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Dying in hospital: a retrospective medical record analysis on care in the dying phase in intensive care units and general wards

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Abstract

Background Care in the dying phase is often suboptimal in hospitals outside specialized palliative care. Studies of the implementation of recommendations for care in the dying phase are rare. Medical records can provide information in this regard.

Methods A retrospective analysis of medical records was conducted for 400 patients who died in six intensive care units (ICUs) and four general wards (GWs) at two German medical centres. To evaluate the care in the dying phase, we descriptively analysed 37 variables reflecting recommendations of the German Palliative Care Guideline. To identify factors associated with important aspects of care, seven of these variables were determined as appropriate for multiple logistic regression.

Results In 299/400 (74.8%) patients, recognition of the dying phase was documented. Patients with the ability to communicate were informed about the impending death in 46/121 (38.0%) and informal caregivers (ICs) in 282/390 (72.3%). Patients' wishes regarding care were documented in 33/122 (27.1%). Monitoring was rarely stopped before death, with significantly lower percentages in ICUs: e.g. vital signs in 30% [14.9% in ICUs vs. 52.9% in GWs; confidence interval (28.4, 47.6)]. Validated symptom assessment tools were used in 272/400 (68.0%), mainly for pain (66.3%). Logistic regression analysis identified setting (ICUs vs. GWs), recognition of the dying phase, patient age, communication ability, and malignant neoplasm as factors significantly associated with aspects of care.

Conclusion The dying phase was not consistently documented, many presumably nonbeneficial interventions continued until death, systematic symptom assessment beyond pain was lacking, and communication with patients and ICs was poorly documented. Findings suggest a need for setting-specific strengthening of healthcare professionals in these settings.

Keywords: dying phase; quality measurement; hospital care; medical record analysis; palliative care; terminally ill; quality improvement

Introduction

In recent decades, end-of-life care has become an integral part of many healthcare systems [1]. In most European countries, ~50% of people die in hospitals outside specialized palliative care units, despite this being the least preferred place of death [2, 3]. Studies in this setting have shown that patients and their informal caregivers (ICs) often perceive the quality of care in the dying phase as suboptimal [2, 4]. Withholding or stopping interventions in the dying phase is now more accepted than in the past [5, 6]. However, the onset of the dying phase

still is often recognized late and nonbeneficial interventions are continued, even until death [6–8].

Several societies and research groups have published recommendations and guidelines for good quality of care in the dying phase [9–11]. In Germany, the S3 Guideline 'Palliative Care for Patients with Incurable Cancer', was published in 2015, updated in 2020, and is valid beyond the oncological setting. The guideline is a consensus-based, evidence-informed framework developed to improve the quality of care for patients with advanced cancer. It contains 16 different

chapters, covering among others principles of palliative care, communication, management of the different symptoms, and care in the dying phase [11]. However, little is known about whether current care aligns with these recommendations. Previous studies assessing care in the dying phase have examined isolated, investigator-selected outcomes rather than comprehensive, guideline-based assessments [12, 13]. A recent review shows that most studies are related to medication or therapeutic interventions [13]. This selected perspective hinders the evaluation of holistic care in the dying phase. In addition, existing studies have focused primarily on either general or critical care [7, 14, 15] or on specific individual diagnosis groups (mainly malignancies) [13]. This fragmented approach limits the identification of overarching challenges and systemic gaps [16]. It also hinders comparability and generalizable conclusions. Therefore, we aimed to evaluate the care in the dying phase holistically and standardized using variables derived from the ‘German S3 Guideline on Palliative Care’ [11]. We examined potential differences between intensive care units (ICUs) and general wards (GWs) and identified potential factors associated with important aspects of care in the dying phase.

Methods

Design, setting, and participants

This retrospective cohort study was part of a consortium project [17] aiming at developing and implementing setting-specific measures to optimize care in the dying phase. We extracted data from the medical records of 400 patients, who died between January 2018 and August 2021 in 10 wards of two German medical centres. Depending on the numbers of deaths, we either drew a random sample or conducted a full sample of 40 patients per ward, with 20 patients who died before and after the outbreak of the COVID-19 pandemic (reference date: 11 March 2020). We aimed to include wards without specialization in palliative care that regularly care for dying patients, ensuring broad heterogeneity. Six ICUs (surgical, cardiological, internal, cardiac surgical, and two interdisciplinary) and four GWs (neurology; gastroenterology; nephrology, endocrinology & rheumatology; and radiotherapy) participated. These wards differed in annual death numbers (range of means 2019–22: 11–201) and bed capacity (12–30). Inclusion criteria were patients aged 18 years or older who died on the ward. Ethical approval was obtained from the Ethics Committee of the Medical Faculty of the University of Cologne (20-1727) and the Ethics Committee of the General Medical Council, Hamburg (2021-200061-BO-bet).

Data collection

The data extraction tool included 11 variables on demographic and clinical characteristics and 37 variables on care in the dying phase. Details on the development of the tool will be described elsewhere. Characteristics included age, gender, length of stay on the ward where the patient died, International Statistical Classification of Diseases Version 10 (ICD-10) diagnosis group, cause of death, and whether death occurred during surgery or after resuscitation. Details on care in the dying phase comprised documentation of information and involvement of patients and ICs (11 variables), physicians’ and nursing documentation regarding the dying phase

(2 variables), (changes of) goal of care (6 variables), (stopping) medication and interventions (14 variables), symptom assessment (3 variables), and involvement of specialized palliative care (1 variable). We defined the dying phase according to the ‘German S3 Guideline on Palliative Care’ as the last 3–7 days of life. Most variables covered the last 3 days, three variables the last 7 days (dialysis/hemofiltration, mechanical ventilation, and palliative care support), and one variable the last 14 days (tumour-targeted treatment).

Anonymized copies of the relevant records were provided by the participating wards. We only considered the medical records of the participating ward. Six trained researchers transferred the data into the data extraction tool using a detailed manual. For quality assurance, data from 20% of cases were extracted by two researchers together [18], and uncertainties were discussed in interdisciplinary meetings involving a palliative care physician.

Data analysis

Variables were analysed descriptively, followed by multiple logistic regression analysis. For categorical variables, we calculated absolute and relative frequencies (valid %). Numerical variables were summarized using medians with quartiles (Q1, Q3). Missing values were excluded from the analysis. We analysed statistical differences between ICUs and GWs as well as differences between before and after the outbreak of the COVID-19 pandemic. To estimate the difference in medians between groups, we performed the Wilcoxon rank-sum test (`wilcox.test` in R) for unpaired data. For categorical variables, proportions were compared using the chi-squared test (`prop.test` in R). Confidence intervals (CIs) were reported for all estimates, with a 95% level.

To identify factors associated with important aspects of care in the dying phase, we calculated binary logistic regression models. We selected seven dependent variables representing relevant sections of the ‘The Dying Phase’ chapter of the ‘German S3 Guideline on Palliative Care’ (Table 1).

Table 1. The dying phase recommendations of the German S3 Guideline on Palliative Care: sections with corresponding selected variables for the multiple logistic regression.

Section	Selected variable
Diagnosing dying	Considered dying by healthcare professionals
Principles and practical issues	Informing the patient about the impending death Informing ICs about the impending death
Treatment of the most common symptoms	Symptom assessment with validated instruments
(Withdrawal) Medications and measures in the dying phase	Stopping measurement of vital signs
Artificial nutrition and hydration	Stopping artificial nutrition
The aftermath of death: the deceased and grief	Farewell ^a
Dying and death and the healthcare team	NA ^b

^aAggregated variable: presence of ICs at the time of death and/or opportunity to say goodbye after death and/or opportunity to say goodbye according to their own needs and wishes.

^bNot applicable: it cannot be represented by a variable of the medical record analysis.

Table 2. Demographic and clinical characteristics of patients within the last 3 days of life in total and divided into GWs and ICUs.

	Total group (n = 400)	GW (n = 160)	ICU (n = 240)	Difference: GW vs. ICU (95% CI)
Age, median (Q1, Q3)	72.5 (61.0, 81.0)	78.0 (66.0, 85.3)	70.0 (57.8, 78.0)	7.0 years ^b (5.0, 11.0)*
Gender, ^a n (%)				
Female	160 (40)	80 (50)	80 (33.3)	16.7% (6.4, 27.0)*
Length of stay (days), median (Q1, Q3)	6.0 (3.0, 13.3)	9.0 (4.0, 18.0)	4.0 (2.0, 10.0)	3.0 days ^b (2.0, 7.0)*
ICD-10 diagnosis group, n (%)				NA ^y
Malignant neoplasm	139 (34.7)	82 (51.3)	57 (23.7)	
Circulatory system	119 (29.8)	41 (25.6)	78 (32.5)	
Digestive system	28 (7.0)	4 (2.5)	24 (10.0)	
Respiratory system	24 (6.0)	7 (4.4)	17 (7.1)	
Infectious and parasitic diseases	23 (5.7)	5 (3.1)	18 (7.5)	
Other	67 (16.8)	21 (13.1)	46 (19.2)	
ICs and/or LGs, n (%)				-4.1% (-8.9, 0.52)
ICs	385 (96.3)	150 (93.8)	235 (97.9)	NA
Only LG	5 (1.2)	5 (3.1)	0	
No ICs and/or LGs documented	10 (2.5)	5 (3.1)	5 (2.1)	
Ability to communicate adequately, n (%)				
Yes	119 (29.8)	90 (56.3)	29 (12.1)	44.2% (34.9, 53.4)*
Partially	6 (1.5)	4 (2.5)	2 (0.8)	NA
Death after resuscitation or during operation, n (%)				
Yes	55 (13.7)	12 (7.5)	43 (17.9)	-10.4% (-17.3, 3.6)*
Considered dying by healthcare professionals, n (%)				
Yes	299 (74.8)	102 (63.7)	197 (82.1)	-18.4% (-27.8, -8.2)*
Documentation of a change in goal of care				
Yes	317 (79.2)	135 (84.4)	182 (75.8)	8.6% (0.2-16.9)*

The relative frequencies are column percentages and correspond to valid percentages.

NA^y, we calculated no differences between settings for diagnosis as diagnosis is highly correlated with the discipline.

NA, numbers are too low for calculation.

^aThe option 'diverse' was also possible but was never stated.

^bAn estimator for the difference in location parameters, which estimates the median of the difference between the groups, is calculated using the Wilcoxon rank-sum test.

*Statistically significant ($P < .05$).

The selection process was based on the clinical expertise of the multiprofessional project team and the adequacy of our data. For example, instead of symptom control, we considered symptom assessment, as it can be derived well from the medical records and is required for adequate symptom-controlling therapy. We selected possible relevant independent variables, including setting, ICD-10 diagnosis group of malignant neoplasm, patient considered dying by healthcare professionals, adequate ability to communicate, and patient age. The selection process was based on clinical assumptions and previous research results [19–23]. Except for patient age, all variables were coded as binary variables. For each model, we simultaneously included the possible relevant independent variables. Multicollinearity was checked by calculating the variance inflation factor. The cut-off value was set to variance inflation factor < 2 . All variables were tested for normal distribution.

The alpha level was set at .05. We did not adjust for multiple testing due to the exploratory design of the study. Data processing and analysis were performed using MS Excel and R version 4.1.1. Reporting followed the STROBE checklist [24].

Results

The median age of the included patients was 72.5 years, 40% of them were female. Most suffered from malignant neoplasm (34.7%). Ability to communicate in the last 3 days of life could be assumed for 29.8%, and partially for another 6%. The

presence of ICs and/or legal guardians (LGs) was documented in 97.5%. Patients who died in ICUs were younger, more likely to be male, had shorter stays, and were less often able to communicate adequately (Table 2).

Application of the recommendations included in the German S3 Guideline on Palliative Care Patients considered dying and changes of goal of care

For 299/400 (74.8%) patients, notes indicated they were considered dying, occurring significantly more often in ICUs than in GWs (82.1% vs. 63.7%; Table 2). Some notes explicitly mentioned 'Patient is dying', while others referenced signals of the dying phase, for instance 'death rattle'. In ICUs, 86.3% of notes regarding the dying phase related to stopping life-sustaining interventions.

Changes in goal of care were documented in 317/400 (79.2%) records, with significantly higher numbers on GWs (84.4%) than ICUs (75.8%). Changes comprised withholding new life-sustaining interventions in 192/317 (60.6%), de-escalation or stopping of those in 105/317 (33.1%), and unspecific documentation of 'symptom-controlled therapy' or synonyms in 181/317 (57.1.2%). In 200/317 (63.1%) cases, changes in goal of care were documented 0–23 h before death (ICU 70.4%; GW 28.1%).

Information and involvement of patients and IC

As the information and involvement of patients depends on their ability to communicate verbally or nonverbally, we

Table 3. Information and involvement of patients and ICs and/or LGs within the last 3 days of life in total and divided into patients who died on GWs and ICUs.

	Total group (<i>n</i> = 400 ^a), <i>n</i> [% (95% CI)]	GW (<i>n</i> = 160 ^a), <i>n</i> [% (95% CI)]	ICU (<i>n</i> = 240 ^a), <i>n</i> [% (95% CI)]	Difference: GW vs. ICU (95% CI)
Conversations with the patient regarding changes of the goal of care	67/122 [54.9 (45.9, 63.6)]	54/92 [58.7 (48.2, 68.4)]	13/30 [43.3 (26.7, 61.6)]	12.7 (-7.2, 38.0)
Conversation with ICs and/or LGs regarding changes of the goal of care	265/390 [68.0 (63.1, 72.4)]	105/155 [67.7 (59.9, 74.7)]	160/235 [68.1 (61.8, 73.8)]	-0.4% (-10.2, 9.5)
Informing the patient about the impending death	46/121 [38.0 (29.7, 47.1)]	37/91 [40.7 (30.9, 51.2)]	9/30 [30.0 (16.1, 48.9)]	10.7% (-10.8, 32.1)
Informing ICs and/or LG about the impending death	282/390 [72.3 (67.6, 76.5)]	102/155 [65.8 (57.9, 72.9)]	180/235 [76.6 (70.7, 81.6)]	-10.8% (-20.5, -1.0)*
Informing ICs and/or LG on changes during the dying process	142/390 [36.4 (31.8, 41.3)]	52/155 [33.6 (26.5, 41.4)]	90/235 [38.3 (32.3, 44.8)]	-4.8% (-15.0, 5.5)
Possibility for patients to express wishes and values	33/122 [27.1 (19.8, 35.7)]	30/92 [32.6 (23.7, 43.0)]	3/30 [10.0 (3.2, 27.5)]	22.6% (6.0, 39.2)*
Opportunity for ICs to participate in the dying process	58/385 [15.1 (11.8, 19.0)]	30/150 [20.0 (14.3, 27.2)]	28/235 [12.0 (8.3, 16.7)]	8% (-0.1, 16.3)
Informing ICs about support offers	41/385 [10.7 (7.9, 14.2)]	21/150 [14.0 (9.3, 20.6)]	20/235 [8.5 (5.5, 12.9)]	5.5% (-1.7, 12.6)

The relative frequencies are column percentages and correspond to valid percentages.

^aThe denominator varies due to (I) differences in the presumed ability to communicate, which was assessed separately for each variable, and (II) whether the variable relates to only ICs or ICs and LGs.

*Statistically significant ($P < .05$).

assessed the presumed ability for each respective variable separately and we differentiated between ICs and LGs, resulting in different sample sizes.

For patients presumed able to communicate, medical records indicated conversations regarding changes in goal of care in 67/122 (54.9%) cases, and for ICs/LGs in 265/390 (68.0%) (Table 3). We found in 46/121 (38.0%) records that healthcare professionals had informed the patient about their impending death. Informing ICs/LGs was documented in 282/390 (72.3%) cases, with significantly lower numbers on GWs (76.6% in ICU; 65.8% in GW). Keeping them informed of changes during the dying process was documented in 142/390 (36.4%) cases.

Patients had opportunity to express wishes and values regarding their care in 33/122 (27.1%) cases, such as wishes regarding bedding or oral care, with significantly higher numbers in GWs (32.6%) than in ICUs (10.0%). For ICs, involvement in the dying process according to their abilities and wishes was documented in 58/385 (15.1%) and support offers from healthcare professionals, such as stress-relief conversations or spiritual care, were noted in 41/385 (10.7%) cases. In 150/385 (38.9%) cases, ICs were present at the time of death. Among the 236 ICs who were not present, documentation showed that 45 (19.1%) had the opportunity to say goodbye in the hospital after death.

Symptom assessment and interventions in the dying phase (Table 4)

In 272/400 (68%) records, healthcare professionals used validated symptom assessment instruments (66.3% pain assessment scales, e.g. numerical rating scale; 5% palliative care assessments, e.g. Integrated Palliative Care Outcome Scale; and 18% others). The most frequently prescribed medications for symptom control were opioids (88.5%), followed by benzodiazepines (44.3%), neuroleptics (15.8%), and anticholinergics (14.8%). Prescription rates were significantly higher on GWs, except opioids. We assessed whether the following interventions were stopped within the last 3 days

before the moment of death: vital signs and blood glucose level measurement, oxygen, antibiotic and tumour-specific therapy, dialysis, mechanical ventilation, and artificial nutrition and hydration. Significant differences between ICU and GW were related to stopping vital signs monitoring (14.9% in ICU vs. 52.9% in GW), blood glucose measurement (32.6% vs. 44.7%), tumour-specific therapy (31.8% vs. 68.8%), and artificial hydration (27.1% vs. 39.5%). The palliative care consultation team supported 78/400 (19.5%) of the patients in the last 3 days of life, with a significant difference between ICUs (4.2%) and GWs (42.5%). Postmortem tasks were documented in 166/400 (41.5%) records, including postmortem examination (51.8%), informing absent ICs/LGs (41.5%), longer conversations with ICs (28.3%), disposal of patient property (27.1%), and postmortem nursing interventions (10.2%).

Exploratory analysis: identification of factors associated with care in the dying phase

In addition to the setting, we analysed whether the recognition of the dying phase, malignant neoplasm diagnosis, adequate ability to communicate, and patient age were associated with important aspects of care in the dying phase (Fig. 1) using binary regression models on seven dependent variables. Patients considered dying had a significantly higher chance of stopping vital signs monitoring [OR = 1.83; CI (1.04, 3.33)] and of documenting IC information about the impending death [OR = 1.86; CI (1.11, 3.09)]. Patients diagnosed with a malignant neoplasm [OR = 1.88; CI (1.08, 3.35)] and with higher age [OR = 1.02; CI (1.01, 1.04)] had a significantly higher chance of documented symptom assessment. Patients with a malignant neoplasm diagnosis had a significantly higher chance of documentation that ICs were able to say goodbye according to their wishes and needs [OR = 2.66; CI (1.66, 4.31)]. No significant association was found between stopping artificial nutrition and informing the patient about the impending death. Next to patients dying in ICUs [OR = 2.36; CI (1.36, 4.11)], patients diagnosed with

Table 4. Symptom assessment and interventions within the last 3 days of life in total and divided into patients who died on GWs and ICUs.

	Total group (<i>n</i> = 400 ^a), <i>n</i> [% (95% CI)]	GW (<i>n</i> = 160 ^a), <i>n</i> [% (95% CI)]	ICU (<i>n</i> = 240 ^a), <i>n</i> [% (95% CI)]	Difference: GW vs. ICU (95% CI)
Measurement of vital signs	<i>n</i> = 390	<i>n</i> = 155	<i>n</i> = 235	
Stopping	117 [30 (25.6, 34.8)]	82 [52.9 (45.0, 60.7)]	35 [14.9 (10.9, 20.1)]	38.0 (28.4, 47.6)*
Measurement of blood glucose	<i>n</i> = 353	<i>n</i> = 123	<i>n</i> = 230	
Stopping	130 [36.8 (31.9, 42.0)]	55 [44.7 (36.1, 53.6)]	75 [32.6 (26.8, 39.0)]	12.1 (0.8, 23.4)*
Oxygen therapy	<i>n</i> = 319	<i>n</i> = 91	<i>n</i> = 228	
Stopping	79 [24.8 (20.3, 29.8)]	21 [23.1 (15.5, 32.9)]	58 [25.4 (20.2, 31.5)]	-2.4 (-13.5, 8.7)
Mechanical ventilation	<i>n</i> = 217	<i>n</i> = 0	<i>n</i> = 217	
Stopping	65 [30.8 (24.5, 36.9)]		65 [30.8 (24.5, 36.9)]	NA
Antibiotic therapy	<i>n</i> = 307	<i>n</i> = 105	<i>n</i> = 202	
Stopping	120 [39.1 (33.8, 44.7)]	45 [42.9 (33.7, 52.6)]	75 [37.1 (30.7, 44.0)]	5.7 (-6.6, 18.0)
Dialysis	<i>n</i> = 134	<i>n</i> = 18	<i>n</i> = 116	
Stopping	60 [44.8 (36.5, 53.4)]	7 [38.9 (19.2, 63.0)]	53 [45.7 (36.8, 55.0)]	-6.8 (-34.3, 20.7)
Tumour-specific therapy	<i>n</i> = 70	<i>n</i> = 48	<i>n</i> = 22	
Stopping	40 [57.1 (45.1, 68.4)]	33 [68.8 (54.0, 80.5)]	7 [31.8 (15.5, 54.3)]	36.9 (10.1, 63.7)*
Artificial nutrition	<i>n</i> = 257	<i>n</i> = 74	<i>n</i> = 183	
Stopping	124 [48.3 (42.2, 54.4)]	40 [54.1 (42.6, 65.1)]	84 [45.9 (38.8, 53.2)]	8.2 (-6.3, 22.6)
Artificial hydration	<i>n</i> = 358	<i>n</i> = 129	<i>n</i> = 229	
Stopping	113 [31.7 (26.9, 36.6)]	51 [39.5 (31.4, 48.3)]	62 [27.1 (21.7, 33.2)]	12.5 (1.6, 23.3)*
ICD	<i>n</i> = 26	<i>n</i> = 5	<i>n</i> = 21	
Deactivation	4 [15.4 (5.5-36.3)]	2 [40.0 (7.5-84.5)]	2 [9.5 (2.1, 33.6)]	NA
Symptom assessment				
With validated instruments	272 [68.0 (63.3, 72.4)]	142 [88.8 (82.8-92.8)]	130 [54.2 (47.8-60.4)]	35.0 (26.1, 43.1)*
Prescription of medication				
Opioids	354 [88.5 (85.0-91.3)]	146 [91.3 (85.7-94.8)]	208 [86.7 (81.7-90.4)]	4.6 (-2.1, 11.2)
Benzodiazepines	177 [44.3 (39.4-49.2)]	87 [54.4 (46.6-62.0)]	90 [37.5 (31.6-43.8)]	16.9 (6.5, 27.2)*
Neuroleptics	63 [15.8 (12.5-19.7)]	45 [28.1 (21.7-35.6)]	18 [7.5 (4.8-11.6)]	20.6 (12.4, 28.9)*
Anticholinergics	59 [14.8 (11.6-18.6)]	54 [33.8 (26.8-41.5)]	5 [2.1 (0.9-4.9)]	31.7 (23.6, 39.7)*
Palliative care support				
Yes	78 [19.5 (15.9, 23.7)]	68 [42.5 (35.0, 50.3)]	10 [4.2 (2.3, 7.6)]	38.3 (29.7, 46.9)*

The relative frequencies are column percentages and correspond to valid percentages.

NA, numbers are too low for calculation.

^aThe sample corresponds to the number of patients that were treated with the respective measure within the last 3 days of life, e.g. antibiotic therapy: patients who did not receive any antibiotics within the last 3 days of life were excluded.

*Statistically significant ($P < .05$).

a malignant neoplasm had a significantly higher chance to be considered dying [OR = 2.34; CI (1.29, 4.36)], as well as patients without ability to communicate [OR = 2.12; CI (1.18, 3.85)].

There were no significant differences in care before and after the outbreak of the COVID-19 pandemic regarding the following variables: talking with patients or their ICs/LGs about the impending death, conversations on changes of the goal of care, presence of ICs at the time of death, and opportunity to say goodbye in hospital after death ([Supplementary Table 1](#)).

Discussion

Statement of principal findings

In this medical record analysis, encompassing both ICUs and GWs, we evaluated the care of patients in the dying phase using a comprehensive set of 37 variables derived from the ‘German Palliative Care Guideline’ [11]. Our results suggest three potential areas for improvement: (i) recognition of the dying phase, (ii) adjusting care in the dying phase, and (iii) communication with patients and ICs.

Strengths and limitations

A methodological strength of our study is the assessment of care, based on the ‘German Palliative Care Guideline’.

By analysing variables derived from these widely agreed recommendations, we systematically assessed the care in the dying phase, ensuring standardization and holistic understanding. The assessment of different departments and both settings, GW and ICU, allows a comprehensive picture and better understanding of the differences between the two settings, which is crucial for measures to improve care.

The limitation of our study is the retrospective design, which poses potential challenges, particularly in the systematic collection of data [25]. Furthermore, it is not possible to determine whether undocumented events did not occur or were simply not documented. It is therefore necessary to use different methodological approaches to obtain a complete and realistic picture of healthcare practice [13]. Data from the other methodological approaches of our consortium project [17] confirm the indications from this analysis (manuscript in preparation). We did not adjust for multiple testing due to the exploratory nature of our study. As a result, some statistically significant findings may reflect type I errors and should be interpreted with caution. Additionally, the denominators for some variables varied due to differences in data availability and the specific characteristics of the patient population, which may have introduced heterogeneity and influenced the results.

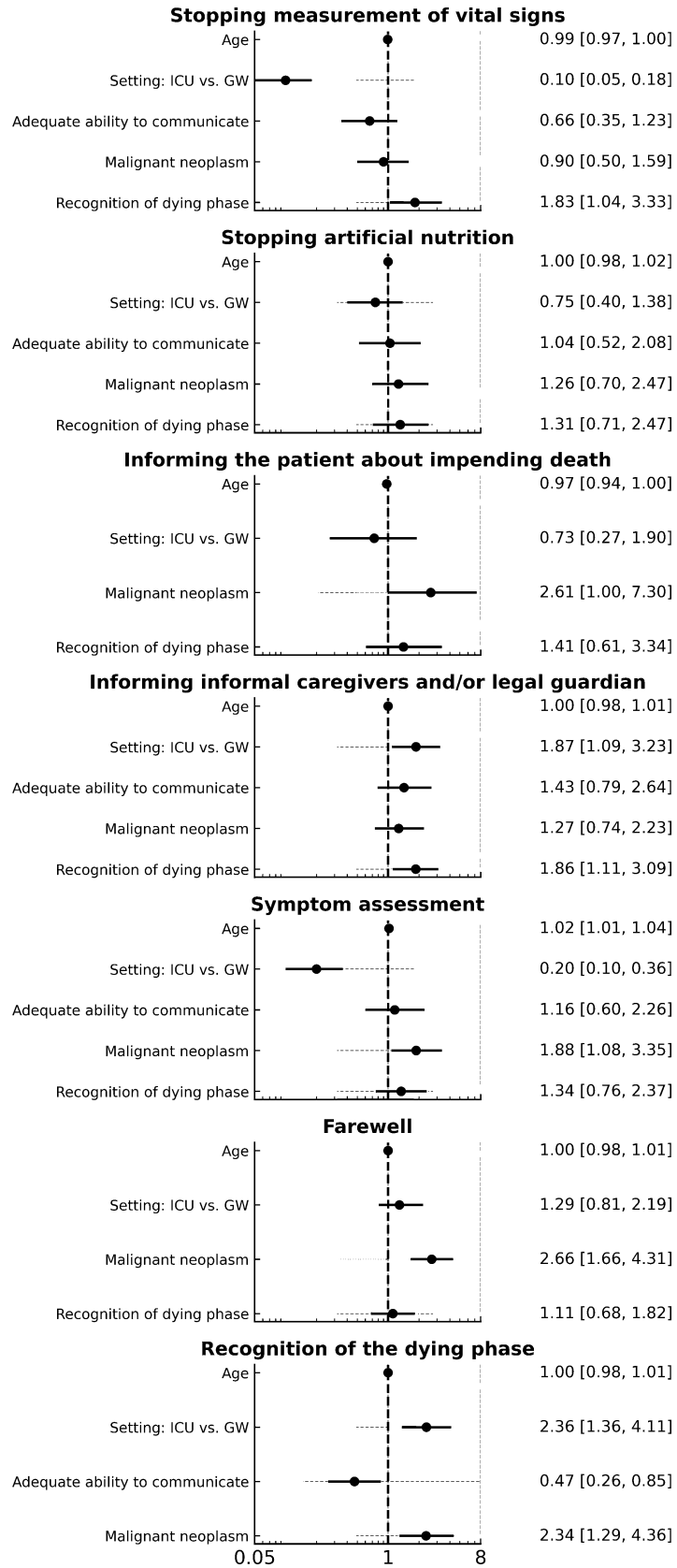


Figure 1 Multiple logistic regression with seven dependent variables (odds ratios and 95% CIs): identification of factors influencing key aspects of care in the dying phase.

Interpretation within the context of the wider literature

Recognition of the dying phase and change of goal of care

The recognition of the dying phase was already identified as a starting point for the improvement of care [26]. Although our findings suggest an improvement compared to a previous study [19], the dying phase was still only documented for about three in four patients, with even significantly lower numbers on GWs. Cancer patients and those unable to communicate had an increased chance of being identified as dying, as also highlighted in previous studies [12, 19]. These challenges and the association of patient characteristics and the likelihood of being recognized as dying should be considered when developing supportive interventions for improving the care. As there is no valid measurement tool to determine the dying phase, the focus should be on training staff to recognize possible predictors [27] and empowering teams to create an environment in which healthcare professionals feel safe to discuss the possibility of imminent death [26]. Reflection aids, such as the adapted surprise question for the dying phase, can be helpful here [28]. In our study, a change of goal of care preceded the dying phase in 79% of the patients, with significantly higher numbers on GWs. Current literature indicates substantial variations in treatment limitation practices across settings [22], countries [14], and diagnosis groups [20]. Our results show—consistent with previous German studies—that withholding life-sustaining interventions is more common than actively stopping them [7, 19]. Healthcare professionals may feel uncertain about distinguishing between stopping nonindicated life-sustaining interventions and euthanasia [29]. Moreover, a significant challenge arises from the use of terms such as ‘symptom-controlled therapy’ or synonyms to define the goal of care. These are vague and ambiguous umbrella terms, leading to different interpretations among healthcare professionals, misunderstandings, and a lack of consensus on actions [30].

Adjusting care in the dying phase

Our data revealed that presumably nonbeneficial measurements and interventions were rarely stopped before death, particularly in ICUs. This is in line with the results of a recent review [8]. Although we could not verify the indication for the documented interventions, an over-provision seems likely. It must be assumed that healthcare professionals remain uncertain about what constitutes nonbeneficial treatment [8, 31]. Implementation of standards and supporting structures seem to be lacking in this regard in daily practice on wards not specialized in palliative care [6]. A prerequisite for adequate symptom control is the assessment of possible symptoms. In our sample, we found standardized symptom assessment only in 68% of cases, mainly with pain assessment scales. This suggests a need for improvement in the systematic assessment of all physical symptoms beyond pain, as well as psychological, social, and spiritual dimensions.

Optimizing communication and involvement of patients and their ICs

In only 38% of the records, it was documented that the patients were informed of their impending death, and patients’ wishes and values regarding care were documented in only 27%. Although these areas are considered crucial for the quality of care [32], several studies have reported comparable

deficits [2, 4, 21]. It may be challenging to have conversations involving death and dying directly with patients [19]. Our data also suggest that there is a need to improve communication with ICs, for instance to inform them on what has to be expected in the dying phase or to offer support services [2, 33]. Therefore, there is an urgent need to strengthen communication skills in healthcare professionals, starting in education and through repeated trainings. Another area for improvement could involve better understanding and documentation of how patients express their wishes and preferences. Future studies should explore the role of advance directives and structured communication tools in facilitating patient-centred care during the dying phase.

Implications for policy, practice and research

The results indicated that there is a need for improvement in the care in the dying phase in German hospitals. Healthcare professionals can be strengthened through trainings and standard operating procedures to build up knowledge and practical expertise. Establishing documentation standards for the dying phase could also be useful [34]. Documentation standards could draw attention to the aspects specified and emphasized in the guideline recommendations and reduce the documentation of unnecessary measures and interventions. They can be used in conjunction with training, reminders, and consistent leadership to facilitate effective integration into practice [35]. The lack of documentation especially in the post-mortem phase in our cohort indicates a lack of awareness that post-mortem care and documentation are not seen as a natural task, which is also reflected in the funding of patient care in the healthcare system, where the treatment contract ends with the patient’s death. When considering tasks such as postmortem care and care for bereaved, changes in the health policy level with appropriate financial compensation are necessary.

The consortium project ‘Dying in hospital - Optimization of care in the dying phase’, of which this retrospective medical record analysis was a part, aimed at the participatory development of ward-specific interventions to improve care in the dying phase [17]. We used the results of the retrospective medical record analysis to inform the participatory development of measurements. Various interventions were developed, including trainings, standard operating procedures, and team meetings to build knowledge, support professionals, and create space for interprofessional exchange. Due to the multi-centre approach, the different settings and departments involved, and the comprehensive view on care in the dying phase, the results can also be used as a starting point for improving care in the dying phase on other wards and hospitals.

Conclusion

Our study suggests that healthcare professionals need to be empowered to recognize the dying phase, to communicate with patients and their ICs, to stop nonbeneficial interventions in a timely manner, and to assess symptoms beyond pain. Supportive interventions should be adapted to the specific challenges and needs of different settings. The implementation of documentation standards for the dying phase may have the potential to improve documentation and quality of care.

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Author contributions

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Supplementary data

Supplementary data is available at *IJQHC* online.

Conflict of interests

None declared.

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Data availability

The dataset analysed during the current study and the R scripts are available from the corresponding author on reasonable request.

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