

“The challenge is the complexity” – A qualitative study about decision-making in advanced lung cancer treatment

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ABSTRACT

Introduction: The value of shared decision-making and decision aids (DA) has been well documented yet remain difficult to integrate into clinical practice. We wanted to investigate needs and challenges regarding decision-making about advanced lung cancer treatment after first-line therapy, focusing on DA applicability.

Methods: Qualitative data from separate, semi-structured focus groups with patients/relatives and healthcare professionals were analysed using systematic text condensation. 12 patients with incurable lung cancer, seven relatives, 12 nurses and 18 doctors were recruited from four different hospitals in Norway.

Results: The participants described the following needs and challenges affecting treatment decisions: 1) Continuity of clinician-patient-relationships as a basic framework for decision-making; 2) barriers to information exchange; 3) negotiation of autonomy; and 4) assessment of uncertainty and how to deal with it. Some clinicians feared DA would steal valuable time and disrupt consultations, arguing that such tools could not incorporate the complexity and uncertainty of decision-making. Patients and relatives reported a need for more information and the possibility both to decline or continue burdensome therapy. Participants welcomed interventions supporting information exchange, like communicative techniques and organizational changes ensuring continuity and more time for dialogue. Doctors called for tools decreasing uncertainty about treatment tolerance and futile therapy. **Conclusion:** Our study suggests it is difficult to develop an applicable DA for advanced lung cancer after first-line therapy that meets the composite requirements of stakeholders. Comprehensive decision support interventions are needed to address organizational structures, communication training including scientific and existential uncertainty, and assessment of frailty and treatment toxicity.

1. Introduction

Patients with advanced lung cancer who are offered non-curative treatment may not understand that therapy is unlikely to cure their cancer [1]. This could affect the ability to make an informed decision about potentially harmful treatment. The purpose of shared decision-making (SDM) is to increase patients' information and control over treatment decisions, so that the decision better reflects the patients'

values and preferences [2]. SDM in the context of lung cancer may lead to less depression, anxiety, and less aggressive therapies [3]. However, complex decision-making processes may lack prerequisites for SDM, and patients may not even realize they have a choice [4–5]. Pardon and colleagues have demonstrated that preferences of patients with lung cancer for information and for shared decision-making with their doctors are not well met [6].

To incorporate SDM in clinical practice, patient decision aids (DA)

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have been developed [7]. DA describe the specific decision to be made, available options and probable outcomes based on existing evidence, including benefits, harms, and uncertainties. Successful use of DA make patients more knowledgeable and clearer about their values, and may enhance risk perceptions [8]. DA for lung cancer screening have been developed and are available in the Ottawa Hospital Research Institute list of DA [9]. DA for lung cancer treatment exist, but they have not been evaluated in randomized controlled trials and therefore not included in the Cochrane review of DA [10]. Even though efforts have been made to develop and implement DA for advanced lung cancer for many years [11–12], SDM and DA seem generally difficult to integrate into clinical practice [13–15]. Most DA are designed to help decision-making concerning equally relevant treatment options. In the setting of progression of advanced lung cancer with no actionable mutations, treatment options are scarce and often need individual adjustments. Therefore, we conducted a study to investigate how stakeholders experienced needs and challenges regarding decision-making about advanced lung cancer treatment after first-line therapy, and their views on the applicability of DA and other decision support interventions.

2. Objectives

We aimed to explore needs and challenges among patients, relatives and healthcare professionals when making decisions about advanced lung cancer treatment, with an emphasis on the usefulness of DA at the time of disease progression. This sub-study is part of a multicenter implementation study where an intervention to support decision-making in advanced lung cancer will be developed, tested, and evaluated (Fig. 1). Data have previously been collected from observed decision-making processes and individual interviews with other patients and relatives after computer tomography (CT) -evaluation, where no DA has been used (sub-studies 1–3). These data will be used together with findings from sub-study 4 to develop an intervention tailored to stakeholders' needs.

3. Methods

Qualitative research methods are used to study human experience as well as expressions of thought, motive and meaning [16]. Systematic text condensation is a method for thematic cross-case analysis of qualitative data [17] inspired by phenomenology but further developed as a pragmatic procedure within the social constructivist tradition.

3.1. Participants and study setting

A research nurse or the consultants invited patients receiving treatment or regular follow-up for incurable lung cancer at four hospitals in Western Norway to participate. Lung cancer treatment in Norway is outlined in national guidelines, with a predetermined treatment plan depending on the molecular profile of the tumor [18]. We aimed for a purposive sample with diversity in age, gender, education among patients, and work experience among clinicians. We wanted discussions about common needs and challenges facing uncertainty about succeeding treatment lines, and thus included different histological classifications.

3.2. Data collection

We conducted three semi-structured focus group interviews with

Table 1
Focus group composition.

Focus group	Participants
1	7 doctors
2	6 nurses
3	4 patients and 4 relatives
4	4 nurses and 3 doctors
5	6 patients and 3 relatives
6	2 nurses and 5 doctors
7	3 doctors
8	2 patients

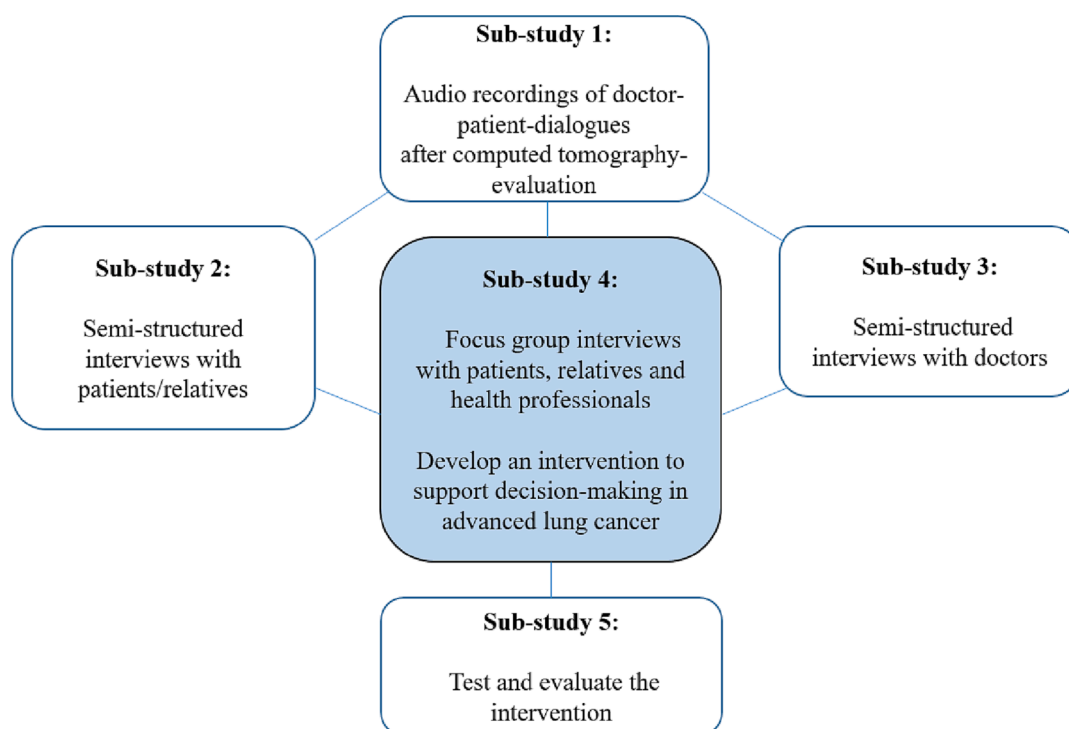


Fig. 1. Study design. This paper is about sub-study 4.

patients and relatives, and five interviews with clinicians during 2021 (Table 1). Doctors and nurses were interviewed together at two sites. At one site only doctors participated and at another site doctors and nurses were interviewed separately due to the large number of participants. Patients and relatives were interviewed together, apart from one group where patients did not bring any relatives. Interviews took place at the participants' hospitals/workplace, except for one interview with clinicians being performed at a seminar. The duration of the interviews was 39–71 minutes. Since existing DA for advanced lung cancer are either outdated according to new treatment guidelines or no longer available [19–23], few participants were acquainted with the concept. During the first interview, it became clear that it was difficult for them to elaborate on preferences, needs and DA applicability without being provided with examples. MAS therefore commenced the succeeding focus group sessions by presenting some DA designs and decision support interventions (DeSI) [24] in a Norwegian setting (Table 2). The slide show was given to demonstrate the range of possible interventions rather than an in-depth discussion about each design. The most common pros and cons were briefly mentioned alongside with each item and revisited later in the interview according to participants' input. SO, pulmonology fellow and PhD-candidate, served as moderator, and MAS, consultant and experienced in qualitative research methods and lung cancer treatment, was observer in the interviews, which were audio recorded and transcribed verbatim by a secretary or SO. Participants were introduced to the researchers' background and goals before the interview commenced. The interview guide covered questions about if and how DA would meet their requirements, but was followed flexibly, allowing participants to discuss what they regarded to be their most important needs and challenges. Participants were actively encouraged to engage in interactive discussions and collaborative exchanges while addressing the questions. Throughout the interviews, informants were able to expand upon their own experiences and perspectives by building upon the insights and viewpoints shared by others within the group. Sample size was guided by the concept of information power [25], and enrolment stopped when the developed categories were assessed rich enough for a thorough description of the investigated views and experiences.

3.3. Data analysis

Data analysis was performed in collaboration between the authors SO, MAS and TM using systematic text condensation [16], a thematic cross-case analysis proceeding through four stages: 1) reading all the material to obtain an overall impression; 2) identifying units of meaning, representing different aspects of the participants' needs regarding decision support and coding for these; 3) condensing and abstracting the meaning within each of the coded groups; and 4) summarizing the contents of each code group to generalized descriptions and concepts reflecting the most important decision support measures reported by the

Table 2

Decision aids and decision support interventions introduced in interviews.

Ottawa Personal Decision Guide [29] designed for any health-related decision to facilitate SDM
A Norwegian web-based DA for advanced prostate cancer [30] presenting videos and texts about the disease, treatment options and prognosis
A Norwegian pilot DA for early-stage lung cancer (not published, based on an interactive web-based DA called "Decide treatment" for bipolar disorder) [31] using patient preference scores to assist decision-making about surgery or stereotactic radiation therapy
A patient information pamphlet about SDM [32] underlining patient autonomy and the importance of questions about options, pros, cons and likelihood of the different alternatives
Communication guidelines for Advance Care Planning [33]
SDM-training [34] based on six steps: introduce the decision to be made, invite the patient to participate, present options, deliberation about patient preferences, decision-making, planning ahead
A tool to assist patient information about further treatment tolerance (The G8 screening tool) [35]

informants. Analysis was done stepwise with new interviews supplementing the sample. TM separately read the interview transcripts and preliminary analysis by SO and MAS, challenging the interpretations and suggesting alternative illustrating quotations. NVivo was used during step 2 of the analysis, and a decision trail [26] documented the choices during the analytical process. This method combines inductive and deductive analysis. Categories and topics are mainly inductively developed from the data. The deductive element involves utilizing the research question and theoretical framework of the researchers to identify categories. This approach, referred to as an editing analysis style by Miller and Crabtree, differs from a theory-driven template analysis style in which categories are developed based on pre-established theoretical concepts [27]. However, the authors' background as doctors (all but RS, who is a philosopher of science) experienced in lung cancer treatment and communication skills training, influenced interpretations, and theory of medical uncertainty was used to specifically look for expressions of uncertainty management and tolerance [28].

3.4. Ethics statement

This study was conducted according to the principles of the Declaration of Helsinki. Informed consent was obtained from all participants. Ethical approval has been granted from the Data Protection Officials and Head of Departments at the four participating hospitals, after initial assessment by The Regional Committee for Medical and Health Research Ethics (2019/876).

4. Results

17 patients with metastatic or locally advanced lung cancer not eligible for curative treatment were invited. Five declined due to concerns about COVID-19 risk or wrong timing. Seven patients brought a relative. We invited 31 clinicians experienced with lung cancer, one cancelled because of acute illness. Information about the 49 participants is presented in Table 3.

The most important topics addressed by the participants were: 1) Clinician-patient-relationship as a basic framework for decision-making; 2) barriers to information exchange; 3) negotiation of autonomy; and 4) assessment of uncertainty and how to deal with it. Below, we elaborate the findings with quotes from the transcripts.

4.1. Clinician-patient-relationship as a basic framework for decision-making

Patients and clinicians agreed that prior acquaintance made the communication easier. Clinicians experienced that enough time per consultation, including time to prepare, and continuity formed the foundation of a good patient relationship. They were not familiar with using DA for other conditions or in other settings. Some clinicians feared that DA could disrupt the natural flow of a conversation and "steal" time. They expressed worries that it could lead to misconceptions in need of correction, and thereby become a "hassle". They regarded interventions and questionnaires as a poor substitute for having enough time to engage in dialogue and getting to know the patient, which was regarded key to explore and come to terms with complex decisions:

"I think forms and schemes disrupt the communication. (...) If I conduct an ECOG (performance status) or ESAS (symptom score) evaluation, it's best to just to keep the questions in mind and make a conversation out of it. I think questionnaires make it kind of stilted."

Nurse#12

"The challenge is the complexity. Every patient is different and needs individual adjustments. Communication is the key. And having enough time to talk and get to know the patient (...).

It's not just about the type of cancer, but it's about the context, comorbidity and everything else. It is a chaos of different factors. So I can't

Table 3
Characteristics of participants.

Patients, N	12
Female, n (%)	6 (50%)
Age, mean (range)	58 (33–78)
TNM classification	
Stage IIB*	1
Stage IIC*	1
Stage IV	10
Histological classification	
Adenocarcinoma	6
Squamous cell carcinoma	1
NOS**	2
Large cell carcinoma	2
Small cell carcinoma	1
Months since start of treatment	23 (6–52)
Line of treatment	
1st line	7
2nd line	2
3rd line	2
4th line	0
5th line	1
ECOG performance status	
ECOG 0	1
ECOG 1	8
ECOG 2	3
ECOG 3	0
Education level	
Not specified	4
Vocational education	4
College or University education	4
Relatives, N	7
Female, n (%)	4 (57%)
Age, mean (range)	60 (50–68)
Relation to patient	
Child	1
Partner	6
Nurses, N	12
Female, n (%)	12 (100%)
Age mean (range)	47 (30–58)
Years of clinical experience	22 (4–34)
Years working with lung cancer	18 (3–30)
Doctors, N	18
Female, n (%)	5 (28%)
Age, mean (range)	46 (30–61)
Years of clinical experience	16,5 (3–27)
Years working with lung cancer	12,5 (0,5–22)

*Not candidate for curative treatment despite staging.

**Non-small cell lung cancer, not otherwise specified.

imagine that it works to hand out a standard brochure (...) What works best is to maintain continuity and to build a relation."

Doctor #16

Patients felt particularly vulnerable at the time of CT-scans and evaluations, after the initial state of shock and chaos following the diagnosis. Several patients had seen many different doctors, and some of them felt that the doctor often did not have enough time for them to fully explain or discuss treatment or side effect. One nurse compared the outpatient clinic with an "assembly line in a factory". In two hospitals it was common practice that a nurse joined the doctor-patient consultation, and after this consultation the patient was offered a conversation with the nurse. This way of organizing the clinic was highly valued by all stakeholders. Even though several patients reported that they eventually were assigned to one or a few doctors, from whom they experienced good follow-up, some still described lack of continuity:

"I miss a personal relationship. Every third month or so, I meet for a check-up, but there is always something new that needs explaining. It's not the same doctor, and that's sometimes a bit burdensome, I think. You

don't get to know each other, don't get that personal touch, and I miss that."

Patient #5

4.2. Barriers to information exchange

The information load in the consultations could be overwhelming both to deliver and receive, and opinions on how a tool could improve information exchange were divided. Several patients and relatives expressed that they did not receive enough information about the treatment course or side-effects, while clinicians experienced that patients had difficulties retaining the information they imparted. Nurses had observed doctors who sometimes spent much time explaining CT-scans and lab-tests, limiting discussions about patients' expectations to cancer treatment, its risks and influence on everyday activities. They were concerned this could make patients opt for more therapy than they really wanted. Some doctors and nurses suggested it was easier focusing on practical information than the fact that life expectancy was limited. Even when treatment had been specified as "life-prolonging", concerns were raised whether patients interpreted this as "curable".

"My impression is that they're told it's incurable- but the main focus in the conversation is still about the treatment (...) But maybe we should just pause after saying it is incurable."

Nurse #5

Even though web-based DA [30] were regarded suitable to improve information exchange for younger or future patients with increased digital competence, several doctors problematized the amount of work and costs required to keep DA updated according to current guidelines. Patients, relatives and clinicians stated that DA should not necessarily give a presentation of survival rates as this is affected by several individual factors. On the other hand, some clinicians suggested it would be advantageous if patients were more prepared prior to CT-evaluations and decision-making conversations, for instance by a form making them conscious about what would be most important to them in case of disease progression. If patients needed more time to make up their mind, a DA was also regarded helpful:

"If they come and are told about progression, they are not always able to make a decision that day. There is so much information, and it takes time to grasp; 5 minutes is perhaps too little. So sometimes we just have to ascertain that there has been a deterioration and that they can come back another day to discuss the possibilities. Then I could have used this kind of tool in the meantime."

Doctor #13

Information exchange could be difficult when patients or families had unrealistic expectations of the treatment or refused prognostic information, clinging to a hope of conquering cancer. Patients at all hospitals received supplementary written information about the scheduled treatment. At one hospital patients were also given a summary of the consultation including diagnosis and the purpose and course of treatment. Despite these measures many patients and relatives felt uninformed:

"I don't know anything about which treatment I'm on. I'm only told to enjoy myself as long as I can (...) Of course, I stay active and have quit smoking, but apart from that.. I don't know what's happening."

Patient #8

"As a relative, I think there has been very little information for me, and little follow-up. I saw many side effects and reactions she had along the way when I was with her the whole time (...) I got scolded fifty times a day (by his wife). (...) And I wish I had more information about support, because it has been really hard."

Relative #2

4.3. Negotiation of autonomy

Certain doctors and patients expressed skepticism regarding the feasibility of achieving the “true essence” of SDM in real-life scenarios. They cited the inherent imbalance in disease-related knowledge, suggesting that decisions should primarily be entrusted to clinical experts rather than reaching a consensus between two equal partners. Even when patients willingly followed a recommendation and expressed satisfaction with the chosen course of action, the participants did not consider these instances as SDM. Clinicians acknowledged that patients are now more engaged in the decision-making process compared to the past. However, they noted that factors such as age, frailty, education, and cultural background could influence the extent of patient involvement. Several patients described few or no options to choose from. They reported a wide range of compromised autonomy, including pressure to end cancer treatment because of side effects that did not matter much to them. Some outlined how they had to fight for further treatment lines, and encouraged others not to take a no for an answer. On the other hand, some described pressure towards continuing treatment that made life unbearable and called for a more open discussion in which refraining from therapy was also an option. Clinicians agreed this was a legitimate choice, yet some patients reported lacking explicit information:

“I didn’t know I was allowed to refuse. But I told them: “No, this just isn’t worth it.” My life should be worth living and have some quality.”

Patient #7

First line treatment decisions usually followed national guidelines without focus on SDM, but decisions about further therapy at the time of progression were described as more complex. Several doctors reported they had an open dialogue with patients trying to meet their prerequisites and values, and experienced patients being responsive to their concerns. They underlined that most patients wanted active cancer treatment as long as possible, even when the risk of severe side effects was considered high and likelihood of benefit low. Experienced doctors described situations where they felt pressured by the patients or their family to continue cancer treatment which the doctor felt was meaningless and futile, compromising their professional autonomy.

“Sometimes you feel like being cornered. And you end up giving them treatment, even though it feels meaningless. The resistance can be immense, so you can’t break through the ice.”

Doctor #12

Even so, the doctors admitted they usually possessed the final power of definition:

“Most of the patients ask us (the doctors) what we would recommend at progression of the disease, stating «we don’t have the prerequisites for knowing what a good choice would be». So they are entirely at our mercy in terms of which information they receive from us. It depends on what we emphasise, then, when we present benefits and side effects – we actually control most of it.”

Doctor #13

4.4. Assessment of uncertainty and how to deal with it

It could be difficult to convey uncertainty regarding expected benefit and risk due to limited evidence after first line therapy. Doctors described it more challenging to discuss uncertainty than breaking bad news, and some preferred to schedule a new consultation, giving the patient time to think and discuss options with next-of-kin before deciding. Treatment decisions were often discussed with colleagues to obtain consensus before doctor-patient consultations, especially if the doctor was unsure whether to initiate or continue cancer therapy, and an “MDT-chemotherapy meeting” formalising this was suggested. Both experienced and inexperienced clinicians reported the benefits of consulting colleagues. At one hospital scheduled therapy was briefly

reviewed by the doctor and nurse together, and this was regarded helpful assessing complex cancer patients’ needs and status. Another way of dealing with uncertainty was trying to predict as precisely as possible what would be the probable outcome for each patient. Several doctors called out for a risk assessment tool before prescribing chemotherapy, like frailty assessment or toxicity prediction, but the existential aspects were hard to address:

“The question is how they perceive their options. If they consider the choice between cancer treatment and palliative care as a choice between life and death...it’s kind of a misconception, really, because either way they all will die.”

Doctor #3

When questioned about how DA could be helpful, some patients were positive towards an interactive web-based DA [30] displaying facts and options even with uncertain outcomes. Still, it was regarded unsuitable for incorporation in consultations. There were divided opinions of the Ottawa Personal Decision Guide [29]. Several considered the questions difficult to understand. Clinicians regarded it important to form an impression of the patient’s values, functional status, and resources as part of the risk assessment before deciding upon treatment together. They found it difficult to envision a DA for advanced lung cancer without targetable mutations mainly because of limited evidence for treatment after first line therapy. Doctors expressed concerns about tools that use algorithms to weigh patient preferences against benefit and risk to guide treatment decisions in this setting, and some relatives and patients shared this concern:

“Most of what we do is supported by guidelines. A tool might be useful when we are in doubt and don’t have clear guidelines. But it doesn’t exist because there are no data to support such a tool. It makes me sceptical (...) because you can’t just put everything into a spreadsheet and suddenly end up with the perfect answer.”

Doctor #5

“I think such a tool will be very complicated. You can easily give the wrong answer, and if that’s used as basis for the decision, it may actually be a mistake. I think it’s risky. I think you need to be quite knowledgeable to answer that.”

Relative #6

4.5. Discussion

This study demonstrates difficulties ensuring adequate information exchange, organizational structures, and patient autonomy in decision-making about advanced lung cancer treatment. Clinicians struggle to meet individual needs and convey complex information about uncertain outcomes. A specific DA that would overcome these challenges seems difficult to create, yet patients, relatives and clinicians were supportive of an intervention to improve the decision-making process.

In line with previous studies, establishment of a clinician-patient-relationship was emphasised as a crucial factor facilitating a dialogue about sensitive topics in life-threatening disease [36]. In addition, organizational changes were suggested, like increased time per consultation, postponing decision-making to a following consultation, participation of a nurse in patient-doctor consultations or a subsequent patient-nurse consultation. This demonstrates the importance of healthcare leaders making SDM a priority in their institutions to generate improvement [37]. Although evidence suggests that use of DA only lengthens a consultation by 2.6 minutes on average [10], and DA may be used both prior to and after clinical encounters to support communication and decision-making, many participants feared it would compromise the already limited consultation time and be disruptive. However, this study illuminates how time was spent on detailed information which patients found difficult to obtain, particularly when receiving bad news about progression of their disease. Using discussion tools paradoxically may put constraints on the range of topics discussed

during the doctor-patient consultation [38]. The need to rather focus on the person and contextual factors have been emphasized by several SDM-researchers [39–41]. How clinicians describe the situation and the words used about prognosis and treatment effect have a crucial impact on patient understanding and ultimately decision-making [42,43]. Available, recommended models for communication about incurable cancer may be highly relevant supplementing the framework of SDM, for instance SPIKES [44] and Advance Care Planning [33]. Quill and Abernethy underline the importance for treating specialists to obtain skills in conversations about prognosis, suffering and goals of treatment in order to achieve a coordinated and sustainable palliative care model [45]. We believe such conversations may contribute to better patient outcomes and successful integration of palliative care in oncology, which is difficult to accomplish [46]. Based on our study, communication training emphasizing how to explore patient perspectives and expectations seems a more appropriate and attainable intervention than developing a DA.

Nelson and colleagues have thoroughly investigated the complex context in which decision-making regarding advanced lung cancer treatment is embedded [4]. Our study demonstrates how clinicians and patients deal with both scientific and existential uncertainty in this setting. Faced with incurable cancer, most patients seek life-prolonging treatment and “hope for the best”. Doctors called for a tool to minimize medical uncertainty concerning benefit and harms by assessing frailty and likelihood of treatment tolerance, which is one of several strategies to manage uncertainty in clinical practice [47]. Acknowledging the existential character of decision-making in life-threatening disease [48–49] may be a constructive point of departure when navigating these landscapes and informing future DA on a theoretical level [50]. Compromised autonomy was described by both patients and doctors as burdensome. The doctor’s responsibility sometimes implies refraining from further cancer treatment despite patients’ wishes, for instance when functional capacity is below required standards. Some of our participants regarded SDM difficult to accomplish in “real life”, yet this may also depend on different interpretations of what practicing SDM is really about. Mendick and colleagues found that patients with breast cancer lacked trust in their own decisions and sought surgeons’ guidance, but still felt ownership of decisions that surgeons made for them [51]. The authors recommend assessing both subjective as well as procedural elements of decision-making when evaluating clinicians’ behaviour and their attempts to ensure patient autonomy. Restoring patients’ autonomous capacity amid uncertainty, vulnerability and lack of power is a challenging yet important aim of SDM [52]. Supporting stakeholders to address and deal with existential and scientific uncertainty may facilitate SDM and improve conditions for autonomous choice.

Even though our focus was on DA applicability, the discussions expanded on the wide range of decision support measures. Spiegle and colleagues have shown that the broader term “Decision Support Intervention” (DeSI) [24], which also encompasses question prompt lists and booklets, had similar effectiveness as the more comprehensive DA [21]. “Decision Support Systems” (DSS) were valued by the doctors in our study, since such statistical models are designed to predict outcomes like overall survival with or without treatment, toxicity, and cost-effectiveness [53]. Artificial intelligence-assisted decision-making is a promising field, also in thoracic oncology. However, these prediction models require evidence which to a large extent is still uncertain after first line treatment for advanced lung cancer with no actionable mutations. In line with international treatment algorithms from NCCN and ESMO, the Norwegian guidelines [18] provide suggestions and recommendations like docetaxel at progression of disease, even though evidence after immunochemotherapy has been limited. Incorporating real-life data to support informed clinical decision-making in the palliative setting has been appreciated both by patients with lung cancer and doctors, yet implementation may be challenging [54]. The importance of carrying on their lives as normal as possible impacts how patients

with lung cancer choose to perceive their situation, and how they want to be informed about options and future prospects [55]. Communication skills thus remain at the core of what is needed to make individual decisions together with individual patients.

5. Strengths and limitations

The strength of our study is the broad investigation gathering perspectives from patients, relatives, nurses, and doctors in four different hospitals, displaying a wide range of needs and challenges important to DA assessment in clinical practice. Based on the diversity of our sample we believe our findings are relevant to other hospitals treating patients with advanced lung cancer, especially when developing decision support measures at the time of progression. However, our study was not designed to evaluate DA for one specific choice in advanced lung cancer treatment, like docetaxel after immunochemotherapy. Since evidence is uncertain regarding several succeeding treatment lines after new first line therapies have become available, our aim was primarily to shed light on stakeholders’ views on which decision support interventions and designs that would be assessed applicable and useful in the setting of this uncertainty, as part of a larger implementation study. These findings are relevant beyond the Norwegian study context, as we share similar treatment guidelines and challenges across many countries.

All authors but one were doctors with the preconception that this group has a special responsibility to facilitate SDM, since they ultimately are in charge of treatment plans. This influenced data collection in the sense that more doctors were recruited to ensure their attitudes and assessment of DA were particularly illuminated at all sites, even though further interviews did not detect new themes. Relatives’ perspectives could have been further investigated, but were assessed sufficient to describe DA applicability in this setting together with the patients’ views. Since all groups described challenging experiences, we believe the participants felt they could utter their opinions in honest terms. Yet, a group with only relatives might have revealed additional aspects. The selection of presented tools may have influenced participant’s perception of DA. Qualifying criteria are developed by the International Patient Decision Aid Standards (IPDAS) Collaboration [56]. The wider term “decision support intervention” (DeSI) [24] has been criticized for including “anything” that supports patients in decision-making [57]. Despite the plethora of similar but not congruent definitions and concepts, we believe the participants got a sufficient impression of the core construct of DA to reflect on their views.

6. Conclusion

Our study suggests it is difficult to develop an applicable DA for advanced lung cancer after first-line therapy that meets the composite requirements of patients, relatives, and healthcare professionals. Instead, comprehensive decision support interventions targeting the complexity of the decision-making process are needed. Based on our findings, we recommend these interventions to address a) organizational structures, ensuring continuity and adequate time for dialogue and deliberation; b) communication training for healthcare professionals including existential and scientific uncertainty to improve information exchange and patients’ autonomous capacity; and c) frailty assessment to support discussions about treatment toxicity.

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Presentation of results

Preliminary findings from this study have been orally presented for the Norwegian expert group for lung cancer research August 2021 and at a national conference for cancer research in Norway, Onkologisk Forum, November 2021.

CRedit authorship contribution statement

Silje Orstad: Data curation, Formal analysis, Investigation, Project administration, Writing – original draft. **Øystein Fløtten:** Conceptualization, Investigation, Writing – original draft. **Tesfaye Madebo:** Data curation, Formal analysis, Investigation, Writing – original draft. **Pål Gulbrandsen:** Conceptualization, Methodology, Supervision, Writing – review & editing. **Roger Strand:** Supervision, Validation, Writing – review & editing. **Frode Lindemark:** Conceptualization, Investigation, Writing – review & editing. **Sverre Fluge:** Data curation, Investigation, Writing – review & editing. **Rune Hørgård Tilseth:** Data curation, Investigation, Writing – review & editing. **Margrethe Aase Schaufel:** Conceptualization, Formal analysis, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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