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***Understanding Quality – Characteristics of  
Specialist Palliative Care in Crisis Contexts and Beyond***

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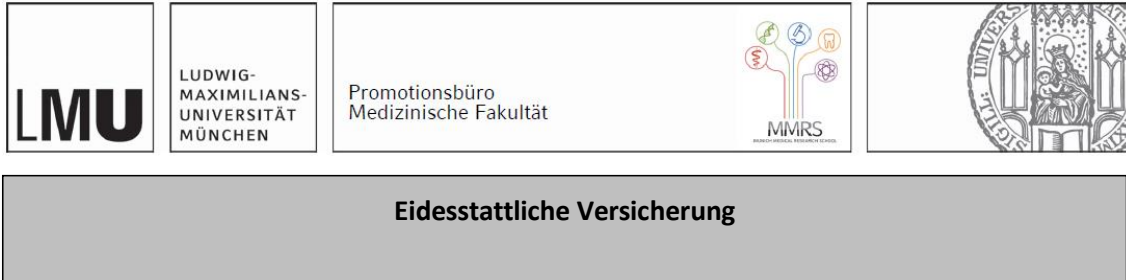
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Ludwig-Maximilians-Universität München

Erstes Gutachten: Prof. Dr. med. Claudia Bausewein  
Zweites Gutachten: Prof. Dr. Georg Marckmann  
Drittes Gutachten: Prof. Dr. Clemens-Martin Wendtner

Dekan: Prof. Dr. med. Thomas Gudermann

Tag der mündlichen Prüfung: 09.09.2024

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**List of abbreviations**

|            |  |
|------------|--|
| WHO        | World Health Organization                            |
| DRG        | Diagnosis Related Groups                             |
| SARS-COV-2 | Severe Acute Respiratory Syndrome Coronavirus type 2 |

## List of publications

### Paper I

**Wikert J**, Gesell D, Bausewein C, Jansky M, Nauck F, Kranz S, Hodiamont F (2022). Specialist palliative care classification: typology development. *BMJ Supportive and Palliative Care*. doi:10.1136/bmjspcare-2021-003435

### Paper II

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- **Wikert J**. Proxy-Assessments bei Patient:innen in der spezialisierten Palliativversorgung – Herausforderungen und Chancen. (accepted for 15. Kongress der Deutschen Gesellschaft für Palliativmedizin, 2024, Aachen)
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- **Wikert J**, Gesell D, Jansky M, Lehmann-Emele E, Bausewein C, Nauck F, Hodiamont F. Specialist Palliative Care in Germany: Comparing Patient Characteristics and Symptom Burden. (18th World Congress of the European Association for Palliative Care, 2023, Rotterdam)
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- **Wikert J**, Bausewein C, Hodiament F. Die ‚Wicked Problems‘ der spezialisierten Palliativversorgung während der COVID-19 Pandemie. (14. Kongress der Deutschen Gesellschaft für Palliativmedizin, 2022, Bremen)
- **Wikert J**, Bausewein C, Hodiament F. Taming Wicked Problems - Structure and Process Characteristics of Specialist Palliative Care During the COVID-19 Pandemic. (12th World Research Congress of the European Association for Palliative Care, 2022, online)
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- **Wikert J**, Bausewein C, Hodiament F. Attitudes of physicians towards standardized palliative care assessments in oncological inpatient settings. (36. Deutscher Krebskongress, 2024, Berlin)
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- Gesell D, Hodiament F, **Wikert J**, Lehmann-Emele E, Bausewein C, Nauck F, Jansky M. Symptom clusters of oncological patients in specialist palliative home care – What are their needs? (36. Deutscher Krebskongress, 2024, Berlin)
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  - Hodiamont F, Gesell D, Schatz C, Nauck F, Boulesteix AL, Jansky M, Leidl R, Kranz S, **Wikert J**, Melching H, Bausewein C. Das COMPANION Projekt – Komplexität greifbar machen. (13. Kongress der Deutschen Gesellschaft für Palliativmedizin, 2020, online)

## **1. Individual contribution of the author**

The author of this thesis contributed to the concept, design, and conduct of both studies. She was significantly involved in all steps of the research, including the development of material (e.g., interview guides, participant information), preparation of the study (e.g., ethical approval, data protection approval), data collection and analysis, and dissemination of results. As the first author of both publications, she was responsible for writing the manuscripts and the whole publication process, including editing and reviewing.

### **1.1 Contribution to Paper I**

JW collected the data and drafted the manuscript with input from all authors. FH and JW analysed and interpreted the results. CB and FH developed the main conceptual idea for the overall project (COMPANION), contributed to analysis and interpretation of results, and supervised the study. DG, CB, MJ, FN, SK, and FH provided critical comments on drafts of the manuscript and approved the manuscript in its final version. JW was responsible for the overall content as the guarantor.

### **1.2 Contribution to Paper II**

JW developed the main conceptual idea for the project. FH and JW contributed to development of study design and interview guide. FH and CB supervised the study. JW independently conducted the interviews, and drafted the manuscript with input from all authors. FH and JW analysed and interpreted the results. All authors provided critical comments on drafts of the manuscript and approved the manuscript in its final version.

## 2. Introduction

*“More often one needs to ask, ‘What goes on here?’ rather than, ‘What is wrong; and how can it be made better?’” - Avedis Donabedian<sup>1</sup>*

### 2.1 Defining Quality

In contemporary healthcare, the study and implementation of quality have become pivotal areas of both academic research and practical application.<sup>2</sup> Quality assessment in healthcare depends on a clear definition of the quality term, a concept challenging to define universally.<sup>1,3</sup> Generally speaking, quality could be considered merely descriptive when it denotes the essence or property of things.<sup>4</sup> However, as a key principle of national and international health policy, definitions go far beyond a pure description and encompass different dimensions of quality.<sup>5</sup> According to the World Health Organization (WHO), the quality of healthcare services is vital for achieving effective universal health coverage. At the same time, reversely, a substantial number of annual deaths worldwide and economic losses are attributed to poor quality care.<sup>6</sup> “[T]he degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with evidence-based professional knowledge”<sup>7</sup> is what the WHO defines as quality of care. Beyond that, it is broadly agreed that quality health services shall conform to the core dimensions of effectiveness, safety, and patient-centeredness.<sup>2</sup> At the same time, ‘good’ healthcare includes access, appropriateness, timeliness, equity, and efficiency.<sup>2</sup> Quality does not arise spontaneously and naturally but requires thorough planning and control.<sup>6</sup> Thus, selecting specific dimensions and criteria to approach quality enters center stage in healthcare quality and significantly shapes the quality management strategies used.<sup>1,2</sup>

#### 2.1.1 Quality dimensions in healthcare

Despite the various definitions of quality of care, there is broad agreement on its importance and that an understanding of its components is essential.<sup>2,3</sup> Introduced by Donabedian's seminal framework, the conceptual triad of structure-process-outcome has provided a comprehensive tool for quality measurement and evaluation.<sup>1,8</sup> According to the Donabedian quality-of-care model, structure is defined as the organizational requirements and features of the setting, in which care is provided.<sup>9</sup> Structure is presumed to affect the process of care, which refers to the actions and interactions of healthcare professionals, patients, and other individuals involved in providing and receiving care.<sup>9,10</sup> Eventually, outcome is described as the consequence of structure and process of care in terms of end results of care, while acknowledging the interrelatedness of the three

categories.<sup>1</sup> Donabedian's framework has been widely applied in healthcare contexts.<sup>11-13</sup> The general triad of structure-process-outcome remains significant for quality measurement and control in healthcare. However, the risk of a reductionist oversimplification of Donabedian's model has recently been discussed by Berwick and Fox.<sup>14</sup> They argue that the increasingly important aspects of patient-centeredness as well as new technology in healthcare are missing in the previous framework.<sup>14</sup> Furthermore, the authors emphasize the importance of a holistic perspective on healthcare as a system including several stakeholders involved. According to Berwick and Fox, this undeniable fact goes beyond Donabedian's description of quality and calls for further research and a deeper understanding of healthcare quality.<sup>14</sup> Nevertheless, the inherent link and complex interplay of structures and processes with outcomes is, in general, undoubted. It becomes obvious that quality management protocols need to rest not only on effects but first of all on structural and procedural characteristics to ultimately enhance quality of care.<sup>10</sup>

Consequently, a judicious selection of these characteristics is imperative to underpin the systematic documentation and representation of healthcare quality in a normative context. Structural characteristics include the tangible infrastructural foundations, resource allocations, and organizational frameworks that undergird the delivery of care. Concurrently, process characteristics encompass the complicated composition of healthcare delivery, including the interplay of multidisciplinary teams, clinical protocols, communication protocols, and the synthesis of therapeutics. The determination of measurable outcomes is a common component of efforts to ensure quality in healthcare. However, several considerations limit the use of outcomes as an exclusive measure of quality.<sup>10</sup> The first central question is whether the outcome of care is, in fact, the relevant measure. Even in situations where outcomes are relevant, and the relevant outcome has been chosen as a criterion, limitations must be reckoned with. Many factors other than medical care may influence outcomes, and precautions must be taken to hold all significant factors other than medical care constant if valid conclusions are to be drawn. Further, according to Donabedian, outcomes are typically delayed in nature, meaning that long periods, perhaps decades, must elapse before relevant results become manifest.<sup>10</sup> Limiting quality assessment to outcome measures without controlling structural and procedural influences will rarely allow for a precise identification and localization of the underlying causes. Some outcomes, e.g., patient attitudes or social restoration, cannot easily be standardized and might be difficult to measure.<sup>15, 16</sup>

Even easy-to-measure and seemingly unmistakable outcomes, like death, are not suitable for evaluating the quality of all health service areas, e.g., palliative care. Moreover, apart from particular operationalized standards, the determination and assessment of quality usually rely on the perspective of the observer.<sup>4, 17</sup> Further, the assessment of

outcomes covers a broad spectrum, considering the impact on patients, professionals, and the organization as a whole.<sup>18</sup> The concepts of success and failure are not rigid but interpreted and judged according to specific circumstances. The presence of multiple demands and a complex array of stakeholders with varying needs leads to the prioritization and potential compromise of goals to achieve outcomes that seem acceptable within the given context.<sup>19, 20</sup> This context includes factors such as patient demographics, the expertise and availability of staff, time constraints, and patient numbers.<sup>20</sup> For instance, achieving the ideal patient experience may not be feasible during periods of high patient influx with unexpected intensive care requirements. In such scenarios, healthcare teams are often required to balance and make decisions between competing objectives to attain the most favorable outcomes. The diverse and changing perspectives of patients, professional and informal caregivers, and policy also influence the prioritization of these goals.<sup>16, 20</sup> Despite these limitations to the use of outcomes as criteria of care, they frequently remain the ultimate validator of the effectiveness and quality of care.<sup>17, 19</sup> However, the use of outcomes requires discrimination, benchmarking, and the careful consideration of influential structures and processes.<sup>17</sup> Chapter 2.2 refers to quality in palliative care under particular consideration of the quality dimensions of structure, process, and outcome quality.

### **2.1.2 Complexity and resilience in healthcare**

Healthcare is considered a complex adaptive system<sup>21</sup>, including human and nonhuman agents, including individuals (healthcare professionals, patients, policymakers), teams, organizational units, structures, equipment, and technologies, all of which constantly interact to pursue high quality.<sup>22, 23</sup> As outcomes represent the product of the complex, non-linear interactions within the complex adaptive system, the effect of inputs, like any quality improvement action, is hard to predict.<sup>21</sup> Researchers, managers, and policymakers increasingly acknowledge complexity as a central characteristic of healthcare systems.<sup>23, 24</sup> Nevertheless, quality improvement protocols in healthcare mostly still address discrete, past problems linearly, which is contradictory to the understanding of healthcare as a complex adaptive system.<sup>25</sup> In contrast to this find-and-fix model, where problems are pre-defined and subsequently solved, more proactive approaches to understanding and sustaining quality in complex adaptive systems gain importance.<sup>21</sup> Over the past decade, resilience engineering has emerged as an innovative approach to quality management in various disciplines.<sup>26</sup> The term refers to cautiously designing and construct-

ing systems in a way to gain resilience.<sup>27</sup> As a well-established concept in disaster management and crisis risk reduction, resilience is increasingly applied to health system debates, referred to as resilient healthcare.<sup>28, 29</sup> Central to resilience engineering is the emphasis on a system's ability to navigate complexity and adapt to fluctuating conditions, both expected and unexpected.<sup>28</sup> Extensive discussions of resilient healthcare and resilience engineering are beyond the scope of this dissertation; however, three key points are notable: First, from an resilient healthcare perspective, problems are shapeable challenges and ideally anticipated before they occur.<sup>30</sup> Secondly, outcomes are not perceived as endpoints; instead, they potentially affect all other aspects of the complex adaptive system within recursive structures. Thirdly, the complexity perspective applied in resilient healthcare reflects the common unpredictability of clinical work, frequent need for structural adjustment, and constant need for flexible process adaptation.<sup>27, 31</sup> During crises, health system resilience is demonstrated by effectively adapting to changing circumstances and minimizing vulnerabilities throughout the system and beyond.<sup>32</sup> The imperative resulting from complex adaptive systems and resilient healthcare perspectives is to move beyond isolated specifications of preferred outcomes in favor of holistic improvement efforts, which address all components of quality.

## **2.2 Quality in palliative care**

### **2.2.1 Palliative care landscape in Germany**

Over the last decades, palliative care has gained importance in healthcare, both nationally and internationally.<sup>33, 34</sup> In Germany, palliative care structures are established in the community setting and inpatient settings, further subdivided into general palliative care and specialist palliative care.<sup>35-37</sup> General palliative care is usually provided by general practitioners, community nursing staff, and/or hospice services in the community, as well as general hospital departments or in nursing homes by healthcare professionals familiar with basic palliative care knowledge.<sup>36</sup> This level of care appropriately meets the needs of most individuals at the end of life. However, when care needs escalate, and thus require more complex and specialized care approaches, it is essential to initiate specialist palliative care. Multidisciplinary teams of highly qualified and experienced healthcare professionals provide specialist palliative care in inpatient palliative care units, as palliative care advisory teams in hospitals, and as specialist palliative home care teams in the community, to the minority of terminally ill patients reliant on this evolved type of palliative care.<sup>34, 37</sup>

### 2.2.2 Quality development in German specialist palliative care

So far, Germany lacks an established, evidence-based method to differentiate patients based on the complexity of their needs to identify those who need specialist palliative care systematically.<sup>38</sup> The main system for patient differentiation is the Diagnosis-Related-Groups (DRG) system, which predominantly considers economic aspects, revenue generation, and a minimum of defined structural parameters while sidelining outcome parameters.<sup>39, 40</sup> The national “S3 Guideline on Palliative Care for Patients with Incurable Cancer” recommends a comprehensive assessment of patient needs, symptom/problem prevalence and burden, and information needs, using validated multi-dimensional tools to best define the complexity of the care situation as a key determinant for the appropriate palliative care setting.<sup>41</sup> However, the application of outcome indicators to palliative care services is sophisticated, because adjustments for differences in case mix are required to ensure fair comparisons among services.<sup>17, 42</sup> Focused efforts are underway to develop a patient-oriented, nationally applicable complexity and case mix classification for adult palliative care patients in Germany to describe concise indicators for resource use and associated costs in palliative care.<sup>38</sup> Furthermore, the German Association for Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin) took initial steps by establishing a certification for palliative care units (established in 2017) and palliative care advisory teams (established in 2023), facilitating the comparability of services.<sup>43, 44</sup> As mentioned before, defined key performance indicators in German specialist palliative care are limited and merely base on financing systems and according requirements.<sup>40</sup> Furthermore, due to extensive variations in regulatory structures and financing systems, specialist palliative care services within the three settings palliative care unit, palliative care advisory teams, and specialist palliative home care remain considerably heterogeneous, characteristics remain unclear and cannot be controlled, which impedes quality development.<sup>35</sup> For sustainable quality progress in specialist palliative care, it is imperative to fully understand and describe the respective care models. Hence, structures and processes could serve as control variables in the prospective comparison of outcome quality, e.g., for benchmarking.<sup>45, 46</sup> Notwithstanding the central domain of outcomes, it is essential to first define what constitutes good quality care. Only after establishing these standards, the outcomes, which are central to quality assessment, can be effectively measured and analyzed.<sup>47</sup> Accordingly, challenges in the context of quality control in German palliative care seem to be rooted in an insufficient understanding of specialist palliative care at the structural and procedural level. There have been continuous efforts to develop sets of quality indicators for palliative care.<sup>48</sup> These have, however, not been described in detail and often been limited to a certain country or context of care, e.g. cancer patients in hospitals.<sup>48</sup> A comprehensive description of characteristics is certainly

required beyond the benefit of quality assurance.<sup>49</sup> It transparently reveals the heterogeneity of specialist palliative care services and enables the identification of structures and processes relevant to quality enhancement.<sup>45, 46, 49</sup> This not-yet-achieved clarity will highlight structures and processes crucial for the sustainable design and delivery of specialist palliative care services, which allows for adaptations as required.

### **2.2.3 The SARS-CoV-2 pandemic – A resilience test for specialist palliative care**

This dissertation has been written at a time when the Severe Acute Respiratory Syndrome Coronavirus type 2 (SARS-CoV-2) pandemic hugely disrupted healthcare systems across the world, including specialist palliative care in Germany. As recognized by the WHO, quality health services are crucial during healthcare emergencies and crises like the pandemic.<sup>50</sup> The continued provision of high-quality palliative care in the highly stressful context of infection control measures and resource scarcity proved extremely challenging.<sup>51</sup> Unlike for other problems, there was hardly any evidence for a specific suitable model of palliative care in circumstances of healthcare emergencies like the pandemic. Although previous disease outbreaks led to various reports about the potential role of (specialist) palliative care and arising problems, no systematically specified lessons learned had been published.<sup>51</sup> Sliding into the SARS-CoV-2 pandemic, it therefore became more important than ever to explore, reflect, and share experiences of specialist palliative care services during this special crisis. Carefully addressing the structures and processes of specialist palliative care appeared to be the only way to anticipate similar future challenges. However, most emerging research projects focused on either insight into the palliative care needs of patients diagnosed with the coronavirus disease or on individual, separate problems, and developments in palliative care provision.<sup>52-54</sup> Furthermore, studies mainly reported on a specific specialist palliative care setting, specific country or reported on the SARS-CoV-2 pandemic without abstracting the main ideas to a transferable, theoretical understanding.<sup>55-57</sup> To provide long-lasting and helpful guidance for future crises it seemed insufficient to describe single impacts of the SARS-CoV-2 pandemic on the individual, country-, and setting-specific level. Considerations of mechanisms should, moreover, include the institutional/meso as well as clinical/micro level of care.<sup>58</sup> Hence, a holistic, conceptual understanding of the impact on specialist palliative care related to the pandemic was required to inform future decisions.

## **2.3 Aims and objectives of this thesis**

The overarching aim of this thesis is to contribute to the further development of quality management and control within the heterogeneous German specialist palliative care



landscape by providing more clarity about important structure and process characteristics.

To answer this aim, a classification in the form of a typology including relevant characteristics has been developed for the description and differentiation of specialist palliative care services in Germany as a first objective. The development process and results of this study are described in detail in the first publication (Chapter 5) of this thesis.

The second publication of this thesis (Chapter 6) represents a qualitative study, aiming at the development of a conceptual understanding of the impact of the SARS-CoV-2 pandemic on structures and processes in specialist palliative care as an example for arising future crises.

**Chapter 5** refers to a qualitative study on creating a comprehensive classification for specialist palliative care services in Germany. The methodology involved the development of a preliminary list of structural and processual characteristics through a literature review, as well as expert interviews, and focus groups conducted between May 2020 and January 2021.

Recognizing the heterogeneity of specialist palliative care, the study suggests using a polyhierarchical approach, like a typology, for better description and differentiation of services. The results led to the identification of several key characteristics, forming the basis of a new typology. This advanced classification provides a refined understanding of the different specialist services within the German palliative care landscape, which is seen as crucial for improving international comprehension and development of specialist palliative care.

**Chapter 6** refers to a constructivist grounded-theory study aimed at a theoretical understanding of how crises affect specialist palliative care, as shown by the example of the SARS-CoV-2 pandemic. This qualitative study across Germany included 23 episodic interviews with healthcare professionals in specialist palliative care settings, conducted between May 2020 and June 2021. In addition, particular pandemic-related parts of the eleven expert interviews from the typology study<sup>45</sup> (Chapter 5) were included to triangulate different perspectives. The findings reveal that the complex nature of palliative care in a crisis cannot be fully understood by examining its separate components. Regarding the different specialist palliative care settings, more similarities than differences were revealed when dealing with crises like the pandemic. Crises lead to unique challenges for specialist palliative care and teams experienced different phases during the pandemic. Key factors aiding proactive team development included access to information, transparent communication, clear instructions, involvement in decision-making, and col-

laborative solution-finding. The study showed that addressing the complex issues in specialist palliative care during crises like a pandemic requires system thinking and a learning approach, enabling teams to advance and evolve rather than just returning to pre-crisis structures and processes.

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### 3. Zusammenfassung

Weltweit befassen sich politische Entscheidungsträger, Gesundheitsdienstleister und Forschungseinrichtungen systematisch mit Fragen der Versorgungsqualität, einschließlich Strukturen, Prozessen und gewünschten Ergebnissen. Die Bedeutung und Notwendigkeit resilienter Gesundheitssystemstrukturen und agiler Prozesse zur Aufrechterhaltung und Verbesserung der Versorgungsqualität werden durch die sich entwickelnden globalen Herausforderungen, einschließlich aktueller und zu erwartender Krisen, unterstrichen. Vor diesem Hintergrund zielt die vorliegende Dissertation darauf ab, zum laufenden Diskurs über die Qualität in der spezialisierten Palliativversorgung beizutragen, indem sie Einblicke in die heterogenen Strukturen und Prozesse der deutschen spezialisierten Palliativversorgung (Paper I) liefert und ein umfassendes Verständnis der spezialisierten Palliativversorgung während Krisen vermittelt (Paper II). Um Optimierungen erfolgreich und nachhaltig voranzutreiben, erfordern alle Qualitätskomponenten standardisierte Dokumentation und kontinuierliche Überwachung. In Bezug auf das Qualitätsmanagement in der spezialisierten Palliativversorgung ist es unerlässlich, die Merkmale von Diensten zu identifizieren und zu konzeptualisieren, die eine Differenzierung ermöglichen. Dieses grundlegende Verständnis stellt den ersten Schritt für alle Bemühungen zur Qualitätsverbesserung dar.

Aus diesem Grund trägt das erste Paper (Paper I) dieser Dissertation zur klaren Beschreibung der Struktur- und Prozessmerkmale der spezialisierten Palliativversorgung bei, indem es eine typologische Klassifikation für jede der drei jeweiligen spezialisierten Versorgungssettings (Palliativstationen, Palliativdienste, spezialisierte ambulante Palliativversorgung) präsentiert. Im Rahmen einer qualitativen Studie mit 11 Expert:inneninterviews und zwei Fokusgruppen wurden Schlüsselmerkmale identifiziert, die eine Differenzierung innerhalb der spezialisierten Palliativversorgung ermöglichen. Dazu wurden wörtliche Transkripte und Feldnotizen der Interviews inhaltsanalytisch ausgewertet, um eine vorläufige Klassifikation für jedes Setting zu entwickeln. Diese vorläufigen Versionen wurden in den setting-spezifischen Fokusgruppen hinsichtlich notwendiger Anpassungen und Änderungen diskutiert. Wörtliche Transkripte und Feldnotizen der Fokusgruppen wurden thematisch durch das Forschungsteam analysiert, um die vorläufigen Typologien zu überarbeiten. Anschließend wurde eine Typologie für jedes der drei Settings entwickelt, um die bestehende Differenzierungsebene in der deutschen Palliativversorgungslandschaft zu verfeinern. Die Anwendung einer Typologie zur umfassenden Beschreibung und Differenzierung von Diensten der spezialisierten Palliativversorgung ermöglicht die Weiterentwicklung gezielter Interventionen, effektiver (gesundheitspolitischer) Maßnahmen und Best Practice, um den Bedürfnissen von Patient:innen und ihren Angehörigen in der Palliativversorgung gerecht zu werden.

Angesichts zunehmender nationaler und globaler Krisen steigt die Bedeutung der Fähigkeit von Gesundheitssystemen, sich auf Störungen vorzubereiten und anzupassen. Die Aufrechterhaltung guter Palliativversorgung erfordert Widerstandsfähigkeit, um jegliche negative Auswirkungen von Krisen auf Strukturen und Prozesse zu minimieren. Um die Besonderheiten der spezialisierten Palliativversorgung in Krisenkontexten besser zu verstehen, bietet das zweite Paper (Paper II) ein konzeptionelles Verständnis der spezialisierten Palliativversorgung während Krisen, exemplarisch dargestellt anhand der SARS-CoV2 Pandemie. Im Rahmen einer konstruktivistischen Grounded-Theory-Studie flossen Informationen auf der Meso- und Mikroebene der Versorgung in die entwickelte Theorie ein. Zu diesem Zwecke wurden Expert:inneninterviews zur Mesoebene der Versorgung mit Interviews mit Gesundheitsfachkräften zur Mikroebene der direkten Patient:innenversorgung während der Pandemie kombiniert. Die Datenanalyse folgte einem schrittweisen Ansatz, der fokussiertes und axiales Kodieren, und die systematische Triangulation resultierender Erkenntnisse im Laufe der Analyse umfasste. Die Ergebnisse verdeutlichten die Bedeutung von Systemdenken und ganzheitlichen Ansätzen bei der Problembewältigung in der spezialisierten Palliativversorgung während Krisen. Da Struktur- und Prozessmerkmale grundsätzlich miteinander verbunden sind, sollten die jeweiligen Herausforderungen in Krisensituationen nicht als isolierte Teile beschrieben und adressiert werden. Vielmehr sollten sie als integrierte Elemente des komplexen adaptiven Systems der palliativen Versorgungssituationen betrachtet werden, die flexibles und dynamisches Management erfordern. In Krisensituationen sind herkömmliche Problemlösungsansätze selten geeignet, um Probleme und Herausforderungen in der spezialisierten Palliativversorgung anzugehen. Paper II stellt fünf unterschiedliche Merkmale vor, die strukturelle und prozessuale Herausforderungen in der spezialisierten Palliativversorgung während Krisen prägen: i) Vernetztheit, ii) Unsicherheit, iii) Dynamik, iv) zugrundeliegende Dilemmata und v) unklare langfristige Ziele. Darüber hinaus wurden vier übergreifende, nichtlineare Phasen als Reaktion auf die Herausforderungen identifiziert. Die entwickelte Theorie kann die Vorbereitung von Teams für (externe) Veränderungen und Disruptionen fördern und die kontinuierliche gemeinsame Entscheidungsfindung im interdisziplinären Team anregen. Der Umgang mit veränderten Rahmenbedingungen und die Anpassung an neue Prozesse erfordern widerstandsfähige und flexible Teams. Letztlich kann das verbesserte Verständnis der spezialisierten Palliativversorgung in Krisenkontexten Teams dabei unterstützen, sich weiterzuentwickeln und einen Zustand des Wachstums zu erreichen, anstatt kontinuierlich isolierte Probleme zu beheben.

Zusammenfassend betonen die in dieser Dissertation präsentierten Ergebnisse die Bedeutung eines detaillierten Verständnisses von Struktur- und Prozessmerkmalen zur Bewertung, Sicherung und Verbesserung der Versorgungsqualität, unter Berücksichtigung

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der hohen Komplexität, die palliativen Versorgungssituationen inhärent ist. Operationalisierte Merkmale, wie sie in Typologien enthalten sind, können dazu beitragen, Strukturen und Prozesse zu organisieren, zu verstehen und zu vergleichen, und sollten der erste Schritt sein, wenn es um Fragen der Versorgungsqualität geht. In der realweltlichen Versorgung und insbesondere während Krisenzeiten sind palliative Versorgungssituationen jedoch äußerst komplex, oftmals unbeständig und dynamisch. Daher ist insgesamt ein ganzheitlicheres und flexibleres Rahmenwerk erforderlich, um Teams zu unterstützen und das Qualitätsmanagement während Krisen zu fördern.



## 4. Abstract (English)

Worldwide, policy-makers, healthcare providers, and research institutions systematically address the quality of healthcare including structures, processes, and desired outcomes. The importance and necessity of resilient healthcare structures and agile processes to maintain and enhance the quality of care is underscored by the evolving global health challenges, including recent and anticipated future crises. Against this background, the present thesis aims to contribute to the ongoing discourse on quality in specialist palliative care by providing insights into the heterogeneous structures and processes of German specialist palliative care (paper I) complemented by a comprehensive understanding of specialist palliative care during crises (paper II). To drive improvement successfully, all quality elements require standardized documentation and continual monitoring. Concerning quality management in specialist palliative care, it is imperative to identify and conceptualize the characteristics of services that allow for differentiation. This fundamental understanding represents the initial step of all quality improvement efforts.

For that reason, the first paper (paper I) of this thesis contributes to a clear description of structure and process characteristics of specialist palliative care by presenting a typological classification for each of the three respective settings. In the context of a qualitative study with 11 expert interviews and two focus groups, key characteristics allowing for differentiation of specialist palliative care were identified. Therefore, verbatim transcripts and field notes of the interviews were analyzed using content analysis to develop a preliminary classification for each setting. These provisional versions were discussed regarding the need for adjustment in the setting-specific focus groups. Verbatim transcripts and field notes of the focus groups were analyzed thematically by the research team to revise and adapt the preliminary typologies. Subsequently, a typology for each of the three German specialist palliative care settings (palliative care unit, palliative care advisory teams, specialist palliative home care) has been developed to refine the existing level of differentiation within the German palliative care landscape. Applying a typology to comprehensively describe and differentiate services within specialist palliative care settings allows for the further development of targeted interventions, effective policies, and implementation of best practices to meet the evolving needs of patients and their families in palliative care settings.

In light of unprecedented national and global crises, the ability of health systems and services to prepare and adapt to disruptions increases in importance. Maintaining high-quality palliative care calls for resilience to minimize any negative impact of crises on structures and processes. To better comprehend specialist palliative care in crisis con-

texts, the second paper (paper II) provides a conceptual understanding of specialist palliative care during crises exemplified by the recent SARS-CoV2 pandemic. In the context of a constructivist grounded theory study, information on the meso- and micro-level of care informed the evolving theory. Therefore, expert interviews focusing on the meso-level of care were integrated with interviews with healthcare professionals discussing the micro-level of direct patient care during the pandemic. Data analysis followed a gradual approach including focused and axial coding and emerging findings were systematically triangulated in the course of analysis. The results clearly showed the importance of system-thinking and holistic approaches in addressing specialist palliative care during crises. As structure and process characteristics are genuinely interconnected, the respective challenges of specialist palliative care services in crisis contexts should not be described and approached as isolated parts. Instead, they should be viewed as integrated elements of the complex adaptive system of palliative care situations, calling for flexible, dynamic management. In crisis contexts, traditional ways of problem-solving are rarely suitable to tackle problems and challenges in specialist palliative care. Paper II introduces five distinct characteristics that shape structural and processual challenges in specialist palliative care during crises: i) interconnectedness, ii) uncertainty, iii) dynamic, iv) underlying dilemmas, and v) unclear long-term goal. Moreover, four overarching, nonlinear phases in response to the challenges were identified. The developed theory can facilitate teams' preparedness for disruptions and stimulate ongoing collaborative decision-making within the multidisciplinary team. Coping with changing circumstances and handling new processes require resilient, flexible specialist palliative care teams. Eventually, the enhanced understanding of specialist palliative care during crises can help teams to move forwards and reach a state of growth instead of continuously struggling to only fix isolated problems.

In conclusion, the findings presented in this thesis emphasize the significance of a detailed understanding of structure and process characteristics to assess, assure, and improve quality, while at the same time considering the high complexities inherent in specialist palliative care situations. Operationalized characteristics as contained in typologies can help to organize, comprehend, and simplistically compare structures and processes and should be the first step when addressing quality. However, in the real-world care context and especially during crisis times, specialist palliative care situations are highly complex, transforming, and dynamic. Consequently, a holistic and more flexible framework is required to support specialist palliative care teams and promote quality management during crises.

## 5. Paper I

### **Specialist palliative care classification: typology development**

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## 6. Paper II

**More than the sum of its parts – A constructivist grounded-theory study on specialist palliative care during crises like the COVID pandemic**

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