Dying in Hospitals –
Multi-method Assessment of Care in the Dying Phase in German Hospitals

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Table of Contents

List of abbreviations

ACP	Advance Care Planning
AMBER	Assessment; Management; Best practice; Engagement; Recovery uncertain
BCD	Best Care for the Dying
CFIR	Consolidated Framework for Implementation Research
ED	Employee-Driven
EMR	Electronic Medical Record
EOL	End-of-Life
GW	General Ward
HCP	Health Care Professionals
IC	Informal Caregiver
ICU	Intensive Care Unit
LPC	Liverpool Care Pathway
MR	Medical Record
PARiHS	Promoting Action on Research Implementation in Health Services
PCW	Palliative Care Ward
RQ	Research Question
TDF	Theoretical Domains Framework
WG	Working Group

List of figures

List of tables

The present thesis was prepared as a cumulative dissertation based on the following publications (sorted by ascending dates of publication):

1. **Kaur S**, Boström K, Ullrich A, Oubaid N, Oechsle K, Schulz H, Voltz R, Kremeike K. Health Experts' Perspectives on Barriers, Facilitators, and Needs for Improvement of Hospital Care in the Dying Phase. International Journal of Clinical Practice. 2024;2024(1):1012971.
2. **Kaur S**, Meesters S, Schieferdecker A, Dangendorf A, Strohbücker B, Oubaid N, Ullrich A, Milke V, Oechsle K, Schulz H, Voltz R, Kremeike K. How to Evaluate Hospital Care in the Dying Phase—Development of a Data Extraction Tool for Retrospective Medical Record Analysis. Journal of Evaluation in Clinical Practice. 2025;31(5):e70174.
3. Meesters S*, **Kaur S***, Milke V, Herrmann C, Schieferdecker A, Oubaid N, Oechsle K, Schulz H, Pfaff H, Voltz R, Kremeike K. Formative evaluation of an employee-driven approach to improve care in the dying phase in hospitals. Palliative and Supportive Care. 2025;23:e135.

The following publications were also published during the period of PhD studies (sorted by ascending dates of publication):

4. Kremeike K, Ullrich A, Schulz H, Rosendahl C, Boström K, **Kaur S**, Oubaid N, Plathe-Ignatz C, Leminski C, Hower K, Pfaff H, Hellmich M, Oechsle K, Voltz R. Dying in hospital in Germany – optimising care in the dying phase: study protocol for a multi-centre bottom-up intervention on ward level. BMC Palliative Care. 2022;21(1):67.
5. Oubaid N, **Kaur S**, Oechsle K, Ullrich A, Milke V, Schieferdecker A, Kremeike K, Meesters S, Herrmann C, Voltz R, Schulz H. Care for the Dying: A Scoping Review of Measures for Clinical Practice With Qualitative Synthesis. OMEGA - Journal of Death and Dying. 2025;0(0):00302228251322860.
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7. Meesters S, Schieferdecker A, **Kaur S**, Oubaid N, Ullrich A, Oechsle K, Schulz H, Voltz R, Kremeike K. Dying in hospital: a retrospective medical record analysis on care in the dying phase in intensive care units and general wards. International Journal for Quality in Health Care. 2025;37(2).
8. Pralong A, Simon ST, Holtick U, Reimer A, Schoerger B, **Kaur S**, Weliwitage J, Hellmich M, Hallek M, Scheid C, Voltz R, Herling M. A cross-sectional survey on health care professionals' approaches, challenges, and support needs when addressing life threat with recipients of an allogeneic hematopoietic stem cell transplantation and with their relatives. Annals of Hematology. 2025;104(1):741-51
9. Pralong A, Herling M, Holtick U, Schoerger B, Reimer A, **Kaur S**, Scheid C, Hallek M, Weliwitage J, Hellmich M, Voltz R, Simon ST. Palliative Care for the Management of Patients with Allogeneic Hematopoietic Stem Cell Transplantation: A Cross-Sectional Survey in Comprehensive Cancer Centers. Oncol Res Treat. 2025:1-13.

Zusammenfassung

Hintergrund

Die meisten Menschen in Deutschland versterben in Krankenhäusern auf nicht-spezialisierten palliativmedizinischen Stationen. Die Versorgung in der Sterbephase wird dort trotz bestehender Leitlinien und Initiativen als unzureichend beschrieben.

Ziel

Ziel der Arbeit ist eine Bestandsaufnahme der Versorgung in der Sterbephase in deutschen Unikliniken als Optimierungsgrundlage. Zwei Forschungsfragen stehen dabei im Mittelpunkt:

(1) Welche Barrieren, Förderfaktoren und Verbesserungsbedarfe bestehen hinsichtlich einer optimalen Versorgung in der Sterbephase aus Expert:innensicht?

(2) Inwieweit können Patient:innenakten als Datenquelle zur Erhebung der Versorgung in der Sterbephase herangezogen werden?

Methoden

Die *mixed-methods* Studie *„Sterben im Krankenhaus - Optimierung der Versorgung in der Sterbephase (StiK-OV)*“ liefert die Datenbasis. Nach einer Vorabbefragung von Expert:innen (Publikation 1), wurde für die Datenerhebung ein Instrument für eine retrospektive Aktenanalyse entwickelt (Publikation 2). In der Implementierungsphase wurde ein stationsspezifischer Arbeitsgruppenansatz zur Maßnahmenentwicklung durchgeführt (Publikation 3). Die Ergebnisse wurden anhand der ökologischen Systemtheorie nach *Bronfenbrenner* synthetisiert.

Ergebnisse

Die Ergebnisse zeigen Barrieren, Förderfaktoren und Verbesserungsbedarfe auf der institutionellen, Team- und Versorgungsebene. Dazu gehören unzureichende Ressourcen, Kommunikation zwischen den Versorgungenden sowie mit Patient:innen und ihren Angehörigen und mangelhafte Symptomkontrolle. Patient:innenakten zeigen, dass klinische Informationen und Interventionen dokumentiert sind, jedoch wenig Dokumentation bezüglich kommunikativer, psychosozialer und spiritueller Aspekte vorhanden ist. Der Arbeitsgruppenansatz erwies sich als umsetzbar und stationsspezifische Maßnahmen wurden entwickelt, jedoch nahm die Beteiligung der Stationsmitarbeitenden im Verlauf ab.

Diskussion und Schlussfolgerung

Über die Bestätigung und Vertiefung bekannter Herausforderungen in der Sterbephase hinaus zeigt die Dissertation, dass Patient:innenakten wertvolle Einblicke in die Versorgung liefern, jedoch als alleinige Datenquelle für die Qualitätserfassung unzureichend sind. Der Arbeitsgruppenansatz ist hilfreich, um Mitarbeitende aktiv in den Optimierungsprozess einzubinden und spezifische Maßnahmen zu entwickeln. Eine nachhaltige Optimierung der Versorgung in der Sterbephase erfordert maßgeschneiderte Maßnahmen auf Teamebene gestützt durch die Ebene der Führungskräfte und institutionelle Rahmenbedingungen.

Summary

Background

In Germany, most people die in hospitals, but providing optimal care in the dying phase remains deficient. Guidelines and recommendations on delivering best possible care in the dying phase exist but have not been implemented in routine care yet.

Aim

The aim of the present dissertation is the provision of a status assessment of hospital care in the dying phase in German hospitals as basis for care optimisation, guided by two research questions:

(1) What are perceived barriers, facilitators, and improvement needs for optimal hospital care in the dying phase in Germany from the perspectives of health experts?

(2) To what extent can medical records provide information on hospital care in the dying phase?

Methods

The mixed methods study *"Dying in Hospitals – Optimisation of Care in the Dying Phase"* provides the data basis. An expert online survey was conducted as project basis (publication 1). A data extraction tool was developed for the retrospective medical records analysis (publication 2). An employee-driven working group approach to develop targeted measures for improving care for dying patients and their informal caregivers (IC) was conducted and evaluated (publication 3). *Bronfenbrenner's* ecological system approach was used to synthesise findings.

Results

The findings include barriers, facilitators and improvement needs across institutional, team and care level, including lacking institutional resources, insufficient communication between health care staff as well as with patients and their IC and insufficient symptom control. Medical records proved to be useful for providing clinical information on medication and interventions, but systematically underrepresented psychosocial, communicative and spiritual care aspects. The employee-driven approach showed to be feasible and generated context-specific solutions on ward-level, yet staff participation decreased over time.

Discussion and conclusion

Findings on known challenges of hospital care in the dying phase were replicated, advanced through a more detailed understanding of dynamics across ecological care levels. Medical records were found to provide valuable insights but are insufficient as a sole data source for care assessment. The employee-driven approach showed that ward-level interventions can engage staff and generate context-sensitive solutions. Sustainable optimisation of care in the dying phase should target tailored interventions on team-level supported by leadership support and institutional integration.

1. Background

1.1 Hospital Care in the Dying Phase

Dying and death today occurs at an advanced age and is frequently preceded by a prolonged period of illness. Over the last decades, the place of dying and death has shifted away from family and community settings towards institutionalized healthcare systems [1, 2]. In high-income countries, and increasingly also in low- and middle-income countries, end-of-life (EoL) care is shaped by a predominant focus on medical interventions, often resulting in maintaining life-sustaining treatment in hospital [2]. Consequently, hospitals have become the most common place of death in many European countries, including Germany. In 2023, a total of 1.028.206 people died in Germany, 43% (441.557) of them in hospitals [3]. It is estimated that approximately up to 80% of all deaths in Germany would have benefited from involvement of specialist palliative care, as the majority among deceased people were older than 80 years [4, 5]. Contrary to popular belief, palliative care wards (PCW) are not the primary places for EoL care in hospitals, as illustrated by the fact that only every second person admitted to a PCW dies there [6]. In 2022, 336 PCWs (of approximately 1893 hospitals) in Germany were counted, meaning that about 17.8% of all hospitals have an PCW. Thus, less than one in five hospitals has a PCW [6]. Consequently, majority of people who die in hospitals do so outside specialist palliative care. Most common places of death are general wards (GWs) and intensive care units (ICUs) [6], with at least 1/3 of patients dying in ICUs [7]. In fact, according to a study investigating hospital care in the last 14 days of life, as many as 57% of all deaths occurred on ICUs of the respective German university hospital [8].

Hospitals objectively are important places for the provision of care in the dying phase. However, this is challenged by the fact that hospitals are subjectively the least preferred place of death for patients and their informal caregivers (ICs), since they prefer to die at home [9-11]. According to the *German Guideline for Palliative Care for Patients with Incurable Cancer (German Palliative Care Guideline)*, the dying phase is operationalised as the final three to seven days of life, characterised by a progressive reduction of physical and psychological functions due to the patient’s deteriorating condition [12]. According to patients and their ICs as well as from health care professionals’ (HCPs) perspective, there are several challenges regarding care in the dying phase on non-specialist PCW. According to the literature, main reasons for discontent with hospital care in the dying phase are (1) poor communication between patients and HCPs regarding required information and (post-mortem) support, (2) limited interpersonal relationships with HPC, (3) uncertainty in decision making, (4) limited time and staff, (5) an inadequate hospital environment, e.g. missing single or farewell rooms, and (6) poor symptom control such as pain, dyspnoea and anxiety [13-21]. EoL hospital care often lacks standardisation and relies on intuitive judgement, making care in the dying phase highly variable based on individual HCPs' motivation and commitment [22, 23]. Moreover, the timely recognition of the dying phase remains inconsistent in routine hospital care [24, 25]. This becomes significant when considering that nursing staff perceived the care in the dying phase as good in situations where death was moderately to highly expected. [14]. Goals-of-care conversations are therefore often postponed due to HCPs' uncertainty about when and how to initiate these discussions, although patients and their ICs would have benefited from earlier exchange on these points [18]. Consequently, unnecessary or unwanted intensified life-prolonging therapeutic and diagnostic procedures are often performed at the end of patients' lives [7, 8, 26].

The involved HCPs also experience emotional and psychological strain when caring for patients in the dying phase [27-29]. A study identified the three most burdening factors: (1) Dealing with high emotional and physical demands in the dying phase, (2) navigating complex relationships with ICs and (3) managing unexpected death [27]. This is amplified on ICUs, where staff experiences significantly higher burden than on GWs [27]. A lack of palliative care expertise and training for HCPs, especially in symptom control and offering spiritual support, further reinforces these challenges [30, 31]. Recent studies showed that despite suffering from life-threatening conditions and high mortality rates, only 0.8% of all ICU patients and 1.4% of long-term ventilated patients received palliative care on ICUs, indicating that the (timely) involvement of specialist palliative care services remains insufficient [14, 32]. However, changing the patient's environment might be promising. E.g., according to another study, patients unfit for continued involvement in aggressive therapies should be transferred from ICUs to palliative care settings, where HCPs trained in palliative care routinely provide high-quality EoL care [31]. Furthermore, HCPs often struggle to communicate with terminally ill patients and underestimate their need for information [33]. These communication challenges may be rooted in HCPs' death anxiety, which leads to avoidant behaviours and delays (timely) decision-making [34]. These current challenges are reinforced by the prevailing curative culture in hospitals, where (outside PCWs) death is usually perceived as a medical failure rather than natural part of the care trajectory [35].

Broadly consented recommendations and initiatives for optimal care in the dying phase exist, but their sustainable implementation in daily routine hospital care has not taken place yet [36-39]. Moreover, systematic processes for assessing and addressing the specific needs of patients requiring palliative care have been implemented only in few institutions [6]. One of the most well-known *top-down* initiatives is the *Liverpool Care Pathway (LCP*), a structured ten-step care pathway introduced in the late 1990s to ensure consistent, high-quality care for the dying [40, 41]. The *LCP* program was accompanied by extensive training and audit requirements. However, its use ultimately failed in practice, largely due to its complexity and rigid implementation [39]. Building on the *LCP*s' concepts, the *Best Care of the Dying (BCD*) recommendations were developed, focusing on the German adaptation of key practices in EoL care [42]. Another related approach was the *Assessment; Management; Best practice; Engagement; Recovery uncertain (AMBER)* care bundle in the UK, designed to prompt early planning for patients with uncertain recovery near EoL [43]. Like the *LCP*, *AMBER* was criticized as inflexible in real-world application in hospital routine care [37, 44].

On a national level in Germany, the *German Palliative Care Guideline [12],* the *Charter for the Care of the Severely Ill and Dying* [45], the *Core Outcome Set for Best Care for the Dying Person* [46] and a consensus paper co-developed by ten German professional societies on palliative care aspects in intensive care medicine were published [47]. The unsustainable implementation of previous efforts and existing guidelines underlines the need for a specific approach to optimise hospital care in the dying phase [9].

1.2 Implementation Science in Healthcare

Addressing persistent deficits in care in the dying phase requires not only clinical thematic knowledge but also an understanding of how evidence can be translated into hospitals, underlining the need for a scientific perspective that connects evidence with practice [48]. Implementation science provides this link by offering frameworks and strategies to translate evidence-based recommendations and research into real-word care. Implementation science emphasises context-specific solutions rather than uniform, standardised "one-size-fits-all" solutions [48]. Within the healthcare sector, implementation science has developed a variety of models and strategies to overcome the translation gap between innovations and routine care, seeking to understand why interventions succeed or fail [49]. Frameworks such as the *Consolidated Framework for Implementation Research (CFIR)* [50]*,* the *Promoting Action on Research Implementation in Health Services (PARiHS)* [51] and the *Theoretical Domains Framework (TDF) [52]* model provide structured approaches to capture the multiple dimensions influencing implementation.

Hospitals operate within hierarchical structures, strict workflows as well as time and cost pressure, making hospitals resistant-to-change settings [53]. The (sustainable) implementation of evidence-based guidelines or interventions with positive outcomes on patient care (e.g. early involvement of specialist palliative care services) remains unsatisfactory in hospitals [54-59]. Barriers are often of organisational or cultural nature [56, 60]. Particularly in EoL care, where needs are complex and time-sensitive, implementation must carefully consider the hospital environment and the multiple stakeholders involved [60, 61].

Improvement efforts must be guided by robust theories that explain why and how individuals, teams and organisations adopt change [49]. Theories on implementation provide a systematic lens to identify mechanisms of change and to design effective, evidence-based interventions [49]. Table 2 summarises key theories on different contexts (the individual professional, the social context, the organisational context and the wider economic and political context) outlining their implications for hospital change [49]. Theories on social context provide the strongest rationale for targeting teams as the primary drivers of change in hospitals as effective teamwork is crucial for implementation success [62]. Theories like *Social Learning Theory*, *Social Network Theory* and theories on teamwork provide specific information mechanisms such as peer modelling, communication, shared goals and the influence of opinion leaders, through which a new clinical practice is either adopted or rejected [49]. An implementation that ignores these dynamics is likely to fail, regardless of strong organisational support or individual staff motivation [22, 23, 49, 63, 64]. Literature provides further evidence that team-based care and specific team-level interventions are effective, leading to a wide range of positive outcomes for patients, HCPs and healthcare systems [62, 65]. From the organisational context, theories like the *Theory of quality management* and *Complexity Theory* emphasise that improvement depends on learning and adaption within healthcare systems. At organisational level, this requires leadership that monitors progress through data, fosters reflection and creates structures in which continuous improvement becomes embedded in daily routines [49]. Further, implementation strategies can broadly be distinguished using two approaches: *top-down* and *bottom-up* (table 1) [66]. *Top-down* strategies are centrally initiated by hospital management, often standardised and aim for broad implementation. While they provide clear guidance by leadership, they are perceived as inflexible in routine practice in hospitals and indicate lower staff engagement, with staff regarding such initiatives as additional work [67, 68]. *Bottom-up* strategies emphasise the participation of frontline staff (staff involved in direct patient care) and adaptation to the setting, fostering ownership, acceptance and a cultural change in the healthcare setting [69, 70]. For this reason, *bottom-up* approaches have also been termed employee-driven (ED) approaches or interventions. They involve healthcare staff in every stage of the innovation process, from identifying problems to developing interventions and implementing them [69]. Their limitation lies in the risk of small-scale impact lacking in necessary resources for widespread change [68, 71].

Studies on implementation in hospital settings show that combining *top-down* and *bottom-up/*ED elements produces better outcomes than using either method alone. For example, numerous studies highlight that leadership involvement combined with input from frontline staff ensures timely, cost-effective and sustainable embedded routine practices [68, 71-74]. A moderate level of administrative intensity (*top-down* control) optimises the benefits of *bottom-up* processes, suggesting that balance is key [72, 75]. Taken together, balanced and combined ED approaches focusing on team-level interventions point to a promising start for realising real change in patient care, but research on how their combination may improve EoL care is still hardly available limited yet [76].

Table 1: Bottom-up vs. Top-down approaches

Top-down	**Bottom-up**
Initiated by hospital management or policy level	Developed by staff directly involved in care
Often standardised	Adapted to local context, needs and routines of wards
May lack acceptance at the frontline	Fosters engagement, ownership, and sustainability of frontline
Covers broader settings	Small scale impact

Table 2: Theories on implementation of change in healthcare, based on Grol et. al. [49]

Level	Theory	Theory description	Implications
Individual professionals	**Cognitive Theories**	Professionals act analytically, weighing pros and cons of alternatives. Change is driven by providing information and decision support.	*Provide professionals with convincing, timely information on desired care and support their decision-making in practice*
	Motivational Theories	Behaviour is determined by individuals' attitude, perceived norms and their sense of control over performing the behaviour.	*Convince professionals of the importance of the new practice, show them they are capable and demonstrate that respected peers support it*
Social Context	**Social Network Theory**	Innovations spread through social networks via opinion leaders and key influencers. Change requires local adaptations and leveraging these networks.	*Identify and utilize local opinion leaders and key persons in the social network to disseminate and champion the change*
	Social Learning Theory	Performance challenges through observation, demonstration and modelling, followed by reinforcement from respected peers.	*Have the desired practice modelled by leaders and reinforced by respected colleagues to encourage adoption*
	Theories on Teamwork	Effective teams, characterized by shared goals, clear roles and psychological safety are better able to implement change because they can share knowledge and coordinate action.	*Creating cohesive teams and where roles are clear encourage one another to work towards common improvement goal*
	Theories on Leadership	Formal and informal leaders are highly influential in promoting or impeding innovation through their authority, control of resources and ability to shape culture.	*Ensure leaders and top management initiate activities, provide continuous support and monitor the change process*
Organisational Context	**Theory of quality management**	Improvement as a continuous cyclical process where plans are made, tested on a small scale, studied and adapted based on experience and data.	*Re-organise work processes around the improvement goal, monitor progress with data and have leaders continuously support these cycles*
	Complexity Theory	Healthcare settings as complex adaptive systems where change is emergent and unpredictable. Focus should be on the systems rather than on individual parts.	*See the target for improvement as a system with many interconnected agents, define minimum specifications for changing and test them*
	Theories on organisational culture	Shared values, norms and routines of an organisation ("the way we do things here") are directly related to its performance and capacity for innovation.	*Create a flexible, innovation-centred culture that stimulates improvement and makes the new practice a core part of the organisations mission*
Economic and political context	**Economic Theories**	Individuals and organisations aim to optimise their goals and are sensitive to financial incentives, risks and reimbursement systems.	*Use financial incentives, such as providing bonuses to teams that succeed or providing a fixed budget to cover materials and to motivate change*
	Theories on Contracting	Use of new practices or guidelines increases when they are built into contracts between buyers and providers.	*Stimulate the adoption of protocols by introducing positive financial incentives for their use within service contracts*

1.3 Aim of the Dissertation

Despite existing guidelines, consented recommendations and implementation efforts, the quality of hospital care in the dying phase remains suboptimal [9]. This highlights the need to understand barriers and facilitators affecting optimal care provision in the dying phase in German hospitals [9, 15]. From implementation science perspective, sustainable implementation of improvement efforts does not only require specific tailored team-based approaches with both ED and *top-down* elements but also measuring and monitoring effectiveness and care outcomes over time. Medical routine data represents a potential source for such purposes as they reflect real-word practice without additional data collection. Medical records (MRs) in general hospital settings could provide a source for systematic assessment and evaluation [77]. However, evidence-based tools for the assessment of hospital care using medical records analysis in the dying phase are still lacking, particularly outside specialised PCWs [78]. Therefore, the aim of this cumulative dissertation is to provide a comprehensive, evidence-based assessment of care in the dying phase in German hospitals as basis for future care optimisation. The dissertation addresses two research questions (RQs):

(1) What are perceived barriers, facilitators, and improvement needs for optimal hospital care in the dying phase in Germany from the perspectives of health experts? (RQ1)
(2) To what extent can medical records (MRs) provide information on hospital care in the dying phase? (RQ2)

The dissertation addresses the identified gaps by investigating the status of hospital care in the dying phase as a basis for care optimisation. It generates data from two German hospitals through three distinct but interrelated studies within one research project [9]. Together, these studies aim to

- **Identify barriers, facilitators and needs for improvement** regarding optimal hospital care in the dying phase (publication 1) [15],
- **Develop a data extraction tool** for retrospective medical record analysis to assess hospital care in the dying phase (publication 2) [78]
- **Generate evidence regarding an ED approach** using working groups (WGs) to develop targeted measures for improving care for dying patients and their ICs (publication 3) [76]

Publication 1 addresses RQ1 by identifying barriers, facilitators and improvement needs from experts' perspective. Publication 2 addresses RQ2 by developing a data extraction tool using MRs for care assessment. Publication 3 integrates findings from both publications 1 and 2 for the implementation of an ED approach to further derive practical implications. By combining quantitative and qualitative methods, this work seeks to contribute actionable insights into clinical practice, care improvements and stimulate future research. Data used and methods employed in the publications are displayed in section 2. The main results of the three publications are outlined in section 3. A synthesis of these results is presented in section 4, structured according to *Bronfenbrenner's* ecological systems model (section 4.1) [79, 80]. The contribution to the literature and implications for practice and research follow in the consecutive sections (section 4.2 and sections 4.3). Central discussion points emerging from this research are discussed in detail in subsections of 4.3, with a focus on their practical implications: documentation of care in the dying phase in MRs (subsection 4.3.1.1) and ED approaches as an implementation strategy for care optimisation (subsection 4.3.1.2). The dissertations' strengths and limitations are discussed in section 4.4, and final conclusions are drawn in section 5.

2 Data and Methods

This dissertation is based on three scientific published within the scope of the study "*Dying in Hospitals – Optimisation of Care in the Dying Phase" (StiK-OV)* [1]. *StiK-OV* is a multi-centre single-arm pre-post intervention study aiming to optimise care in the dying phase in hospitals on ten non-palliative care wards in two university hospitals (six ICUs, four GWs)**.** The project is structured into three phases: (1) systematic collection of existing measures, e.g. through a scoping review [81] (phase 1), (2) development and implementation of ward-specific measures using an ED approach and (3) generalisation and dissemination of results (figure 1). Baseline and post evaluation involves MR analysis, interviews with IC, group interviews with ward staff and a staff survey. Ethical approval was obtained from the ethics committee of the *Medical Faculty of the University of Cologne* on 19.04.2021 (20-1727) and by the ethics committee of the *General Medical Chamber, Hamburg* on 03.08.2021(2021-200061-BO-bet). The study is registered in the *German Clinical Trials Register* (DRKS00025405). Further details on the *StiK-OV* study are outlined in the study protocol [9].

This dissertation integrates findings from project phases 1 and 2 (figure 1). In phase 1, an expert online survey was conducted as project basis [15] (publication 1, figure 2). In phase 2, a data extraction tool was developed and applied to *N*=400 MRs of *N*=10 wards for the retrospective MR analysis in baseline and post survey [78, 82] (publication 2, figure 3). In the implementation phase, an WG approach to develop and implement measures for care optimisation on participating wards was conducted and evaluated [76] (publication 3, figure 4). The methodical characteristics of each publication are summarised in table 3.

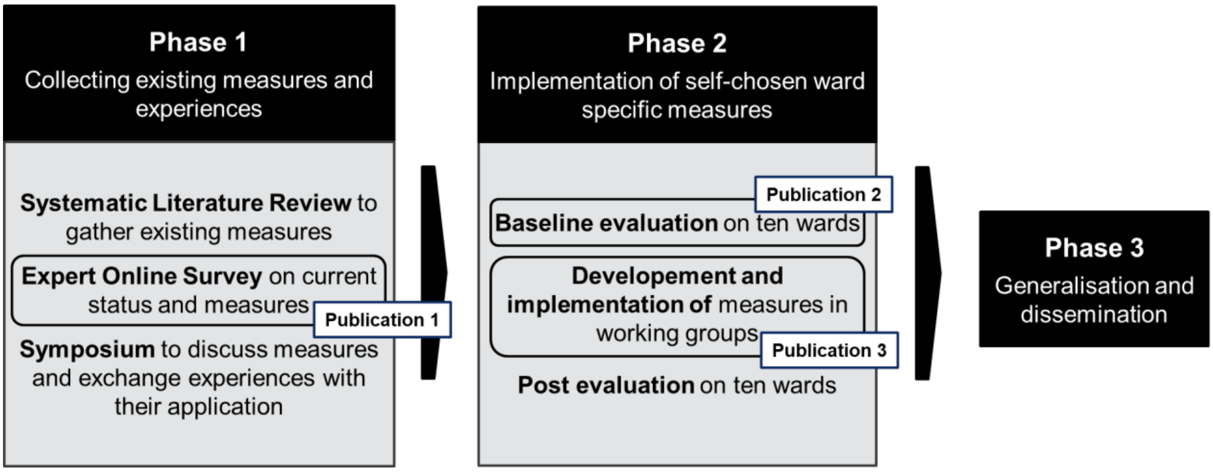


Figure 1: StiK-OV project phases and overview of publications

Publication 1 [15] addresses the overarching research question and RQ1 by exploring facilitators, barriers and improvement needs for optimal care in the dying phase. Including expert perspectives is essential for identifying relevant aspects of care optimisation that may not be readily apparent from MRs or patients' perspective alone [83]. The study presents findings from an expert online survey conducted among national health experts in EoL care. A purposive sample of *n*=65 participants from various healthcare sectors contributed qualitative survey data, which were analysed using qualitative content analysis. Participants also provided information on sociodemographic data and professional background (sector, discipline, years of experience) quantitatively analysed using *SPSS* [15].

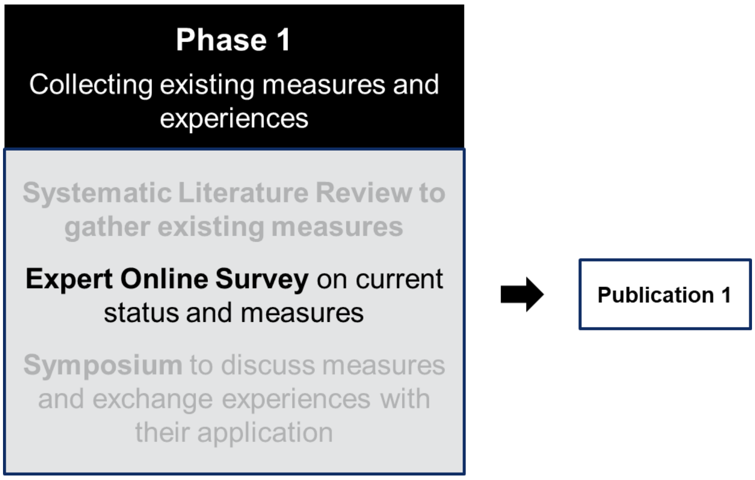


Figure 2: Expert online survey (publication 1)

Publication 2 [78] addresses the overarching research question and RQ2 by developing a tool to assess hospital care in the dying phase through MR analysis. The findings focus on the development, piloting and application of a tool for retrospective MR assessment of care in the dying phase. The tool was developed based on recommendations of the *German Palliative Care Guideline* (version 1.1) [84]. It was piloted with *N*=40 MRs from *N*=4 wards within another research project [85, 86]. The tool was adapted according to the updated version of the

German Palliative Care Guideline (version 2.2) in the *StiK-OV* study [12]. It was then applied to *N*=400 MRs from the baseline survey and tested for content validity and feasibility. Information density per topic and domain was calculated. Content fit between documented notes in the MRs and guideline-derived variables was also assessed. The final tool was iteratively refined by elimination of low-frequency or poorly operationalizable variables in multiple consensus rounds [78].

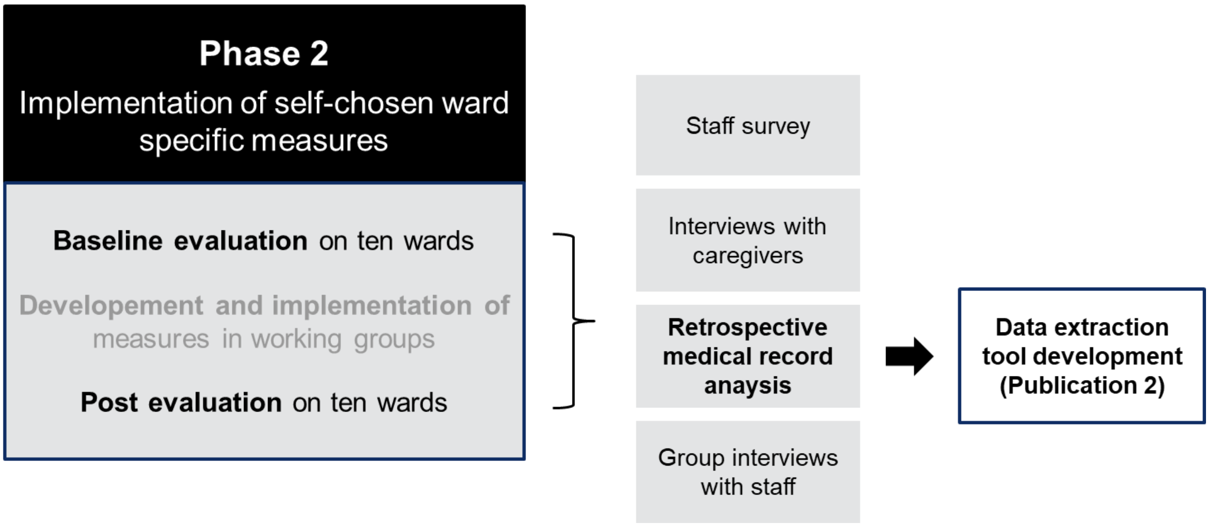


Figure 3: Data extraction tool (publication 2)

Publication 3 [76] builds on the findings of publication 1 and 2 by testing an ED approach to translate barriers and improvement needs into interventions. While publication 1 and 2 provide insights into the state of hospital care, this publication addresses how measures to improve care in the dying phase can be developed in the hospital setting. The publication contributes to both RQs by generating evidence of a participatory approach to optimise care in the dying phase. The study describes and formatively evaluates a ward-specific ED approach to optimise care in the dying phase. Multiprofessional WGs (*N*=10) were established on participating wards to develop and implement measures tailored to ward conditions. Each WG met regularly over a year. Data was collected through *N*=79 documentation sheets, a WG online survey (*N*=44), oral feedback from WG participants and data from the baseline survey. The evaluation of the intervention was conceptually informed by the *CFIR 2.0* framework [50]. This framework was used as a structure to analyse contextual dynamics. Domains of the *CFIR 2.0* particularly relevant to this study included: *Outer Setting* (respective university hospital), *Inner Setting* (e.g. ward communication and culture), *Characteristics of Individuals* (e.g. staff motivation, engagement) and *Implementation Process* (e.g. planning, adapting, action of measures) [76].

The different methodical approaches of the three publications complement each other. Each study focuses on a different perspective of hospital care in the dying phase. The combination of methods offers a triangulated view that integrates subjective needs from health experts' perspectives, objective data of MRs and improvement strategies from an ED approach.

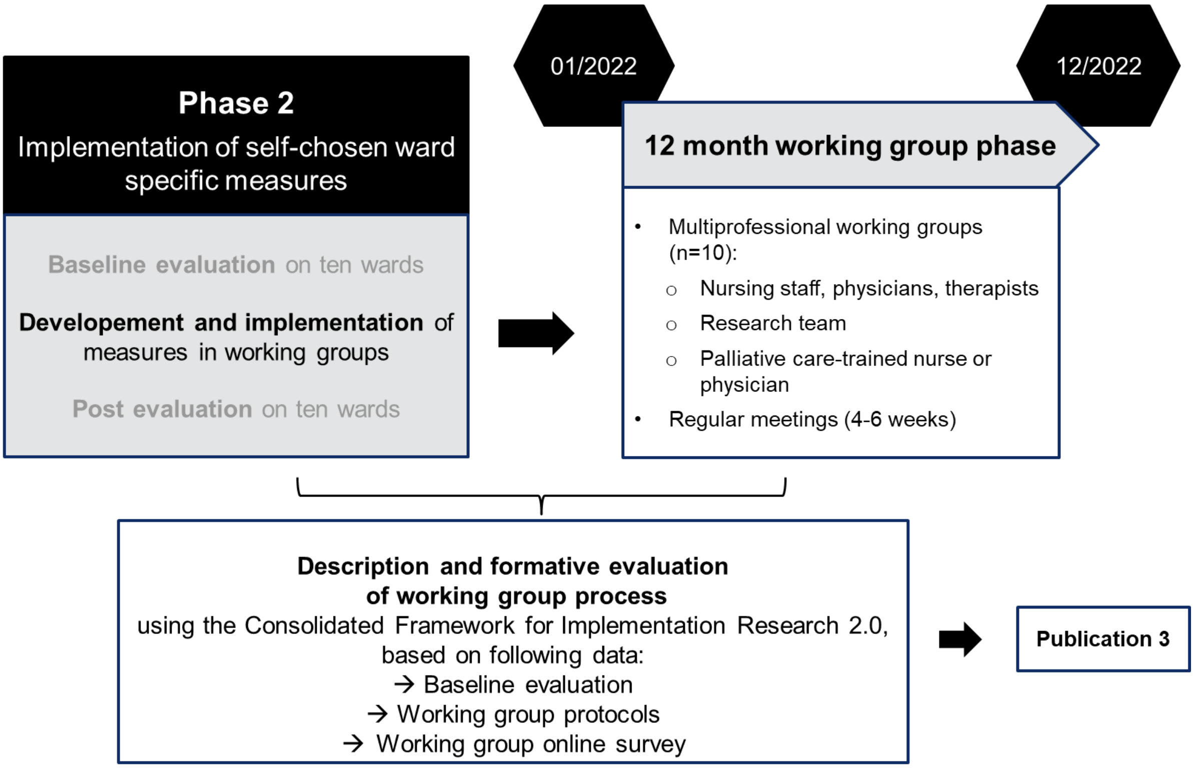


Figure 4: Working group process (publication 3)

The findings of the three publications will be analysed and integrated using *Bronfenbrenner's* ecological model [79, 80] in section 4. *Bronfenbrenner's* model is a widely applied systems theory framework that examines how individuals are influenced by multiple, nested environmental levels that interact with each other. Initially, it was meant to describe human development and behaviour through complex interactions within interconnected levels [79, 80], but has been also used in health research [87-91]. The model was chosen for several reasons. Firstly, the integration of results due to its multilevel perspective enables a structured interpretation of results across different care levels. The structured approach provides more detailed insight into areas for improvements. Secondly, the model's focus on interactions between levels allows for the integration of findings from all publications. This facilitates the examination of hospital care in the dying phase from different perspectives and through several methods. By applying this framework, barriers and facilitators identified in publication 1, the development and application of the data extraction tool from publication 2 and the evaluation and description of the WG approach in publication 3 can be systematically mapped to the according care level. Third, the ecological perspective aligns with the complexity of hospital care, which involves not only HCPs and patients, but also organisational structures and policies. This comprehensive view supports the identification of targeted, multilevel interventions for care optimisation.

Table 3: Overview of methodical approaches used in publications

Publication	Data	Tool	Participants	Sampling	Data collection and analysis	Aim
1	**Expert online Survey**	Anonymous self-developed online questionnaire with *N*=8 open-ended qualitative questions.	Of N=165 **health experts, n=65 (39%)** completed the survey.	Purposive sampling: We sent a survey invitation including the online Link to *n*=165 health experts targeting people with diverse backgrounds in end-of-life care and hospital practice known to the project team. Data was collected via LimeSurvey. Data collection took place in March 2021, including two reminders.	Descriptive Analysis using *SPSS*. Qualitative Analysis using *MAXQDA 2020*: Combined deductive and inductive approach.	Exploration of facilitators, barriers and needs for providing optimal care in the dying phase in hospitals.
2	**Medical records**	Data extraction tool (*Excel*-sheet) containing 11 variables on demographic and clinical characteristics and 39 variables on care in the dying phase retrieved from the German Guideline for Palliative Care [12] (see Appendix).	**Medical records** of ***N*=**400 patients who deceased on participating wards, *N*=10 wards (*n*=6 intensive care units, *n*=4 general wards) across *N*=2 university hospitals	Depending on the numbers of death, we either drew a random sample or carried out a full collection of *n*=40 patients for each ward, with *n*=20 patients who died before and after the outbreak of the COVID-19 pandemic respectively (reference date: 11.03.2020). Patients, who died between January 2018 and August 2021.	Information density and content validity; descriptive statistics (frequencies, percentages) using *R Studio*.	Development and piloting of a structured tool for assessing the hospital care in the dying phase via medical record analysis.
3	**Working group protocols**	Structured protocol: meeting duration, number of participants, field notes on the procedure and atmosphere, ToDos, etc.	***N*=79 working group protocols from** working groups conducted on *N*=10 participating wards (*n*=6 intensive care units, *n*=4 general wards) across *N*=2 university hospitals	Each working group meeting was recorded by one research team member. Records were debriefed by the whole research team to include all impressions in the protocol. Working groups took place between February 2022 and December 2022.	Qualitative content analysis, using *MAXQDA 2022:* Deductive-directed approach by assigning relevant passages to the respective construct of the adapted *CFIR 2.0**.	Description and evaluation of a ward-specific employee-driven approach to develop and implement measures to improve care in the dying phase

	Working group online survey	Anonymous self-developed questionnaire: one question regarding the profession, *N*=16 questions on different aspects of satisfaction with the working group process, and N=3 open questions regarding participants' motivation, insights, and suggestions for improvement (see Appendix).	Of the *N*=78 invited **working group participants**, ***n*=44** completed the survey.	Convenience sampling: We sent the survey invitation including the online link via mail to all participants, regardless of frequency of participation in meetings. Data was collected via *LimeSurvey*. Data collection took place in January 2023, including one reminder.	Descriptive analysis of quantitative data with *SPSS* Statistics Qualitative content analysis of the open questions, using *MAXQDA 2022*: Deductive-directed approach by assigning relevant passages to the respective construct of the adapted *CFIR* 2.0*.	
	Baseline evaluation	For details on baseline evaluation (medical record analysis, group interviews with staff, staff survey, interviews with informal caregivers) see *StiK-OV* study procotol [9]				

**Consolidated Framework for Implementation Research*

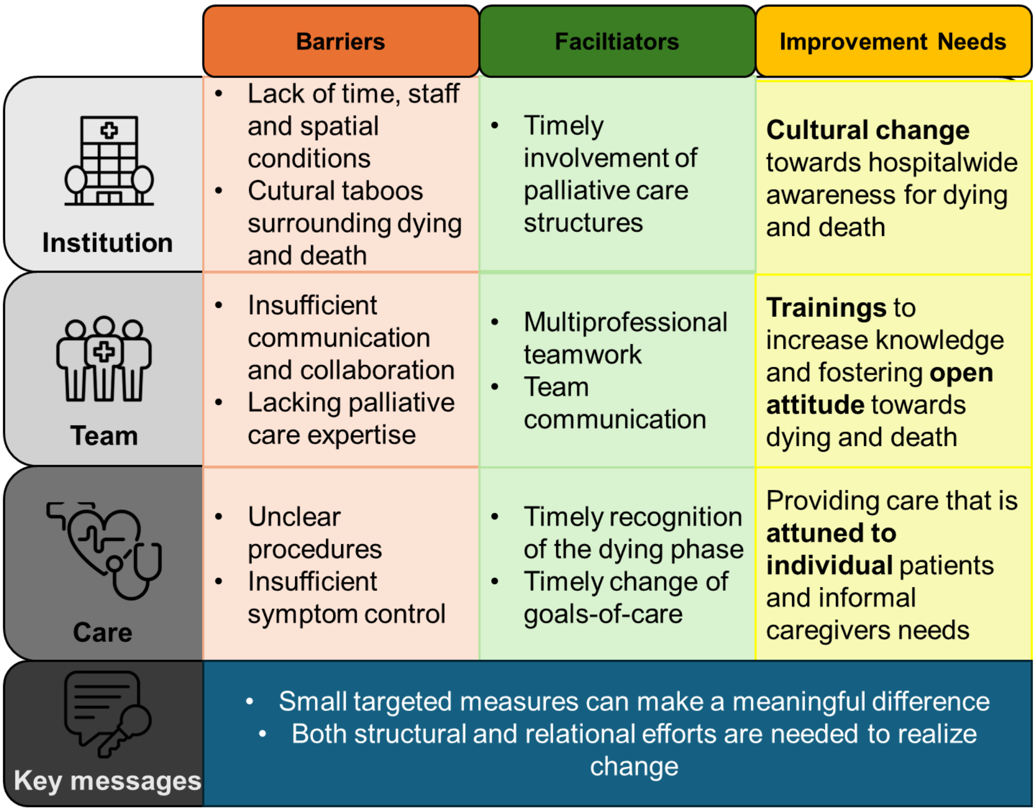
3 Results

The following section presents the main findings of each publication in a compact and visual format. The infographics serve as a bridge into the discussion, where the results are synthesised and discussed considering the overarching RQs and practical implications in section 4.

3.1 Publication 1: Expert Online Survey

3.1.1 Summary

Figure 5 presents results from publication 1 (located in phase 1 of the *StiK-OV* study [9]), with detailed methods provided in section 2 and table 3. The infographic illustrates the perspectives of the *N*=65 health experts on the current state of hospital care in the dying phase. These results address RQ1 by identifying barriers, facilitators and needs for improvement on three care levels: (1) institutional environment, (2) team and (3) direct care of dying patients and their ICs. Experts described structural and communicative challenges and pointed to enabling factors such as HCPs' awareness towards death and dying and their palliative care expertise. Common improvement needs included e.g. cultural shifts toward openness around death and dying, trainings and a more patient-centred approach and greater involvement of ICs [15].



	Barriers	**Faciltiators**	**Improvement Needs**
Institution	• Lack of time, staff and spatial conditions • Cutural taboos surrounding dying and death	• Timely involvement of palliative care structures	**Cultural change** towards hospitalwide awareness for dying and death
Team	• Insufficient communication and collaboration • Lacking palliative care expertise	• Multiprofessional teamwork • Team communication	**Trainings** to increase knowledge and fostering **open attitude** towards dying and death
Care	• Unclear procedures • Insufficient symptom control	• Timely recognition of the dying phase • Timely change of goals-of-care	Providing care that is **attuned to individual** patients and informal caregivers needs
Key messages	• Small targeted measures can make a meaningful difference • Both structural and relational efforts are needed to realize change		

Figure 5: Main findings of the expert online survey (publication 1)

3.1.2 Manuscript

This is a post print manuscript of publication 1, accepted on 22.08.2024 in the *International Journal of Clinical Practice* (Impact Factor 2024: 2,4).

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Research Article

Health Experts' Perspectives on Barriers, Facilitators, and Needs for Improvement of Hospital Care in the Dying Phase

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Introduction. Globally, hospitals are an important place in end-of-life care and most frequent place of death in Germany (47%), but at the same time, the least preferred one—both for patients and their informal caregivers. As hospital care in the dying phase on non-palliative care wards has rarely been studied systematically, we assessed the current state of care in the dying phase in hospitals as a first step. *Methods*. In an online survey, $N = 165$ national health experts were invited to answer eight open questions on care aspects, facilitators, barriers, and needs for improvement as well as COVID-19 pandemic specifics regarding hospital care in the dying phase. Sociodemographic data were analysed descriptively, and responses were analysed using qualitative thematic analysis. *Results*. Of $n = 65$ experts, 52% work as nursing staff and 30% as physicians. We identified facilitators, barriers, and needs for improvement regarding 11 topics on the following three levels: institutional level (general institutional conditions, hospital culture, and integration of specialist palliative care), team level (attitude towards and dealing with death and dying, competencies, communication, and teamwork) and care level (dying phase, symptom control, patient centredness, and involvement of informal caregivers). *Conclusion*. Improving care in the dying phase has to overcome barriers on various levels. We assume that rather "small" measures will find their way into clinical routine and contribute to the improvement of hospital care in the dying phase.

1. Introduction

Hospitals play a crucial role in providing end-of-life care for a substantial portion of the population in developed countries [1], despite the fact that a majority of patients desire to die at home [2]. The percentage of deaths occurring in hospitals varies significantly across different countries, with examples such as 34% in the Netherlands [3], 42% in Sweden [4], 47% in England [5], and 61% in Spain [3]. In Germany, too, hospitals are the primary place of death (47%) [6]. At the same time, they are also the least preferred choice for both patients and their informal caregivers (IC (this includes all persons close to the patient, regardless of whether they are involved in the actual patient care)) [7]. Dissatisfaction with care in the dying phase arises from various aspects like insufficient symptom control or lacking information regarding the dying process [8, 9]. Internationally, efforts have been made to optimise care for dying patients resulting in complex interventions such as the *AMBER Care Bundle* (Assessment; Management; Best practice; Engagement; Recovery uncertain) or the *Best Care for the Dying Patient* (BCD) recommendations with a recent update [10, 11]. In a similar manner, different approaches have been developed to optimise care in German hospitals, such as the *National Guideline on Palliative Care for Patients with Incurable Cancer* [12] in 2020. This guideline consists of evidence- and consensus-based recommendations for dying patients formulated by 70 professional societies. Due to the COVID-19 pandemic, a project has been launched to ensure good care for dying people and their IC under pandemic conditions [13].

Despite these broadly consented recommendations for optimal care in the dying phase, dissatisfaction of patients and IC persists [7]. One possible explanation is that sustainable implementation of these recommendations has not yet taken place, particularly in nonspecialist palliative care wards, where most hospital patients die [14]. The provision of palliative care in hospitals faces specific challenges: financial constraints, reduction of staff, shifting role expectations and interprofessional practice that can be barriers to the delivery of optimal hospital care in the dying phase [15]. In addition, landmark interventions like the *BCD* or the *AMBER Care Bundle* were developed using a top-down approach, making them rather inflexible and complex in their application within hospitals and specific wards [16, 17].

The current dissatisfaction and the apparent gaps in implementing existing guidelines and interventions emphasize the high demand for improvement of optimal care in the dying phase on nonspecialist palliative care wards. To address this, the project *Dying in Hospital–Optimisation of Care in the Dying Phase* aims to improve hospital care in the dying phase [18]. In the first project phase, an online survey was conducted among health experts to map the current care situation in hospitals. This survey aimed to identify facilitators, barriers, and needs in the dying phase.

The insights gathered within the survey will, along with a kick-off symposium conducted afterwards, aid in identifying potential measures and areas of improvement to optimise hospital care in the dying phase during the project.

2. Material and Methods

2.1. Study Design. This survey is part of a three-phase single-arm pre-post study (see Figure 1). The overall study aim is to optimise care in the dying phase on ten nonspecialist palliative care wards at two German university hospitals [18]. Survey data presented in this paper were collected in project phase 1. Along with a literature review and symposium, it formed the basis for the project's second phase. The survey was conducted prior to the symposium to provide a solid data foundation for discussions [18]. Ethical approval was obtained from the Ethics Committee of the Medical Faculty of the University of Cologne on 09.02.2021 (20-16109).

2.2. Data Collection and Sample. The questionnaire for the online survey consisted of eight self-developed open-ended questions regarding optimal hospital care in the dying phase (Table 1) and was developed by four authors (KK, KB, AU, and NO). Sociodemographic data (Table 2) were also collected.

We sent the survey invitation including the online link (LimeSurvey) and study information via email to 165 national health experts known to the research team. The health experts represented initiatives and research projects related to hospital care in the dying phase, health insurances funds, hospital federations, and various expert associations and professional societies (palliative care, nursing, neurology, hospice care, chaplaincy, geriatrics, and cancer). Relevant stakeholders from politics, health professionals from participating university hospitals, and experts affiliated with the research team from other research projects were also invited. On the welcome page of the online survey, participants were informed that all responses were collected anonymously and data were used for scientific analysis only. Experts gave informed consent to participate in the online survey by clicking the "continue" button before starting. Local servers were used to ensure data protection, and no personal information was linked to survey results.

Data collection took place from March 17, 2021, to April 09, 2021, with reminders sent at two and three weeks after the initial invitation.

2.3. Data Analysis. Only completed questionnaires were included in the final dataset. Sociodemographic data were analysed descriptively (frequencies and standard deviation) using IBM SPSS Statistics 28 [19]. Free text answers were analysed by means of qualitative thematic analysis [20] using MAXQDA (2020 v.2) [21]. Data were first analysed deductively, creating categories based on the open questions (Table 1). The data were then recategorized inductively based on the most important topics regarding dying in hospitals named by experts, resulting in comprehensive categories derived from the material. Then, content within the respective categories was assigned depending on whether it presented a barrier, facilitator, or a need for improvement. Three authors (SK, KB, and KK) discussed codes until reaching consensus. Data were then recoded using the final topics. Eventually, the most important topics were reflected to answer the qualitative research question (code system is provided in the supplementary materials (available here)). Quotes in German language were translated to English by two authors (SK and KB).

3. Results

3.1. Sample Sociodemographic Data. Of $N = 165$ invited experts, $n = 65$ (39%) completed the survey. For details on sociodemographic data, see Table 2.

3.2. Results of Open Questions. We classified the answers into the following three different levels: institutional, team, and care levels. Within these levels, barriers, facilitators, and needs for improvement regarding 11 topics are reported as well as main specifics during the COVID-19 pandemic (Figure 2).

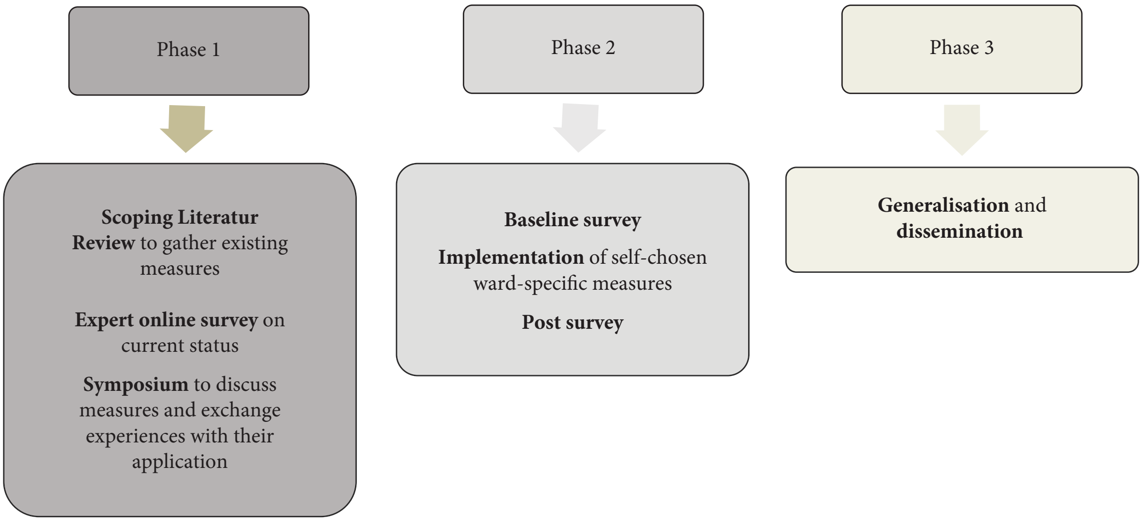

Figure 1: Dying in hospital: optimisation of care in the dying phase project phases [18].

Table 1: Eight open questions on optimal hospital care of patients in the dying phase.

(1) Please name and describe the three most important aspects that spontaneously come to your mind when you think about care of patients in the dying phase?
(2) What is particularly positive about care of patients in the dying phase from your point of view?
(3) In your opinion, where are the needs for improvement in the care of patients in the dying phase?
(4) What specific factors impede the optimal care of patients in the dying phase?
(5) What specific factors facilitate the optimal care of patients in the dying phase?
(6) If you could decide: What is the next step for the optimisation of care of patients in the dying phase?
(7) What specifics are you experiencing regarding the care of patients in the dying phase due to the current COVID-19 pandemic?
(8) Is there anything else that is important to you regarding care in the dying phase that has not yet been addressed in this questionnaire?

Table 2: Sociodemographic data of experts ($N = 65$), *number of participants, and **multiple answers possible.

Characteristics	Total sample	*n* (%*) $N = 65$ (100)
Age	47.9 ± SD 11.89 years	
Gender	Female	46 (71)
	Male	19 (29)
Area of professional activity**	Intensive care	16 (25.0)
	Oncology	16 (23.4)
	Palliative care	13 (20.3)
	Management	12 (18.8)
	Neurology	9 (14.1)
	Cardiology	3 (4.7)
	Geriatrics	3 (4.7)
	Surgery	3 (4.7)
	Nephrology/endocrinology/rheumatology	4 (6.3)
	Internal Medicine	5 (7.8)
	Gastroenterology	2 (3.1)
	Other (e.g., outpatient hospice service)	3 (4.7)
Profession**	Nursing staff	33 (52.4)
	Physician	19 (30.2)
	Social worker	4 (6.3)
	Chaplain	3 (4.8)
	Psychologist	1 (1.6)
	Other (e.g., hospice management and medical assistant)	7 (11.1)

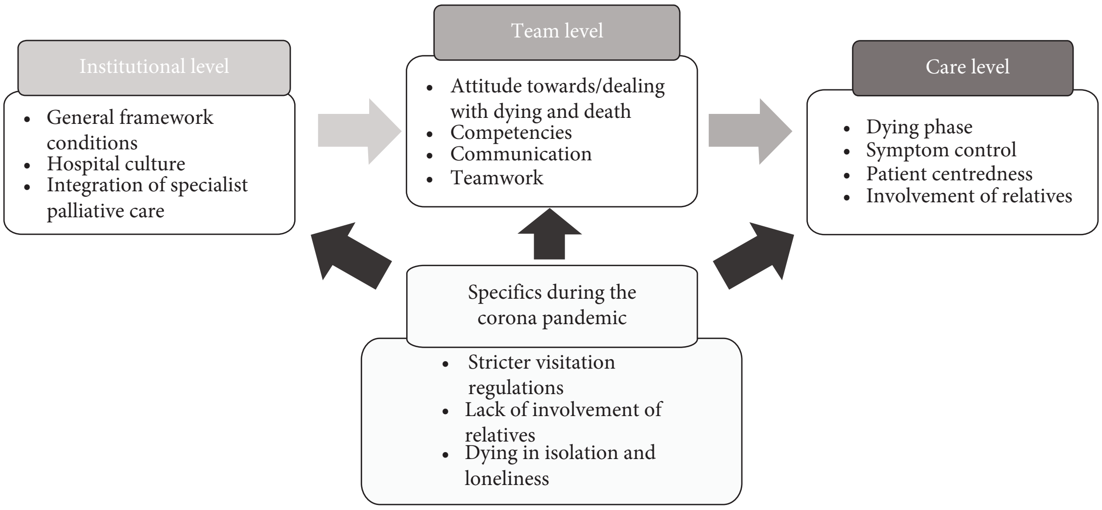

Figure 2: Important topics of care in the dying phase subdivided according to different levels of hospital care.

3.2.1. Institutional Level. On institutional level, barriers, facilitators, and needs for improvement on three topics were named by the experts (Table 3).

Within the domain general institutional conditions, experts described a shortage of time and staff as well as poor spatial conditions that impede optimal care in the dying phase. Therefore, they demanded an *"establishment of conditions (premises, structures, and time requirements) that allow a compassionate care of the dying"* (P65, Q4), e.g., more single rooms and a calm environment that enables privacy. Experts described a prevailing curative hospital culture. Death, dying, and care in the dying phase were often regarded as a taboo and are not spoken about in daily practice:

> *""We cure. People don't die here." [Death] is often seen as a failure."* (P57, Q4)

This attitude towards dying and death has negative consequences for the care of patients as there are no standard procedures about changes of goals-of-care:

> *"A medical zigzag path when dying is delayed as long as possible even though it is no longer avoidable."* (P110, Q4)

Therefore, experts recommended the establishment *"[...] of a hospital-wide policy that removes the taboo surrounding dying"* (P128, Q4) and made suggestions such as memorial rituals and a hospital-wide mission statement.

In this context, experts named the integration of specialist palliative care on nonpalliative care wards as a necessary next step. They stated the need of timely initiation of transfer to palliative care wards and the involvement of specialist palliative care such as hospice services, chaplains, and ethics counselling. Especially the consultation of hospital palliative care support teams was described as helpful:

3.2.2. Team Level. On the team level, barriers and facilitators on four topics were named by the experts (Table 4).

As an important topic regarding care in the dying phase, experts named the staff's individual attitude towards/dealing with dying and death. Individual attitudes may depend on different cultural backgrounds and experiences:

> *"Some of the colleagues have a fear of contact with this patient group. Some of them come from a different cultural background, thus have a different relationship with dying, some of them have had stressful experiences themselves. Some of the care appears to be only [physical] care- less empathetic - perhaps also to protect themselves."* (P150, Q3)

Furthermore, experts named intrapersonal competencies such as empathy, charity, and openness as well as palliative care expertise as facilitating factors. Training and education for medical and nursing staff in palliative care, awareness, symptom control, and communication were described as a need for improvement. Also, effective teamwork was considered as a helpful and important factor for care in the dying phase:

> *"I work in a good team that got each other's backs. We support each other to take care of the patient as good as possible, besides the daily madness."* (P119, Q2)

Cooperation was described as poor in some aspects, for example, lack of appreciation of care provided by nursing staff:

> *"Interprofessional teamwork needs to perform well during the provision of care. It is important to involve the nursing staff and to acknowledge their competences in the field of symptom management."* (P103, Q4)

Table 3: Facilitators, barriers, and needs for improvement of optimal hospital care in the dying phase on the institutional level.

Topic	Barriers	Facilitators	Needs for improvement
General institutional conditions	Lack of timely and personnel resources, unsuitable spatial conditions High workload and strains of healthcare staff	Adequate timely and personnel resources and suitable spatial conditions	More time and personal resources and suitable spatial conditions
Hospital culture	Taboo of dying and death Dying and death as failure in care Ambivalent procedures of changes in goals of care	Hospital-wide policy to gain awareness for death and dying in hospital	Establishment of palliative care concept, guidelines, and standardized procedures
Integration of specialist palliative care	Late involvement of specialist palliative care services	Early integration of specialist palliative care	More (timely) integration of specialist palliative care

Table 4: Facilitators and barriers of optimal hospital care in the dying phase on the team level.

Topic	Barriers	Facilitators	Needs for improvement
Attitude towards/dealing with dying and death	Individual fears and avoidant attitude towards care in the dying phase/death	Individual confrontation/examination with the issue care in the dying phase/dying and death	More acceptance of care in the dying phase and the issue death
Competencies	Lack of palliative care expertise/experiences in the care of dying patients	Intrapersonal competencies, e.g., empathy Palliative care know-how and care experience	Education for healthcare staff to strengthen awareness for dying/death and increase knowledge in end-of-life care
Teamwork	Insufficient teamwork and cooperation, e.g., interdisciplinary disagreements	Interprofessional and interdisciplinary teamwork Cross sectional care, e.g., cooperation with general practitioners	Improvement of effective teamwork and communication about patient care between physicians and nursing staff and between different wards
Communication	Insufficient, unclear communication about treatment	Clear communication in the team/with other professions about care decisions	

In this context, experts emphasized the importance of communication between all professional groups about care decisions.

3.2.3. Care Level. On care level, experts named barriers and facilitators on four topics (Table 5).

As an important topic experts named the adequate recognition and communication *"[. . .] about the beginning of the dying phase and what is happening/can happen now, e.g., bronchial rales, pauses in breathing, etc."* (P98, Q1) to patients and their IC. Measures in the dying phase were reported to have a wide scope of openness and creativity, even simple measures can have a large impact:

> *"You can make a difference with small gestures and actions (e.g. light, music, etc.)."* (P127, Q2)

Experts stated that *"everything that is good for the patient is allowed"* (P103, Q2), such as aromatherapy, LED candles, ritual boxes, bereavement letters, and use of music.

Symptom control was also described as beneficial. It was noted that the adjustment as well as administration of medication needs to be improved, especially regarding pain therapy. Experts also reported that especially the dying phase enables to provide care attuned to individual patient needs:

> *"When I accompany the patients, I [...] take time for the dying, care for them with dignity and fulfil their last wishes and needs."* (P150, Q2)

However, they claimed that the staff receives insufficient information so that patients' wishes are not sought. Therefore, they stated the need for a patient-centred approach in the care in the dying phase:

> *"Find out more about the patient's wishes, religiousness, spirituality . . . in advance and document it. Always document and explore the patient's presumed will."* (P141, Q3)

Another important aspect reported by the participants was the (timely) involvement of patient's IC. Personal meetings with IC for information on the dying process, care decisions, and support offers were mentioned as examples:

> *"Patients and their IC should be given the opportunity to realize and express that the dying phase has begun. They should be given the opportunity to look back on their lives, the good and the difficult, in order to say goodbye."* (P92, Q1)

3.3. Specifics during the COVID-19 Pandemic. When asked about specifics during the COVID-19 pandemic, the circumstances reinforced the aspects which were already considered problematic in general, e.g., *"restriction of communication due to wearing protective clothing, additional staff workload due to quarantines, staff absences and putting on/removing protective clothing"* (P61, Q7). Experts named the restrictions or ban of visiting rules as an influential factor leading to a lack of involvement of IC:

> *"In extreme cases IC were allowed in too late or could not say goodbye to the patient."* (P141, Q7)

Due to these circumstances, patients would suffer from isolation of their IC and often *"die alone in the hospital, sometimes without being noticed directly [by the health professionals]. Not until the next visit"* (P119, Q7).

3.4. Kick-Off Symposium. To discuss the results of the online survey as well as of the scoping review (will be published elsewhere), they were presented at a symposium as a kick off to phase 2 of the whole project. The same experts who took part in the survey were invited to this kick-off symposium.

The first results of the expert discussion confirmed the relevance of already known aspects on the individual and societal level of care in the dying phase. These include, for example, the need for better recognition of the dying phase, involvement of IC, open communication, and resources in terms of personnel, time, and space.

On this basis, present experts discussed suitable measures for its improvement and exchanged experiences regarding their application. Thematically related German research projects such as *PallPan* [13], *SPES VIVA* [22], *Handlungsempfehlungen Sterbephase (HES)* [23], and *Avenue-Pal* [24] were presented by guest speakers to deepen certain aspects. These included those related to palliative care of severely ill and dying people and their IC in pandemic times to include pandemic-related aspects in the project.

4. Discussion

The survey results give important insights into barriers, facilitators, and needs for improvement of hospital care in the dying phase. These aspects are displayed on three different levels of hospital care from health experts' perspective. Beyond confirmation of important aspects that are already known, they added new insights underpinned by valuable expert quotes. By surveying experts who are concerned with the topic in clinical practice, politics, research, education, and other areas of healthcare, the micro (care), meso (team), and macro (institutional) levels are integrated (see Figure 2) [25]. Therefore, the experts contribute to a mapping of the current care situation in hospitals that is close to practice. The discussed survey results together with the enriching contributions of speakers from existing national projects present areas for improvement of care in the dying phase that should be targeted by measures in the following project phases.

Overall, our results capture a comprehensive picture of contemporary hospital care. On the institutional level, our results give various examples for barriers, e.g., late integration of specialist palliative care that can impair the quality and delivery of care provided to patients with cancer [26]. In addition, our results show that the hospital environment and working conditions (spatial, personnel and timely resources) are often deemed not suitable for end-of-life care [15, 27]. Overall, our results reflect the prevailing hospital culture, which aggravates an optimal care in the

Table 5: Facilitators, barriers of optimal hospital care in the dying phase on the care level.

Topic	Barriers	Facilitators	Needs for improvement
Dying phase	Unclear communication about the dying phase towards patient and IC	Recognition of the dying phase	Tools for recognition of the dying phase
	Lack of communication in the team about changes of goals of care	Timely changes of goals of care	
		Creative measures that can have a large impact	Use of unconventional and creative measures
Symptom control		Symptom management and pain relief	Clear/standardised procedures for administration of medications
Patient-centredness	Insufficient information about patients' needs and wishes	Providing care that is attuned to individual patients needs	More patient-centred care, e.g., consideration of patient's wishes
Involvement of informal caregivers	Insufficient or untimely information and support of IC	(Timely) involvement of and communication with IC	

dying phase. On the team level, it is important that health professionals in general have basic palliative care skills [27]. Our results expressed a need of staff with palliative care expertise and identified concrete areas that need to be targeted by (further) education, e.g., symptom control, communication with IC, or intrapersonal competencies. The need for improvement of practice and education of healthcare staff as well as needed changes in hospital policy were also identified in a recent study [28]. As health professionals' communication with patients and IC is the most common cause for complaints by patients and their IC [27, 29, 30], our results confirm the need for improvement of teamwork and communication. This also applies to different cooperation levels, e.g., between physicians and nursing staff. On the care level, our findings underline that insufficient symptom control and poor participation in decision making are main barriers for optimal care in the dying phase, complementing study results from patient and their IC perspective [29, 31].

As the survey took place during the COVID-19 pandemic, we also assessed pandemic-related specifics in the survey and presented a project dealing with palliative care during pandemic times [13] at the following symposium. Within this framework, the need for a specialised care concept targeting the involvement of IC during pandemic times was emphasized.

To implement change, a multilevel framework that identifies relevant factors at the macro-(external context), meso-(organisational) and micro-(provider/patient) levels appears to be most appropriate [32]. This helps to explore factors that may influence successful implementation of improvement interventions [33]. Studies highlighted that challenges in implementation are mostly related to the hospital environment [34]. Our results also elucidate that unsuitable hospital conditions can have impact on other care levels and provision of adequate care in the dying phase [34, 35]. In this context, participating experts voiced concerns regarding implementing complex approaches in the hospital environment. Interventions like the BCD using this top-down-approach were reported to fail in some cases due to its complexity and inflexible application [10]. In our study, health experts suggested small interventions in steps such as the use of aromatherapy at the care level or staff training at the team level, which we think have a greater chance of being incorporated into actual clinical practice. Therefore, we assume that these small interventions suggested by health experts could be more feasible and effective for improving care.

Changing the general hospital conditions such as personnel, timely, and spatial resources often needs considerable time and political effort [15, 36]. Therefore, it is important on focusing on expertise, communication, motivation, and attitude of health care staff to realize change in ongoing procedures. A bottom-up approach including the implementation of measures on care and team level in the identified areas seems more appropriate for hospitals than a uniform top-down implementation solely failing due to complexity [34]. A bottom-up approach describes a strategy that focuses on involving healthcare providers and other relevant stakeholders in the implementation process by emphasizing their active participation and input [36, 37]. A recent systematic review also stated the need of staff involvement for change in healthcare organisations. Especially the key role of nurses in the change process was highlighted [37]. We followed the bottom-up principle by including health experts' perspectives, giving them the platform to address and discuss relevant topics and measures in a national context. Some of the healthcare providers that participated in the survey will implement tailored, self-chosen measures on ten wards in two university hospital during the further course of the project [18]. As healthcare staff attitudes and practices vary due to different religions and cultures from country to country, any type of similar improvement project can benefit from such a bottom-up approach [38]. Overall, the results of the first phase of the project provided a basis for the next stages of the project. We assume that addressing the topic death and dying on the wards and developing measures creates awareness and will have a catalytic effect of change beyond the care level. The implemented measures will be evaluated in a pre-post design. These measures might result in a generalizable concept that is useful in other hospital settings as well. A second final symposium will be held inviting the same experts to discuss the findings obtained in the project [18].

4.1. Strengths and Limitations. Our results shed light into barriers, facilitators, and needs for improvement of optimal care on three different levels of hospital care in the dying phase by an expert survey using seven open questions. Structured interviews with health professionals and IC could possibly add more in-depth insights. Nevertheless, the survey results add valuable aspects and related quotes regarding optimal hospital care in the dying phase from health experts' perspective. It is one of our study's strengths that these experiences stem from a heterogeneous sample of national experts in the field of hospital care.

5. Conclusion

Hospital care in the dying phase shows needs for improvement on several levels. Changing the general conditions in hospitals usually requires considerable time and political effort.We therefore assume that relatively small measures will find their way into clinical routine and contribute to the improvement of hospital care in the dying phase more easily.

Data Availability

The survey data used to support the findings of this study are available from the corresponding author upon request.

Conflicts of Interest

The authors declare that there are no conflicts of interest.

Acknowledgments

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Supplementary Materials

Supplementary Table 1: codesystem with names and numbers of codings. (*Supplementary Materials*)

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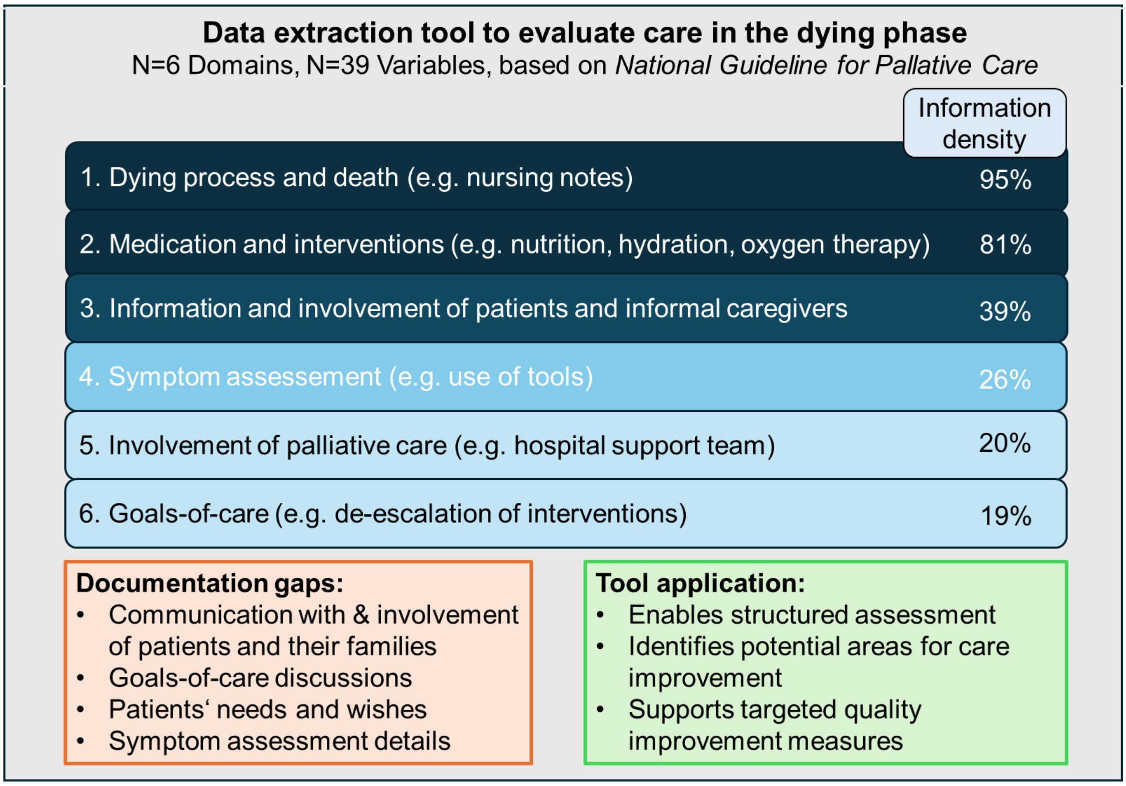
3.2 Publication 2: Data Extraction Tool

3.2.1 Summary

Figure 6 presents findings from publication 2 (located in phase 2 of the *StiK-OV* study [9]), with detailed methods provided in section 2 and table 3. The infographic highlights the core features and findings of the development and testing of a guideline-based data extraction tool to assess hospital care in the dying phase through retrospective MR analysis (see Appendix). The final tool includes *N*=39 variables, structured across six domains and ranging from medication and monitoring to communicational aspects. Application to *N*=400 records revealed significant variation in documentation density of domains: while clinical aspects such as the dying process and medication were well documented, details on patient and ICs' preferences, symptom assessment and treatment goal were frequently missing [78]. The results respond to RQ2 by examining the extent MRs can provide information on hospital care in the dying phase for care assessment. The tool enabled a structured retrospective analysis of routine documentation and the extent to which recommendations and QIs regarding care in the dying phase are reflected within documentation. The tool demonstrated adequate content validity and offers a structured way to identify gaps in routine documentation, serving as a starting point for targeted improvements e.g. templates [78].



Data extraction tool to evaluate care in the dying phase

N=6 Domains, N=39 Variables, based on *National Guideline for Pallative Care*

	Information density
1. Dying process and death (e.g. nursing notes)	95%
2. Medication and interventions (e.g. nutrition, hydration, oxygen therapy)	81%
3. Information and involvement of patients and informal caregivers	39%
4. Symptom assessement (e.g. use of tools)	26%
5. Involvement of palliative care (e.g. hospital support team)	20%
6. Goals-of-care (e.g. de-escalation of interventions)	19%

Documentation gaps:
- Communication with & involvement of patients and their families
- Goals-of-care discussions
- Patients' needs and wishes
- Symptom assessment details

Tool application:
- Enables structured assessment
- Identifies potential areas for care improvement
- Supports targeted quality improvement measures

Figure 6: Main findings of development of data extraction tool (publication 2)

3.2.2 Manuscript

This is a post print manuscript of publication 2, accepted on 26.05.2025 in the *Journal of Evaluation in Clinical Practice* (Impact Factor 2024: 2,1).

Journal of Evaluation in Clinical Practice

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Journal of Evaluation in Clinical Practice
International Journal of Public Health Policy and Health Services Research

ORIGINAL PAPER OPEN ACCESS

How to Evaluate Hospital Care in the Dying Phase—Development of a Data Extraction Tool for Retrospective Medical Record Analysis

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Keywords: dying in hospital | dying phase | medical record analysis | palliative care | quality of care

ABSTRACT

Background: Hospitals are the most common place of death in European countries, including Germany, where nearly half of the population dies in hospitals, mostly outside specialised palliative care wards. At the same time, quality of hospital care in the dying phase is reported as poor. Although existing (inter-)national guidelines provide outcome variables, their evaluation of implementation is lacking. This study aims to develop and test a structured tool for data extraction from medical records (MRs) to evaluate hospital care in the dying phase. The provision of such a tool can help to identify needs for improvement of care.
Methods: We developed a data extraction tool by operationalizing recommendations for the dying phase of the evidenced-*based German National Palliative Care Guideline*. The tool was used to extract notes from MRs of $n = 400$ deceased patients of 10 general wards and intensive care units at two University Medical Centres. We analysed the tool's information density and content validity. Descriptive statistics were calculated as frequencies and percentages.
Results: The final tool consists of 39 variables in six domains. Initially, 55 variables were derived from guideline recommendations. With regard to content validity, notes for 37 (67%) variables could be extracted from the MRs, while 16 variables were removed due to poor or unclear documentation. Two additional variables were identified inductively and included in the final tool. Notes could be extracted for all domains, while information density (% of MR with notes) varied: (1) Dying process and death ($n = 380$, 95.0%), (2) Medication and interventions ($N = 323$, 80.7%), (3) Information and involvement of patients and informal caregivers ($n = 155$, 38.8%), (4) Symptom assessment ($n = 105$, 26.3%), (5) Involvement of specialised palliative care ($n = 78$, 19.5%), (6) Goals-of-care ($n = 76$, 19.0%). Variation in documentation can reflect differences in care provision or recording practices, suggesting a need for documentation standards.

Abbreviations: DNI, do-not-intubate; DNR, do-not-resuscitate; EC, expert consensus; IC, informal caregiver; ICU, intensive care unit; MR, medical record; MRA, medical record analysis; QI, quality indicators.

Conclusion: The tool enables a structured retrospective analysis of guideline-recommended aspects of care in the dying phase in MRs, applicable to both general wards and intensive care units. It can support quality improvement by identifying documentation gaps and areas of care improvement, and can contribute to target interventions in different hospital settings. To obtain a comprehensive understanding of the care provided, MR analysis should be combined with other methods and perspectives and tested in other settings.

Trial Registration: The study is registered in the German Clinical Trials Register (DRKS00025405).

1 | Background

A significant proportion of the population in European countries dies in hospitals making them an important setting for end-of-life care [1]. In Germany, 47% of all deaths occur in hospitals, mostly outside specialised palliative care wards [2–4]. At the same time, the hospital is the least preferred place of death for both, patients and their informal caregivers (IC) [5]. Care in the dying phase in hospitals outside of palliative care wards is reported to be poor [6–8]. For example, the onset of the dying phase outside of palliative wards is often recognised too late [9]. Communication about the dying process is reported to be poor, life-sustaining treatment is also often inappropriate, and pain and symptom management insufficient [6]. Patients continue to receive life-sustaining treatments such as mechanical ventilation or dialysis despite an indicated change in goals-of-care or signs of the beginning of the dying phase [10]. IC may not be informed in time to be present at the patient's death or to say goodbye [11]. These findings contribute to the perception of poor quality care in the dying phase and highlight the need for structured evaluation and improvement.

Several guidelines have been published that define recommendations for high quality of care in the dying phase [9, 12–15]. At the international level, the *AMBER Care Bundle* focuses on care for patients with uncertain recovery and aims to improve decision-making, joint communication, and care planning [15]. The *Best Care for the Dying Patient* recommendations focus on symptom control, communication, psychosocial and spiritual support in the last days of life [12]. In Germany, the national Guideline *Palliative Care for patients with incurable cance*r has been developed and is applicable beyond the oncological setting [9]. It includes evidence- and consensus-based recommendations and quality indicators (QI), among others also on care in the dying phase [9].

An assessment of the current care provision can serve as a first step in optimising care in the dying phase [16]. It enables the identification of areas with need for improvement and subsequently supports the implementation and evaluation of interventions [17]. There are well-known challenges in directly assessing dying patients' experiences directly as they are burdened and In a reduces functional status [18–20]. Therefore, most studies use retrospective proxy report by health care professionals or ICs [17, 20]. This can be done using qualitative and quantitative methods. A widely used quantitative method that allows generalisation and comparison of results across large numbers of patients is medical record analysis (MRA) [21, 22]. Retrospective MRA is often used where a prospective approach is not feasible due to ethical considerations mentioned above [23, 24]. Medical records (MRs) can offer information on health care delivery and clinical information [25, 26]. Studies measuring the quality of end-of-life care in hospitals outside specialist palliative care ward by MRA already exist [18, 27–39]. They assessed clinical information like recognition of the dying phase, (life-sustaining) treatment decisions, the existence of Do-Not-Resuscitate/Do-Not-Intubate (DNR/DNI) orders and symptom management. Only one study of the above cited evaluated the documentation of conversations with IC [30]. The cited studies focused on patients suffering from specific diseases or belonging to certain age groups. Also, most existing studies used self-developed data extraction tools without clearly describing their development process or systematically linking them to evidence-based frameworks. This lack of standardised, guideline-based tools limits the assessment of care quality and the generalisability and comparability of results. To our knowledge, no validated tool exists that enables structured retrospective analysis of care in the dying phase across hospital settings based on national guideline recommendations, regardless of hospital department type or patient group. Therefore, the aim of the presented study is 1) the development and 2) application of an evidence-based data extraction tool for MRA of patients who deceased on general wards and intensive care units (ICU). For this purpose, we operationalized recommendations and QI of the German *Palliative Care* Guideline [9].

2 | Methods

As part of a multicenter retrospective cohort study [40], a data extraction tool was developed (phase 1) in three steps (version 1.1). The tool was then applied to extract data from MRs of $n = 400$ patients' deceased on $n = 10$ wards of two medical centres (phase 2). We analysed the information density and content validity of the extracted MR notes (see Figure 1). Based on the results, we finalised the data extraction tool (version 2.0).

2.1 | Phase 1 Development of Data Extraction Tool

2.1.1 | Step 1: Draft (Version 1.0)

The data extraction tool (version 1.0) was drafted within a pilot project that aimed to assess the care for dying patients at one medical centre [41]. The 2015 *German Palliative Care Guideline* is structured in eight chapters and contains key recommendations and 10 QIs [41, 42]. Two authors (AD, BS) operationalized 32 variables based on 3/11 QIs and recommendations regarding care in the dying phase of four guideline chapters: *Dying phase* (16/45), *Breathlessness* (1/21), *Cancer Pain* (3/43) and *Communication* (5/22). Variables were operationalized if they pertained

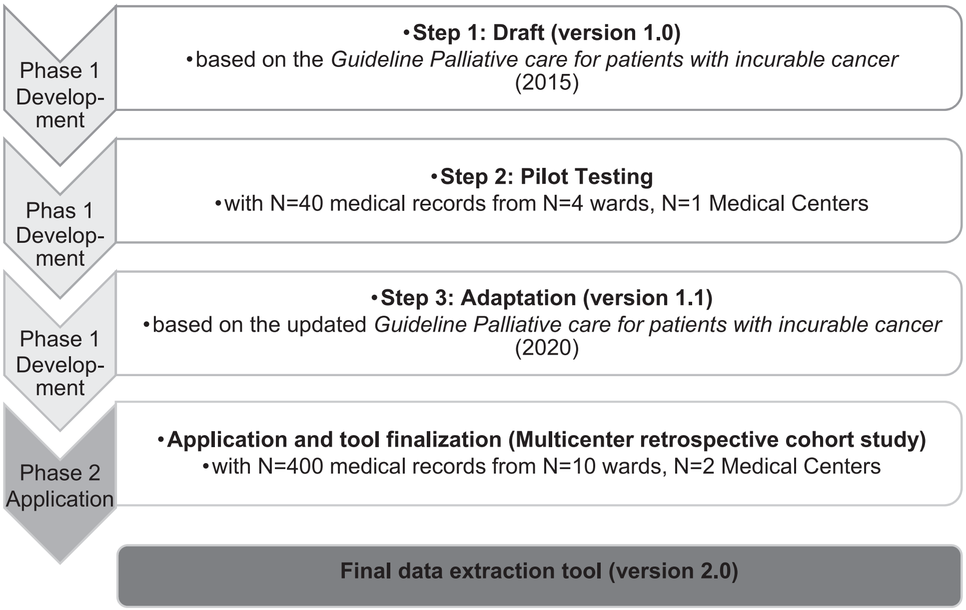

FIGURE 1 | Development and application of a data extraction tool for the retrospective medical record analysis of deceased patients.

TABLE 1 | Overview of operationalization sources (recommendations and quality indicators) and tool structure (domains, sub-domains and variables) from data extraction tool versions 1.0 and 1.1.

		Drafted tool (version 1.0) (2016) Based on the 2015 Guideline version, piloted in one medical centre	Adapted tool (version 1.1) (2021) Based on the 2020 Guideline version, adapted for two medical centres
German Palliative Care Guideline (2015/2021)	Recommendations	25/131	38/136
	Quality indicators	3/10	4/11
Tool structure	Domains	6	7
	Sub-domains	/	20
	Variables	32	55

to hospital care in the dying phase and the required information was potentially available in a patient's MR. The draft was organised into six domains (version 1.0) (see Table 1).

As an example of how guideline recommendations were translated into measurable variables, the recommendation stating that ‘tumour-specific medications and interventions should be discontinued in the dying phase’ was operationalized by identifying any documentation of such treatments—for example, chemotherapy, immunotherapy, or targeted therapy—within the last 72 h of life. Rather than a binary coding, we applied a four-category coding system to reflect the clinical course (1) not planned (2) stopped, (3) started, and (4) continued. This allowed for a more differentiated analysis of practice patterns in relation to guideline recommendations.

2.1.2 | Step 2 Pilot

The draft was piloted with $N = 40$ MRs of patients deceased on four different non- palliative care wards (internal ICU, nephrology, urology, visceral surgery). The last 10 patients deceased before 1 April 2016 were selected on each ward. Inclusion criteria were age ≥ 18 and death as reason for discharge from the ward. MRs were available electronically from one and printed from three wards. As the guideline defines the dying phase as the last three to 7 days of patients' life [9], two researchers (AD, BS) extracted notes from MRs related to patients' last three days of life into an Microsoft excel sheet. Some variables extend to the last 7 and 14 days, when recording information about chemotherapy or radiation. The draft appeared to provide a useful basis for a further development of the tool for application in a broader context.

2.1.3 | Step 3 Adaptation (Version 1.1)

For use in a multicenter retrospective cohort study for optimising hospital care in the dying phase [40], we used this first draft. In light of the 2020 updated version of the German Palliative Care Guideline, the draft was adapted and extended [9]. The updated version is structured in 16 chapters. Updated and new recommendations were operationalized and existing operationalizations from steps 1 and 2 were adapted through regular consensus discussions among five researchers

(SK, KK, NO) including one physician with palliative care expertise and clinical experience (AS) and one psycho-oncologist with clinical experience (AU) from two medical centres. Overall 55 variables were operationalized based on 4/11 QIs and recommendations regarding care in the dying phase of five guideline chapters: *Dying phase* (30/46), *Breathlessness* (1/18), *Cancer Pain* (3/43), *Communication* (5/19), and *Principles of Palliative Care* (1/10).

The adapted tool (version 1.1), presented as a Microsoft excel sheet, contains patients' demographic and clinical characteristics ($n = 11$ variables) and $n = 55$ variables on hospital care in the dying phase. The variables were structured into $n = 20$ sub-domains and $n = 7$ domains for improved manageability (see Table 1 and Appendix SA). Variables mostly refer to the last 3 days of patients' lives, with some extending to the last 7 and 14 days (see Appendix SA).

The adapted tool (version 1.1) was pre-tested using $n = 3$ MRs of the study sample. Therefore, seven researchers from both medical centres extracted notes from the same MRs in three consecutive rounds to test interrater-reliability. After discussing discrepancies, subsequent adjustments finally yielded consensus across all users of the tool (version 1.1).

2.2 | Phase 2 Application and Tool Finalisation (Multicenter Retrospective Cohort Study)

2.2.1 | Sample

The adapted tool (version 1.1) was applied to the MRs of $N = 400$ deceased patients from $N = 10$ wards ($n = 40$ MRs each) in two medical centres. We aimed to include wards without specialisation in palliative care that regularly care for dying patients, ensuring broad heterogeneity. Participating wards included six ICUs (cardiological, cardiothoracic surgical, internal, 2x surgical) and four general wards (gastroenterology, neurology, nephro-, endocrino- & rheumatology, radiotherapy). These wards differed in annual death numbers (range of means 2019–2022: 11-201) and bed capacity (12–30). $N = 6$ wards used electronical and $N = 4$ wards paper-based MRs. Patients who died between January 2018 and August 2021 were included by randomised sampling. Depending on the numbers of death, we either drew a random sample or carried out a full collection of $n = 40$ patients for each ward, with $n = 20$ patients who died before and after the outbreak of the COVID-19 pandemic respectively (reference date: 11.03.2020). Inclusion criteria were age ≥ 18 and death as the reason for end of care in this ward.

2.2.2 | Data Collection

On each ward, staff members of the participating hospital wards provided the printed and anonymized MRs to the research team. Six researchers transferred notes regarding the variables from the MRs into the data extraction tool from September 2021 until December 2022. During this time, four different procedures were applied to achieve a common understanding of the variables and to reduce extraction errors:

1. Researchers extracted data from a randomly selected 20% of MRs [43, 44], either jointly or individually and comparing results afterwards.
2. As recommended [42], a detailed manual for data extraction and a medication list were developed and continuously updated and used.
3. Regular cross-site meetings were scheduled to address questions and uncertainties during the extraction process.
4. Joint MR extraction and consultation with specialist palliative care expertise occurred as needed, for example, to answer questions on medication [43].

2.2.3 | Data Analysis

To assess the applicability of the adapted tool (version 1.1), we analysed the generated data on domain and sub-domain level. We examined information density quantitatively and content validity qualitatively [44]. Both, information density and content validity, indicated which guideline-based variables could realistically be assessed using MR documentation. For information density, we calculated the number and percentage of MRs where we found notes for all variables, at least for one variable (party) or no variable in the sub-domain. Content validity was assessed through a structured, iterative consensus process. First, the operationalized guideline recommendations were independently reviewed by a multidisciplinary team consisting of three scientists experienced in palliative care research (KK, SM, SK) and one palliative care physician (AS). Each team member assessed whether the operationalized variables clearly and accurately reflected the specific guideline recommendations. The team then met repeatedly to discuss discrepancies in their assessments of variables' alignment with guideline recommendations until consensus was reached on the inclusion, adjustment or removal of variables. Variables were retained only if the team could agree on a clear, unambiguous link to the guideline recommendations. Data processing and analysis was performed using RStudio 4.12.

3 | Results

We developed and applied a data extraction tool in two phases: (1) by operationalizing recommendations regarding care in the dying phase of the German *National Palliative Care Guideline* into variables and (2) extracting data from MRs of $n = 400$ deceased patients of 10 non-palliative wards at two medical centres. Data from MRs could be extracted for all seven domains of the tool (version 1.1). However, information density (see Table 2) and content validity (see Table 3) of generated data varied considerably within the domains.

The content of the extracted notes showed that 37 out of 55 variables (67%) represented the guideline recommendation. Due to low or unclear documentation, 16 of 55 initially operationalized variables (32%) were removed. We added two variables inductively during the extraction process, as notes provided more information than expected. Concrete examples of variables and reasons for their removal are listed below at domain level. For a summary of all changes to the adapted tool please refer to Table 3. The final data extraction tool (version 2.0) consists of $n = 6$ domains, $n = 18$ sub-domains and $n = 39$ variables (see Table 3 for the changes, the (number of) variables and sub-domains. Appendix SA shows the final tool).

TABLE 2 | Information density on (sub-)domain-level for version 1.1 ($N = 400$ MRs, $N = 10$ wards, $N = 2$ medical centres).

Information density	Number of variables	Notes found in MRs		
		Yes[a] ***N* (%)**	**Partly**[b] ***N* (%)**	**No** ***N* (%)**
Domain 1: Dying process and death		380 (95.0)		20 (5.0)
1.1 Nursing notes	4	20 (5.0)	356 (89.0)	24 (6.0)
2.2 Physicians' notes	4	48 (12.0)	336 (84.0)	16 (4.0)
Domain 2: Medication and interventions		323 (80.7)		
2.1 Monitoring and life-sustaining Interventions	8	/	397 (99.2)	3 (0.8)[c]
2.2 Medication for symptom control	2	357 (89.2)	9 (2.3)	34 (8.5)
2.3 Sedation	2	2 (0.5)	123 (30.7)	275 (68.8)
2.4 Artificial nutrition & hydration	3	62 (15.5)	304 (76.0)	34 (8.5)[c]
Domain 3: Information and involvement of patients and informal caregivers		155 (38.8)		
3.1 Patients' information about impending death	3	5 (1.3)	46 (11.5)	349 (7.2)
3.2 Informal caregivers' information about patients' impending death	3	56 (14)	241 (60.2)	103 (5.8)
3.3 Involvement and support of informal caregivers	2	15 (3.8)	73 (18.2)	312 (8.0)
3.4 Involvement and consideration of patients' wishes	3	1 (0.2)	99 (24.8)	300 (5.0)
3.5 Shared decision making	3	47 (11.7)	238 (9.5)	115 (8.8)
3.6 Informal caregivers' presence at patients' death	2	10 (2.5)	180 (5.0)	210 (2.5)
3.7 Information of informal caregivers about patients' death (deleted)	2	89 (22.2)	48 (12.0)	263 (5.8)
3.8 Steps after patients' decease (version 1.1) *Indications after death (version 2.0)*	2	26 (6.5)	68 (17)	306 (76.5)
Domain 4: Symptom assessment		105 (26.3)		
Assessment of pain and other symptoms	3	51 (12.7)	94 (23.5)	255 (63.8)
Domain 5: Involvement of specialised palliative care		78 (19.5)		
Hospital palliative care support team	1	78 (19.5)	0	322 (80.5)
Domain 6: Goals-of-care		706 (19.0)		
6.1 Change of goals-of-care	7	27 (6.8)	67 (16.7)	306 (6.5)
6.2 Holistic approach (deleted)	1	58 (14.5)	0	342 (5.5)
Domain 7: Continuity of care (deleted)				
7.1 Number of nurses	1	373 (3.2)	0	27 (6.8)
7.2 Number of physicians	1	376 (94.0)	0	24 (6.0)

Note: Percentage and number of MRs for which notes were found for the variables on (sub-)domain level. Domains are arranged in descending order to their information density and the average percentage of MRs with notes for at least one variable is displayed. On sub-domain level the table shows the number and percentage of MRs for which notes for all variables was found (yes), for at least one variable was (partly) was found and for which no notes were found (no).

[a] Information was found for all variables in the sub-domain.

[b] Information found for at least one variable in the sub-domain.

[c] No notes found that interventions were conducted.

3.1 | Domain 1: Dying Process and Death

For this domain, highest information density was analysed (95% of $n = 400$ MRs). The domain consists of two sub-domains (*1.1 Nursing notes* and *1.2 Physicians' notes*). We operationalized four variables respectively for each sub-domain and made following changes:

- Treatment decisions and interventions in the dying phase should be documented and continually re-assessed (Expert consensus (EC) 19.6), we collected this information within the variable 're-evaluation of treatment measures'. Notes showed that especially in ICUs, re-evaluation is often not possible as death occurs very soon after change of interventions or goals-of-care. Therefore, notes were moved to the **domain 6 Goals-of-care** and the variable was deleted from both sub-domains.
- According to the guideline recommendation containing criteria to assess whether the dying phase has begun, for example, changes in breathing, skin, emotions and consciousness (EC 19.1), we collected this information within the variable 'dying process'. Notes in both sub-domains reflect content of guideline recommendation.

TABLE 3 | Changes to the adapted tool after the application phase (number of variables and sub-domains).

	Number of variables		Types and reasons for change					
			Variable deleted					Variable added
(Sub-)Domain	Version 1.1	Version 2.0	Lack of documentation	Inadequate operationalization	Clinically not relevant	Notes moved to another domain	Variable aggregated within	Operationalization possible
Domain 1: Dying process and death								
1.1 Nursing notes	4	1			1	2		
1.2 Physicians' notes	4	1			1	2		
Domain 2: Medication and interventions								
2.1 Monitoring and life-sustaining interventions	8	8						
2.2 Medication for symptom control	2	2						
2.3 Sedation	2	2						
2.4 Artificial nutrition and hydration	3	2		1				
Domain 3: Information and involvement of patients and informal caregivers								
3.1 Patients' information about impending death	3	1	2					
3.2 Informal caregivers' information about patients' impending death	3	2	1					
3.3 Involvement and support of informal caregivers	2	2						
3.4 Involvement and consideration of patients' wishes	3	1		1		1		
3.5 Shared decision making	2	3		1				

(Continues)

TABLE 3 | (Continued)

	Number of variables		Types and reasons for change					
			Variable deleted					Variable added
(Sub-)Domain	Version 1.1	Version 2.0	Lack of documentation	Inadequate operationalization	Clinically not relevant	Notes moved to another domain	Variable aggregated within	Operationalization possible
3.6 Informal caregivers' presence at patients' death	3	1						
3.7 Information of informal caregivers about patients' death (deleted)	2	0		1		1		
3.8 Steps after patients' decease (version 1.1) Indications after death (version 2.0)	2	1		1				
Domain 4: Symptom assessment								
Assessment of pain and other symptoms	3	3						
Domain 5: Involvement of specialised palliative care								
Hospital palliative care support team	1	1						
Domain 6: Goals-of-care								
6.1 Change of goals-of-care	6	7		1				
6.2 Holistic approach (deleted)	1	0		1				
Domain 7: Continuity of care (deleted)								
7.1 Number of nurses	1	0		1				
7.2 Number of physicians	1	0		1				
Total Number	**55**	**39**	**−3**	**−6**	**−2**	**−6**	**−1**	**+2**

- Regarding the variable ‘moment of patient's death’, notes contained no further information besides the time of patient's death. As this date is already recorded in the demographic data, the variable is deleted from both sub-domains.
- Regarding notes in the variable ‘information after patient's death’, notes mostly contained ICs' notification of patients' death. Death notifications were also extracted in the variables in sub-domain *3.8 Steps after patients' decease (Re-named Indications after death)*. Notes were moved to *3.8* and the variable was deleted.

3.2 | Domain 2: Medication and Interventions

Notes on this domain were extracted from 80.7% of MRs. The domain consists of four sub-domains and 15 variables. After assessing notes on this domain, following changes were made on variable-level:

- *Monitoring and life-sustaining interventions (99.2%):* according to guideline recommendation stating that life sustaining interventions should be stopped in the dying phase (EC 19.31–19.36), we extracted notes on continuation/stopping of vital signs and blood glucose monitoring, oxygen therapy, mechanical ventilation, dialysis/hemofiltration, tumour-specific therapy, artificial nutrition and hydration and antibiotic therapy and deactivation of an implanted cardioverter-defibrillator within eight variables. All variables reflect content of guideline recommendation.
- *Medication for symptom control (91.5%):* drug substances from the groups of opioids, antipsychotics, benzodiazepines and anticholinergics should be started or continued (EC 19.31), therefore we extracted this within two variables. Both of them reflected guideline recommendation.
- *Sedation (31.2%):* according to guideline recommendation, palliative sedation should be carried out by competent physicians and nurses experienced in palliative care (EC 19.37). We extracted this information in two variables, assessing whether palliative sedation or deep continuous sedation was carried out.
- *Artificial nutrition and hydration (86.5%):* according to guideline recommendation EC 19.38, patients' need for artificial nutrition and hydration should be assessed on an individual basis. We extracted this information within the variable ‘needs assessment for nutrition and hydration'. The content of notes showed that this information was not sufficiently documented. Therefore, this variable was deleted, two variables remain.

3.3 | Domain 3: Information and Involvement of Patients and Informal Caregivers

Notes were extracted from 38.8% of MRs. The domain contains of eight sub-domains. Following changes on variable-level were made per sub-domain:

- *Patients' information about impending death (12.8%) and 3.2. ICs’ information about patients' impending death (74.2%):* as the dying patient and their IC should be adequately informed about the impending death and expected changes in the dying phase (EC 19.7), we operationalized three variables on patients and ICs being informed (1) about the impending death, (2) about expected changes in the dying phase, and (3) their reactions on the impending death. Notes on (2) und (3) were lacking of documentation, therefore they were deleted from the tool; one variable remains, respectively.
- *Involvement and support of informal caregivers (22%):* as ICs should receive offers of support (EC19.8), we operationalized two variables assessing their wishes/resources and support offers. Both of them reflected guideline recommendation.
- *Involvement and consideration of patients' wishes (25%):* as treatment decisions and measures in the dying phase shall be in accordance with the needs of the dying patients and ICs (EC 19.5), we operationalized this recommendation in three variables: (1) patients' verbalised wishes, (2) patients' non-verbalised wishes, feelings and needs through various indicators like facial expressions, gestures, and body language (EC 19.9), (3) involvement of wishes in further treatment. Notes in (2) lacked selectivity compared to notes in **Symptom assessment (domain 4)** and were moved there. Extracted notes in (3) did not adequately reflect clinical practice due to inadequate operationalizability of the guideline recommendation. Consequently, both variables were deleted from the tool.
- *Shared decision-making (71.2%):* useful notes on patients' documented wishes, in documents as living will or communicated by ICs, were found in the MRs and operationalized in an additional variable as it reflects guideline recommendations (EC 4.7, 19.5).
- *Presence of informal caregivers at patients' death (47.5%):* Two variables assessed whether (1) ICs were present when the patient died and if they were not present, were able to say goodbye (EC 19.10). Both variables reflect guideline recommendation.
- *Information of ICs about patient's death (32.4%):* ICs should be informed of patients' death in a sensitive and timely manner (EC 19.39). Two variables assessed (1) if there were any notes about the person that informed the ICs about the patient's death and (2) the circumstances of this information. The notes on both variables showed that only physicians informed ICs about patients' death in person. As these variables did therefore not add any further information, the sub-domain was deleted from the tool.
- *Steps after patient's death (23.5%):* ICs shall be allowed to say goodbye in accordance with their needs and resources, cultural practices and religious duties (EC 19.40). Therefore, we created two variables to assess (1) whether there are any notes that ICs were informed about the next steps after patient's death and (2) if they were able to say goodbye in accordance to their needs and resources. Notes from both variables showed that they were not selectively from each other. Therefore, variables were merged into one and the sub-domain was renamed into *indications after death*. As described above, notes from Domain 1 (variable ‘information after patient's death’) were added to the sub-domain.

3.4 | Domain 4: Symptom Assessment

Notes were extracted from 26.3% of MRs. The guideline states that assessment of pain intensity and other symptoms should be carried out by the health care team for example, by use of one-dimensional pain scales (EC 9.1–9.3). We operationalized three variables assessing if a symptom assessment was carried out, which symptoms were assessed and if an assessment tool was used. Content of extracted notes reflects guideline recommendations. As mentioned above, notes from the sub-domain *3.4 Involvement and consideration of patients' wishes in the dying phase* were moved to this domain.

3.5 | Domain 5: Specialist Palliative Care

As patients from non-palliative care wards can receive specialist palliative care for example, through a hospital palliative care support team, we operationalized a variable assessing how many times the hospital palliative care support team was involved in patient treatment (QI 11). Notes were extracted from 19.5% of MRs, indicating low information density in comparison to other domains. However, notes reflected the content of guideline recommendation; therefore, no changes were made.

3.6 | Domain 6: Goals-of-Care

Lowest information density was analysed for domain 6 (19% of MRs). The domain contains of two sub-domains, following changes were made:

- *Change of goals-of-care (24.5%):* notes on time of changes of goals-of-care and information weather escalation of therapy, life-sustaining therapy or symptom-oriented therapy has been determined (EC 6.15–6.19) were extracted for six variables. The time of DNR/DNI orders were also found in MRs and operationalized in an additional variable as it reflects guideline recommendations (EC 4.7).
- *Holistic approach (14.5%):* the recommendations states that all dimensions of quality of life should be considered (EC 19.4, 19.30). Therefore, the operationalized variable extracted notes that other dimensions (social, psychological, spiritual) beyond the physical one were considered in care decisions and interventions. Notes did not adequately reflect the guideline recommendation. Consequently, the sub-domain and its variable were deleted from the tool.

3.7 | Domain 7: Continuity of Care (Deleted)

According to the guideline, dying patients should be supported with continuity of care (EC 19.16, 19.27). Therefore, we extracted the number of physicians and nursing staff that were involved in the patients' care were extracted from 93.6% of MRs. However, the notes lacked information regarding the continuity of staff, making it unclear whether the same HCP consistently participated in care. The domain was deleted from the tool as notes did not adequately reflect clinical practice due to inadequate operationalizability of the guideline recommendation.

4 | Discussion

We developed a data extraction tool to assess hospital care in the dying phase from MRs of deceased patients using evidence-based variables derived from the *German National Palliative Care Guideline* [9]. The tool consists of a comprehensive set of 39 variables structured into $n = 18$ sub-domains and $n = 6$ domains, completed by $n = 11$ variables regarding clinical and demographic characteristics. The tool proved to be feasible to extract notes for all relevant domains of care in the dying phase. However, information density and content validity varied considerably within the domains.

4.1 | Reflection of Guideline Recommendations in Medical Records

The tool enables to analyse if QIs and recommendations on care in the dying phase are represented in MR documentation. However, analysis of information density showed that MRs did not consistently reflect all relevant guideline recommendations. We were able to extract more notes for objective and quantifiable variables (e.g., medication and interventions) rather than subjective variables (e.g., related to information, care of and communication with patients and their ICs). Domains such as 'symptom assessment' and 'goals-of-care' had significantly lower documentation density than domains such as 'dying process and death'. One possible reason for this is that the documentation of the process and stage of dying includes formal and routine documentation requirements, such as recording the time of death. In contrast, symptom assessments and changes in goals-of-care are less formally embedded in documentation processes—particularly outside of palliative care settings. Moreover, these aspects require communication and reflection processes that may not be consistently undertaken or documented, particularly in acute care settings with high workload and limited training in end-of-life care [6]. Our data thereby supports previous study results showing that objective data, such as vital sign monitoring, is more reliably documented than subjective free-text data [45], suggesting potential gaps in medical record documentation and care delivery.

One of the foremost challenges in documentation of the patients last days of life lies in the different perception of high-quality end-of-life-care among health care professionals, especially in the area of communication and information [45]. Studies showed that care documentation in acute settings are incomplete and lacking in continuity with little emphasis on psychosocial aspects of care. This variation impacts the way information is documented by different healthcare professionals in MRs, potentially influencing the reliability of data obtained from MRs [26]. Our findings raise the question whether healthcare professionals prioritise documenting aspects such as medication and interventions over conversations with patients and their IC. The lack of a standardised documentation standard limits the assessment of care by MRs [42]. Implementation of documentation standards could reduce documentation of avoidable interventions in MRs and focus on the aspects emphasised in the guideline recommendations [45].

Furthermore, the operationalization of some variables proved challenging, for example, holistic approach in patient care, highlighting the difficulty in operationalization of qualitative outcomes that allow for more interpretation [46]. This emphasises the need for more operationalization of subjective aspects during MRA [46]. A manual and regular meeting between data extractors enables subjective aspects to be assessed more reliably. Therefore, variables have been selected for the tool that can be adequately mapped to match the documentation as well as possible. The decision to operationalise certain recommendations in variables rather than others stem from the need to prioritise aspects of care deemed more measurable within MRs.

4.2 | Use of Medical Records to Assess Hospital Care in the Dying Phase

The data within MRs were not primarily documented for research purposes and, as a result, may lack both quality and quantity for scientific evaluation/data analysis [47]. It is crucial for data sources intended for research purposes to be both reproducible and valid. This highlights a weakness in the reliability of MRA as a data source [47]. The quality of the MRs can be influenced by a number of factors, for example, paper-based versus electronic record [48]. On the other hand, unlike methods such as participant observation, where the data collection may influence outcomes, medical record data remains unaffected by the data collection process [46, 49, 50]. MRA is limited to the information documented in MRs and may not offer a comprehensive view of the care delivered to patients [46]. It is important to note that MRA assesses the documentation of care in the dying phase rather than the actual provision of care. Relying solely on record analysis may not present a complete picture, underscoring the importance of additional assessment instruments [51]. Nevertheless, the utilisation of MRs in research can be valuable as they reflect real-world healthcare practices [46]. MRs have a significant impact on the quality of care provided. Accurate and detailed documentation ensures that healthcare providers have access to essential information, which can lead to more effective decision-making and improved patient outcomes [45]. Additionally, thorough documentation plays a crucial role in care coordination among different providers, enhancing communication and information flows in the team and continuity of care for patients. As mentioned above, the implementation of documentation standards could foster quality of MR documentation. Comprehensive documentation also serves as a means of accountability, enabling healthcare organisations to demonstrate the quality of care they provide and to identify areas for improvement [39, 52].

The implementation of the tool in clinical practice offers opportunities and challenges. A potential facilitator is the tools' development based on a national guideline, that may foster acceptance among healthcare professionals and its applicability across different wards. However, potential barriers include limited time and staff resources and variation in documentation cultures across wards and professions. For successful implementation, institutional support, staff training, and integration into existing documentation workflows are essential. Piloting and adapting the tool to the local context could help to further tailor it to the needs of the setting and promote its sustainable use [53].

4.3 | Strengths and Limitations

To our knowledge, we developed the first standardised data extraction tool built on evidence-based guideline recommendations and QIs on care in the dying phase instead of self-selected outcomes [9]. This approach thereby facilitates a holistic overview of hospital care in the dying phase, including not only interventions and medication but also communication and involvement of patients and their ICs. As we used data from ten different non-palliative wards of two medical centres to develop the tool, we enhance the generalisability of results. The tool is applicable for both general wards and intensive care units, irrespective of the hospital department or the primary disease of the deceased patient, ensuring data comparability across wards.

Limitations relate primarily to the method of MR documentation, as it only provides indications on care provision, as it is not always known what might have happened beyond the documentation. The information gathered from patient record analysis serves to identify areas of care that either meet established standards or require improvement, including details of medication, interventions, and communication. Potential for bias in the interpretation of the free-text data as well as incomplete or inaccurate documentation exists, influencing validity and reliability of results.

5 | Conclusion

The results of our study highlight specific documentation gaps in care in the dying phase. To address these gaps, the use of the developed tool may provide useful insights on how to support quality improvement efforts, including structured documentation templates and targeted staff training. The developed tool allows for a structured retrospective analysis of the routine documentation in MRs and the extent to which recommendations and QIs regarding care in the dying phase are reflected. To gain a full understanding of the care provided to patients in this phase, future research could complement MRA with qualitative methods, such as interviews with IC and healthcare professionals [20]. Such a *mixed-methods* approach could contribute to knowledge about barriers to high-quality care not captured in MRs and provide insights into how to improve both documentation and quality of care in the dying phase.

Author Contributions

R.V. is Principal Investigator and responsible for the study design and dissemination. K.K. is responsible for the study design, project management, recruitment, data collection, data analysis and dissemination. K.O., A.U. and H.O. are responsible for the study design, recruitment of wards, data analysis and dissemination. S.K., S.M., N.O., A.U., A.D., B.S., and A.S. are responsible for development of the data extraction tool. S.K., S.M. and N.O. are responsible for data collection, data analysis and dissemination. All authors read and approved the final manuscript.

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Ethics Statement

Ethical approval was obtained from the ethics committee of the Medical Faculty of the University of Cologne on 19.04.2021 (20-1727) and by the ethics committee of the General Medical Chamber, Hamburg on 03.08.2021 (2021-200061-BO-bet). We collected pseudonymized patient data; therefore, no written or verbal informed consent was needed.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data available on request due to privacy/ethical restrictions.

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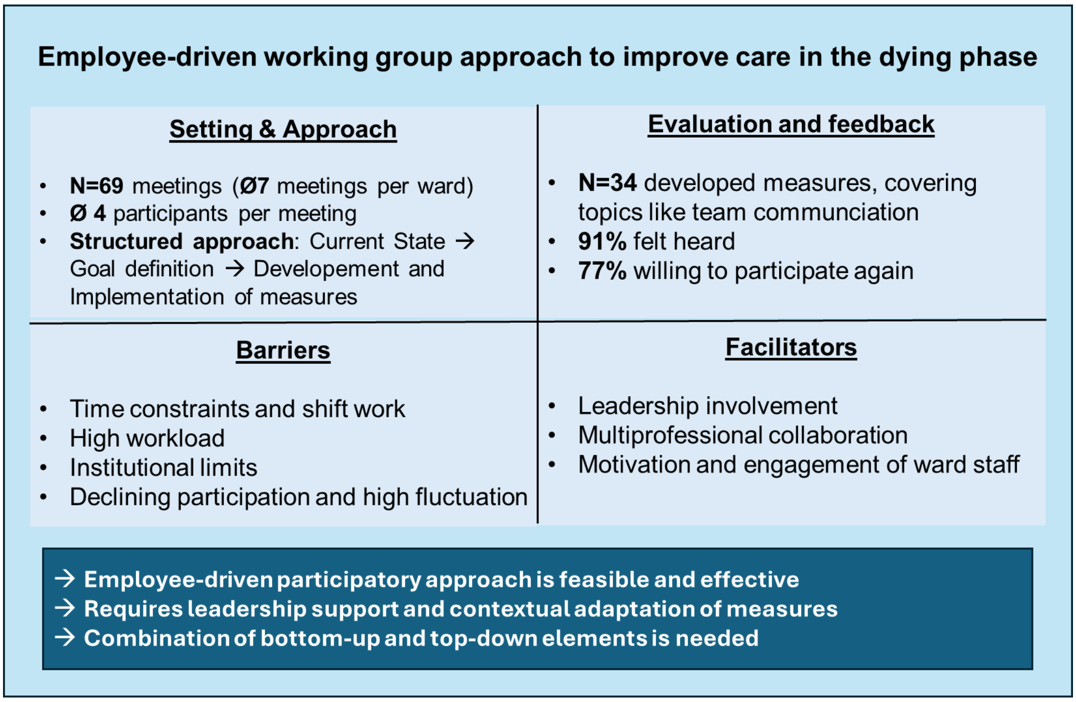
Supporting Information

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

3.3 Publication 3: Working Group Process

3.3.1 Summary

Figure 7 shows results from publication 3 (located in phase 2 of the *StiK-OV* study [9]), with detailed methods provided in section 2 and table 3. Publication 3 served as a translational step by translating previous findings into practice. The infographic summarises the results of the description and formative evaluation of an ED approach to improve care in the dying phase on non-specialist PCWs. Across participating wards (*N*=10), *N*=69 WG meetings were held in which HCPs jointly co-developed *N*=34 tailored measures. Measure topics included improving team communication (e.g. multidisciplinary meetings), strengthening IC support (e.g. flyers for the bereaved), involving supporting structures (e.g. palliative care hospital support team and chaplains), direct patient care (e.g. training in aroma therapy) and creating a more adequate environment for dying patients (e.g. redesign of a farewell room). While most participants reported satisfaction with the process and expressed willingness to engage again in the WG online survey, participation decreased over time due to limited time resources, staff turnover and organisational constraints. Leadership involvement, interprofessional exchange in WGs and adapting measures to ward routines proved essential to maintain participation. The findings illustrated that ED change is feasible and will be accepted by staff in acute care if properly implemented. The description of this WG approach with its' procedure, barriers and facilitators may serve as a practical orientation for other institutions to guide similar initiatives [76].



Employee-driven working group approach to improve care in the dying phase

Setting & Approach

- **N=69** meetings (**Ø7** meetings per ward)
- **Ø 4** participants per meeting
- **Structured approach**: Current State → Goal definition → Developement and Implementation of measures

Evaluation and feedback

- **N=34** developed measures, covering topics like team communciation
- **91%** felt heard
- **77%** willing to participate again

Barriers

- Time constraints and shift work
- High workload
- Institutional limits
- Declining participation and high fluctuation

Facilitators

- Leadership involvement
- Multiprofessional collaboration
- Motivation and engagement of ward staff

→ Employee-driven participatory approach is feasible and effective
→ Requires leadership support and contextual adaptation of measures
→ Combination of bottom-up and top-down elements is needed

Figure 7: Main findings of working group process (publication 3)

3.3.2 Manuscript

This is a post print manuscript of publication 3, accepted on 05.06.2025 in *Palliative & Supportive Care* (Impact Factor 2024: 2,1)

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Original Article

Formative evaluation of an employee-driven approach to improve care in the dying phase in hospitals

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Abstract

Objectives. The hospital setting is often perceived as slow to change. While employee-driven approaches offer a promising alternative to traditional top-down methods, guidance is limited. This study provides a description and formative evaluation of an employee-driven working group (WG) approach to tailor ward-specific measures to improve care in the dying phase. The aim is to evaluate the WG process and offer practical insights for transferability to other hospitals.

Methods. Formative mixed-methods evaluation of a WG process to tailor ward-specific evidence-informed measures on 10 wards outside specialized palliative care at 2 German medical centers. To analyze factors relevant for the WG process, the *Consolidated Framework for Implementation Research 2.0* was applied. Data included baseline evaluation (medical record analysis, staff survey and focus groups, informal caregiver interviews), WG protocols, and an online survey with WG participants.

Results. Multiprofessional WGs were established on all hospital wards, with an average of 7 meetings per ward within 1 year and 4 participants per meeting. Adapting the process to participants' wishes and needs were crucial, particularly regarding the desired degree of external input. We identified 4 barriers (e.g. declining participation, institutional limits) and 7 facilitators (e.g. involvement of staff in leading positions, multiprofessional composition). The WGs tailored 34 measures, e.g. team meetings to improve communication within the team. Participants' views were generally positive: 91% felt able to share their thoughts, 66% were satisfied with the outcome, and 77% would participate again.

Significance of results. The employee-driven approach was feasible and useful for tailoring ward-specific measures. However, integrating top-down elements proved to be beneficial. The identified barriers and facilitators provide insights for transferring an employee-driven approach to other hospitals to improve care in the dying phase outside specialized palliative care settings.

Clinical trial registration. The study was registered in the German Clinical Trials Register (DRKS00025405).

Introduction

Driving change in the hospital setting is challenging. Literature on implementing innovations highlights a change-resistant environment with barriers like lack of time and staff resources, complex care processes or entrenched hierarchies (Cadeddu et al. 2023). Moreover, innovations often follow a top-down approach, facing mistrust and resistance (Burcharth et al. 2014; Cadeddu et al. 2023). While these challenges exist in curative settings, they are as or even more present in the context of care in the dying phase, particularly in hospital wards with a predominantly curative focus (Docherty et al. 2008; Mayland et al. 2017; Robinson et al. 2014). Patients and informal caregivers frequently reported inadequate quality of care in the dying phase in these contexts (Docherty et al. 2008; Mayland et al. 2017; Robinson et al. 2014). In Europe, approximately 50% of people die in hospitals outside specialized palliative care, leading to initiatives like the *Liverpool Care Pathway* (Ellershaw and Wilkinson 2011), the *Best Care of Dying* recommendations (Ellershaw and Lakhani 2013; Montag et al. 2014) or the *German Guideline Palliative Care for Patients with Incurable Cancer* (German Guideline Programme in Oncology 2020). However, these rather complex and inflexible initiatives faced implementation challenges (Di Leo et al. 2015; Koffman et al. 2019).

Employee-driven (ED) approaches offer a promising alternative (Cadeddu et al. 2023). They often involve small, tailored interventions that enable short-term testing of new ideas and flexible adaption (Cadeddu et al. 2023). Challenges include the development of new structures and the question of how to organize and enable ED innovations (Cadeddu et al. 2023). Despite their potential, research that provides insights and guidance on practice and creating conditions of ED approaches is limited (Cadeddu et al. 2023).

Our project "Dying in hospital in Germany – Optimising care in the dying phase" adopts an ED approach using working groups (WGs) to tailor ward-specific evidence-informed measures. The objective is to improve the quality of care for patients in the dying phase on wards that are not specialized in palliative care (Kremeike et al. 2022). The aim of this study is to provide both a comprehensive description and formative evaluation of the ED WG approach to tailor ward-specific measures. We applied the *Consolidated Framework for Implementation Research 2.0* (*CFIR 2.0*) (Damschroder et al. 2022) to understand how such an approach can be structured and what conditions facilitate or hinder its implementation. By detailing the process, the research team aims to generate insights that support replication and adaption to other hospital settings.

Methods

Study design

This mixed-methods formative evaluation was carried out as part of a single-arm baseline-post study including 3 phases (Kremeike et al. 2022). The formative evaluation described below focuses on the tailoring of ward-specific measures in WGs within the second study phase (see Fig. 1).

Setting and recruitment

In one medical center, invitations were sent to department directors of 14 wards, of which 8 declined and 1 did not respond. Reasons for declining participation varied: 3 wards cited low mortality rates, while 4 wards pointed out to specific challenges and burdens posed by their patient populations, such as dying infants, that do not align with overall study aims. One ward declined due to their involvement in other research projects. In the other medical center, the research team agreed on selecting 2 intensive care and 3 peripheral wards, and contacted wards based on high mortality rates. All wards responded and agreed to participate, requiring the research team to make a final selection of 5 wards. Finally, 6 ICUs and 4 GWs located at 2 German medical centers participated in our study. All wards are not specialized in palliative care but regularly care for dying patients and cover a wide range of disciplines.

The WG process

We planned to start the WG process on all wards in February 2022 with an introductory meeting, followed by periodic hour-long meetings every 4 to 6 weeks until end of 2022. The WGs should consist of a minimum of 3 to 5 ward staff members of different professions, supported by the research team and a palliative care-trained nurse or physician. The research team was responsible for organizing the meetings (e.g. sending meeting invitations and protocols) and supporting tasks, such as preparing drafts and providing relevant literature. The nurse or physician with training in specialized palliative care from the respective hospital attended the meetings. The purpose of their attendance was to provide expertise, answer questions related to palliative care and ensure the clinical appropriateness of the developed measures. Recruitment was coordinated through ward contacts, typically senior physicians for medical staff and nurse team leaders for nurses, therapists, and counsellors.

Data collection

We applied the *CFIR 2.0* to collect relevant factors for the evaluation of the WG process to ensure that all relevant factors that could influence the WG process are comprehensively addressed (Damschroder et al. 2022). It includes 5 major domains with respective constructs: outer setting, inner setting, characteristics of individuals involved, implementation process, and innovation. We adapted the constructs to our evaluation aims and data, e.g. by removing, redefining and/or adding new constructs. Figure 2 shows the operationalization of the major domains with data collection sources for evaluation and adapted constructs can be found in Supplemental material 1. We used data from the baseline evaluation and the WG protocols to contextualize how the development of measures is affected by the ward (= inner and outer setting). Collecting contextual data is crucial in implementation studies, as the effectiveness of interventions and their ability to reach all relevant target groups is critically influenced by the context in which they are implemented (Pfadenhauer et al. 2017). WG protocols and the concluding online WG survey were used to evaluate the implementation of the WG process (= innovation and individuals). For each ward, we created an Excel sheet containing the relevant data for the *CFIR 2.0* domains and constructs.

Baseline evaluation

Between September 2021 and April 2022, medical record analysis, focus groups, and a staff survey as well as interviews with informal caregivers were conducted on the respective wards. Details on methods used and results are published elsewhere (Kremeike et al. 2022; Meesters et al. 2025).

WG protocols

One research team member recorded details on each WG meeting, using a structured protocol. Therein, we documented meeting duration, number of participants, field notes on the procedure (e.g. discussions, selection of measures) and atmosphere. The research

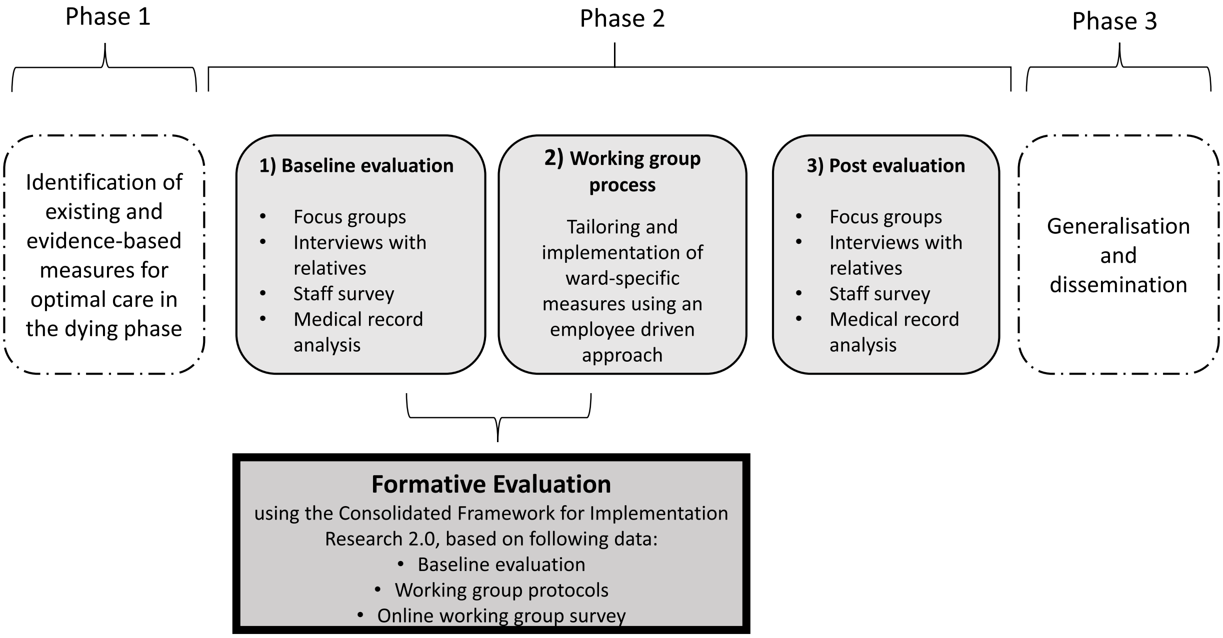

Figure 1. Project phases of the study *Dying in hospital in Germany– Optimising care in the dying phase* (Kremeike et al. 2022)

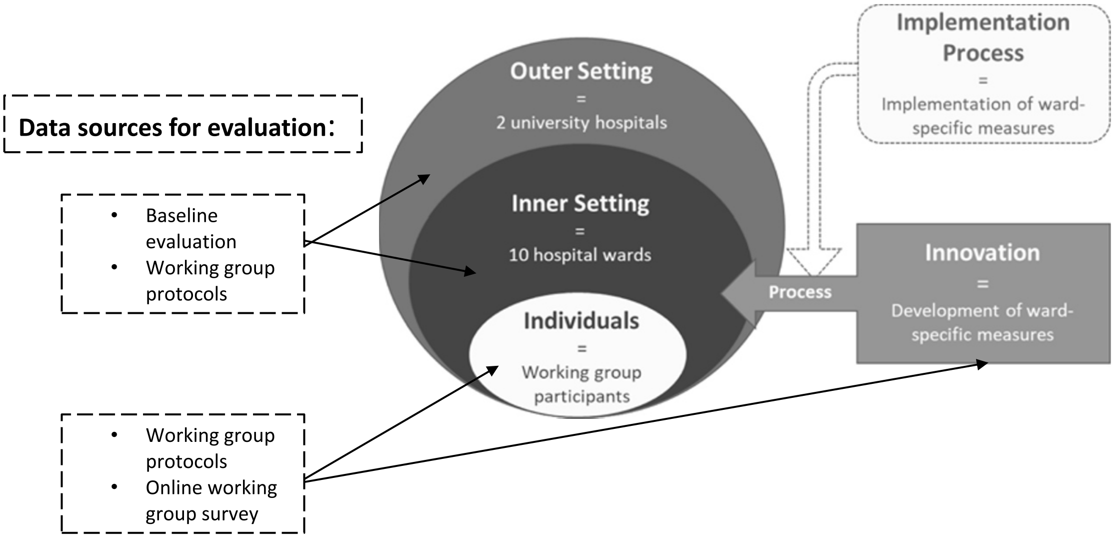

Figure 2. Operationalization of the major domains of the CFIR 2.0. Adapted from Damschroder et al. (2022). The updated consolidated framework for implementation research based on user feedback. Implementation Science, 17, 75. https://doi.Org/10.1186/s13012-022-01245-0. Image adapted by the center for implementation, © 2022. Version: V2024.01. https://thecenterforimplementation.com/toolbox/cfir.

team debriefed each meeting to ensure the inclusion of all impressions in the protocol.

Online WG survey and qualitative feedback

To gather feedback on the WG process from the participants' perspective, the research team conducted an online WG survey after the final meeting for each WG. The self-developed questionnaire consisted of 1 question regarding the profession, 16 question on satisfaction with the WG process (5-point-Likert scale) and 3 open-ended questions regarding motivation, insights and suggestions for improvement of the WG process. The survey link (LimeSurvey) was emailed to all WG participants (regardless of frequency of participations in meetings). The survey was open from 13 to 31 January 2023, with a reminder sent 2 weeks after the initial invitation. We also collected qualitative feedback in the final WG meeting by asking WG participants to give feedback regarding the following questions:

- Which things have worked well?
- What have we achieved/What have we learnt?
- What did not go well? (What was missing?)
- What would you have wished for/what do you still need?

Data analysis

Qualitative data (staff focus groups, informal caregiver interviews, WG protocols) were analyzed by qualitative content analysis (Kuckartz 2012). We used a deductive-directed approach based on

CFIR 2.0. WG protocols, the interviews, and focus group transcripts were uploaded into *MAXQDA 2022* and 4 researchers (S.M., S.K., V.M., C.H.) assigned relevant passages to the respective constructs of the adapted *CFIR 2.0*. The assignment was discussed constantly to clarify ambiguities and to foster a common understanding of domains and categories across all researchers.

Quantitative data (retrospective medical record analysis, staff and online WG survey) was analyzed descriptively (frequencies, percentages) using *IBM SPSS Statistics 28* (IBM Corp 2021; Kremeike et al. 2022) and *R Studio*. To inform the *CFIR 2.0* constructs, we selected suitable items and variables from the staff survey and the retrospective medical record analysis. Four-point Likert scales from the staff and WG surveys were condensed to 2 points ('disagree', 'agree'), and 5-point scales were reduced to 3 points ('disagree', 'neutral', 'agree'). Percentages were calculated for each of the response categories. Missing values were excluded from the analysis.

Results

Firstly, we describe the context in which the WG process was implemented (outer and inner setting), based on baseline evaluation data ($n = 400$ medical records, $n = 201$ staff questionnaires, $n = 10$ staff focus groups, $n = 12$ interviews with informal caregivers) and $n = 79$ WG protocols. This is followed by the description of the WG process and its evaluation based on quantitative and qualitative feedback from the WG participants and WG protocols.

Description of the context

a. Outer setting: medical centers

The 10 participating wards are affiliated to 2 medical centers located in 2 large German cities, each city with over a million inhabitants. The medical centers comprise about 60 and 80 departments and institutes with 1500 and 1800 beds, respectively. The number of employees ranges between 11,000 and 14,900. Both hospitals offer a hospital palliative care support team alongside a palliative care ward. As the WGs began in February 2022, the process was impacted by staff shortages due to the COVID-19 pandemic and therefore increased workload and strain especially on ICUs. Additionally, one of the hospitals experienced a 11-week strike by nurses from April to July 2022.

b. Inner setting: hospital wards

The participating wards comprised 4 GWs (neurology; gastroenterology; internal medicine; radiotherapy) and 6 ICUs (internal [$n = 2$], surgical [$n = 2$], interdisciplinary [$n = 2$]). The mean number of deaths per year varied greatly, ranging from 11 to 200 (mean 2019–2022). To capture the inner setting, the authors assessed aspects related to communication and collaboration, on culture and resources already in place for the care of dying patients.

Communication and collaboration: The staff survey showed, that on 8 wards, the majority agreed that communication works well, while on 2 wards only 35.7% and 48.4% agreed, respectively (range 35.7–100%; mean 80.9%). Moreover, the staff only partly felt like being part of a multi-professional team (range 57.9–94.5%; mean 71.5%). On 4 wards, less than 90% of the staff agreed that there was a generally friendly climate (range 78.5–100%; mean 91.9%) and that team members treated each other respectfully (range 85.7–100%; mean 94.3%). The focus groups and WG protocols revealed that primarily nurses criticized an inadequate delivery of information and lack of exchange within the team. They wished for more inclusion in decision-making regarding changes of goal-of-care as they are closer to patients and their informal caregivers.

Culture: While staff on most wards reported that dying is accepted on their ward and that they are able to provide at least some dignity in dying, staff on 2 wards described a culture where dying is considered as a defeat. This culture impairs the care for dying patients from their perspective and leads to conflicts within the team.

Finally, the authors identified the main challenges that staff members perceive in caring for patients in the dying phase which could be assigned to 6 areas: (1) challenging and delayed decision making on change of goal-of-care, including involvement of patients and/or informal caregivers, (2) lack of time for and knowledge on care for dying patients, (3) inadequate exchange and information flow within the team and with other disciplines and professions, (4) challenging and inadequate information of patients and/or informal caregivers about the impending death, (5) lack of supporting structures for staff in case of strains, (6) lack of concepts for care of dying patients during weekends and nights. All wards already had individual resources to provide good care for the dying, e.g. farewell rooms. These were included in the planning of interventions.

Description of the WG process

The WG process was structured with the same 3 steps for every WG. This standardized procedure was intended to ensure the comparability of the WGs, while also enabling a ward-tailored process. No predefined standards or measures were presented to the WGs at the beginning, in order to maintain the ED character of the process. Palliative care professionals were available throughout to support participants if needed and at least one member of the research team attended every meeting.

(1) Presentation of ward-specific results from the baseline evaluation: In the first meeting, the research team provided ward-specific results from the baseline evaluation on resources, staff knowledge about care in the dying phase, the current situation, challenges of providing this care, and potential measures for improvement. The presentation of baseline results ensured that perspectives beyond those of the small number of WG participants were considered. It was also intended to help identify relevant areas for improvement.

(2) Selection of prioritized topics: Using the baseline evaluation results, the WG identified areas needing improvement and prioritized them. To support the collecting process, methods such as mind mapping on a flipchart were used to visualize and cluster topics. Agreement on prioritized topics was reached through discussion or point vote.

(3) Planning of ward-specific measures: In this final step, the WGs developed concrete measures based on the previously prioritized topics. To support the planning, we combined 2 approaches: First, the content-related planning process of the measures was aligned with the toolkit from the *AMBER Care Bundle* "Last Days of Life" (Koffman et al. 2019), which served as a structural guide. Second, the planning of the implementation of the measures was supported by an implementation model (Grol and Wensing 2020), which emphasizes systematic

Table 1. Overview of number of participants, professions, number of meetings of WGs

Hospital ward	Ø Number of participants	Profession*	Number of meetings
ICU 1	4	N, P	7
ICU 2	3	N, P, T	7
ICU 3	4	N, P	6
ICU 4	4	N, P, T	12
ICU 5	6	N, P, T	5
ICU 6	3	N, P, T, C	5
GW 1	5	N, P	8
GW 2	5	N, P, T, C	7
GW 3	5	N, P, C	6
GW 4	5	N, P, C	6

*N = nurse, P = physician, T = therapist (occupational, physical, and speech therapy), C = counselling.

steps for translating ideas into practice. The WGs were encouraged to reflect on current practice and challenges related to the prioritized topics of care in the dying phase on their wards. Accordingly, they formulated *SMART* targets that are *specific, measurable, achievable, result oriented, and time scheduled* (Ogbeiwi 2017). Consequently, concrete ward-specific measures were derived. These included defined target groups, implementation steps, responsibilities, and timeframes. While the discussion was primarily driven by the participants, palliative care professionals were available to support the development of measures. In addition, the research team maintained a collection of evidence-informed measure examples based on a previous scoping review (Oubaid et al. 2025) to support the planning process when required, without superseding the participants own ideas.

WGs were established on all participating wards with 5 to 12 meetings throughout the year ($n = 69$ in total). The introductory meeting was planned for February and was realized for 5 WGs. The starts of the remaining WGs were delayed with the final WG starting in June. While the WG composition was multiprofessional, not every meeting was. For the number of participants, meetings and professions see Table 1. The WG composition varied over time: some wards ($n = 7$) maintained a permanent WG team, although not all participants attended every meeting. The other wards had a dynamic WG team with participants changing from meeting to meeting. Our standardized procedure to guide the WG process had to be tailored to meet the varying needs and requirements. For instance, the required meeting duration and structure varied between the WGs. Some WGs were more self-organized, directing the process, developing documents independently, and generating many ideas, while others needed more guidance and input from the research team.

The WG participants developed $n = 34$ measures during the WG process (see Table 2). The measures can be grouped thematically into the following topics:

- Informal caregivers; e.g. a flyer for the bereaved with support offers and information after the patients' death.
- Care in the dying phase; e.g. training for nursing staff regarding aroma therapy and oral care in the dying phase.
- Spatial setting; e.g. redesign of a farewell room.
- Team communication; e.g. a weekly multiprofessional palliative care team meeting.
- Supporting structures; e.g. overview of specialist palliative care structures and other support structures in hospitals for ward staff.

The measures aimed to facilitate communication processes within the team and with informal caregivers, to enhance knowledge and certainty in the care for patients in the dying phase, to establish supporting structures for the staff, and to improve the spatial concept of rooms for patients and their IC. The measures were tailored to the specific needs and structures of each ward. For example, 2 wards identified a need to improve team communication. One ward established a weekly multiprofessional team meeting to improve the overall internal communication and foster collaboration between nursing, medical, and therapeutic staff. Another ward introduced a monthly, interdisciplinary case discussion, primarily aiming to enhance communication between the ward team and other medical disciplines. These examples illustrate how the same general objective – improving communication – led to differently structured and solutions tailored to specific wards.

Evaluation of the WG process

a. Experiences and feedback from the perspective of the WG participants

In the following, the results of the online WG survey are presented as well as qualitative feedback that gathered in the final WG meeting. Of 78 invited, $n = 44$ (61.5%) completed the survey. The results will be reported according to organizational, communication/cooperation-related and outcome-related aspects. This is followed by the identification of barriers and facilitators of the WG process.

Organizational aspects

Most participants (70%) were satisfied with the organization of the WGs by the research team (e.g. scheduling, meeting rooms). Challenges arose in the scheduling of meetings due to shift schedules, particularly impacting nursing staff. Seventy-one percent of the participants felt that the time frame of the meetings was appropriate, with some wishing for continuation of meetings. Overall, 64% were satisfied with the WG process (realization, preparation, and follow-up work.)

Aspects related to communication/cooperation

Most participants (75%) rated the cooperation between the research team and the WG participants as satisfactory. Eighty percent felt they could express their opinion freely and 91% they could share their own thoughts and ideas. In the final meeting, participants highlighted the collaboration and cross-professional exchange, describing it as an 'exchange at eye level'. Communication with and moderation by the research team was describe as professional and helpful.

However, participants wished for more involvement of managing positions, e.g. senior physicians, to accelerate development and coordination processes. The decreasing numbers

Table 2. Overview of facilitators and barriers for the working group process at ward and WG level

Level	Facilitators	Barriers
Ward	• High relevance of the topic dying and death on ward before initiation of the research study • Ward staff is attuned to care need of patients and their informal caregivers in the dying phase • Existing materials/structures to build on quickly	• Ward-specific dynamics/conflicts slowing down the process, e.g. strained team-intern relationships • Institutional limits, e.g. non-possible electronical integration of documents
Working group	• Multiprofessional composition to integrate multiple perspectives • Motivation and engagement of WG participants to e.g. gain knowledge and optimise care • Involvement of staff in managing positions (e.g. senior physicians) for faster task assignments and coordination • Involvement of 'opinion leaders' with strong opinions and high motivation impacting other WG participants • Combination of both small and easy to implement as well as larger and more intensive to implement measures to keep working group participants motivated	• High fluctuation und declining participation of WG participants leading to cancellation and rescheduling of meetings • Limited timely and personal resources/staff shortage impeding the overall WG process despite participants commitment and motivation

of participants over time was perceived as negative for the process.

Aspects regarding the desired outcome

Participants were satisfied with results of the WGs (66%) and with the selection of measures on their ward (66%). The majority (77%) would be willing to participate in the WG again.

In the last meeting, participants generally found the selection of measures suitable, though one WG wished for more measures and the others wanted faster planning. One WG wished for more input regarding adequate care in the dying phase from palliative care experts during development, while others felt the process was adequate.

b. Barriers and facilitators of the WG process

We identified barriers and facilitators of the WG process based on the data of the WG protocols, which were grouped into 2 levels: ward and working group (see Table 2).

Discussion

Key findings

Research on the organization and conditions necessary for implementing ED innovations is limited. A recent scoping review found that only 12 out of 60 ED innovation studies included a robust evaluation (Cadeddu et al. 2023). Our study provided a comprehensive description and evaluation of an ED approach for tailoring measures to optimise hospital care in the dying phase. Baseline evaluation revealed considerable heterogeneity between the wards, highlighting the need for tailored interventions. We successfully established WGs on all participating wards and the WGs tailored 34 measures, demonstrating the feasibility and utility of the ED approach. While most participants viewed the WG process positively and would participate again, satisfaction with the results of the WGs and selected measures was mixed. Identified facilitators and barriers at both ward and WG levels provided valuable insights into the WG process.

Feasibility and utility of the ED approach

The successful formation of WGs and participatory tailoring of measures confirm the feasibility of the ED approach. The baseline evaluation showed highly variable ward conditions, necessitating tailored interventions. Although all WGs consistently tailored measures within 5 thematic areas, the measures were individually designed to fit each ward's unique requirements and structures. For instance, communication-focused measures ranged from interdisciplinary team meetings to efforts to improve documentation. Tailoring interventions and implementation strategies is indispensable for changes in complex healthcare settings (Baker et al. 2010; Geerligs et al. 2018; Wensing and Grol 2020). A systematic review on implementation processes for hospital-based interventions demonstrated the need to understand staff engagement and beliefs about the intervention and to generate strategies to address existing barriers (Baker et al. 2010; Geerligs et al. 2018). Our approach allowed tailoring from the beginning of both the measures and implementation strategies to the structural and staff requirements of the wards, ensuring flexibility for adaption. Another advantage was that the multiprofessional team appeared to benefit from working together in the WGs, which fostered communication and cooperation. Baseline findings indicated that staff members often felt only partially integrated into a multiprofessional team, and on some wards, only a minority agreed that communication works well. Bringing together the different professional groups in the WGs did not hinder open expression but instead fostered exchange at an equal level, promoting mutual understanding. Beyond tailoring measures, the WGs served as a platform to exchange views on patient care in the dying phase and to address internal conflicts or differing perspectives. A recent review on the implementation of ED innovations highlights that closer collaboration is an important benefit of these approaches on team level (Cadeddu et al. 2023).

Although the study demonstrated general feasibility of the ED approach, significant barriers to its implementation emerged. These barriers were rooted in well-known time and resource constraints within hospital settings. Despite high motivation and independently generated ideas, the integration of additional tasks into already demanding workloads led to fluctuations and a declining participation over time. This was despite the substantial organizational efforts undertaken by the research team to support the WG process. This aligns with existing research indicating that staff may perceive ED processes as extra work (Cadeddu et al. 2023). Additionally, only 66% of participants were satisfied with the results. Some measures, such as electronic documentation integration, could not be realized as desired by the WG. Others were not yet implemented at the end of the WG process due to unexpected delays. This reflects existing literature, pointing to the hospitals' high level of complexity and lack of organizational resources as important barriers to successful implementation of interventions (Cadeddu et al. 2023; Fournier and Jobin 2018; Van Beers et al. 2022). Nevertheless, most participants endorsed the ED approach and would recommend it to other hospital wards.

Key insights for transfer to other settings

Our detailed account of the WG process – including its structure, required resources, and processual adaptions – may serve as a practical orientation for other institutions aiming to apply similar ED approaches. As in most ED approaches (Cadeddu et al. 2023), the initiation of the WGs depended on the respective department directors' approval, with staff leading the subsequent process. Therefore, it is crucial that directors, staff in leading positions and other staff members are motivated to optimise care in the dying phase. Some directors may underestimate the importance of palliative care and the need for improvement (Lind et al. 2017). To extend the process to other wards, ways to communicate the importance of palliative care on non-specialized wards and to motivate ward directors and staff to participate in such a process need to be elicited. In line with existing literature, staff in managing positions played a key role in successful tailoring the measures (Cadeddu et al. 2023; Van Beers et al. 2022), as their involvement streamlined coordination processes and task assignment. Recent reviews highlighted that effective change requires engagement across all hierarchical levels, with mid- and high-level managers functioning as role-models and bridging the gap between organizational directives and execution of measures (Cadeddu et al. 2023; Van Beers et al. 2022). This fosters a culture of co-creation and ownership of the measures at all hierarchical levels (Cadeddu et al. 2023; Van Beers et al. 2022). A well-balanced mixture of bottom-up and top-down approaches appears most effective, though further research is needed to determine the optimal ratio (Cadeddu et al. 2023).

For the ED approach to be effective, dedicated individuals must take responsibility for the process. In our study, the research team handled all organizational tasks. For broader implementation, hospitals must allocate personnel time and space to manage and oversee the process. External support may also be beneficial, as WG participants requested more external guidance and input. Staff members' limited knowledge of potential measures may hinder the development of effective measures. For instance, the involvement of hospice services represents a valuable resource for improvement (Seaman et al. 2016), yet this was presumably not known and therefore not considered as an appropriate measure. In our study, specialized palliative care supported content-related questions but did not actively engage in tailoring measures. For future applications, intensifying the involvement of specialized palliative care could be beneficial, without limiting the autonomy of the WG participants.

Strengths and limitations

One strength of the study is the use of the updated *CFIR* version, ensuring a structured evaluation of barriers and facilitators (Damschroder et al. 2022). Without frameworks, critical aspects may be overlooked, compromising validity and generalizability (Geerligs et al. 2018). We assessed the ward setting and challenges from staff perspectives, providing valuable practical insights. The inclusion of 10 GWs and ICUs across different departments of medical centers enhances the comparability and transferability of our results. Despite successful tailoring of measures, long-term sustainability remains uncertain. As planned, the research team withdrew after the WG process, preventing further involvement in the implementation of the measures. Further research examining the process after a longer period is necessary.

Conclusion

The ED approach proved feasible and useful for tailoring of ward-specific measures aiming to optimise hospital care in the dying phase. Participants of the WGs tailored a wide range of measures and were generally satisfied with the process. Successful implementation requires individuals taking responsibility, engagement across all hierarchical levels, and external support. The optimal balance between bottom-up and top-down strategies remains unclear. The overview of identified measures provides a base to tailor own measures to optimise care in the dying phase on other wards. As part of the research project, the measures will be prepared and published more detailed for further use. When transferring the approach to other hospitals, the identified barriers and facilitators are an important guidance for effective implementation.

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Ethical approval. This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Committee of the Medical Faculty of the University of Cologne on 19 April 2021 (20-1727) and by the Ethics Committee of the General Medical Chamber, Hamburg on 03.08.2021 (2021-200061-BO-bet). Qualitative Interviews: Participants, both ward staff and informal caregivers of deceased patients, give written informed consent before participating in the interviews. Staff and working group survey: Participants give their consent to participate by clicking on the 'continue' button before starting the online survey and thereby agree to have their data collected and analyzed anonymously. Retrospective Medical Record Analysis: The staff councils of the 2 medical centers agreed to the collection of data from medical records of deceased patients. Pseudonymized data were collected, therefore no written or verbal informed consent is needed.

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4 Discussion

This dissertation provides a comprehensive assessment of care in the dying phase in the German hospital context. By integrating expert perspectives (publication 1), objective data from MRs (publication 2) and practical data from an ED approach (publication 3), this research identifies multilevel barriers and facilitators regarding optimal care as well as implications on implementation strategies for care optimisation in the dying phase.

The following section 4.1 will integrate the findings using *Bronfenbrenner's* ecological model [79, 80]. Section 4.2 examines the contribution to the field. Section 4.3 discusses implications for practice and research, with focus on documentation of care in the dying phase in MRs (section 4.3.1.1) and ED approaches as an implementation strategy for care optimisation (section 4.3.1.2). The dissertations' strengths and limitations are discussed in section 4.4.

4.1 Integrated Synthesis of Main Findings

The key findings of this dissertation were analysed and integrated using *Bronfenbrenner's* ecological model [79, 80]. Applied to the hospital setting, *Bronfenbrenner's* model allows for an understanding of the current state of hospital care in the dying phase across multiple levels (table 4): The **micro-level** is the first level defined as immediate surrounding of the patient such as their ICs and HCPs [79]. This level encompasses direct patient care like symptom management and spiritual aspects, and involvement of patients' IC. **The meso-level** refers to interactions and connections between individuals at the micro-level, including relationships between patients, ICs and their HCPs [79], pointing to team dynamics when caring for patients in the dying phase. The **macro-level** involves the micro- and meso-level and additionally comprises cultural norms and systems as well as policies impacting the individuals [79]. This level represents the hospital itself with its' institutional structures and culture. As summarized in table 4, topics recur across the three publications using different methods and perspectives and illustrate how individual, team and organisational factors are independent. The ecological perspective serves as an analytical lens linking qualitative data from expert perspectives (publication 1), objective data from MRs (publication 2) and practical implications of an ED approach (publication 3). This integration reveals how organisational conditions shape care delivery and identifies leverage points for care optimisation. This overview will be further contextualised in the following section on contributions to the field along the RQs.

Table 4: Synthesis of main results based on Bronfenbrenner's ecological systems model [79, 80]

Level	Topic	Expert online survey [15]	Data extraction tool [78]	Working group process [76]	Integrated insight
Macro	**Institutional structures and culture**	- Taboo around dying and death - Lack of hospital-wide policies - Resource constraints (staffing, time, spatial conditions) - Lack of standards/SOPs for care in the dying phase	Under-representation of psychosocial and spiritual care aspects, focus on medication and interventions	- Declining meeting participation - Cancellation/ Re-Scheduling of meetings e.g. due to shift work - Lack of time for adequate care for patients and their informal caregivers in the dying phase - Structural barriers for sustainable implementation, e.g. IT systems - Importance of leadership involvement - Measures included spatial setting, e.g. redesign of a farewell room	*Institutional culture and resource constraints are key factors influencing care in the dying phase and the implementation of change*
	Integration of specialist palliative care	Late involvement of specialist palliative care	Few documentations on the involvement of palliative care hospital support team	- Measures included information on supporting structures, e.g. overview of specialist palliative care structures	
Meso	**Team collaboration and communication**	Gaps in interprofessional communication	Few documentation of team discussions or decisions	- Ward-specific dynamics/conflicts slowed down the process - Inadequate exchange and information flow within team and other health care professionals - Employee-driven approach was feasible and effective to develop measures for care improvement - Measures included implementation of team meetings	*Effective communication and team structures and palliative care expertise are essential for sustainable improvements and require targeted support and training*

Level	Topic	Expert online survey [15]	Data extraction tool [78]	Working group process [76]	Integrated insight
Micro	**Patient-centred care and communication**	- Insufficient and unclear conversations with patients about goals-of-care - Insufficient knowledge about patient wishes and needs	Few documentations of conversations with patients and their informal caregivers and on patients' needs and preferences	- Lack of knowledge on care for dying patients - Challenging and delayed decision making on change of goal-of-care, including involvement of patients - Challenging and inadequate information of patients about the impending death	*Conversations with patients and informal caregivers should be better documented and staff should be supported through training and tools*
	Symptom management	- Gaps in palliative care expertise, e.g. symptom control and relief - Lack of standards for care in the dying phase, e.g. standard operating procedures	Few documentations of symptom assessment using scales or tools	Measures included training for nursing staff in aroma therapy and oral care	*Symptom control remains a cornerstone of care in the dying phase and requires clear protocols, documentation and training*
	Spiritual care and rituals	Recognised as very important but rarely institutionalised and overlooked in routine care	Few documentations on psychosocial and spiritual needs	Measures included ritual boxes and integration of chaplains	*Spiritual and emotional aspects of care in the dying phase are valued but need stronger integration into hospital routines and documentation*
	Involvement of informal caregivers	Insufficient conversations with involvement and support of informal caregivers	Few documentations of presence, conversations or support offered to informal caregivers	- Challenging and delayed decision making on change of goal-of-care, including involvement of informal caregivers - Challenging and inadequate information of informal caregivers about the impending death - Measures included communication training - Measures included development of materials, e.g. flyer for the bereaved	*Involving informal caregivers in care in the dying phase is crucial and requires practical tools and trainings*

4.2 Contribution to the Field

Based on the synthesis of findings given in the previous section and table 4, the following section discusses the contribution of this dissertation to the field along with the RQs. The findings of this dissertation illustrate barriers, facilitators and improvement needs (RQ1) and highlight chances and limits of using MRs as a data source for assessing hospital care in the dying phase (RQ2). The findings are based on a multi-perspective status assessment for care in the dying phase in two German hospitals: a qualitative expert online survey (publication 1) [9], the development of a tool for MR analysis (publication 2) [78] and description and evaluation of an ED approach to improve care in the dying phase (publication 3) [76].

In relation to RQ1, the findings of this dissertation consist of barriers, facilitators and development needs for optimal hospital care in the dying phase across multiple care levels. Drawing to *Bronfenbrenner's* ecological model [79, 80] (table 4), this framework allows linking structural, team and care aspects as independent determinants of care in the dying phase in the German hospital context. **At macro level**, **both institutional culture and resource constraints emerged as key factors influencing care in the dying phase and implementation of change.** The expert survey and the WG process revealed a consistent pattern: the prevailing curative culture within hospitals coupled with resource constraints, like missing single rooms and limited time and staff, impedes the provision of adequate EoL care [15, 92]. The focus on curative approaches in the dying phase was further evident in the MR analysis, showing that therapeutic and medical interventions are more frequently documented comparing to psychosocial aspects of care [76, 82]. In further studies, both medical and nursing staff observed that clinical cultures and organisational systems routinely favoured life-sustaining care, which may have led to excessive therapeutic interventions and overuse of medication in EoL care [93, 94]. Findings align with previous research identifying spatial conditions and time constraints as main barriers integrating palliative care into routine practice reported by nursing staff and physicians [19, 20]. Findings stated the lacking (timely) involvement of specialist palliative care services by experts [15], with only few documentations of involved palliative care hospital support team found in MRs [76, 82]. This appears to be striking as early palliative care involvement has robust empirical support improving care outcomes like symptom alleviation and comfort [8, 59, 95-98]. **From an ecological perspective, these macro-level conditions establish the organisational context that directly shape team dynamics and individual care practices**. In conclusion, resource constraints and cultural barriers constitute as concrete barriers on the macro-level, suggesting that interventions addressing both organisational structures and cultural transformation are essential for meaningful change, but take considerable political and timely efforts [49, 94].

At meso-level, team dynamics, effective communication and palliative care expertise are essential for care provision in the dying phase [15, 76], representing a starting point for implementation of change [49]. The expert online survey and WG process identified insufficient information exchange in the team and ward-specific conflicts as key barriers of EOL care [15, 78]. These findings align with broader evidence of a recent systematic review stating that EOL care fundamentally depends on interprofessional collaboration and shared decision-making [99]. Also, the ward climate, team competencies and leadership are interconnected elements requiring institutional support [100, 101]. **The ecological framework reveals how macro-level constraints translate into meso-level challenges: time and staff limitations directly contributed to declining meeting participations in the WG process [76]**. However, the model also illuminates bidirectional influences: the WG approach confirmed **that participatory ED approaches at meso-level may be a feasible implementation strategy** that can shift institutional practices [76]. This aligns with implementation science studies emphasising the crucial role of team-level factors for successful interventions in healthcare settings [69]. Improving care in the dying phase requires both structural and team efforts. Rather than relying solely on *top-down* approaches, sustainable change appears to require targeted support for teamwork, communication and focus on the attitudes and motivation of staff at ward level [15].

At micro-level, **conversations with patients and ICs should be better documented and clear protocols for symptom control are required. Spiritual and emotional aspects of care need stronger integration into hospital routines and documentation, and IC should be adequately involved in the dying phase**. Across all three publications, findings revealed insufficient documentation and implementation of goals-of-care discussions, patient wishes and psychosocial and spiritual aspects of care in the dying phase [15, 76, 78]. The MR analysis showed few documentation of standardised tools for symptom assessments and involvement of patient and their ICs [78], while WG members identified lacking knowledge, decision-making and confidence in providing EOL care [76]. These findings align with systematic reviews identifying symptom control, withdrawing and withholding life-sustaining technologies in ICU settings, clear decision-making, maintaining personal dignity, family involvement and receiving spiritual care as key elements of a “good death” from patient and family perspective [93, 102]. An integrative review identified poor symptom management as main shortcoming from patient and family perspective [16]. Similarly, research on ICUs communication advocated for early goals-of-care discussions and interprofessional communication platforms, e.g. video conferences with ICs [31, 94, 103]. Despite this evidence, the integration of spiritual care and involvement of ICs remains adequate in routine hospital care [15, 78, 104]. **The ecological lens illuminates how micro-level conditions are not isolated care aspects but systemic issues of conditions at higher level**: inadequate goals-of-care discussions and patient-centred care (micro-level) reflect both insufficient team communication and competencies (meso-level) and institutional taboos around dying and death in hospital culture (macro-level). However, the WG approach demonstrated that **small, targeted measures on ward-level** [15, 76], such as trainings, ritual boxes, information materials for bereaved ICs and checklists, can address these care gaps, suggesting potential for an ED approach even with constraining macro-level structures [76].

Overall, table 4 illustrates how findings converge across methods and care levels: cultural and structural barriers at the macro-level manifest in challenges in team dynamics at the meso-level and ultimately impact the quality of direct patient care in the dying phase at the micro-level.

Concerning RQ2, the findings of the dissertation highlight the extent to which MRs can provide information on care in the dying phase. They revealed both the potential of MRs to capture objective clinical interventions and the gaps in containing psychosocial, spiritual and communicative aspects of care [78]. These findings indicated that EoL conversations between HCPs and patients are inadequately captured in MR documentation [105]. This under-documentation of psychosocial and communicational aspects of care was confirmed by similar results of other studies: gaps in the documentation of symptom assessments, goals-of-care discussions, family involvement and spiritual care were reported [106, 107]. Moreover, results of the *ETHICUS-2* study, which explored EoL care practices on European ICUs, revealed that patient's wishes are unknown and not sufficiently recorded: only 28.6% of MRs had a documented change of goals-of-care and 26.4% of records had a documented advance directive to express a living or therapeutic will [26, 108]. A study investigating documentation in 17 rural and nonrural community hospitals revealed a low prevalence of goals-of-care documentation indicating that fewer than 1 in 10 seriously ill patients had a documented goals-of-care discussion [109]. Documentation in nursing homes showed similar results: physical aspects were documented, but psychological, social and existential issues were rarely recorded [110, 111]. One study also identified variability in existing documentation practices between GWs and ICUs: changes in goals-of-care were documented more often in GWs (84.4%) than ICUs (75.8%) [82]. Current documentation practices seem to omit patients' holistic needs, conversations as well as treatment goals and care decisions [112, 113]. These results appear particularly striking since missing or inconsistent documentation can indicate actual care gaps or poor traceability [82]. Pointing to the synthesised findings on micro-level in table 4, health experts emphasised the importance of patient-centred care, symptom management, spiritual aspects and the involvement of ICs in the care in the dying phase [15]. Ward staff identified challenges related to these topics on their ward and developed measures targeting these, such as communication trainings [76]. At the same time, documentation in

MRs hardly reflected these aspects of care, indicating a gap between needs and documented reality. The synthesised findings show a discrepancy and structural disconnect from topics which experts and HCPs identify as important and their actual documentation in MRs. This deficit was not only perceived from HCPs' and patients' perspective, but also empirically measurable through the application of the data extraction tool [78].

Overall, the results suggest that while MRs enable analysis of care in the dying phase regarding clinical information, they remain insufficient to capture the psychosocial, spiritual and communicative dimensions of care. This limits their capacity as a sole source of quality assessments because they systematically underrepresent dimensions of care especially valued by patients and ICs [78, 82]. These insights underline the need to critically reflect on the role of MRs within quality assessment frameworks. How these limitations can be addressed in clinical practice and research will be further discussed in section 4.3.2.

Finally, the findings of the dissertation showed that central challenges in hospital care in the dying phase are well known and interconnected, but persistent. Findings aligned closely with topics repeatedly reported in existing studies, highlighting that current issues remain insufficiently addressed in practice. However, the findings of the publications provide a detailed and structured mapping across connected ecological levels [79, 80] and add more details and depth e.g. via health experts' perspectives [15]. MR analysis complemented the understanding via qualitative notes [78]. The WG approach proved to be suitable to identify and addressed challenges on ward level [76]. The persistence of these findings shifts the focus from generating new evidence on what constitutes optimal care in the dying phase to effectively implementing existing evidence-based knowledge into routine practice [30, 60]. Research should focus on practical implications that can translate established recommendations and findings into sustainable changes in routine care delivery, supporting previous calls for context-sensitive implementation strategies [60]. Such implications for practice and research will be outlined in the following section. Two central topics of this dissertation will then be discussed in detail regarding their practical implications: documentation of care in the dying phase in MRs (section 4.3.1.1) and ED approaches as an implementation strategy for care optimisation in the dying phase (section 4.3.1.2).

4.3 Implications for Research and Clinical Practice

4.3.1 Practical Implications

Based on the dissertation findings summarised in table 4 and discussed in section 4.2, the following section provides practical implications for optimising care in the dying phase, directed at both hospital management levels and hospital frontline staff (see table 5). Successful change depends on both the skills of frontline staff but also on the organisational environment and support (table 2) [114].

At management level, creating a conducive environment is crucial. Within the organisational context, leadership is responsible for maintaining continuous improvement cycles by using data to monitor progress and embed this process in the ward routine (see table 2). This involves regular assessments of care in the dying phase using structured tools to identify improvement needs, e.g. MR analysis [78, 82]. Testing and implementation of small-scale context-specific interventions embedded into hospital routines and supported by hospital/ward leadership is crucial to ensure institutional and leadership support [76]. For frontline staff, training and increasing palliative care competencies are crucial for fostering confidence and awareness among ward staff. Improving team communication and collaboration and increasing competencies help to ensure high quality care in the dying phase and successful implementation [15, 62, 99]. To be effective, all interventions must the adapted to the ward context.

Table 5: Practical implications to improve hospital care in the dying phase

Level	Recommendation	Rationale
Hospital management	Establishment of a regular multi-method assessment of the quality of care in the dying phase (e.g. medical record analysis)	*Identification of improvement needs and progress monitoring*
	Support of ward-level initiatives for care improvements initiatives and provision of time and resources to hospital staff	*Signal of institutional commitment on leadership level*
	Implementation of small, feasible interventions rather than complex large-scale top-down programs	*Small-scale interventions are more sustainable and easier to implement*
Hospital staff	Training in symptom management, communication and psychosocial aspects of end-of-life care	*Building competencies, fostering confidence and strengthening awareness of ward staff is crucial to realise care improvement*
	Strengthening team communication and collaboration	*Reduction of misunderstandings in care decisions, fostering effective teamwork as a starting point for improvement*
	Small ward-specific interventions adapted to ward practice	*Context-specific adaptation of intervention is crucial*

4.3.1.1 Documentation of Care in the Dying Phase in Medical Records

As outlined in section 4.2, current documentation practices in the care in the dying phase are inconsistent. The poor representation of psychosocial and communicative dimensions in MRs highlights the need for structured documentation standards for care in the dying phase. Good documentation is needed for several reasons: it ensures information flow, continuity and quality of care, facilitates communication among ward staff and supports clinical decision-making and audits/quality improvements [115]. Structured documentation can drive culture change by making care in the dying phase visible and discussable and enhances transparency and accountability in care processes [116].

Efforts to improve documentation of EoL care exist and are summarised in table 6. The identified studies indicate that interventions within the electronic MR (EMR) are effective to improve the quality, completeness and accessibility of clinical documentation of palliative and EoL care aspects [113, 117-120]. Structured, centralised and user-friendly EMR tools integrated into workflow led to significant and measurable improvement of documentation processes [119]. Interventions such as a structured note template successfully increased the richness of documentation quality regarding emotional assessment needs of patients and ICs [113, 121]. Interventions also boosted compliance of code status documentation [117] and enhanced advance care planning (ACP) documentation and viewing [118]. Creating a centralised navigator within the EMR to consolidate all information related to EoL care proved to be effective in a paediatric setting [117]. It also led to more integration of supporting structures in deaths, e.g. chaplains and social workers [117]. A systematic review reinforced these findings and added that EMR-based nudges consistently improved documentation rates of ACP and goals-of-care discussions [120]. A study aiming to enhance documentation of spiritual care aspects found that an initial “mock audit” with HCPs was fundamental for the overall improvement process [122], emphasising the need to establish regular MR analysis followed by feedback sessions and audits for an ongoing improvement process [122]. Another study analysed the effectiveness of EMR-based reminders, which showed to effectively enhance ACP documentation rates [123]. However, one study showed that while documentation became richer, it did not automatically translate into further treatment actions [113]. Also, nudges boosted documentation rates, but their effect on outcomes like ICU transfers or mortality was inconsistent or not significant [120].

Altogether, EMR based interventions to improve documentation of EoL care have been shown to be effective to enhance documentation quantity and quality. They should be combined with continuous education measures such as staff training and organisational support like audits to raise awareness for and to foster consistent improvement of documentation practices [124-126].

Based on results of publication 2, a draft for a guideline-based structured template for documentation of hospital care in the dying phase is developed [12, 78] (table 7). The template is structured around six key domains identified as essential by operationalising the *German Palliative Care Guideline* [12]. Domains address information that was found to be poorly documented in MRs by using mandatory fields and structured prompts. It provides field types for objective and subjective data for procedural assessments (e.g. time of death) as well as nuanced assessments (e.g. patient wishes). The template is designed to appear as an integrated note template or navigator in the EMR to streamline information. Following steps should be taken to advance the design, to test and implement the drafted template into routine care:

1. The drafted template should be discussed in focus groups by a team of HCPs including physicians, nursing staff, therapists, palliative care experts and IT specialists to ensure **clinical relevance, usability and integration** in the existing documentation system.
2. Prior to hospital-wide implementation, the template should be **pilot-tested** in different wards (e.g. ICUs and GWs of different medical fields) to identify workflow issues, gather user feedback and adapt the template accordingly.
3. **Training sessions and a manual** are essential: the training should emphasise why documentation is important regarding patient care, linking it directly to the guideline recommendations and care outcomes.
4. The drafted template should be **integrated into the existing EMR system and workflows:** for instance, an EMR alert could suggest using the template when the code status is changed or when certain clinical indicators are documented.
5. Data assessed by the drafted template could be used for **audits, feedback and quality improvements**. Regular, automated reports on completion rates on each topic (e.g. symptom assessment) could be generated. Providing data and feedback to the wards may highlight areas for improvement and foster quality enhancements.

To ensure the tool is clinically relevant and user-friendly, implementation should involve frontline staff through focus groups and feedback sessions. Its’ success depends on leadership involvement, that prioritizes high quality documentation as part of providing optimal care in the dying phase. Improving documentation is not only a technical issue but also an organisational and cultural challenge.

Table 6: Overview of studies investigating documentation improvement of end-of-life care in the hospital

Intervention	Description	Outcome	Learning
Structured Note Template [113]	Implementation of a structured note template (*Smartphrase*) within the electronic medical record for palliative care encounters, specifically for prompting emotional and psychological assessment	- Documentation of emotional assessment increased from 63.9% to 74.6% (p< 0.03). - Increase of the overall quantity and richness of documentation of emotional needs - Reduction of using generic phrases	*While structured templates improve documentation of emotional needs, the documentation often remains descriptive Additional prompts or recommendations to address identified needs and the use of screening tool are necessary for clinically meaningful quality improvements*
End-of-life Navigator [117]	Development of an *End-of-life Navigator* for paediatric end-of-life care to consolidate advance care planning documents, code status order and psychosocial support notes	- 35% increase in supporting documentation for code status changes (96% compliance) - 25% increase of deaths supported by psychosocial teams (e.g. social worker, chaplain) - More post-mortem documentation	*A systematic approach to documentation, such as a navigator, is helpful for standardising and improving paediatric end-of-life care and facilitates electronic data collection*
Integrated nudges and prompts in medical records (Systematic Review) [120]	Systematic review evaluating the effectiveness of electronic medical record integrated “nudge” interventions promoting advance care planning among healthcare professionals	- Consistent positive effects on documentation of advance care planning, serious illness conversations, prognosis communication and goals-of-care documentation - Most studies reported statistically significant improvements	*Nudges in electronic medical records can effectively improve documentation and communication practices related to end-of-life care*
Palliative Nursing Care Document [119, 124]	Quality improvement initiative to develop new palliative nursing care documentation that reflects holistic care and patient perspectives	- Significantly higher level of compliance in nursing assessments - Concise, accurate and comprehensive approach to documenting nursing care and patients’ perspectives including psychosocial and spiritual aspects	*Continuous education and robust organisational support are crucial for sustaining improvements in nursing documentation and preventing documentation becoming a “tick box” exercise. Structured documentation ensures and enhances information transfer*
Advance Care Planning Navigator [118]	Implementation of an advance care planning navigator to improve accessible advance care planning documentation for hospitalised patients (age 75+ or with serious illness)	- Increase of advance care planning documentations from 28.1% to 41.6% (p<0.001)	*Enhancing usability through increased visibility and workflow-integrated tool significantly improved documentation rates and clinician viewing*

Table 7: Drafted template aligned with findings of data extraction tool [78]

Domain 1: Dying process and death	
Recognition of dying phase:*	*[Checkbox]*
Date/time of recognition of dying phase:*	*[Date/Time picker]*
Clinical signs observed:*	*[Free text]*
Time of patients' death:	*[Date/Time picker]*
Notes: Details and post-mortem	*[Free text]*
Domain 2: Medication and interventions	
Life-sustaining interventions:* (select all that apply)	☐ Vital signs *[Dropdown: Continued / Reduced / Stopped]* On *[Date/Time picker]* ☐ Blood glucose *[Dropdown: Continued / Reduced / Stopped]* On *[Date/Time picker]* ☐ Antibiotics *[Dropdown: Continued / Reduced / Stopped/ Not Applicable]* On *[Date/Time picker]* ☐ Artificial nutrition/hydration *[Dropdown: Continued / Reduced/ Stopped/ Not Applicable]* On *[Date/Time picker]* ☐ Ventilation/Hemofiltration *[Dropdown: Continued / Reduced / Stopped]* On *[Date/Time picker]* ☐ Chemotherapy/immunotherapy/oral tumour therapy/radiotherapy *[Dropdown: Continued / Reduced / Stopped]* On *[Date/Time picker]*
Medication initiated/continued:* (select all that apply)	☐ Opioids: *[free text]* ☐ Antipsychotics: *[free text]* ☐ Benzodiazepines: *[free text]* ☐ Anticholinergics: [*free text]* ☐ Other: *[free text]*
Notes: Rationale for interventions/changes	*[Free text]*

Domain 3: Information and involvement of patients/IC	
Patient informed of impending death:*	☐ Yes: *[Date/Time picker]* ☐ No (Reason*: [Dropdown: Patient non-responsive / Other: [Freetext]])*
IC informed of impending death:*	☐ Yes: *[Date/Time picker]* ☐ No (*Reason: [Dropdown: No IC available / Other: [Freetext]])*
Notes: Patients expressed wishes or fears:*	*[Freetext]*
IC Support	
Support offered:*	☐Yes ☐No
Notes: Reaction, questions, expressed needs*	*[Freetext]*
IC present at death:*	☐Yes ☐No
Post-death rituals:	☐Yes ☐No
Notes: Cultural/religious considerations	*[Freetext]*
Domain 4: Symptom assessment	
Assessment Tool used:*	*[Dropdown: NRS / MIDOS / IPOS / HOPE / VAS / VRS / BPS / Delir Score / Smiley-Scale / Other: [Freetext] / Not Applicable (patient unresponsive)]*
Symptom score: (0=none, 10=worst) (select all that apply	☐ Pain: *[Numeric Field 0-10]* ☐ Breathlessness: *[Numeric Field 0-10]* ☐ Nausea: *[Numeric Field 0-10]* ☐ Anxiety: *[Numeric Field 0-10]* ☐ Agitation/Delirium: *[Numeric Field 0-10]* ☐ Other: *[Numeric Field 0-10]*
Notes: nonverbal indicators	*[Freetext]*
Date and time:	*[Date/Time picker]*

Domain 5: Goals-of-care	
Goal-of-care:*	☐ Escalation/enouncement of life-sustaining therapy ☐ De-escalation/enouncement of life-prolonging or -sustaining therapy ☐ Escalation of new life-prolonging or -sustaining therapy ☐ Other: *[Free text]* ☐ *[Date/Time picker]*
Code status (DNR/DNI):*	☐ Status: *[Dropdown: DNR / DNI / DNR & DNI]* ☐ Date Order Placed/Confirmed*: *[Date/Time Picker]*
Advanced directives:	☐ Living will document or similar reviewed ☐ No formal documents, wishes communicated by: *[Freetext]* ☐ Other: *[Freetext]*
Notes: Wishes and details	*[Freetext]*
Domian 6: Involvement of specialist teams	
Palliative Care Hospital Support Team:	☐ Consult requested: *[Date/Time Picker]* ☐ Consult completed: *[Date/Time Picker]* ☐ Not Requested
Other, e.g. chaplains:	☐ Type: *[Freetext]* ☐ Consult requested: *[Date/Time Picker]* ☐ Consult completed: *[Date/Time Picker]*

*Mandatory fields

4.3.1.2 Employee-driven Approaches in Hospitals

In the discussion of translating knowledge into hospital routine, the findings of the ED approach emerge as a promising starting point to realise change on ward levels [76]. The tested WG approach in publication 3 offers important insights into how change processes in EoL care can be initiated on hospital ward level. Findings comprise both the potential and challenges of ED approaches in hospitals, which need to be interpreted considering practical insights (see table 8).

Table 8: Overview of potential, limitations and learnings of employee-driven approaches in hospitals

Potentials	Limitations	Learning
Mobilises staff engagement and ownership	Time pressure, shift work and workload reduce participation	Leadership commitment and active support of staff
Enhances interprofessional exchange and team communication	Declining staff participation over longer project duration	Allocation of protected time and resources for staff to participate
Generate context-sensitive and ward-specific solutions	Interventions risk of being perceived as extra work by staff	Embedding interventions into existing routines and processes
Increases awareness of care topics	Lack of structural and institutional integration into hospital routines	Combination with selected top-down strategies

As stated before, a primary advantage is the mobilisation of staff engagement and ownership, which is an essential factor for successful improvement and can foster a deeper commitment to new initiatives [49, 60]. This process naturally enhances teamwork and communication, as ward staff must collaborate to identify challenges and solutions [76]. This is especially important when considering that good team communication is a cornerstone of EoL care [127, 128]. HCPs are experts in identifying relevant care gaps and developing realistic solutions for their ward considering the variation in initial conditions across hospital wards, e.g. workflows and palliative care expertise [69]. Staff involvement and education prove beneficial when the composition is multiprofessional [129] as WGs were in the *StiK-OV* study [9]. This approach led to development and implementation of context-specific solutions, that are more sustainable than generic and inflexible *top-down* initiatives [15, 61]. As shown in publication 3, the WGs successfully tailored *N*=34 ward-specific measures, proving that ward-specific solutions can be effectively developed within ward structures [9, 76]. As seen in other quality improvement studies, this can also increase overall awareness of care, such as goals-of-care discussions or better symptom control [76, 126, 130]. Considering existing barriers like time pressure and workload, participation in ED approaches could be perceived as extra work [69], leading to staff turnover disrupting the process [126] and lower engagement over a longer duration [76, 126, 131].

Key learnings highlight strategies to overcome these limitations (table 8): To sustain engagement and counter participation decrease, leadership commitment and active visible organisational support are crucial [60]. In the *StiK-OV* study, the involvement of staff in managing position proved to be a facilitating factor for sustaining engagement of staff [76]. Furthermore, the wards' participation in the study itself signalled organisational support, which was perceived positively by staff [76]. Protected time and resources for staff to participate is an important factor in ensuring staff engagement and preventing work overload [127]. In the *StiK-OV* study, participation in the WG meetings was facilitated through active invitation by their team leaders, which enabled staff to participate despite limited timely and personnel resources [76]. Integrating such interventions into institutional structures in the long term (e.g. into hospital-wide quality structures) seems to be beneficial. The use of digital tools for progress tracking and coordination can make the process more transparent and structured [132].

Altogether, this dissertation highlights the potential and limitations of participatory ED approaches in complex and sensitive areas like hospital care in the dying phase. Similar approaches are adaptable for other hospital contexts, if they are supported by institutional frameworks, leadership recognition and complemented by top-down strategies.

4.3.2 Implications for Future Research

Further implications for research to enhance quality and reliability of findings can be derived from this project. While this dissertation provides important insights into barriers, facilitators, care improvements and practical implications, gaps which require further investigation were also revealed.

Systemic research on hospital culture hierarchy and interprofessional dynamics influencing care could be useful to further examine the role of organisational leadership in establishing EoL care as visible institutional priority [69]. Cross-country comparisons are useful to identify system-level factors that facilitate and hinder delivering optimal care in the dying phase alongside studies focusing on scaling effective interventions and quality measures to other hospitals (e.g. non-academic) and regions (e.g. rural) [114].

Future research should use mixed-method approaches, e.g. MR analysis with observational studies to provide deeper contextual insights into actual care practices [15]. Prospective studies on care assessment should involve patients' and ICs' experiences as well as their needs to understand the subjective dimension of care delivery [133, 134]. Their experiences provide crucial insights that may not be captured through staff perspectives alone. Tools and frameworks to systematically document and respond to the specific needs of ICs should be further developed [135].

Implementation research is needed to evaluate additional implementation models in EoL care. Studies should examine long-term outcomes and such focus on sustainable implementation of interventions, while investigating strategies for scaling ward-level changes to achieve hospital-wide change in EoL care practices [69, 76]. Implementation science frameworks like *CFIR* or *TDF* should be used to analyse contextual factors in routine care [136].

Research on quality assessments and documentation tools is needed: The data extraction tool needs further validation and refinement across diverse hospital settings to establish broader applicability and reliability. Also, further development and testing of the drafted documentation template is needed, along with the integration into routine documentation and quality monitoring processes [78]. Future research should also examine how improved documentation affects care processes and patient outcomes like symptom control, communication, ward staff behaviour and decision-making [120].

4.4 Strengths and Limitations

Limitations of the three individual publications have been discussed in detail in the respective publications [15, 76, 78]. This section focuses on discussing those that are not already reported in the respective publications and mainly highlight overall strengths and limitations of this dissertation.

When considering limitations of this dissertation, it becomes apparent that data derived from two university hospitals are restricted in their generalisability as they are specific to the academic German/European healthcare context [9]. They may not be fully transferred to other hospital types, e.g. rural or non-academic. Data was retrieved from subjective (expert online survey and WG approach) and objective (medical records) staff perspectives, not capturing direct patient and IC perspectives and experiences. In publication 1, experts with various professional backgrounds participated in the survey, inviting those known to the research team, pointing to a possible selection bias. Therefore, relevant aspects from a much wider pool of experts have not been captured. The use of open-ended questions in an online format limited the depth of responses compared with in-depth interviews or focus groups and did not allow for clarifying follow-up questions. Institutional context data, e.g. hospital size, region, governance, were not collected, limiting contextual interpretation. Data was collected during the COVID-19 pandemic and therefore may overemphasise pandemic-related issues in the survey.

The development of the data extraction tool in publication 2 relied on retrospective data of MRs, which may not reflect actual care but rather documentation practices, e.g. documentation of goals-of-care discussions [137]. This documentation bias restricts the validity of MRs as a sole source for status assessment. Although consensus meetings were held, no formal statistical assessment like *Cohens Kappa* of interrater agreement was performed, which may limit its' level of agreement and standardisation potential [138]. While the tool was developed based on a national guideline [12], content analysis war only assessed internally by the research team, without further external validation. Differences between electronic and paper-based medical records may have affected information density and comparability across wards. This potential bias was not analysed systematically.

The evaluation of the ED approach in publication 3 was only evaluated in the short-term, which limits the sustainability and outcomes of ward-level initiatives and developed measures over a longer period. The implementation of the WG approach relied heavily on study project funds and support by the research team, that is not routinely available in standard care [69]. Also, there is a possibility that staff behaviour changed due to awareness of participating in a research study (Hawthorne effect) [139]. This may have contributed to observed feasibility of the WG approach. Positive findings may not be contributed solely to the approach itself, but also to modified behaviour during the study period [139]. Furthermore, the participating wards already demonstrated high awareness and competencies in providing EoL care. This may result in a ceiling effect, where applicability of the WG approach to other settings may be restricted due to already high care delivery on wards.

Despite these limitations, this dissertation entails several overarching strengths. The key strengths are the application of *Bronfenbrenner's* ecological model [79, 80] as an integrative framework that allowed for a multi-level analysis of care in the dying phase. Using this model enabled systematic triangulation of findings across three publications This approach demonstrated interdependencies between institutional structures, team dynamics and patient care that might remained insufficiently addressed through single-level analysis. Further, the dissertation is conceptually grounded in implementation science and quality management theory, ensuring methodological depth and theoretical constancy. The validity of findings is strengthened by combining subjective expert survey data, objective medical record data and practical data from the WG approach. This mixed-methods approach ensures that barriers, facilitators and improvement needs (RQ1) were not only identified with both subjective and objective data but also assessed in a practice-oriented study outlined in publication 3. The datasets obtained are large and diverse: an expert online survey with *N*=65 health experts, *N*=400 MRs and insights from an ED approach implemented on ten wards outside specialist palliative care of two university hospitals, using *N*=79 working group protocols and *N*=44 feedback surveys. Using the multi-level approach not only summarises all findings but also synthesises care aspects on institutional, team and care levels into a coherent model. The overview captures the complexity of hospital care in the dying phase and fosters transferability to other settings. This dissertation provided a practical focus, contributing to implementation science and health services research in palliative care. Findings shed light on participatory WG approaches to develop small, easy-to-implement and ward-specific measures to improve hospital care in the dying phase. Also, a draft of a template based on an evidence-based guideline and findings of other (implementation) studies was developed for further adaptation and implementation in hospitals. Overall, this dissertation offers valuable, practice-oriented insights into German hospital care in the dying phase and contributes substantially to its relevance for clinical practice and future research.

5 Conclusion

This cumulative dissertation aims to assess the current state of hospital care in the dying phase outside specialised palliative care as basis for care optimisation in Germany. Together, the findings encompass perceived barriers, facilitators and improvement needs for optimal hospital care in the dying phase and evaluate the potential of MRs as a source for quality assessment. Across three publications, findings confirmed that the main challenges are not new but persist across micro-, meso- and macro-levels. The dissertation demonstrated that MRs could capture clinical interventions but underrepresent psychosocial and communicative dimensions, limiting their value as stand-alone source. Perspectives of implementation science were integrated into palliative health services research by incorporating insights from an ED approach aiming to optimise hospital care in the dying phase. The dissertation demonstrated that improving hospital care in the dying phase requires systematic assessment and tailored participatory ED approaches to realise change in hospitals, underlining tailored interventions on team-level can have significant impact if supported by institutional culture and leadership. Taken together, this dissertation contributes both methodical and practice-oriented evidence to the field, thereby offering a structured basis for optimising hospital care in the dying phase.

"How pathetic it was to try to relegate death to the periphery of life when death was at the centre of everything" – these words of the writer Julian Barnes should remind us that dying cannot be treated as a marginal issue but must be recognised as central in healthcare and policy.

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Appendix

I. Data extraction tool (Publication 2)

Demographic data & clinical characteristics

	Items (n=11)	Option
a.	How old was the patient, when the patient died?	18- 115 years
b.	What was the patients’ gender?	☐ Male ☐ Female ☐ Divers
c.	Which date of death is documented?	dd.mm.yy
d.	When was death recorded?	☐ 0-4 am ☐ 4-8 am ☐ 8-12 am ☐ 12-4 pm ☐ 4-8 pm ☐ 8- 0 pm
e.	On which date was the patient admitted to the ward where the patient died?	dd.mm.yy
f.	Which ICD-10 diagnosis group* is the patient most likely to be classified in?	☐ Maligant neoplasm ☐ Diseases of the circulatory system ☐ Diseases of the nervous system ☐ Diseases of the respiratory system ☐ Diseases of the digestive system ☐ Diseases of the genitourinary system ☐ Endocrine, nutritional or metabolic diseases ☐ Injury, poisoning or certain other consequences of external causes ☐ Certain infectious or parasitic diseases ☐ Mental or behavioural disorders ☐ Covid-19
g.	What was the cause of death? (according to death certificate)	☐ Infection, sepsis ☐ Heart failure, cardiac arrhythmia ☐ Respiratory failure ☐ Bleeding, haemorrhagic shock ☐ Cerebral cause of death ☐ Other
h.	Did the patient die during surgery or after unsuccessful resuscitation?	☐ Yes, death during surgery ☐ Yes, death after resuscitation ☐ No
i.	Was the patient adequately able to communicate?	☐ Yes ☐ No ☐ Partly
j.	Are there indicators of people who are involved in the process besides the patient?	☐ Informal caregivers ☐ Legal guardian ☐ No
k.	Are there any notes that a living will and/or a power of attorney was available for the health care staff?	☐ Yes ☐ No ☐ Patient able to communicate

Domain 1: Dying process and death

Items (n=8)	Option	Guideline Recommendation Number (EC) or Quality indicator (QI) [12]
1.1 Nursing notes		
a. Are there any notes about the re-evaluation of care decisions and interventions in the dying phase in the nursing notes?	☐ Yes, once ☐ Yes, several times ☐ No	19.6
b. Are there any notes about the dying process in the nursing notes?	☐ Yes ☐ No ☐ Stopping of intensive care therapy	19.1 19.2
c. Are there any notes about the occurrence of death in the nursing notes?	☐ Yes ☐ No	
d. Are there any notes about the time after death in the nursing notes?	☐ Yes ☐ No	
1.2 Physicians' notes		
a. Are there any notes about the re-assessment of care decisions and interventions in the dying phase in the physician's notes?	☐ Yes, once ☐ Yes, several times ☐ No	19.6
b. Are there any notes about the dying process in the physician's notes?	☐ Yes ☐ No ☐ Stopping of intensive care therapy	19.1 19.2
e. Are there any notes about the moment of death in the physician's notes n?	☐ Yes ☐ No	
c. Are there any notes about the time after death in the physician's notes?	☐ Yes ☐ No	

Domain 2: Medication and interventions

Items (n=15)	Option	Guideline Recommendation Number (EC) or Quality indicator (QI) [12]
2.1 Monitoring and treatment		
a. Was an implanted cardioverter-defibrillator (ICD) deactivated?	☐ No ☐ Yes ☐ No ICD ☐ No information about de-activation	19.36
b. Were vital signs routinely measured and documented?	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	19.33 19.34
c. Was the blood glucose level (routinely) monitored?	☐ Not planned ☐ Stopped ☐ Continued ☐ Started	

	☐ Not reported	
d. Was oxygen therapy given?	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	8.18
e. Was antibiotic therapy given?	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	19.31 19.33
f. Has dialysis/peritoneal dialysis or hemofiltration been performed? (7 days prior death)	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	19.33
g. Was mechanical ventilation been performed? (7 days prior death)	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	19.33
h. Has chemotherapy/immunotherapy/oral tumour therapy/radiotherapy been administered? (14 days prior death)	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	19.32 QI 6
2.2 Medication for symptom control		
a. Were medications of the following substance classes prescribed?	☐ Opioids ☐ Antipsychotics ☐ Benzodiazepines ☐ Anticholinergics ☐ Multiple answers ☐ No	19.17 19.28 19.31
b. Were medications of the following substance classes administered?	☐ Opioids ☐ Antipsychotics ☐ Benzodiazepines ☐ Anticholinergics ☐ Multiple answers ☐ No	
2.3 Sedation		
a. Was "palliative sedation" carried out?	☐ Yes ☐ No ☐ Not reported	19.31 19.37
b. Was deep continuous sedation, that was started before the dying process, carried out?	☐ Yes ☐ No ☐ Not reported	
2.4 Artificial nutrition and hydration		
a. Are there any notes that the need for artificial nutrition or hydration was assessed?	☐ Yes ☐ No	19.38
b. Are there any notes that artificial nutrition was administered enteral or parenteral?	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	
c. Are there any notes that artificial hydration was administered?	☐ Not planned ☐ Stopped ☐ Continued ☐ Started ☐ Not reported	

Domain 3: Information and involvement of patients and informal caregivers

Items (n=20)	Option	Guideline Recommendation Number (EC) or Quality indicator (QI) [12]
3.1 Patients’ information about impending death		
a. Are there any notes that the patient was informed that the patient is dying?	☐ Yes ☐ No ☐ Not able to communicate	19.7
b. Are there any notes that the patient was informed about changes to be expected in the dying phase?	☐ Yes ☐ No ☐ Not able to communicate	
c. Are there any notes how the patient reacted to the impending death?	☐ Yes ☐ No ☐ Not able to communicate	
3.2 Informal caregivers’ information about patients’ impending death		
a. Are there any notes that the informal caregivers were informed that the patient is dying?	☐ Yes ☐ No ☐ No informal caregivers	19.7
b. Are there any notes that the informal caregivers were informed about changes to be expected in the dying phase?	☐ Yes ☐ No ☐ No informal caregivers	
c. Are there any notes on how the informal caregivers reacted on patients impending death?	☐ Yes ☐ No ☐ No informal caregivers	
3.3 Involvement and support of informal caregivers		
a. Are there any notes that the informal caregivers could participate in the care of the dying patient according to their resources and wishes?	☐ Yes ☐ No ☐ No informal caregivers	19.5 19.8
b. Are there any notes that the informal caregivers received support offers from health care professionals?	☐ Yes ☐ No ☐ No informal caregivers	
3.4 Involvement and consideration of patients’ wishes		
a. Are there any notes that the patient had the opportunity to talk about wishes or aspects important to him?	☐ Yes ☐ No ☐ Not able to communicate	19.5
b. If the patient has not been able to verbalize: Are there any notes that the patient's wishes, feelings and needs were observed and assessed through facial expressions, gestures, breathing, muscle tone, eye contact, movement patterns, reactions, and para-verbal sounds?	☐ Yes ☐ No ☐ Patient able to communicate	19.9
c. Are there any notes that the expressed patient’s wishes, principles were considered in the treatment?	☐ Yes ☐ No	
3.5 Shared decision making		

a. Are there any notes whether the goal-of-care was agreed with the patient?	☐ Yes ☐ No ☐ Patient not able to communicate	19.5 4.7
b. Are there any notes that the presumed will of the patients who was unable to communicate has been assessed?	☐ *Yes, via living will* ☐ *Yes, via informal caregivers* ☐ *Yes, via health care professionals* ☐ *Yes, via legal guardian* ☐ *Yes, multiple answers* ☐ *No*	
c. Are there any notes whether goals of care were agreed with informal caregivers?	☐ Yes ☐ No ☐ No informal caregivers	
3.6 Informal carers' presence at patients' death		
a. Are there any notes that informal caregivers were present when the patient died?	☐ Yes ☐ No ☐ No informal caregivers	19.40
b. Are there any notes that informal caregivers, that were not present when the patient died, were able to say goodbye?	☐ Yes ☐ No ☐ No informal caregivers	
3.7 Information of informal caregivers about patient's death		
a. Are there any notes that informal caregivers were informed the patient's death?	☐ Yes, nurse ☐ Yes, physician ☐ Yes, others ☐ No ☐ No informal caregivers	19.39
b. Are there any notes about the circumstances of the information about the patient's death to the informal caregivers?	☐ Yes ☐ No ☐ No informal caregivers	
3.8 Indications after death		
a. Are there any notes of what happened after patients' death?	☐ Yes ☐ No	19.40 19.41
b. Are there any notes that the informal caregivers were informed about the next steps after patient's death?	☐ Yes ☐ No ☐ No informal caregivers	
c. Is there information that informal caregivers were able to say goodbye in accordance to their needs and resources after patients' death?	☐ Yes ☐ No ☐ No informal caregivers	

Domain 4: Symptom assessment

Items (n=3)	Option	Guideline Recommendation Number (EC) or Quality indicator (QI) [12]
Assessment of pain and other symptoms		
a. Were symptoms assessed?	☐ Yes, via clinical evaluation ☐ Yes, via assessment tool ☐ Yes, via both clinical evaluation and assessment tool ☐ No	QI 2 9.1 9.2 9.3 19.12 19.14 19.25 19.26
b. Please use free text to list the symptoms that were assessed clinically: e.g. anxiety, breathlessness, sleep disturbances, delirium	*Free text*	
c. Was a symptom assessment carried out?	☐ Yes, via NRS ☐ Yes, via MIDOS ☐ Yes, via IPOS ☐ Yes, via HOPE ☐ Yes, via VAS ☐ Yes, via VRS ☐ Yes, via Delir Score ☐ Yes, via Smiley-Scale ☐ Yes, via BPS ☐ Yes, via another tool ☐ Multiple answers ☐ No	

Domain 5: Involvement of specialized palliative care (7 days prior death)

Items (n=1)	Option	Guideline Recommendation Number (EC) or Quality indicator (QI) [12]
Was the hospital palliative care support team involved in the patients' care?	☐ Yes ☐ No	QI 11

Domain 6: Goals-of-care

Items (n=8)	Option	Guideline Recommendation Number (EC) or Quality indicator (QI) [12]
6.1 Change of goals-of-care		
a. Was a change of goal-of-care documented?	☐ Yes ☐ No ☐ Termination of resuscitation/surgery	4.7 6.15 6.16 6.17 6.18 6.19
b. Are there any notes, that escalation / enouncement of life-sustaining therapy	☐ Yes ☐ No	

and interventions has been determined?		19.43
c. Are there any notes, that de-escalation/enouncement of life-prolonging or -sustaining therapy has been determined?	☐ Yes ☐ No	
d. Are there any notes, that escalation or new life-prolonging or -sustaining therapy has been determined?	☐ Yes ☐ No	
e. Please use free text to list terms that were used to describe the naming of superordinate concepts, e.g. symptom-orientated therapy, palliative therapy, best-supportive care?	*Free text answer*	
f. At which time took the change of goal-of-care place?	☐ 0-23h prior death ☐ 24-47h prior death ☐ 48-72h prior death ☐ >72h prior death ☐ No change of goal-of-care ☐ Not reported	
g. At what time was Do-Not-Resuscitate (DNR)/ Do-Not-Intubate established (DNI)?	☐ *Before 3 days prior death* ☐ *During the last 3 days prior death* ☐ *No DNR/DNI documented* ☐ *Not reported*	
6.2 Holistic approach		
a. Are there any notes that other dimensions beyond the physical one was considered in care decisions and interventions?	☐ Yes, following dimensions ☐ No	19.4 19.30

Domain 7: Continuity of care		
Item (n=2)	**Value**	**Guideline Recommendation Number (EC) or Quality indicator (QI) [12]**
7.1 Number of nurses	☐ 1-x ☐ Not reported	19.16 19.27
7.2 Number of physicians	☐ 1-x ☐ Not reported	

**Categories according to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10) ICD-10 Version:2016 (who.int)*

Added after application phase

Deleted

II. Questionnaire used in Working Group Online Survey (Publication 3)

1. Demografische Angaben

Welche Tätigkeit üben Sie auf Ihrer Station aus?

☐ ärztliche Tätigkeit

☐ pflegerische Tätigkeit

☐ psychosoziale / therapeutische / seelsorgerische Tätigkeit

☐ andere Tätigkeit

2. Bitte bewerten Sie folgende Aussagen:

	Trifft gar nicht zu				Trifft voll zu
Ich hatte bereits vor dem ersten Treffen der Arbeitsgruppe eine klare Vorstellung davon, was mich dort erwartet.	○	○	○	○	○
Der zeitliche Umfang der Arbeitsgruppentreffen war passend gewählt.	○	○	○	○	○
Ich konnte meine eigene Meinung/ eigene Themen einbringen.	○	○	○	○	○
Ich konnte meine Gedanken frei äußern	○	○	○	○	○
Ich war zufrieden mit der Organisation der Arbeitsgruppen (Terminvereinbarung, Räume, etc.)	○	○	○	○	○
Ich war zufrieden mit dem Arbeitsgruppenprozess (Durchführung, Vor- und Nachbereitung).	○	○	○	○	○
Meine Erwartungen an die AG wurden insgesamt erfüllt.	○	○	○	○	○
Ich habe anderen Stationsmitarbeitenden von der Arbeitsgruppe erzählt.	○	○	○	○	○
Ich würde mich erneut bereit erklären, an der Arbeitsgruppe teilzunehmen.	○	○	○	○	○
Die Zusammenarbeit zwischen Arbeitsgruppe und dem Forschungsteam hat gut funktioniert.	○	○	○	○	○
Das Forschungsteam war kompetent.	○	○	○	○	○
Ich war insgesamt zufrieden mit der Arbeit des Forschungsteams.	○	○	○	○	○
Ich war zufrieden mit dem Ergebnis der Arbeitsgruppen.	○	○	○	○	○
Ich war zufrieden mit der Auswahl der Maßnahmen zur Verbesserung der Sterbephase auf unserer Station.	○	○	○	○	○

Es hat gut funktioniert, die in der Arbeitsgruppe entwickelten Maßnahmen auf der Station umzusetzen.	○	○	○	○	○
Ich würde anderen Stationen empfehlen, Maßnahmen zur Verbesserung der Sterbephase im Rahmen einer solchen Arbeitsgruppe zu entwickeln.	○	○	○	○	○

3. Offene Fragen

Was war Ihre Motivation, an der Arbeitsgruppen teilnehmen?

Was haben Sie daraus mitgenommen?

Haben Sie Verbesserungsvorschläge in Bezug auf die Organisation und Durchführung der Arbeitsgruppen?

Wenn ja, welche?

III. Schriftliche Erklärung zum geleisteten Beitrag

Publikation 1:

Kaur S, Boström K, Ullrich A, Oubaid N, Oechsle K, Schulz H, Voltz R, Kremeike K. Health Experts' Perspectives on Barriers, Facilitators, and Needs for Improvement of Hospital Care in the Dying Phase. International Journal of Clinical Practice. 2024;2024(1):1012971.

Die Doktorandin, Sukhvir Kaur, leistete wesentliche Beiträge zur Datenauswertung. Sie bereinigte, analysierte und interpretierte die Daten, dabei wandte sie eine von ihr ausgewählte Methode an und schrieb den Manuskriptentwurf. Sie überarbeitete den Entwurf gemäß den Rückmeldungen der Co-Autor:innen und übernahm den Prozess der Einreichung und Revision des finalen Manuskripts

Publikation 2:

Kaur S, Meesters S, Schieferdecker A, Dangendorf A, Strohbücker B, Oubaid N, Ullrich A, Milke V, Oechsle K, Schulz H, Voltz R, Kremeike K. How to Evaluate Hospital Care in the Dying Phase—Development of a Data Extraction Tool for Retrospective Medical Record Analysis. Journal of Evaluation in Clinical Practice. 2025;31(5):e70174.

Die Doktorandin, Sukhvir Kaur, leistete wesentliche Beiträge zum Studiendesign, zur Erhebung der Patient:innenakten an der Uniklinik Köln und der Datenauswertung. Sie war an der Extraktion der Daten aus den Akten der Uniklinik Köln beteiligt und interpretierte die Daten, dabei wandte sie eine von ihr ausgewählte Methode an und schrieb den Manuskriptentwurf. Sie überarbeitete den Entwurf gemäß den Rückmeldungen der Co-Autor:innen und übernahm den Prozess der Einreichung und Revision des finalen Manuskripts

Publikation 3:

Meesters S*, **Kaur S***, Milke V, Herrmann C, Schieferdecker A, Oubaid N, Oechsle K, Schulz H, Pfaff H, Voltz R, Kremeike K. Formative evaluation of an employee-driven approach to improve care in the dying phase in hospitals. Palliative and Supportive Care. 2025;23:e135.

Dr. Sophie Meesters und die Doktorandin, Sukhvir Kaur, leisteten beide wesentliche Beiträge zum Studiendesign und führten die Konzeption, Organisation und Umsetzung des Arbeitsgruppenprozesses an der Uniklinik Köln durch. Sie erhoben, bereinigten, analysierten und interpretierten die Daten des Arbeitsgruppenprozesses. Dabei wandten sie eine von ihrer ausgewählten Methode an und schrieben den Manuskriptentwurf. Sie überarbeiteten den Entwurf gemäß den Rückmeldungen der Co-Autor:innen. Sukhvir Kaur übernahm den Prozess der Einreichung, beide übernahmen die Revision des finalen Manuskripts.

IV. Eigenerklärung

Hiermit versichere ich an Eides statt, dass ich die vorliegende Dissertationsschrift selbstständig und ohne die Benutzung anderer als der angegebenen Hilfsmittel angefertigt habe. Alle Stellen - einschließlich Tabellen, Karten und Abbildungen -, die wörtlich oder sinngemäß aus veröffentlichten und nicht veröffentlichten anderen Werken im Wortlaut oder dem Sinn nach entnommen sind, sind in jedem Einzelfall als Entlehnung kenntlich gemacht. Ich versichere an Eides statt, dass diese Dissertationsschrift noch keiner anderen Fakultät oder Universität zur Prüfung vorgelegen hat; dass sie - abgesehen von unten angegebenen Teilpublikationen - noch nicht veröffentlicht worden ist sowie, dass ich eine solche Veröffentlichung vor Abschluss der Promotion nicht ohne Genehmigung der / des Vorsitzenden des IPHS-Promotionsausschusses vornehmen werde. Die Bestimmungen dieser Ordnung sind mir bekannt. Die von mir vorgelegte Dissertation ist von Prof. Dr. Raymond Daniel Voltz betreut worden.

Darüber hinaus erkläre ich hiermit, dass ich die Ordnung zur Sicherung guter wissenschaftlicher Praxis und zum Umgang mit wissenschaftlichem Fehlverhalten der Universität zu Köln gelesen und sie bei der Durchführung der Dissertation beachtet habe und verpflichte mich hiermit, die dort genannten Vorgaben bei allen wissenschaftlichen Tätigkeiten zu beachten und umzusetzen.

Übersicht der Publikationen

- Kaur S, Boström K, Ullrich A, Oubaid N, Oechsle K, Schulz H, Voltz R, Kremeike K. Health Experts' Perspectives on Barriers, Facilitators, and Needs for Improvement of Hospital Care in the Dying Phase. International Journal of Clinical Practice. 2024;2024(1):1012971.
- Kaur S, Meesters S, Schieferdecker A, Dangendorf A, Strohbücker B, Oubaid N, Ullrich A, Milke V, Oechsle K, Schulz H, Voltz R, Kremeike K. How to Evaluate Hospital Care in the Dying Phase—Development of a Data Extraction Tool for Retrospective Medical Record Analysis. Journal of Evaluation in Clinical Practice. 2025;31(5):e70174.
- Meesters S*, Kaur S*, Milke V, Herrmann C, Schieferdecker A, Oubaid N, Oechsle K, Schulz H, Pfaff H, Voltz R, Kremeike K. Formative evaluation of an employee-driven approach to improve care in the dying phase in hospitals. Palliative and Supportive Care. 2025;23:e135.

Ich versichere, dass ich alle Angaben wahrheitsgemäß nach bestem Wissen und Gewissen gemacht habe und verpflichte mich, jedmögliche, die obigen Angaben betreffenden Veränderungen, dem IPHS-Promotionsausschuss unverzüglich mitzuteilen.

23.02.2026
Datum

Unterschrift