



Universiteit
Leiden
The Netherlands

Can routine register data be used to identify vulnerable lung cancer patients of suboptimal care in a German comprehensive cancer centre?

Godde, K.; Siegerink, B.; Fugemann, H.; Keune, D.; Sander, S.; Schneider, A.; ... ; Goerling, U.

Citation



Godde, K., Siegerink, B., Fugemann, H., Keune, D., Sander, S., Schneider, A., ... Goerling, U. (2021). Can routine register data be used to identify vulnerable lung cancer patients of suboptimal care in a German comprehensive cancer centre? *European Journal Of Cancer Care*, 30(4). doi:10.1111/ecc.13398

Version: Publisher's Version
License: [Creative Commons CC BY-NC-ND 4.0 license](#)
Downloaded from: <https://hdl.handle.net/1887/3276107>

Note: To cite this publication please use the final published version (if applicable).

ORIGINAL ARTICLE

Can routine register data be used to identify vulnerable lung cancer patients of suboptimal care in a German comprehensive cancer centre?

Kathrin Gödde¹  | Bob Siegerink² | Hella Fügemann^{1,3} | Dietmar Keune⁴ |
 Steffen Sander⁴ | Alice Schneider⁵ | Jacqueline Müller-Nordhorn^{1,6} |
 Christine Holmberg^{1,3,7} | Nina Rieckmann¹ | Nikolaj Frost⁸ | Ulrich Keilholz⁴ |
 Ute Goerling⁴ 

¹Institute of Public Health, Charité-Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

²Center for Stroke Research (CSB), Charité-Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

³Institute of Social Medicine and Epidemiology, Brandenburg Medical School Theodor Fontane, Brandenburg an der Havel, Germany

⁴Charité Comprehensive Cancer Center, Charité-Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

⁵Institute of Biometry and Clinical Epidemiology, Charité - Universitätsmedizin Berlin, Corporate Member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

⁶Bayerisches Landesamt für Gesundheit und Lebensmittelsicherheit, Bayerisches Krebsregister, Erlangen, Germany

⁷Faculty of Health Sciences Brandenburg, Brandenburg Medical School Theodor Fontane, Potsdam, Germany

⁸Department of Infectious Diseases and Pulmonary Medicine, Charité-Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany

Correspondence

Ute Goerling, Charité Comprehensive Cancer Center, Charité-Universitätsmedizin Berlin, corporate member of Freie Universität Berlin, Humboldt-Universität zu Berlin, and Berlin Institute of Health, Berlin, Germany.
 Email: ute.goerling@charite.de

Funding information

CoreNAVI is part of the research consortium 'NAVICARE - Patient-oriented health services research' and is funded by the German Ministry of Education and Research (01GY1601).

Abstract

Objectives: Several patient factors have been described to influence access to optimal cancer care like socioeconomic factors or place of residence. In this study, we investigate whether data routinely collected in a clinical cancer registry can be used to identify populations of lung cancer patients with increased risk of not receiving optimal cancer care.

Methods: We analysed data of 837 lung cancer patients extracted from the clinical cancer registry of a German university hospital. We compared patient populations by two indicators of optimal care, namely implementation of tumour board meeting recommendations as well as the timeliness of care.

Results: There was a high rate of implementation of tumour board meeting recommendations of 94.4%. Reasons for non-implementation were mainly a patient's own wish or a worsening of the health situation. Of all patient parameters, only tumour stage was associated with the two optimal care indicators.

Conclusion: Using routine data from a clinical cancer registry, we were not able to identify patient populations at risk of not getting optimal care and the implementation

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. European Journal of Cancer Care published by John Wiley & Sons Ltd.

of guideline-conform care appeared to be very high in this setting. However, limitations were the ambiguity of optimal care indicators and availability of parameters predictive for patients' vulnerability.

KEYWORDS

cancer care, cancer registry, care indicators, lung cancer, optimal care, vulnerable patients

1 | INTRODUCTION

Lung cancer is one of leading causes of death worldwide (Ferlay et al., 2019) and has the highest mortality in comparison to all cancer entities in Germany. A lung cancer diagnosis is often made in an already progressed stage of the cancer and the 5-year survival rate is low with 20% for women and 15% for men (Robert Koch-Institut & Gesellschaft der epidemiologischen Krebsregister in Deutschland e.V., 2017). The care for lung cancer patients can be very complex and a further gain in complexity due to abundant co-morbidities occurs frequently (Dutkowska & Antczak, 2016; Schram et al., 2008). Lung cancer care hence requires the integration of a variety of health disciplines like physicians, psycho-oncologists, social workers and more. The high mortality rate makes early integration of palliative care also recommendable (Temel et al., 2010).

As care plans for lung cancer patients may vary due to the patient's individual situation, definition of indicators for optimal care is rather difficult. Care in accordance with state-of-the-art medical evidence is approximated by the development and definition of evidence-based treatment guidelines along with the definition of specific quality indicators. The guidelines for lung cancer treatment were recently revised and published for lung cancer in Germany and eight quality indicators have been defined for the strongest recommendations (Leitlinienprogramm Onkologie, 2018a, 2018b). The establishment of regular tumour board meetings (TBMs) in cancer centres in Germany is thought to ensure this guideline conform treatment. In these meetings, physicians of different disciplines and, if applicable, other health staff jointly discuss and decide on a therapy plan for a patient to which we refer to as tumour board recommendation in the present study. The patient's treatment trajectory and according to that the implementation status of TBM recommendations is documented in the clinical cancer registry of cancer centres for internal and external quality control (Mensah et al., 2017). For example, guideline conformity of the patient's actual treatment in accord to quality indicators is subject of investigation during external audits as prerequisite for certification as cancer centres. Taking this process into consideration, we hypothesised the parameter 'Implementation of Tumor board recommendations' may be used as valuable and general quality indicator for guideline-conform (optimal) care in a binary manner.

As another optimal care indicator, timeliness of care was used in previous studies (Freeman et al., 1995; Olsson et al., 2009; Stokstad et al., 2017). For this matter, intervals between different time points along the patient's care trajectory, for example, the time interval

between dates of diagnosis and start of treatment, are measured and shorter time intervals are usually considered as more advantageous for the patient (Olsson et al., 2009; Stokstad et al., 2017).

International studies describe different patient parameters that may lead to a higher risk of not accessing optimal cancer care. Characteristics of these vulnerable patient populations include a lower socioeconomic status of a patient, a rural residence with the lack of local health services as well as cultural influences like language barriers (Berglund et al., 2010; Du et al., 2015; Dunn et al., 2017; Nayar et al., 2014). In accordance with these findings from countries with different health systems, associations between lower socioeconomic status and rural residence with disparities in cancer care, like utilisation of cancer prevention and early detection (Seidel et al., 2009), have been reported for Germany as well (Ernst et al., 2010; Hartung & Johansen, 2017).

The aim of this study was to investigate the possibility of using routinely collected patient data documented by a clinical cancer registry of a large university hospital to identify vulnerable patient populations at risk of not receiving optimal lung cancer care. Early identification of these patient populations could allow for an early referral of vulnerable patients to additional support offers. To do so, we asked if documented patient parameters were associated with two previously described optimal care indicators that were readily accessible by the documented data of the registry, namely implementation of TBM recommendations (primary research question) as well as timeliness of care (secondary research question).

2 | METHODS

2.1 | Study population

Patient data were retrieved from the clinical lung cancer registry of a large German university hospital. The initial dataset included data on 864 patients from 1738 TBMs held between January 2013 and July 2018. Data were extracted from the registry on 07 July 2018 using filters for the following inclusion criteria:

- diagnostic code ICD-10 C34 (lung cancer)
- diagnosis in the years 2013 to 2015
- age older than 18 years
- status as a primary case (as defined by being either diagnosed and treated at this university hospital or being diagnosed elsewhere but receiving the main part of treatment at the hospital).

Further, datasets of TBMs were excluded from analysis by following criteria:

- TBMs held in the year 2018 to ensure a follow-up time of the recommendations of at least 6 months prior analysis.
- TBMs with the implementation status 'unknown' or no implementation status documented.

2.2 | Primary research question

Implementation of TBM recommendations was used as outcome to approximate guideline-conform lung cancer treatment in the investigation of the primary research question. Choosing this indicator is based on the pre-assumption that TBM recommendations are in accord with the guidelines that were defined for treatment in Germany (Leitlinienprogramm Onkologie, 2018a, 2018b). This guideline conformity of the recommendations is annually audited in the quality assurance process of the hospital as well as by external monitors as a prerequisite of certification as tumour centre that is hold by the hospital of this investigation. Implementation status of the recommendation is standardly followed up and documented in the registry and the status is used in the present study as a binary parameter.

Overall rate of implementation was calculated per TBM recommendation (implemented recommendation versus non-implemented recommendation) (Compare Dataset 1 in Figure 1). For TBM recommendations where reasons for non-implementation of TBM recommendations were documented, these were thematically grouped and reported descriptively.

For comparison of patients according to their implementation status of TBM recommendations, we created two groups according to the implementation status of a patient's TMB recommendations. We compared patients with 'all recommendations per patient implemented' versus patients with 'at least one of all recommendation per patient not implemented' (Compare Dataset 2 in Figure 1).

2.2.1 | Statistical analysis for primary research question

Patient groups by TBM implementation were described by selected parameters that are documented in the registry using univariate comparisons. For analysis of categorical variables, we used either Chi²-Test or, in case of $N < 5$, Fisher's exact test. Where possible, point estimates with 95% confidence intervals were given. To investigate the robustness of our results, some analyses were stratified by intention of the primary treatment (curative/palliative).

2.2.2 | Patient parameters

We analysed the association between the following patient parameters and the status of tumour board implementation per patient: Sex,

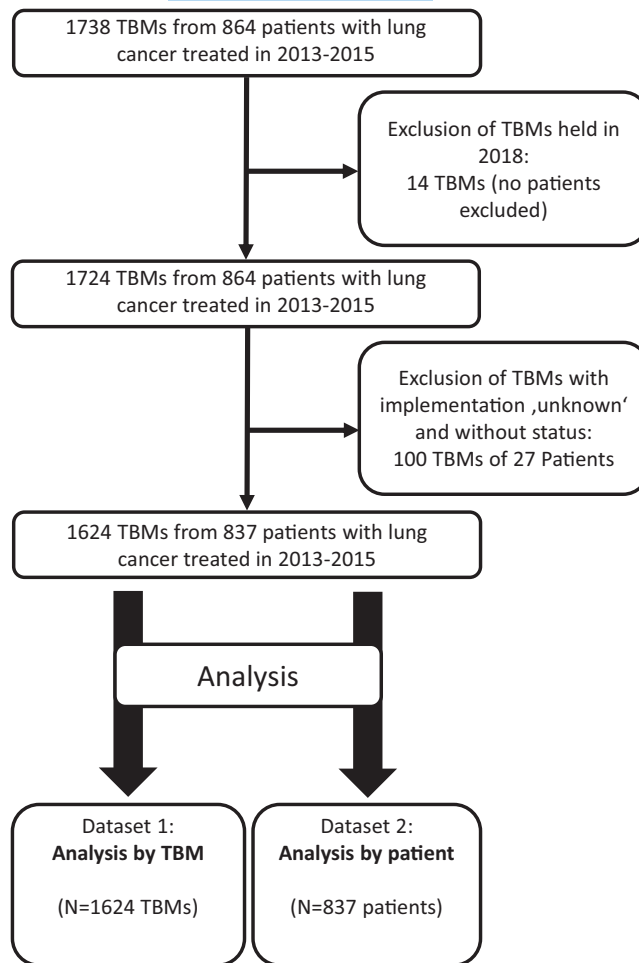


FIGURE 1 Flow chart illustrating exclusion of observations from initial dataset according to previously described exclusion criteria. Final dataset was analysed either per tumour board meeting (Dataset 1) or per patient (Dataset 2) for investigation of primary research question. Analysis of the secondary question was based on the same patient population of Dataset 2. TBM, tumour board meeting

age, vital status one year post-diagnosis, tumour stage (as defined by the Union for International Cancer Control, UICC), prevalence of further tumours, utilisation of hospital's social service, psycho-oncological consultation, physical performance status (as defined by the Eastern Cooperative Oncology Group, ECOG), place of residency (via postal code), type of health insurance (statutory/private), smoking status, intention of primary therapy. Several parameters had missing data. For our analysis, we treated missing values as completely at random if not stated otherwise.

2.3 | Secondary research question

For this investigation, we used timeliness of care as outcome that was previously used as an indicator for optimal care (Olsson et al., 2009; Stokstad et al., 2017). In the present study, we assume that a timelier diagnosis and a timelier start of a treatment are preferable

in terms of optimal care. We calculated the lengths (in days) of the following two intervals between documented time points along patient's care paths in the dataset:

- Time between dates of hospital admission and diagnosis.
- Time between dates of diagnosis and the start of the primary treatment (any treatment type).

2.3.1 | Statistical analysis for secondary research question

Cox regression analyses were carried out to analyse the association of patient parameters with the lengths of intervals of the patients' care paths resulting in hazard ratios and their corresponding confidence intervals. We calculated the crude model and also adjusted for place of residency, psycho-oncological consultation, sex, age and tumour stage and additionally for intention of treatment and social service consultation in the case for the interval 'diagnosis until start of primary treatment'. Described variables in the adjusted model were included by blockwise inclusion of all parameters. By adjusting, we try to reduce the effect of confounding where possible. Negative values have been omitted from the analysis (e.g. occurring if time point of diagnosis prior to admission date).

For all analyses, IBM SPSS statistical software (Version 25) was used.

2.3.2 | Ethics statement

The study has been performed according to the Declaration of Helsinki and was approved by the local ethical committee.

3 | RESULTS

From the total extracted data set, TBMs were excluded according to the defined exclusion criteria as depicted in the flow chart in Figure 1. Hence, the dataset for analysis included documentations from 837 patients with 1624 TBMs.

3.1 | Primary research question: Implementation of TBM recommendations

3.1.1 | Analysis per TBM recommendation

The implementation rate of TBM recommendations (Figure 1, Dataset 1) was high with 94.4%. Of the 91 non-implemented TBM recommendations in the dataset, a detailed reason for non-implementation was given for 42 recommendations. Reasons for

TABLE 1 Reasons for non- implementation of tumour board meeting recommendations. Detailed reasons were given for 42 of 91 non-implemented tumour board meeting recommendations

Given reasons for non-implementation of recommendations (N = 91)

Patient's decision (N = 19)
Progress of cancer (N = 3)
Worsening of patient's general state of health/patient's death (N = 3)
Therapy not possible due to patient's condition (e.g. therapy intolerance) (N = 6)
Change of therapy (N = 11)
Unknown reason (N = 49)

non-implementation are thematically grouped where appropriate and illustrated in Table 1. Predominant reasons for non-implementation were a patient's own choice as well as the progression of the cancer or the worsening of a patient's health status.

3.1.2 | Analysis per patient

Distribution of patient characteristics for the total dataset as well as in comparison between implementation statuses of the TBM recommendations is shown in Table 2. Patients were presented in a TBM twice in median and about half of the patients were presented in ≥ 2 TBMs. For 89.1% of the patients, recommendations were implemented of all TBMs they were presented in and no patient had more than one non-implemented TBM recommendation.

Most patient parameters were comparable between implementation statuses of the TBM recommendations. Observed differences in univariate comparisons between parameters reflect a more progressed stage of the disease indicated by a shift of tumour stages to more severe stages in patients with a non-implemented TBM recommendation. All further investigated patient characteristics were comparable between implementation groups (Table 2).

Comparisons of patients by treatment intention of the primary treatment showed differences that reflect a more severe disease stage for patients with a palliative treatment intention (Table S1). We stratified the dataset for the initial treatment intention to account for these differences in the study population and compared the patients between TBM implementation statuses within the two strata. After stratification, the patient populations were still comparable between implementation statuses of the TBM recommendations (Table S2). Comparable to the unstratified analysis, differences were seen in the two strata by a shift to more severe UICC tumour stages in patients with a non-implemented TBM recommendation. In addition, a lower proportion of patients is alive one year after diagnosis in the patient group with a non-implemented TBM recommendation. Described effects were more pronounced in the patient stratum with a palliative treatment intention.

In summary, only parameters reflecting the severity of the cancer or disease stage per se were associated with the implementation of a patient's TBM recommendations.

TABLE 2 Patient parameters according to implementation status of tumour board meeting recommendations

Characteristic	Total (N = 837)	Implementation of TBM recommendation		p-value ^a
		Yes (N = 746)	No (N = 91)	
Sex				
Female	38.1 (319)	38.5 (287)	35.2 (32)	0.540
Male	61.9 (518)	61.5 (459)	64.8 (59)	
Age				
Mean (95% CI)	65.91 (± 10.39)	65.92 (± 10.38)	65.85 (± 10.55)	0.076 ^b (-2.24; 2.39)
<50 years	7.3 (61)	7.2 (54)	7.7 (7)	0.966
50–59 years	19.1 (160)	19.4 (145)	16.5 (15)	
60–69 years	33.2 (278)	33.1 (247)	34.1 (31)	
70–79 years	32.1 (269)	31.9 (238)	34.1 (31)	
≥80 years	8.2 (69)	8.3 (62)	7.7 (7)	
Vital status of patient 1 year after diagnosis				
Alive	53.9 (451)	54.7 (408)	47.3 (43)	0.179
Dead	46.1 (386)	45.3 (338)	52.7 (48)	
Tumour stage (UICC)				
I	18.1 (151)	19.0 (141)	11.0 (10)	0.010
II	8.2 (68)	7.8 (58)	11.0 (10)	
III	25.1 (209)	23.6 (175)	37.4 (34)	
IV	48.7 (406)	49.7 (369)	40.7 (37)	
Further tumours				
Yes	27.7 (232)	27.9 (208)	26.4 (24)	0.762
No	72.3 (605)	72.1 (538)	73.6 (67)	
Social service consultation				
Yes	80 (670)	80.3 (599)	78.0 (71)	0.609
No/unknown (not in-house)	20 (167)	19.7 (147)	22.0 (20)	
Psycho-oncological consultation				
Yes	56.2 (470)	56.1 (418)	57.1 (52)	0.110
No	4.7 (39)	4.2 (31)	8.8 (8)	
Unknown (not in-house)	39.1 (327)	39.7 (296)	34.1 (31)	
ECOG Index (at 1st TBM presentation)				
0	31.1 (260)	30.7 (229)	34.1 (31)	0.435
1	23.4 (196)	22.9 (171)	27.5 (25)	
2	6.5 (54)	6.8 (51)	3.3 (3)	
3	3.7 (31)	3.5 (26)	5.5 (5)	
4	1.2 (10)	1.2 (9)	1.1 (1)	
Unknown	34.2 (286)	34.9 (260)	28.6 (26)	
Place of residency				
Berlin	86.2 (708)	86.3 (631)	85.6 (77)	0.437
Brandenburg	10.7 (88)	10.4 (76)	13.3 (12)	
Others	3.0 (25)	3.3 (24)	1.1 (1)	
Health insurance				
SHI	92.4 (524)	92.5 (469)	91.7 (55)	0.817
PHI	7.6 (43)	7.5 (38)	8.3 (5)	

(Continues)

TABLE 2 (Continued)

Characteristic	Total (N = 837)	Implementation of TBM recommendation		p-value ^a
		Yes (N = 746)	No (N = 91)	
Smoking status				
Smoker	44.2 (370)	44.5 (332)	41.8 (38)	0.703
Non-smoker	38.7 (324)	38.7 (289)	38.5 (35)	
Never-smoker	4.3 (36)	4.4 (33)	3.3 (3)	
Unknown	12.8 (107)	12.3 (92)	16.5 (15)	
Intention of primary treatment				
Palliative	55.2 (428)	55.8 (387)	50.6 (41)	0.378
Curative	44.8 (347)	44.2 (307)	49.4 (40)	

Data given as percentage (N) for categorical variables or mean \pm SD, if stated.

^aGroups are compared via Chi-square test if $N > 4$, otherwise comparison was done by Fisher's exact test.

^bMeans are compared using the difference of the means \pm 95% confidence intervals.

3.2 | Secondary research question: Timeliness of care indicators

To answer the secondary research question, we investigated the association of patient characteristics with two time intervals along the patients' trajectory, namely the time interval between hospital admission and lung cancer diagnosis as well as between diagnosis and the start of the primary therapy (Table 3 and Table 4).

3.2.1 | Interval between hospital admission and lung cancer diagnosis

By Cox regression analysis, we investigated the association of selected patient parameters with the length of the interval from hospital admission until the diagnosis (Table 3). Note that hazard ratios ≥ 1 should be interpreted here as an increased chance for a patient to have a shorter time interval from hospital admission until receiving the lung cancer diagnosis. The investigated population of lung cancer patients had a median duration from admission until diagnosis of 4 days (range: 0–212 days, interquartile range (IQR) = 2–11 days). The median interval lengths differ between tumour stages with 6 days (range 0–113 days, IQR = 1–19 days) in Stage I, 3 days (range: 0–212 days, IQR = 1–9 days) in Stage II, 4 days (range: 0–153 days, IQR = 2–11.5 days) in Stage III and 4 days (range 0–60 days, IQR = 2–8 days) in stage IV. We observed hazard ratios >1 for tumour stages II–IV compared to tumour stage I in the crude as well as in the adjusted analysis. None of the other patient parameters were associated with the time interval between hospital admission and diagnosis.

3.2.2 | Interval between lung cancer diagnosis and start of the primary therapy

By Cox regression analysis, we further investigated the association of the interval length between lung cancer diagnosis and the starting date of the primary therapy (Table 4). Again, hazard ratios ≥ 1 should be

interpreted as an increased chance for shorter times between diagnosis until start of the primary treatment. The median duration from diagnosis until start of treatment (any treatment type) was 20 days (range:

TABLE 3 Cox regression for outcome 'time from patient admission until diagnosis'

Parameter	Crude HR	95% CI	Adjusted HR	95% CI
Place of residency				
Berlin	1.0		1.0	
Brandenburg	1.04	0.81; 1.35	1.04	0.80; 1.35
Others	1.29	0.81; 2.07	1.41	0.87; 2.28
Psycho-oncological consultation				
Yes	1.0		1.0	
No	0.96	0.66; 1.40	1.0	0.69; 1.49
Not inhouse	0.89	0.75; 1.04	0.91	0.77; 1.07
Sex				
Male	1.0		1.0	
Female	1.14	0.98; 1.34	1.17	0.996; 1.38
Age at diagnosis (per year increase)				
Age at diagnosis (per year increase)	1.00	0.996; 1.01	1.01	0.997; 1.013
Tumour stage (UICC)				
1	1.0		1.0	
2	1.38	1.02; 1.88	1.41	1.03; 1.92
3	1.31	1.05; 1.64	1.35	1.07; 1.70
4	1.44	1.17; 1.77	1.43	1.15; 1.78

Note: The hazard ratio of receiving a timely cancer care treatment is calculated by taking into consideration the time to event (from admission to diagnosis) and reported as crude and adjusted values. HR > 1 indicates a higher probability of shorter time intervals between admission to diagnosis. $N = 642$ patients were included in the calculation of the adjusted model. Datasets with missing information were excluded from the analysis

TABLE 4 Cox regression for outcome 'time from diagnosis until start of primary therapy (any treatment type)'

Parameter	Crude HR	95% CI	Adjusted HR	95% CI
Place of residency				
Berlin	1.0		1.0	
Brandenburg	1.04	0.82; 1.31	0.99	0.78; 1.27
Others	1.26	0.83; 1.92	1.23	0.80; 1.89
Intention of treatment				
Curative	1.0		1.0	
Palliative	1.54	1.33; 1.79	1.69	1.31; 2.17
Psycho-oncological consultation				
Yes	1.0		1.0	
No	0.88	0.63; 1.24	1.04	0.71; 1.52
Not inhouse	0.92	0.8; 1.07	1.00	0.84; 1.17
Social service consultation				
Yes	1.0		1.0	
No/not inhouse	1.08	0.90; 1.28	1.12	0.92; 1.37
Sex				
Male	1.0		1.0	
Female	1.09	0.94; 1.25	1.12	0.96; 1.31
Age at diagnosis (per year increase)				
1.0	1.0	0.99; 1.01	1.00	0.99; 1.01
Tumour stage (UICC)				
1	1.0		1.0	
2	1.07	0.79; 1.44	1.02	0.75; 1.39
3	1.55	1.24; 1.93	1.36	1.07; 1.73
4	1.53	1.26; 1.86	0.97	0.71; 1.33

Note: The hazard ratio of receiving a timely cancer care treatment is calculated by taking into consideration the time to event (from diagnosis to treatment) and reported as crude and adjusted values. HR > 1 indicates a higher probability of shorter time intervals between diagnosis to treatment. N = 719 patients were included in the calculation of the adjusted model. Data sets with missing information were excluded from the analysis.

0–410 days, IQR = 5–42.75). The median interval lengths differ between tumour stages with 35 days (range: 0–212 days, IQR = 0–69.25 days) in Stage I, 35 days (range: 0–171 days, IQR = 14–60 days) in Stage II, 20 days (range: 0–183 days, IQR = 6–38 days) in Stage III and 16 days (range 0–410 days, IQR = 4–35 days) in stage IV. A hazard >1 was observed in tumour stages II and III compared to tumour stage I as well as for a palliative treatment intention. None of the other patient parameters was associated with the interval length between lung cancer diagnosis and start of the primary therapy.

4 | DISCUSSION

In the present study, we aimed to make use of patient data of a hospital's clinical cancer registry to identify vulnerable lung cancer

patients at risk of not receiving optimal care. Results showed that from our analysis and with the chosen study design, vulnerable patient populations of not receiving optimal cancer care could not be discerned. These results should however be understood in the light of the validity of the optimal care indicators and the availability of appropriate patient data.

Overall, a high rate of implementation of TBM recommendations most likely reflects a high degree of guideline-conform treatment in the investigated population of lung cancer patients in the setting of a German university hospital in a metropolitan area. Here, implementation of TBM recommendations in the actual treatment plans of a patient is likely a valid indicator for a patient to receive guideline-conform treatment as this is evaluated during internal and external audits for quality management and certification purposes. However, our data show that the reverse assumption is likely an unreliable indicator for non-guideline-conform (or even suboptimal) cancer care. Observed reasons for non-implementation of TBM recommendations were a patient's own wish or a worsening of a patient's health state. However, these particular results should be interpreted in light of their limited generalisability as only for <50% of non-implemented recommendations detailed reasons were recorded. The status of residual recommendations was assigned by the documentalist in the registry judged by the absence of data on the recommended treatment in the hospital documentation system after a reasonable amount of time. Differences between implementation statuses of the TBM recommendations were seen for patient parameters indicating the disease severity, like cancer stage or vital status one year post-diagnosis. Based on these findings, non-implementation might even reflect patient-oriented treatment in accord with the patients' current health situation, rather than non-guideline conformity of treatment as we had initially assumed for this chosen indicator. Based on the present data set and study design, it cannot be judged if non-implementation of a TBM recommendation due to a patient's health status is a reaction to a new health situation posterior to the TBM or the result of neglecting the patient's individual situation before or during a TBM. In conclusion, differences in the distribution of patient parameters between implementation statuses of TBM recommendations have a rather low informative value to reflect differences in optimal cancer care. For a valid and comprehensive picture, the patients' treatment after non-implementation of a TBM recommendation would have to be followed and evaluated for each individual case and judged for guideline conformity. Furthermore, the low event size of not implemented TBM recommendations alone leads to a low power in our comparisons and limits the possibility to provide detailed multivariable analyses, making it per se difficult to reliably identify patients' characteristics that are associated with suboptimal care.

Time intervals between different time points of the patients' cancer care trajectory (hospital admission, lung cancer diagnosis and start of primary treatment) were previously suggested (Olsson et al., 2009) and used here as further indicators for optimal cancer care. Overall, the median time intervals of the investigated study population are in accordance with recommended time intervals

as stated by different studies or international cancer associations (Leitlinienprogramm Onkologie, 2018b; Olsson et al., 2009). Patients with later cancer stages showed a higher probability of shorter time intervals for both time intervals and palliative treatment intention was associated with shorter times from diagnosis until treatment. These observed differences are likely due to different diagnostic and treatment regimen and processes depending on the stage and severity of the lung cancer disease (Leitlinienprogramm Onkologie, 2018b) as well as due to differences in disease complexity (Stokstad et al., 2017). It should be pointed out that the differences should not be interpreted as less optimal care on the ground of longer time intervals solely. For example, curative treatment paths usually involve surgical resection of the tumour that can require a longer time span for preparation compared to the time span to start a palliative systemic therapy (Olsson et al., 2009). Overall, patient populations vulnerable of not receiving optimal cancer care could not be identified here.

To answer the present research question, further investigations on indicators for optimal care from the abundant data of the registry need to be conducted. This may include more individualised and detailed approaches to acknowledge the complexity and diversity of disease manifestations and treatment regimens. These indicators for optimal care may then also be tested with respect to their association with disease outcomes.

Investigated patient parameters were largely comparable between implementation statuses as well as regarding to the lengths of the investigated time intervals. However, it needs to be considered that further factors may influence the receipt of or access to optimal lung cancer care, such as comorbidities (Blazeby et al., 2006; Jalil et al., 2013; Kurtz et al., 2010; Wood et al., 2008), socio-economic status or language barriers (Berglund et al., 2010; Dunn et al., 2017; Nayar et al., 2014). These parameters were not available for investigation in our study, because they are not standardly or comprehensively recorded in the registry. The primary purpose of the used clinical registry is the collection of mandatory data for reporting to epidemiological and clinical cancer registries in Germany (Arbeitsgemeinschaft Deutscher Tumorzentren e.V. & Gesellschaft der epidemiologischen Krebsregister in Deutschland e.V., 2014) as well as for internal and external quality control of medical care in accord with evidence-based guidelines (Mensah et al., 2017). For identification of vulnerable patient populations of not receiving optimal cancer care, a more detailed parameter set of the patient's individual and personal situation would need to be included in the data collection. For example, assessment tools used for screening of geriatric patients could be valid instruments to standardly document and evaluate the patient's individual situation (Hurria et al., 2007; Lachs et al., 1990; Nikolaus, 2001) as well as routinely collection of patient-reported outcome measures as reported for some care schemes in the US (Basch et al., 2020).

Further, some parameters had a high degree of missing data. We assumed these to be completely at random for our analysis, although this can potentially lead to erroneous effect estimations. For example, an association of TBM implementation status with

the ECOG performance may be underestimated as this parameter may be preferentially documented if the performance status is limited (ECOG \neq 0) as indicated by higher rates of missing values in the group of patients with a curative initial treatment or with a non-implemented TBM recommendation. In terms of generalisability, the specific setting in a certified centre and university hospital of the investigated patient population has to be considered. Certified cancer centres in Germany offer patients a very comprehensive set of treatment options that may not be equally available in uncertified hospitals. However, these hospitals are responsible for the treatment of about 40% of lung cancer patients in Germany (Richter-Kuhlmann, 2019). Moreover, treatment in a comprehensive cancer centre focusses on innovative treatment options (Mensah et al., 2017) and hence the patient population of the investigated dataset may not be generalisable to the basic population of lung cancer patients in Germany with regard to their disease stage and manifestation as well as the treatments provided. For example, the investigated population is slightly younger, but distribution of tumour stages is comparable to data for Germany (Robert Koch-Institut & Gesellschaft der epidemiologischen Krebsregister in Deutschland e.V., 2017). As all patients investigated of our dataset were presented in a lung cancer TBM meeting, they may have an increased probability to receive guideline-conform treatment per se. Hence, patient population for future studies on identification of vulnerable patients should be generalisable to the general population of lung cancer patients and include patients that are treated in non-certified hospitals or are not presented in a TBM.

In summary, even though we were not able to identify vulnerable patient populations based on routinely collected data in the clinical registry and selected indicators, it is not to say that use of appropriate indicators in a more population-based study design could be of help to identify vulnerable patient groups and hence improve care of lung cancer patients.

ACKNOWLEDGMENTS

The authors thank Katrin Ramin for her support with the paper.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

All authors contributed to the study conception and design. Registry data were extracted and provided by Dietmar Keune, Steffen Sander and Ulrich Keilholz. Data analysis was performed by Kathrin Gödde, Ute Goerling, Bob Siegerink, and Alice Schneider. The first draft of the manuscript was written by Kathrin Gödde, and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The registry data are not publicly available due to privacy or ethical restrictions but could be available from corresponding author on reasonable request.

ORCID

Kathrin Gödde  <https://orcid.org/0000-0003-3672-2032>

Ute Goerling  <https://orcid.org/0000-0001-8157-3836>

REFERENCES

- Arbeitsgemeinschaft Deutscher Tumorzentren E.V., & Gesellschaft der Epidemiologischen Krebsregister in Deutschland E.V. (2014). *Einheitlicher Onkologischer Basisdatensatz* [Online]. <https://www.tumorzentren.de/onkol-basisdatensatz.html>
- Basch, E., Wilfong, L., & Schrag, D. (2020). Adding patient-reported outcomes to medicare's oncology value-based payment model. *JAMA*, *323*, 213–214.
- Berglund, A., Holmberg, L., Tishelman, C., Wagenius, G., Eaker, S., & Lambe, M. (2010). Social inequalities in non-small cell lung cancer management and survival: A population-based study in central Sweden. *Thorax*, *65*, 327–333.
- Blazeby, J. M., Wilson, L., Metcalfe, C., Nicklin, J., English, R., & Donovan, J. L. (2006). Analysis of clinical decision-making in multi-disciplinary cancer teams. *Annals of Oncology*, *17*, 457–460.
- Du, X. L., Parikh, R. C., & Lairson, D. R. (2015). Racial and geographic disparities in the patterns of care and costs at the end of life for patients with lung cancer in 2007–2010 after the 2006 introduction of bevacizumab. *Lung Cancer*, *90*, 442–450.
- Dunn, J., Garvey, G., Valery, P. C., Ball, D., Fong, K. M., Vinod, S., O'Connell, D. L., & Chambers, S. K. (2017). Barriers to lung cancer care: Health professionals' perspectives. *Supportive Care in Cancer*, *25*, 497–504.
- Dutkowska, A. E., & Antczak, A. (2016). Comorbidities in lung cancer. *Pneumonologia I Alergologia Polska*, *84*, 186–192.
- Ernst, J., Zenger, M., Schmidt, R., Schwarz, R., & Braehler, E. (2010). Medical and psychosocial care needs of cancer patients: A systematic review comparing urban and rural provisions. *Deutsche Medizinische Wochenschrift*, *135*, 1531–1537.
- Ferlay, J., Colombet, M., Soerjomataram, I., Mathers, C., Parkin, D. M., Piñeros, M., Znaor, A., & Bray, F. (2019). Estimating the global cancer incidence and mortality in 2018: GLOBOCAN sources and methods. *International Journal of Cancer*, *144*, 1941–1953.
- Freeman, H. P., Muth, B. J., & Kerner, J. F. (1995). Expanding access to cancer screening and clinical follow-up among the medically underserved. *Cancer Practice*, *3*, 19–30.
- Hartung, T. J., & Johansen, C. (2017). Sozioökonomischer Status und Krebs. *Forum*, *32*, 318–323.
- Hurria, A., Lichtman, S. M., Gardes, J., Li, D., Limaye, S., Patil, S., Zuckerman, E., Tew, W., Hamlin, P., Abou-Alfa, G. K., Lachs, M., & Kelly, E. (2007). Identifying vulnerable older adults with cancer: Integrating geriatric assessment into oncology practice. *Journal of the American Geriatrics Society*, *55*, 1604–1608.
- Jalil, R., Ahmed, M., Green, J. S., & Sevdalis, N. (2013). Factors that can make an impact on decision-making and decision implementation in cancer multidisciplinary teams: an interview study of the provider perspective. *International Journal of Surgery*, *11*, 389–394.
- Kurtz, J. E., Heitz, D., Serra, S., Brigand, C., Juif, V., Podelski, V., Meyer, P., Litique, V., Bergerat, J. P., Rohr, S., & Dufour, P. (2010). Adjuvant chemotherapy in elderly patients with colorectal cancer. A retrospective analysis of the implementation of tumor board recommendations in a single institution. *Critical Reviews in Oncology Hematology*, *74*, 211–217.
- Lachs, M. S., Feinstein, A. R., Cooney, L. M. Jr., Drickamer, M. A., Marottoli, R. A., Pannill, F. C., & Tinetti, M. E. (1990). A simple procedure for general screening for functional disability in elderly patients. *Annals of Internal Medicine*, *112*, 699–706.
- Leitlinienprogramm Onkologie (2018a). (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): *Prävention, Diagnostik, Therapie und Nachsorge des Lungenkarzinoms, Leitlinienreport 1.0, 2018, AWMF Registernummer 020/007 OL*. <http://leitlinienprogramm-onkologie.de/Lungenkarzinom.98.0.html>
- Leitlinienprogramm Onkologie (2018b). (Deutsche Krebsgesellschaft, Deutsche Krebshilfe, AWMF): *Prävention, Diagnostik, Therapie und Nachsorge des Lungenkarzinoms, Langversion 1.0, 2018, AWMF-Registernummer: 020/007OL*. <http://leitlinienprogramm-onkologie.de/Lungenkarzinom.98.0.html>
- Mensah, J., Graeven, U., & Wesselmann, S. (2017). Nationales Zertifizierungsprogramm Krebs. *Der Onkologe*, *23*, 711–718.
- Nayar, P., Qiu, F., Watanabe-Galloway, S., Boilesen, E., Wang, H., Lander, L., & Islam, M. (2014). Disparities in end of life care for elderly lung cancer patients. *Journal of Community Health*, *39*, 1012–1019.
- Nikolaus, T. (2001). Das geriatrische Assessment Aktueller Erkenntnisstand hinsichtlich der Eignungskriterien (Diskrimination, Prädiktion, Evaluation, Praktikabilität). *Zeitschrift Für Gerontologie Und Geriatrie*, *34*, 1036–1042.
- Olsson, J. K., Schultz, E. M., & Gould, M. K. (2009). Timeliness of care in patients with lung cancer: A systematic review. *Thorax*, *64*, 749–756.
- Richter-Kuhlmann, E. (2019). *Zertifizierte Krebszentren: Nachweis besserer Versorgung*. Dtsch Arztebl International.
- Robert Koch-Institut, & Gesellschaft der Epidemiologischen Krebsregister in Deutschland E.V. (Hrsg.) (2017). *Krebs in Deutschland für 2013/2014*. Berlin.
- Schram, M. T., Frijters, D., van de Lisdonk, E. H., Ploemacher, J., de Craen, A. J., de Waal, M. W., van Rooij, F. J., Heeringa, J., Hofman, A., Deeg, D. J., & Schellevis, F. G. (2008). Setting and registry characteristics affect the prevalence and nature of multimorbidity in the elderly. *Journal of Clinical Epidemiology*, *61*, 1104–1112.
- Seidel, D., Becker, N., Rohrmann, S., Nimptsch, K., & Linseisen, J. (2009). Socio-demographic characteristics of participation in the opportunistic German cervical cancer screening programme: Results from the EPIC-Heidelberg cohort. *Journal of Cancer Research and Clinical Oncology*, *135*, 533–541.
- Stokstad, T., Sørhaug, S., Amundsen, T., & Grønberg, B. H. (2017). Medical complexity and time to lung cancer treatment – A three-year retrospective chart review. *BMC Health Services Research*, *17*, 45.
- Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., Dahlin, C. M., Blinderman, C. D., Jacobsen, J., Pirl, W. F., Billings, J. A., & Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, *363*, 733–742.
- Wood, J. J., Metcalfe, C., Paes, A., Sylvester, P., Durdey, P., Thomas, M. G., & Blazeby, J. M. (2008). An evaluation of treatment decisions at a colorectal cancer multi-disciplinary team. *Colorectal Disease*, *10*, 769–772.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Gödde K, Siegerink B, Fügemann H, et al. Can routine register data be used to identify vulnerable lung cancer patients of suboptimal care in a German comprehensive cancer centre?. *Eur J Cancer Care*. 2021;30:e13398. <https://doi.org/10.1111/ecc.13398>