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The elicitation of quality of life preferences for lung cancer treatment from the perspective of patients and treating physicians: results of two discrete choice experiments

Martin Emmert[1,2] · Stefan Rohrbacher[1,2] · Marie Ringlein[1] · Ksenia Ibler[1,2] · Florian Gürtler-Daiß[3] · Michael Koller[4] · Brunhilde Steinger[2,3] · Jacqueline Müller-Nordhorn[2] · Vinzenz Völkel[3] · Monika Klinkhammer-Schalke[2,3] · Sophie Friebel[1]

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Abstract

Purpose Maintaining or improving the health-related quality of life (QoL) of lung cancer patients is essential throughout treatment. To support shared decision-making and improve patient–physician communication, patients' preferences should be understood and considered in clinical decision-making; however, existing research indicates notable discrepancies between patient and physician priorities. This study therefore aims to elicit and compare their preferences regarding QoL dimensions in lung cancer care in Germany.

Methods Based on systematic literature reviews as well as qualitative analysis, two discrete choice experiments (DCEs) were applied to elicit the preferences of patients and treating physicians. In the DCE scenarios, both groups chose between alternative QoL profiles reflecting different health states during lung cancer treatment. Data were analyzed using multinomial logit models.

Results The final DCEs comprised five common attributes — activities of daily living, shortness of breath, anxiety, social life, and emotional impairment — and one group-specific attribute: financial difficulties in the patient DCE and severity of pain in the physician DCE. Overall, 162 patients (mean age: 60.39 years, SD 10.05) and 154 referring physicians (mean age: 51.26 years, SD 11.28) participated. All model coefficients were statistically significant ($p<0.001$). Patients prioritized "Shortness of breath" (28.0%; level range of 1.417) and "Activities of daily living" (23.8%; level range of 1.207), while "Emotional impairment" (6.4%; level range of 0.323) ranked lowest. In contrast, treating physicians emphasized "Shortness of breath" (26.0%; level range of 1.114) and "Severity of pain" (22.5%; level range of 0.962); again, "Emotional impairment" ranked lowest (4.8%; level range of 0.207).

Conclusions Overall, patients and treating physicians showed broad agreement regarding the importance of several central QoL dimensions, particularly shortness of breath and activities of daily living. At the same time, differences in the weighting of selected attributes suggest that individual QoL priorities should be addressed explicitly in patient–physician communication.

Keywords Lung cancer · Quality of life · Discrete choice experiment · Patients · Treating physicians

JEL classification I14

✉ Martin Emmert
martin.emmert@uni-bayreuth.de

[1] Faculty of Law, Business & Economics, Institute for Healthcare Management & Health Sciences, University of Bayreuth, Prieserstraße 2, 95444 Bayreuth, Germany

[2] Bavarian Cancer Registry, Bavarian Health and Food Safety Authority, 90441 Nuremberg, Germany

[3] Tumor Center Regensburg, Center of Quality Management and Health Services Research, University of Regensburg, Am BioPark 9, 93053 Regensburg, Germany

[4] Center for Clinical Studies, University Hospital Regensburg, Franz-Josef- Strauß-Allee 11, 93053 Regensburg, Germany

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Introduction

Cancer remains a major public health challenge and one of the leading causes of death worldwide. In 2022, nearly 10 million people died from cancer and approximately 20 million new cases were diagnosed [1], making lung cancer the leading cause of cancer mortality, accounting for 1.80 million deaths globally [2]. In Germany, approximately 500,000 people are diagnosed with cancer each year [3]. With approximately 57,000 new cases annually, lung cancer is the third most frequently diagnosed tumor entity, yet with about 44,800 deaths in 2020 it ranks as the leading cause of cancer-related mortality nationwide [2, 3]. Since the late 1990s, age-standardized incidence rates of lung cancer have declined among men but increased among women [4]. One study further demonstrated substantial inequalities in lung cancer, showing that trends vary by socioeconomic status, gender, and age: Income inequalities increased among retired individuals, whereas educational and occupational disparities decreased in the working-age population [5]. In 2023, the economic burden of lung cancer (ICD-10 C33/C34) was estimated at nearly €5.7 billion, with slightly higher costs for men (€3.0 billion) than for women (€2.7 billion) [6].

Lung cancer is among the tumors with the poorest prognosis, reflected by a low relative 5-year survival rate of 25% in women and 19% in men [3]. One reason for this may be found – at least to some extent – in the fact that patients are mostly being diagnosed at an advanced stage [3]. For example, at the time of initial diagnosis, 57% of patients were already in UICC (Union for International Cancer Control) stage IV, while an additional 20% of women and 22% of men were in UICC stage III [3]. It is therefore not surprising that both the diagnosis and subsequent therapy are frequently accompanied by distressing symptoms and side effects that substantially affect patients' quality of life (QoL) [7]. In addition to physical symptoms (e.g., persistent cough), patients also experience psychological (e.g., anxiety) and social burdens (e.g., loss of social roles) [2, 8, 9]. Further challenges arise from metastasis-related symptoms (e.g., headaches) as well as various treatment-related side effects (e.g., nausea) [10, 11]. Consequently, the QoL of lung cancer patients is particularly impaired [12, 13]; with distress levels of lung cancer being the highest compared to other types of cancer [14]. Moreover, 90% of patients with advanced lung cancer suffer from fatigue, loss of appetite, shortness of breath, cough, and pain [15]. Another study on non-small cell lung cancer found that pain, dyspnea, cough, and fatigue were the most common symptoms within the first months after surgical resection [16]. Thus, improving – or at least maintaining – QoL is an important objective in the treatment of lung cancer patients.

To foster patient-centered lung cancer care, their preferences and needs should be well understood and considered – or ideally prioritized – by treating physicians. In this context, a recently published systematic review summarized and compared treatment preferences between physicians and patients across 37 studies, covering six treatment-related aspects (e.g., health benefit, adverse effects, impact on QoL). The review highlighted that substantial preference differences appear to exist between physicians and patients, underscoring the importance of thorough communication in treatment decision-making [17]. However, only four studies (from the United States [18], Italy [19], Australia [20], and China [21]) specifically compared preferences for lung cancer treatment between physicians and patients. In sum, all four studies identified differences, which were smaller in some contexts [20] and more pronounced in others [18, 19, 21]. For example, one study from China showed that oncologists place higher relative importance on overall survival time than patients (48% vs. 38%), whereas patients valued functional status more highly than oncologists (23% vs. 13%) [21]. These findings emphasize the need to incorporate patients' priorities into shared decision-making in lung cancer treatment [18].

Against this background, the present study aims to elicit and compare the preferences of patients and treating physicians regarding QoL dimensions in lung cancer treatment. By doing so, it addresses the paucity of evidence in general and from Europe and Germany in particular. The findings may indicate whether, and to what extent, physicians' preferences align with those of patients. Specifically, we sought to answer the following questions: (1) Which QoL dimensions are most important for both patients and treating physicians'? (2) How do patients and treating physicians' rate different QoL dimensions in the context of lung cancer treatment? and (3) What relative importance do both groups assign to these dimensions?

Materials and methods

This study used two separate discrete choice experiments (DCEs) in order to elicit and compare patients' and treating physicians' preferences for QoL dimensions during lung cancer treatment. Therefore, we performed systematic literature reviews followed by both qualitative as well as quantitative research methods.

DCEs are increasingly applied in health care to capture consumer preferences for services such as treatment options [22–26]. As a stated preference method, DCEs employ survey data to systematically elicit individual preferences through a series of hypothetical choice scenarios, commonly referred to as "choice sets" [27]. Grounded in two

key economic theories – random utility theory and Lancaster's theory [28, 29] – DCEs assume that respondents select the option within each choice set that provides them with the greatest satisfaction or "utility" [27]. By analyzing these decisions, researchers are able to identify which characteristics (attributes) are valued by consumers and to quantify the relative importance of each attribute [27, 30].

Study design

We adhered to standardized research practices for conjoint analysis as recommended by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) Conjoint Analysis Good Research Practices Task Force for the design and analysis of DCEs [31–33]. Both studies received ethical approval from the University of Regensburg (internal reference number 23-3303_1-101), and informed consent was obtained from all participants.

Systematic literature search procedure

First, we conducted a systematic literature search for studies aiming to identify relevant QoL dimensions in overall cancer care, with a particular focus on lung cancer-related studies from the perspectives of both patients and treating physicians. The searches were performed in Medline (via PubMed) and the Cochrane Library and were carried out in October 2023, targeting English- and German-language publications since 2012. Both reviews followed the recommendations of the Cochrane Collaboration Guideline [34]. In addition, the database search was supplemented by a manual search using the snowball method.

The search strategy was segmented into the three components "lung cancer" (e.g., neoplasm, carcinoma, tumor), "preference" (e.g., attitude, value, perception), and "quality of life" (e.g., health status, well-being, dimension). For all three components, we derived search terms from previously published secondary studies (e.g [35–37]), and combined them with MeSH terms, and similar expressions. Based on the systematic literature search, 20 of 9,780 identified studies were considered relevant and included in the data analysis (Supplemental Material 1). Of these, 12 studies employed a DCE design [18, 21, 25, 38–46], five studies applied other quantitative approaches (e.g., ranking- or rating-based methods) [47–51], and three studies used a qualitative design [52–54]. In terms of perspective, 15 studies examined patients' views [25, 38–42, 44, 46–51, 53, 54], two studies focused on the views of physicians [43, 45], and three studies addressed both perspectives [18, 21, 52]. Finally, most publications originated from the United States (n = 8) [18, 39, 41, 46–49, 51] and China (n = 7) [21, 38, 42–45, 52], followed by single studies from Australia (n = 1) [53], Germany (n = 1) [25], and Japan (n = 1) [40], as well as two cross-country studies (e.g., Italy, Belgium) [50, 54]. In sum, we identified 22 individual QoL dimensions from the 20 included studies that were considered at least somewhat important. In addition, we incorporated eight further dimensions derived from other studies (e.g [55, 56]), and established QoL questionnaires (e.g., EORTC QLQ-LC29 [57], QLQ-C30). This resulted in a final set of 30 QoL dimensions, which were carried forward to the next step (see Supplemental Material 2/3).

Qualitative steps

Next, we conducted semi-structured interviews (March/April 2024) with 16 randomly selected lung cancer patients (mean age 63 years, 37.5% female) as well as 16 treating physicians/oncologists (mean age 55 years, 25.0% female). The recruitment of participants was carried out through contacting lung cancer centers and patient self-help groups in Germany.

In the first step, respondents received a brief survey by postal mail, e-mail, or through participating hospitals prior to the interviews. The survey assessed the importance of predefined QoL dimensions (see above) in treatment decisions and allowed participants to suggest additional dimensions. Subsequently, semi-structured interviews were conducted to explore preferences in more depth, identify key dimensions and levels, refine wording, and test the comprehensibility of the hypothetical DCE choice tasks (see below). Special attention was paid to ensure that attribute labels and descriptions were understood as intended. All participants provided written informed consent and received a compensation of €100 upon completion of the qualitative study. Based on these findings (see Supplemental Material 2/3) and the consolidation of related QoL dimensions (e.g., chest pain, pain in arm/shoulder, and pain in other body parts were merged into severity of pain), five dimensions were identified as particularly important for treatment decision-making from the perspectives of both patients and physicians: activities of daily living, shortness of breath, anxiety, social life, and emotional impairment. Additionally, financial difficulties were stressed by patients, and severity of pain by physicians (Table 1).

Quantitative steps

Both survey instruments shared a comparable structure with four sections. First, respondents answered several questions regarding the perceived importance of different QoL domains in lung cancer care. Here, respondents evaluated the relevance of different QoL dimensions (see above) using a 5-point scale (1 = not at all important; 5 = very important)

Table 1 Summary of attributes and levels used in the discrete choice experiments (DCE)

Attribute	Description and levels given in DCE questionnaire
Activities of daily living[$,#]	*This dimension refers to a person's ability to successfully manage daily tasks and responsibilities as well as being independent (e.g., eating, dressing, washing, taking medication, walking, climbing stairs).*
	Slightly restricted
	Moderately restricted
	Severely restricted
Shortness of breath[$,#]	*Shortness of breath or breathlessness refers to difficulty breathing or the feeling of not getting enough air.*
	Slight (only when walking fast)
	Moderate (when walking normally)
	Severe (even when walking slowly)
Anxiety[$,#]	*Anxiety about the future refers to worry about the development of the disease. This relates in particular to the tumor progressing and leading to a deterioration in the general state of health.*
	Small anxiety about the future
	Moderate anxiety about the future
	Great anxiety about the future
Social life[$,#]	*This refers to patients' contact with family members, friends, and the community, which is important for mental health and well-being. For example, family life may be affected by the treatment of the disease.*
	Slightly affected
	Moderately affected
	Severely affected
Emotional impairment[$,#]	*This refers to a patient's emotional state with regard to the frequency and presence of negative feelings (e.g., tension, worry, depression).*
	Rarely present
	Sometimes present
	Often present
Financial difficulties[$]	*This dimension relates to financial burdens as a result of the disease, which may arise due to additional expenditure and/or loss of income. The reduction or loss of work can be accompanied by difficulties in coping with financial obligations and expenses.*
	Slight financial difficulties
	Moderate financial difficulties
	Severe financial difficulties
Severity of pain [#]	*Pain can be perceived as a dull, sharp, stabbing or pulling sensation and can have various causes. The pain may occur in the whole or a part (e.g., chest, arm/shoulder area) of the body. Pain can also occur in the event of a surgery (e.g., hub pain, surgical area).*
	Mild pain
	Moderate pain
	Severe pain

[$] This attribute applies for patients

[#] This attribute applies for treating physicians

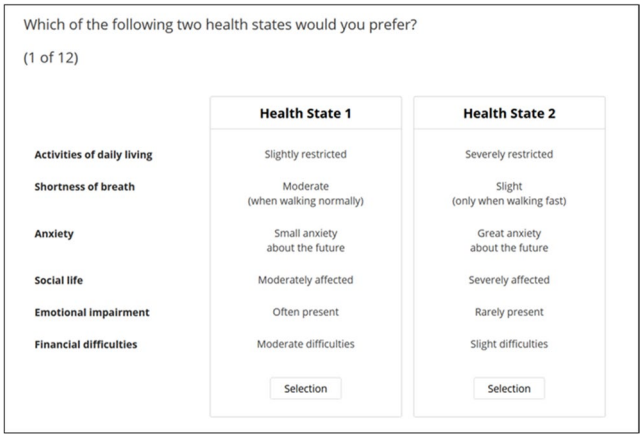


Fig. 1 Example choice task for patients

and selected the domain they considered most important during lung cancer treatment. The second section included the DCE, in which participants made choices between various hypothetical health states during lung cancer treatment. Subsequently, different formats for presenting QoL measurements were evaluated (not discussed here). The final section comprised anonymous questions about the respondents' personal characteristics (e.g., age, gender).

The DCEs were implemented in Sawtooth Software Lighthouse Studio 9.16.8. Unlike traditional ranking approaches, DCEs present respondents with paired hypothetical alternatives (e.g., different health states during lung cancer treatment) and infer preferences from their choices [25]. Both experiments used a full-profile design with six attributes per choice set, generated by the balanced overlap method to achieve low standard errors and high D-efficiency [58, 59]. The design ensured level balance (i.e., meaning each level appears with the same frequency) and orthogonality (i.e., meaning each pair of levels appears with the same frequency across each pair of attributes) [60]. Respondents were required to select one of two health states during lung cancer treatment (forced-choice tasks), reflecting realistic trade-offs between attribute levels. The number of attributes (six) was consistent with the recommended DCE standards of four to eight [61, 62]. Figure 1 provides an example choice task. The clarity and comprehensibility of the questionnaire was pilot-tested with 15 lung cancer patients and 15 referring physicians, leading to minor revisions.

The survey samples

Patient recruitment was carried out through multiple channels. For example, nationwide, patient self-help groups were contacted, and lung cancer centers in Germany were asked to support recruitment (e.g., via flyers and posters). In addition, office-based pulmonologists and oncologists as well as rehabilitation centers were approached, patient

events were attended, and online communities (e.g., Facebook groups) were included. Both printed (e.g., flyers, posters) and online-based information materials were provided for recruitment. All materials contained a link and a QR code through which participants could access the web-based survey. The surveys were conducted in November 2023 in German. As an incentive, respondents received a compensation of 50 euros.

Furthermore, we purchased a database from a commercial provider (ArztData AG) containing contact information (e.g., postal and email addresses) of health-care providers in the German outpatient sector specializing in internal medicine and haematology or internal medicine and pulmonology, with a focus on lung cancer. In total, 1,926 contacts were identified. In addition, 95 physicians affiliated with certified lung cancer centers in Germany (www.oncomap.de) were contacted and invited to participate or to forward the study information to colleagues. Here, we used a sequential strategy to achieve high response rates. In a first step, 1,000 treating physicians were contacted via email, which contained a link to participate online (web-based survey). After one week, one reminder was sent out. In a second step, the remaining treating physicians were contacted via email and again reminded after one week. The survey was conducted in October 2023 in German. Participants received a compensation of between 75 and 100 euros.

Sample size

According to Johnson's commonly applied rule of thumb, a minimum sample size of 75 participants would be required for a DCE with the present design specifications (i.e., ten choice tasks per respondent, two alternatives, and up to three attribute levels) [63]. This number has been discussed as the lower threshold for estimating main effects. To enhance statistical robustness, however, we aimed to double this number and include at least 150 participants, following more recent recommendations for robust parameter estimation [26, 64].

Statistical methods

Analyses of the general survey questions were conducted using SPSS (IBM Corp. Released 2019. IBM SPSS Statistics for Windows, Version 26.0, Armonk, NY: IBM Corp). Descriptive statistics were applied to summarize demographic and preference-related data. For the analysis of the DCEs, we used R Statistical Software (Version 4.2.2; R Foundation for Statistical Computing, Vienna, Austria) with the packages "mlogit" [65] and "gmnl" [66], which enable the estimation of multinomial logit (MNL) and related models. The datasets were structured in long format. Accordingly, the patient dataset comprised 3,240 observations (i.e., 162 patients, 10 choice tasks per respondent, 2 alternative health states per choice task), while the physician dataset contained 3,080 observations (i.e., 154 physicians, 10 choice tasks per respondent, 2 alternative health states per choice task). We estimated standard MNL models with both homoscedastic [29] and heteroscedastic error terms [67]. In addition, we employed the random parameter (RPL) model [68] to test for individual preference heterogeneity as well as the latent class (LC) model [69] with group sizes ranging from two to five groups to test for group-specific preference heterogeneity. The MNL model provides straightforward estimation and interpretation but does not capture unobserved heterogeneity, which can be revealed through the RPL and LC models.

We applied effect coding for all attributes [32, 70], which allows the estimation of coefficients and standard errors for each attribute level as deviations from the overall attribute mean. Consequently, results are independent of an arbitrary reference category, as the coefficients within each attribute sum to zero. The relative importance of each attribute was determined by the range of its estimated coefficients; specifically, we calculated the difference between the highest and lowest level coefficients for each attribute and expressed this value as a proportion of the total range across all attributes.

Model choice

We used the Bayesian Information Criterion (BIC) and the Consistent Akaike Information Criterion (CAIC) to determine the best-fitting model (see Supplemental Material 4 and 5). The standard Akaike Information Criterion (AIC) was not applied, as it tends to overestimate the optimal number of classes in multiclass models, whereas BIC and CAIC have been shown to perform well [71].

Results

Sample characteristics

In total, 371 patients and 282 treating physicians participated in our study and opened the link to the online survey. However, 135 patients and 83 physicians stopped answering immediately after the introduction page and left the survey. This led to 236 patients and 199 treating physicians who started to answer the survey. Based on this, the following evaluation reports on the 162 patients (43.67% completion rate) and 154 treating physicians (54.61% completion rate) who provided consistent responses and completed the DCE part of the questionnaire.

As can be seen in Table 2, the mean age of patients was 60.39 years (SD 10.05) while slightly more than half of patients (56.2%) were female. In addition, most patients (40.7%) reported (technical) university entrance qualification as the highest educational level. In addition, the majority of the respondents (86.4%) are covered by statutory health insurance and 34.0% of all respondents report their health status to be good or better. On average, the cancer diagnosis had been established 3.5 years (SD 3.3) prior to the survey. During the course of their illness, approximately 60% of respondents had developed metastases. Around 60% of all respondents had already received chemotherapy and about 45% had undergone radiotherapy. In contrast, the mean age of participating physicians was 51.26 years (SD 11.28) while the majority of all respondents were male (72.1%). In addition, the mean experience of the treating physicians was reported to be 23.36 years (SD 10.56) and the average number of lung cancer patients treated per year was 60.75 patients (SD 36.70). Finally, most participating physicians were specialized either as a pulmonologist (53.9%) or a hematologist/oncologist (29.9%).

Descriptive rating and ranking results

Patients rated – on a 1–5 scale (1 = not all important; 5 = extremely important) – "Activities of daily living" as the most important QoL dimension (4.79; SD 0.56), followed by "Shortness of breath" (4.51; SD 0.80), and "Social life" (4.35; SD 0.81) (Supplemental Material 6). When asked to select the single most important domain, 37.0% chose "Activities of daily living". While physicians similarly emphasized "Activities of daily living" (4.72; SD 0.60) and "Shortness of breath" (4.66; SD 0.60), these were followed by "Severity of pain" (4.45; SD 0.79). In contrast, "Shortness of breath" (38.3%) received the highest rating as the single most important dimension, followed by "Activities of daily living" (30.5%).

Results of the discrete choice experiments

The best fitting single class models with lowest BIC and CAIC appeared to be the standard MNL for patients and the MNL with heteroscedastic errors for physicians (see Supplemental Material 4 and 5). However, relative estimation results vary only marginally across all model types. In all estimated single class models, the signs of the estimates are in line with intuitive behavior. The applied models yielded significant coefficients for all attributes in both analyses ($p < 0.001$), indicating that, regardless of their placement, all attributes were relevant to the decisions of both lung cancer patients and treating physicians (see Supplemental Material 7). It should be noted, however, that not all mean levels reached statistical significance; for instance, the level "Sometimes present" was not significant for "Emotional impairment." Among patients, the highest preference weights were observed for "Shortness of breath" (coef.: −0.680; SE: 0.047) and "Activities of daily living" (coef.: −0.586; SE: 0.044), whereas "Emotional impairment" received the lowest weight (coef.: −0.155; SE: 0.041). Results for physicians followed a similar pattern, with "Shortness of breath" showing the highest preference weight (coef.: −0.540; SE: 0.044), followed by "Severity of pain" (coef.: −0.464; SE: 0.042). Again, "Emotional impairment" was rated least important (coef.: −0.088; SE: 0.034).

A similar ranking emerges from the calculation of the relative importance of all QoL dimensions for both groups. As outlined above, relative importance was derived from each dimension's coefficient range, expressed as a share of the total range across the dimensions (Table 3). In addition, Table 3 reports the odds ratios (OR) for each level to assess their impact on health state choices. For instance, the likelihood of selecting a health state with only slightly restricted "Activities of daily living" is 1.597 times higher than that of selecting a health state at the mean level for this dimension. As illustrated in Fig. 2, the preference pattern of patients displayed a relatively wide range of results. The QoL dimensions "Shortness of breath" (28.0%; level range of 1.417) and "Activities of daily living" (23.8%; level range of 1.207) received the highest weights, whereas "Emotional impairment" (6.4%; level range of 0.323) ranked lowest. For treating physicians, "Shortness of breath" emerged as the dominant dimension (26.0%; level range of 1.114), followed by "Severity of pain" (22.5%; level range of 0.962) and "Activities of daily living" (18.7%; level range of 0.799); again, "Emotional impairment" ranked lowest (4.8%; level range of 0.207).

For both samples, the latent class model with two groups showed the best fit according to BIC and CAIC criteria (see Supplemental Material 8). However, this solution was considered questionable, as the second group contained only a small number of observations ($n = 18$ patients; $n = 20$ treating physicians) and showed no meaningful internal structure. In contrast, the first group showed results that were nearly identical to those of the single-class models; none of the attributes or attribute levels were statistically significant within the smaller groups. Therefore, we selected the best-fitting single-class models for further analysis: The MNL model with homoscedastic errors for patients and the MNL model with heteroscedastic errors for physicians.

Table 2 Key Characteristics for both patients ($n=162$) and treating physicians ($n=154$)

	Patients ($n=162$)		Referring physicians ($n=154$)	
	Mean (SD) or *n*	Range or %	Mean (SD) or *n*	Range or %
Age				
Mean (SD)	60.39 (10.05)	20–81	51.26 (11.28)	26–77
Gender				
Male	63	38.9%	111	72.1%
Female	91	56.2%	40	26.0%
Diverse	3	1.9%	1	0.6%
Missing	5	3.1%	2	1.3%
Educational attainment				
Secondary general school or less	30	18.5%	n.a.	n.a.
Intermediate secondary school	61	37.7%	n.a.	n.a.
(Technical) University entrance qualification	66	40.7%	n.a.	n.a.
Missing	5	3.1%	n.a.	n.a.
Marital status				
Married	91	56.2%	n.a.	n.a.
Widowed	11	6.8%	n.a.	n.a.
Divorced	23	14.2%	n.a.	n.a.
Separated	29	17.9%	n.a.	n.a.
Others	3	1.8%	n.a.	n.a.
Missing	5	3.1%	n.a.	n.a.
Health Status				
Good or better	55	34.0%	n.a.	n.a.
Satisfactory	76	46.9%	n.a.	n.a.
Bad or worse	26	16.0%	n.a.	n.a.
Missing	5	3.1%	n.a.	n.a.
Household size				
One person	45	27.8%	n.a.	n.a.
Two persons	78	48.1%	n.a.	n.a.
Three or more persons	34	21.0%	n.a.	n.a.
Missing	5	3.1%	n.a.	n.a.
Health insurance coverage				
Statutory Health Insurance	140	86.4%	n.a.	n.a.
Private Health Insurance	14	8.6%	n.a.	n.a.
Others	3	1.8%	n.a.	n.a.
Missing	5	3.1%	n.a.	n.a.
Place of living				
Large city/suburbs (at least 100,000 inhabitants)	67	41.4%	n.a.	n.a.
Middle-size city (20,000–100,000 inhabitants)	41	25.3%	n.a.	n.a.
Small city, village (less than 20,000 inhabitants)	49	30.2%	n.a.	n.a.
Missing	5	3.1%	n.a.	n.a.
Year of diagnosis (i.e., duration since diagnosis)				
Mean (SD)	3.47 (3.33)	1–19	n.a.	n.a.
< 1 year	57	35.2%	n.a.	n.a.
1–5 years	72	44.4%	n.a.	n.a.
5 years +	27	16.7%	n.a.	n.a.
Missing	6	3.7%	n.a.	n.a.
Metastases				
Yes	97	59.9%	n.a.	n.a.
No	55	34.0%	n.a.	n.a.
I don`t know	4	2.5%	n.a.	n.a.
Missing	6	3.7%	n.a.	n.a.
Location of medical care				

Table 2 (continued)

	Patients ($n=162$)		Referring physicians ($n=154$)	
	Mean (SD) or *n*	Range or %	Mean (SD) or *n*	Range or %
Inpatient-based (e.g., hospital)	63	38.9%	n.a.	n.a.
Outpatient-based (e.g., specialized practice)	68	42.0%	n.a.	n.a.
Outpatient-based (e.g., general practice)	16	9.9%	n.a.	n.a.
Others	9	5.6%	n.a.	n.a.
Missing	6	3.7%	n.a.	n.a.
Received treatments				
Surgery	71	43.8%	n.a.	n.a.
Radiotherapy	73	45.1%	n.a.	n.a.
Chemotherapy	95	58.6%	n.a.	n.a.
Missing	6	3.7%	n.a.	n.a.
Number of treatments in total				
0	3	1.9%	n.a.	n.a.
1	40	24.7%	n.a.	n.a.
2	48	29.6%	n.a.	n.a.
>=3	65	40.1%	n.a.	n.a.
missing	6	3.7%	n.a.	n.a.
Experience (in years)				
Mean (SD)	n.a.	n.a.	23.36 (10.56)	1–50
Practice type				
Inpatient-based (e.g., hospital)	n.a.	n.a.	75	48.7%
Outpatient-based (e.g., practice)	n.a.	n.a.	27	17.5%
Both inpatient- and outpatient-based	n.a.	n.a.	50	32.5%
Missing	n.a.	n.a.	2	1.3%
Number of patients per year				
Mean (SD)	n.a.	n.a.	60.75 (36.70)	1-109
Medical specialty				
Internist/Pulmonologist	n.a.	n.a.	83	53.9%
Internist/Hematologist/Oncologist	n.a.	n.a.	46	29.9%
Thoracic surgeon	n.a.	n.a.	12	7.8%
Others	n.a.	n.a.	11	7.1%
Missing	n.a.	n.a.	2	1.3%

Discussion

The objective of this study was to elicit and compare the preferences of patients and treating physicians regarding QoL dimensions in lung cancer treatment in Germany. Understanding the extent to which physician preferences align with those of patients is essential for developing more patient-centered models of care. As outlined above, evidence directly comparing QoL-related preferences between patients and their treating physicians remains scarce. To the best of our knowledge, only four primary studies (United States [18], Italy [19], Australia [20], and China [21]) have examined this research question. Therefore, the present study aimed to determine new evidence on patient and physician preferences for lung cancer care within the limited body of comparative research. When focusing specifically on the QoL dimensions included in our DCEs, our findings both confirm central patterns reported previously and provide novel insights that extend or challenge existing knowledge. To understand whether our findings are consistent with or divergent from earlier studies, it is essential to examine how analogous QoL dimensions were represented and valued. To facilitate a transparent interpretation of the DCE findings, the following discussion is structured along the QoL attributes included in the experiments, while emphasizing the main cross-cutting patterns across patient and physician preferences.

Shortness of breath emerged as the most influential QoL dimension in our DCE, exerting the strongest impact on health-state choices in both patients (28.0% relative importance) and physicians (26.0%). This dominant role is well supported by the broader literature but is operationalized differently in comparable studies. For example, Zhang et al. [21] did not include shortness of breath as a standalone

Table 3 Estimated parameters of multinomial logit (MNL) models

Attributes and levels	Patients ($n=162$)							Referring physicians ($n=154$)						
	Coeff.	OR	SE coeff.	95% CI		*p*	Difference (highest - lowest level)	Coeff.	OR	SE coeff.	95% CI		*p*	Difference (highest - lowest level)
Activities of daily living[$,#]														
Slightly restricted	0.468	1.597	0.050	0.370	0.566	<0.001	1.207	0.331	1.392	0.044	0.244	0.417	<0.001	0.799
Moderately restricted	0.271	1.311	0.047	0.177	0.364	<0.001		0.137	1.147	0.040	0.059	0.216	0.001	
Severely restricted	-0.739	0.478	0.052	-0.842	-0.636	<0.001		-0.468	0.626	0.046	-0.559	-0.377	<0.001	
Shortness of breath[$,#]														
Slight (only when walking fast)	0.603	1.827	0.051	0.501	0.704	<0.001	1.417	0.447	1.564	0.045	0.358	0.536	<0.001	1.114
Moderate (when walking normally)	0.212	1.236	0.047	0.119	0.305	<0.001		0.220	1.246	0.041	0.139	0.301	<0.001	
Severe (even when walking slowly)	-0.815	0.443	0.053	-0.919	-0.710	<0.001		-0.667	0.513	0.052	-0.770	-0.563	<0.001	
Anxiety[$,#]														
Small anxiety about the future	0.238	1.269	0.048	0.144	0.332	<0.001	0.626	0.277	1.319	0.042	0.193	0.360	<0.001	0.593
Moderate anxiety about the future	0.150	1.162	0.048	0.054	0.246	0,002		0.040	1.041	0.040	-0.040	0.120	0.321	
Great anxiety about the future	-0.388	0.678	0.050	-0.487	-0.290	<0.001		-0.317	0.728	0.043	-0.401	-0.232	<0.001	
Social life[$,#]														
Slightly affected	0.303	1.354	0.048	0.208	0.398	<0.001	0.738	0.272	1.312	0.044	0.186	0.358	<0.001	0.607
Moderately affected	0.131	1.140	0.049	0.035	0.227	0,007		0.064	1.066	0.041	-0.016	0.144	0.115	
Severely affected	-0.434	0.648	0.050	-0.533	-0.336	<0.001		-0.336	0.715	0.043	-0.420	-0.251	<0.001	
Emotional impairment[$,#]														
Rarely present	0.192	1.212	0.049	0.095	0.289	<0.001	0.323	0.130	1.139	0.040	0.051	0.209	<0.001	0.207
Sometimes present	-0.061	0.941	0.048	-0.156	0.034	0.207		-0.077	0.926	0.040	-0.155	0.001	0.051	
Often present	-0.131	0.877	0.049	-0.227	-0.035	0.007		-0.053	0.949	0.041	-0.133	0.027	0.193	
Financial difficulties[$]														
Slight financial difficulties	0.271	1.311	0.049	0.175	0.367	<0.001	0.759	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Moderate financial difficulties	0.217	1.243	0.047	0.124	0.311	<0.001		n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
Severe financial difficulties	-0.488	0.614	0.050	-0.587	-0.389	<0.001		n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
Severity of pain[#]														
Mild pain	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	0.419	1.520	0.045	0.329	0.508	<0.001	0.962
Moderate pain	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.		0.125	1.133	0.040	0.046	0.204	0.002	
Severe pain	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.		-0.543	0.581	0.049	-0.641	-0.446	<0.001	
Model constant (Intercept)	-0.120	0.887	0.055	-0.229	-0.012	0.029		n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	

[$] This attribute applies for patients.[#] This attribute applies for referring physicians.OR – odds ratio (OR = exp(coeff)); SE – standard errors; CI – confidence interval

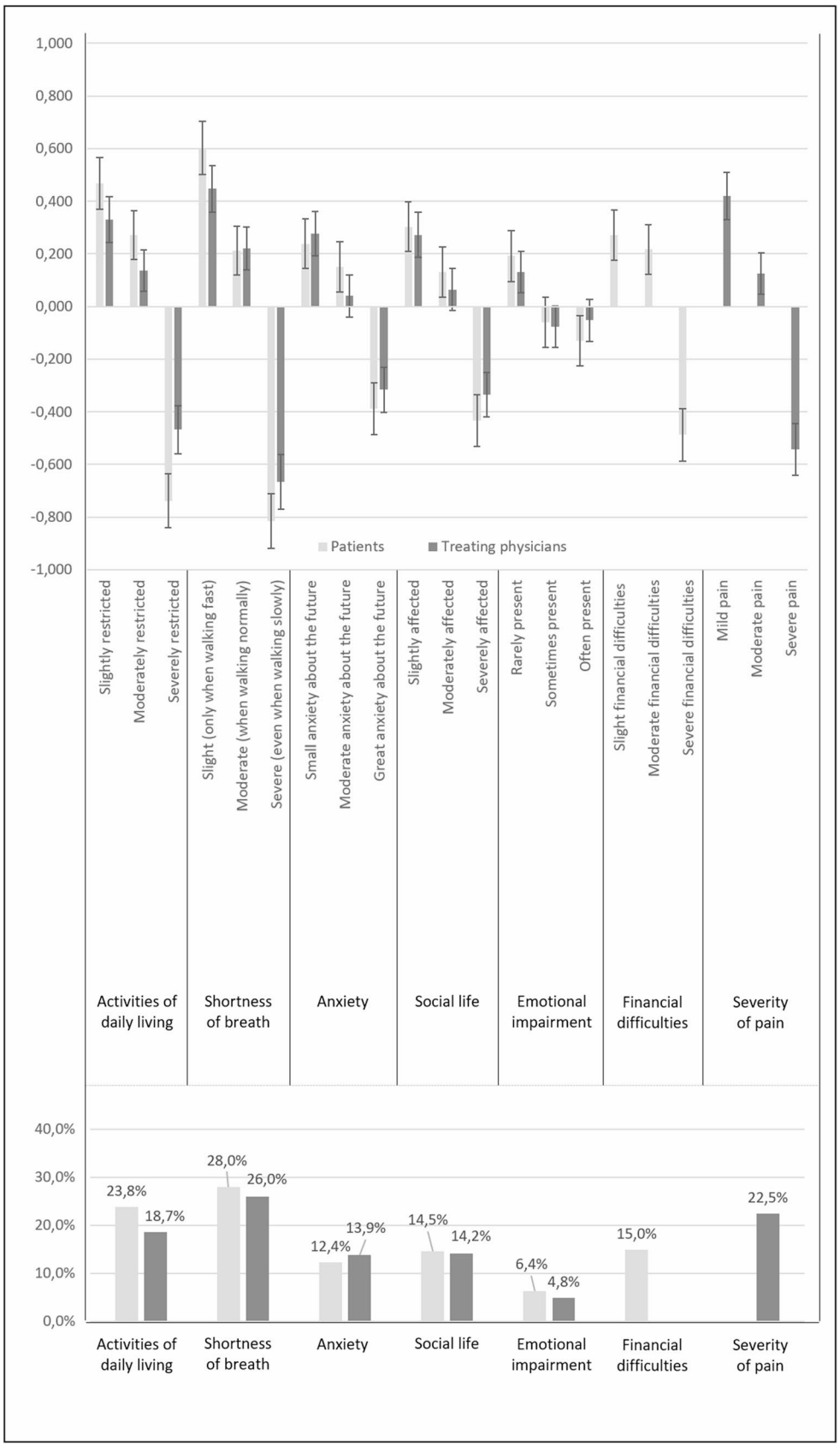


Fig. 2 Graphic display of level estimates with 95% CI (Discrete Choice Experiment) and mean relative importance of attributes for both subgroups

attribute; however, their "physical functioning status" attribute – defined by the patient's level of independence and ability to conduct routine daily activities – might capture the functional consequences of breathlessness to a considerable degree. In their mixed logit and latent class analyses, physical functioning was among the most influential attributes for patients (23%) and particularly important for a "physical-functioning-focused" class, which assigned 40% relative importance. The strong emphasis on functioning strongly confirms our findings, especially considering that shortness of breath is one of the primary drivers of functional impairment in lung cancer. Blinman et al. provide the most explicit confirmation among the four comparator studies [20]; here, shortness of breath appears among the most important expected and experienced QoL problems associated with adjuvant chemotherapy. It ranked consistently within patients' "most troublesome symptoms," with meaningful interference in daily activities. Next, while Pacchiana et al. did not isolate shortness of breath, they did emphasize the significance of "symptom control" as one of the strongest justifications for accepting maintenance therapy even in the absence of survival gains [19]. Finally, Hauber et al. also did not measure shortness of breath directly, but severe fatigue – defined partly by inability to participate in normal physical and social activities – might serve as a proxy since it may indirectly capture exertional intolerance consistent with breathlessness [18]. The strong therapeutic aversion to severe fatigue is in line with the strong preference we observe for less burdensome shortness-of-breath levels. Overall, it seems that shortness of breath or its functional proxies dominate patient and physician preference structures. This finding aligns with clinical evidence; for example, one recent study has shown a negative correlation between shortness of breath severity and global health-related QoL among lung cancer patients [72]. In addition, symptom burden reviews consistently identify shortness of breath as one of the most prevalent and distressing symptoms in this patient group [73]. Finally, multivariate analyses suggest that shortness of breath is one of the strongest independent predictors of physical functioning decline and reduced overall QoL [74].

Second, the *activities of daily living* (functional status) ranked just below shortness of breath in our DCE, with patients (23.8%) and physicians (18.7%) assigning substantial weight to this QoL dimension. Therefore, functional status is the second cornerstone of QoL-based decision-making in our model that is in line with comparable studies. First, Zhang et al. showed physical functioning to be one of the most important attributes among both patients and treating oncologists (here, overall survival time was ranked first) [21]. Second, the Australian study by Blinman et al. further supports our findings by showing that the QoL aspect "problems doing what I wanted" ranked among the most troublesome patient-reported issues during adjuvant chemotherapy at the six-month follow-up [20]. The study by Pacchiana et al. also emphasizes the importance of preserving QoL and maintaining functioning – although not disaggregated by specific domains. Their finding that patients accept maintenance therapy even in the absence of survival gains if QoL and symptoms remain stable might support the assumption that preserving daily functioning is of great importance. Finally, Hauber et al.'s operationalization of fatigue – defined as the inability to work or perform normal activities – might also serve as a proxy for functional decline. In addition to this, clinical evidence strongly supports the high importance of activities of daily living. For example, Chiou et al. demonstrated that physical functioning declines substantially with increasing symptom burden and represents one of the strongest predictors of global QoL [74]. Similarly, one longitudinal analysis further showed that loss of independence and difficulty in performing routine activities have a meaningful impact on QoL and clinical outcomes [75]. Taken together, these findings demonstrate that maintaining functional capacity is of primary importance in lung cancer care.

Third, *social life* was included as a distinct QoL attribute in our DCE, but carried lower relative importance than shortness of breath and activities of daily living. This finding is similar to comparable studies, although they only capture social dimensions indirectly. For example, Blinman et al. did not operationalize social functioning as a separate QoL domain [20]; however, their QoL data indicate relevant impairments in daily and social participation. Specifically, the symptom "problems doing what I wanted" ranked among the most troublesome experienced issues during adjuvant chemotherapy, reflecting constraints in role and social functioning rather than purely physical limitations. This pattern supports the interpretation that social participation is affected in lung cancer care, even if not explicitly prioritized in preference structures. Also, Hauber et al. similarly link severe fatigue with reductions in both physical and social engagement ("cannot participate in normal social activities") [18]. Here, survival outcomes dominate treatment trade-offs, leading to a secondary role for social participation. Finally, Pacchiana et al. do not quantify social functioning as a QoL domain [19]; however, their findings explicitly indicate that relational aspects of care influence patients' motivation. Here, patients described maintenance therapy as a way to "continue to receive care from the medical team and to feel protected," highlighting the importance of the doctor–patient relationship and of the perceived support from clinicians in their treatment decisions. This backs the finding that social dynamics matter affectively but do not dominate treatment-related decision-making. Based on

the descriptions provided in the study by Zhang et al., social functioning was not included as a decision-related attribute [21]. Besides this, social functioning also plays a clinically meaningful role in treatment of lung cancer. For example, Luszczynska et al. showed that perceived social support is positively associated with emotional well-being and global QoL [76]. Likewise, Chiou et al. found that social and role functioning declined with higher symptom burden, indicating that social participation was affected indirectly through physical limitations [74]. In addition, Polanski et al. showed that social functioning contributed to daily well-being but was closely tied to physical and psychological status [77]. Together, these findings support those from our DCE study; that is, social functioning is relevant for overall QoL but less influential than physically grounded attributes when facing treatment-related trade-offs.

Fourth, based on our findings, *anxiety* received substantially lower relative importance compared with physical symptoms or functional limitations. This preference pattern aligns closely with the two comparator studies that assessed psychological factors. For example, Pacchiana et al. reported high levels of distress on the Distress Thermometer [19]; here, distress was not associated with willingness to pursue maintenance therapy, indicating that emotional burden did not lead to treatment-related preference shifts. This supports our finding that anxiety is clinically meaningful but does not have a strong impact on explicit trade-off decisions. Similarly, Blinman et al. found that emotional well-being – measured via the Hospital Anxiety and Depression Scale – influenced the survival benefit patients considered sufficient to justify adjuvant chemotherapy [20]; however, emotional states did not outweigh the importance of physical symptoms or toxicity expectations. Finally, neither Zhang et al. [21] nor Hauber et al. [18] evaluated anxiety. Based on those findings, anxiety seems to be an important attribute for both patients and treating physicians but is consistently less influential than the attributes stated above. The clinical literature also supports this interpretation. For example, Koch et al. documented substantial psychosocial burden among lung cancer patients [78], while physical symptoms (e.g., such as shortness of breath) remained the strongest determinants of QoL. Additionally, Rutkowska et al. similarly found that anxiety and distress increased with symptom severity but exerted weaker independent effects on QoL [79]. These findings confirm that anxiety contributes to overall well-being but remains secondary to physically driven QoL limitations in medical decision contexts.

Fifth, *emotional impairment* was consistently the lowest-ranked attribute in our study. This preference pattern is supported by indirect evidence from the comparator studies. In this context, Pacchiana et al. showed that distress levels were high but did not meaningfully affect patients' willingness to continue maintenance therapy [19]. Likewise, Blinman et al. found that emotional well-being influenced the minimum survival benefit patients deemed acceptable for adjuvant chemotherapy, yet emotional status did not surpass physical symptoms or expected toxicities in importance [20]. Again, neither Zhang et al. [21] nor Hauber et al. [18] included emotional attributes in their study approach. Together, those findings suggest that emotional factors shape broader motivational orientations but exert limited weight in discrete preference-related trade-offs. From a clinical point of view, Xu et al. demonstrated that depression substantially reduces QoL and operates both directly and through reduced social support [80]. Koch et al. also reported high emotional burden but identified physical symptoms as the primary drivers of functional outcomes [78]. Finally, Rutkowska et al. found that distress worsens with symptom burden yet remains a secondary determinant of QoL [79]. Those preference patterns seem to be in line with our findings, showing emotional impairment to be clinically relevant but of comparatively lower importance in lung cancer-related decision scenarios.

Sixth, *financial difficulties* (patients only) played a moderate but meaningful role and was ranked third among patients (relative importance of 15%). Among the comparable studies, only Zhang et al. incorporated economic considerations, reporting moderate relative importance for monthly treatment costs [21]. This pattern aligns with our findings and suggests that financial burden is a non-negligible consideration across different health system contexts, even if not the primary determinant of preferences. The evidence base here is quite limited since the remaining studies did not include financial aspects, thus highlighting an important gap of research. Furthermore, clinical evidence supports the relevance of economic burden. For example, González et al. demonstrated that financial toxicity in lung cancer is strongly associated with poorer QoL and greater functional limitations [81]. In addition, Kurt et al. also showed that some patients reported financial strain contributing to distress [72]. In sum, these findings indicate that economic considerations meaningfully shape the experience of lung cancer, which is consistent with the moderate importance attributed to financial difficulties in our DCE.

Seventh, treating physicians ranked *pain severity* (physicians only) as the second most important attribute (22.5%). This finding is consistent with Zhang et al., where pain also emerged as a relevant treatment attribute, although with somewhat lower relative importance among oncologists and patients [21]. The remaining comparator studies did not explicitly model pain [18–20]. Overall, the available evidence suggests that pain is a robust driver of preferences when included as an attribute. Regarding clinical evidence, Chiou et al. identified pain as a major contributor to reduced physical functioning and global QoL [74]. In addition,

Polanski et al. similarly found that chest pain and cancer-related pain substantially impair QoL and daily functioning [77], further validating the prominent role of pain reflected in physician preferences.

Taken together, our results demonstrate a coherent pattern in which physically related QoL dimensions (i.e., shortness of breath and the ability to perform daily activities, in particular) dominate both patient and physician preferences in lung cancer care. These findings are broadly aligned with the limited comparative literature confirming attributes or similar proxies from other studies [18–21]. In contrast, social life, anxiety, emotional impairment, and financial difficulties were valued, but consistently ranked lower and showed weaker influence in explicit trade-off scenarios. Based on this, the latter dimensions might be assigned a secondary role. Pain, although evaluated only in the physician sample, proved to be a robust and important attribute whenever it was included [21]. Overall, our study presents preference patterns that highlight the central role of physical functioning and symptom burden in driving treatment preferences and underscore the need for care models that prioritize these domains while acknowledging – but not overstating – the influence of psychosocial and economic factors.

Finally, there is a substantial alignment between the preferences of patients and physicians; both groups consistently value reducing shortness of breath and preserving daily functioning the most, emphasizing the primacy of physical symptom burden in treatment decisions. However, meaningful divergence also emerges: Patients tend to also focus on financial difficulties, while physicians place comparatively greater emphasis on the severity of pain. In this context, the apparent divergence regarding those two dimensions (i.e., financial difficulties and severity of pain) should be interpreted considering the group-specific attribute-development process. These findings do not imply that both groups assigned different weights to the same attribute; rather, the preparatory literature review and qualitative work identified financial difficulties as an additional relevant dimension for patients and severity of pain as an additional relevant dimension for physicians, which was then reflected in the final DCE design. Nevertheless, these gaps may reflect persistent blind spots in standard care pathways. Such preference heterogeneity may, if unaddressed, reduce the effectiveness and acceptability of treatment decisions and contribute to suboptimal patient-centered value. Therefore, it seems essential to address these gaps by systematically integrating preference-related measures into lung cancer care. For example, shared decision-making models have been shown to improve the alignment between patient values and clinical recommendations [82]. Second, routine monitoring of patient-reported outcomes enhances early detection of physical, psychosocial, and economic distress and improves QoL and survival [83]. Third, stated-preference methods, such as DCEs, offer a structured way to make patient trade-offs explicit and to quantify preference heterogeneity in a transparent and reproducible manner [84]. These approaches may translate directly into practice through short preference-elicitation tools, structured value checklists, or DCE-derived decision aids that could be integrated into routine consultations. Fourth, communication skills training for oncologists could be shown to have a positive impact on empathy, patient satisfaction, and alignment in decision-making [85]. In addition, systematic screening for factors influencing economic challenges in lung cancer patients (e.g., occupation, insurance, income) combined with referral to social–legal counseling, return-to-work programs, or community-based support can mitigate economic burden and better align care with patient needs [86, 87]. Together, these approaches may offer – at least to some extent – a practical pathway to reduce preference divergences and support a more patient-centered, value-focused lung cancer care.

As with any study, there are several limitations that have to be considered. First, as described above, patient recruitment was carried out through multiple channels (e.g., patient self-help groups, lung cancer centers, office-based pulmonologists/oncologists, patient events, online communities). Following this, we were not able to detect a reliable response rate but only a completion rate. Second, our applied sampling strategy may have led to some selection and participation bias. Web surveys are likely to overrepresent individuals who are more digitally engaged, health-literate, or motivated to participate, leading to limited external validity [88]. For example, physician surveys are consistently affected by low response rates and selective participation, which can lead to systematic response bias and an overrepresentation of particularly engaged clinicians [89]. Third, it is important to mention that our study was conducted within the German health-care context. Future research would benefit from cross-country comparisons to strengthen generalizability. Fourth, our study analyses – as applied in DCEs – respondents' stated preferences with regard to hypothetical health states; however, their actual responses may differ in daily care situations. Fifth, despite rigorously following best-practice guidelines with regard to both attribute and level development, participants may still have interpreted certain QoL dimensions differently. In this case, the attributes and levels set might not fully capture all relevant dimensions of lung cancer-related QoL. Sixth, a considerable number of individuals left the survey immediately after the introduction page and therefore did not provide DCE choice data. While these early dropouts did not result in incomplete DCE choice sequences, they may indicate selection bias. The final sample may overrepresent participants who were more motivated, digitally engaged, less burdened, or more interested in QoL-related issues. This

should be considered when interpreting the generalizability of the findings. Seventh, because the survey was anonymous and web-based, we could not formally verify patient diagnoses or physician identity through medical records, professional registration numbers, or institutional login procedures. Thus, some degree of misclassification cannot be fully excluded. Finally, lung cancer comprises clinically heterogeneous subtypes, including small-cell and non-small-cell lung cancer; thus, preferences may vary according to tumor type, disease stage, prognosis, treatment pathway, and symptom burden. Our study was not designed to estimate subtype-specific preference structures. Future research should therefore examine whether QoL-related preferences differ across clinically relevant lung cancer subgroups.In sum, this study adds to the literature by presenting one of the first comprehensive comparisons of lung cancer patients' and treating physicians' preferences regarding QoL dimensions in Germany. Using two parallel DCEs, we found that both groups consistently assigned high relative importance to shortness of breath and activities of daily living, although physicians valued severity of pain more strongly than patients, while patients placed greater weight on financial difficulties. In both groups, emotional impairment emerged as the least influential attribute in structured decision scenarios. Our findings indicate a shared recognition that physical functioning and respiratory symptoms are central for evaluating health states during lung cancer treatment. However, nuanced differences in the weighting of certain QoL domains suggest that patients and physicians may prioritize some aspects of treatment experience differently. This confirms existing literature demonstrating divergences between patient- and clinician-reported preferences in lung cancer care [18–21]. Our results contribute novel evidence to the European context, where preference comparisons in lung cancer remain scarce. Specifically, this is the first study to compare German lung cancer patients and physicians using a methodologically robust DCE design. It therefore provides valuable insight for aligning clinical communication, advancing shared decision-making, and guiding patient-centered care pathways.

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Author contributions All authors contributed to the study conception. ME, SR and SF developed the study design and preference elicitation framework, ME and SR derived the analytical results. ME, KI and SF analyzed the literature. The first draft of the manuscript was written by ME and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability Data available on request from the corresponding author (martin.emmert@uni-bayreuth.de).

Declarations

Ethics approval and consent Ethics approval for this study was obtained from the ethics committee of the University of Regensburg (internal reference number 23-3303_1-101).

Role of the funder/sponsor The funder had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Consent to participate Informed consent was obtained from each participant. All participants participated voluntarily and could end their participation at any time. All participants were informed about the study prior to participation and gave consent to use the data for publication.

Registration ClinicalTrials.gov NCT06252233. Registered on February 2024.

Conflict of interest The authors declare that they have no competing interests.

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