, therapy, end-of-life care, and living with advanced cancer. Patients valued benevolent, patient-centered care, but also reported positive experiences about the care they were already receiving. In terms of the therapy, patients described the value of feeling secure about receiving the "right" treatment and trusting the physicians' competence. Sharing personal preferences for end-of-life care, receiving information on alternative treatment options, and being encouraged to ask questions were considered important and refer to a desire for self-direction. These findings suggest that HCPs need to take more initiative to talk to patients with advanced lung cancer about their personal values, wishes, and goals, as patients are often reluctant to disrupt their perceived structures in medical care with personal questions or are unsure of the importance of their own values, wishes, and goals for end-of-life care.

The findings can be interpreted using the theoretical framework. Values in the dimensions of "conservation" and "openness to change" [27] seem to be particularly guiding for patients as they navigate their situation. Security is allocated to the dimension "conservation" in the theory of Schwartz, which refers to "avoidance of change" [27]. At first glance, "avoidance" and "openness" in regard to change seem contradictory. However, when already experiencing change due to the disease, values in the dimension "conversation" perhaps indicate also the wish to stop or slow the rate of change (from the patients' perspective) as they try to adapt. "Benevolence" according to Schwartz refers to the "in-group" defined as those "with whom one is in frequent personal contact," mostly referring to personal contacts [27], not expectations of professionals. Since patients with advanced cancer have frequent contact with HCPs, benevolent treatment was also assigned to this value. Regarding coming to terms with the diagnosis, some descriptions of the process also did not match Schwartz's value types. This might point to limitations of the description of values by the Theory of Basic Human Values in the context of serious illness and patient-physician interactions. It can be discussed whether peacefulness, self-respect, and hope are values, needs, or coping strategies. However, various aspects of cognition and emotion are relevant in the context of decision making. Values in the dimension of "self-enhancement" [27] were not found, consistent with quantitative research in values using Schwartz's Portrait Values Questionnaire, where "self-transcendence" values reached higher scores than "self-enhancement" values [38]. Stimulation was only important to some patients. In the quantitative findings of Fegg et al., stimulation was of low importance [38].

The findings contribute to aspects of patient-centered care at the end of life, as values and associated wishes or goals are crucial in patient-centered care. Enabling patients to express and reflect on personal information and values is considered important to improve quality of care, above all in the context of aggressive EOL care [2].

Patients seek the guidance of physicians so they can pursue personal goals. It is also associated with a sense of security, which is supported by research [2]. Patients needed time (e.g., one year) to accept their limited prognosis. As lung cancer is mostly detected in an advanced stage [8], many patients might discuss therapy offerings in a vulnerable stage of adjusting to their diagnosis. Especially at the EOL, ambivalence is common [50]; prognostic awareness may also vary between realistic and unrealistic expectations [51].

Genuine care for patients' health, including the goal of prolonging life and QoL, might provide a defensible sense of security and the patient's feeling that their physician is not giving up on them. Early integration of palliative care into oncologic care aims to combine both goals (prolonging life and QoL) and should be discussed in ACP [52]. Regarding the rotation of HCPs, continuity of contact and documentation of information should be considered when implementing ACP.

Feeling prepared for the end of life and finding peace and acceptance was valued by patients and is an underlying goal of ACP [53]. Considering patients' focus on the present [6] and the interviewed patients' tendency not to plan because of the uncertainty about the future, short-term goals, and preferences, such as finding a distraction or regaining physical abilities, might be relevant to patients along with planning for the end of life. Many patients did not feel the need to affect therapy decisions and did not plan for the (near) future but wanted to influence their care at the EOL and felt responsibility for their family members after their death. This goal seems to be important from the perspective of patients and is already mentioned in previous studies [32].

Importantly, our study's participants expressed a reluctance to address personal values in patients' conversations with physicians. Being able to share personal values that reflect experienced distress, e.g., the worry of lacking

social support or uncertainty of future, could enhance dignity in care for patients in palliative care, according to Chovinov et al. [54].

While patients mainly described their experienced loss, conversations about values, wishes, and goals can offer the opportunity to emphasize personal and external resources. Resources mentioned in the interviews include stable relationships with friends and family, the improvement of physical strength, or the self-determined use of one's own time for personal valuable activities. In the salutogenetic approach according to Antonovsky, generalized resistance resources in life crises promote mental health [55]. A resource-based approach could have a positive impact on the mental health of lung cancer patients. Therefore, when developing interview guides for ACP or value clarification tools, a resource-oriented orientation and language would be advisable.

One criticism of ACP refers to a possible shift of responsibility to patients, which can be perceived as a relief for physicians but on the downside might burden patients [53]. Nonetheless, most studies show benefits of ACP [56], while only a minority indicate increased distress or unpleasant feelings due to ACP conversations [57]. Communication about values and goals remains important considering low congruency between HCPs and patients concerning treatment preferences. Furthermore, HCPs should be aware that providing ACP does not guarantee, but contributes to, satisfaction and QoL besides other aspects of care [53].

4.1. Strengths and Limitations. Participants were interviewed at home via telephone or in the hospital. The clinical setting could have influenced their statements because of social desirability and interruptions of interviews by HCPs. The development of categories was discussed within the team, but no independent coding was done. The qualitative content analysis according to Kuckartz contains the possibility to first identify main categories deductively and afterwards identifying subcategories inductively. By changing this order, the values have always been interpreted in relation to certain thematic areas. This could have influenced the allocation of values. The authors have therefore decided to present the allocation to the categories transparently in the supplementary material. We did not document information on how many patients in the hospital met the inclusion criteria at the time of recruitment. Although in ACP family members and their caregiver should be included, this research is entirely based on patient-reported perceptions. The findings also only refer to patients from one hospital. However, the qualitative design allowed insights into patients' experiences and the exploration of important values from patients' perspective.

5. Conclusion

The value dimension "openness to change" represents patients' struggle to adapt to the changes in their lives due to their diagnosis and prognosis. The need to feel secure in the medical setting translates mainly in "conservation" values. Especially the desire to influence the care at end of life was expressed while simultaneously describing a reluctance to express personal information in medical interactions. This shows the need for a proactive attitude in physicians and improved interprofessional collaboration. Further research should explore how to elicit values and improve the integration of the discussion of values in the hospital setting and should explore how interprofessional communication can be improved in this context.

Data Availability

The data used to support the findings of this study are included within the supplementary information file.

Disclosure

This study was part of a master thesis in health service research.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

Regina Poß-Doering and Matthias Villalobos contributed equally to this study.

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Supplementary Materials

Figure S1: interview guide. Table S1: category system. Table S2: code book. (*Supplementary Materials*)

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