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***Specialist Palliative Care – Regional accessibility of services  
and characteristics of patients in the community setting***

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zum Erwerb des Doktorgrades der Humanbiologie  
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Ludwig-Maximilians-Universität München

vorgelegt von  
**Daniela Rosemarie Gesell**

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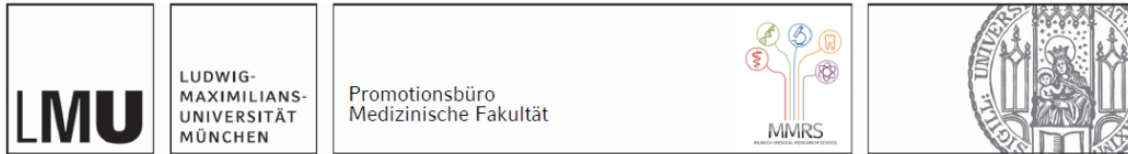
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# Contents

<b>Affidavit.....</b>	<b>3</b>
<b>Contents .....</b>	<b>4</b>
<b>List of abbreviations .....</b>	<b>5</b>
<b>List of publications .....</b>	<b>6</b>
<b>1. Individual contribution of the author .....</b>	<b>10</b>
1.1 Contribution to Paper I.....	10
1.2 Contribution to Paper II.....	10
<b>2. Introduction .....</b>	<b>11</b>
2.1 Palliative care in Germany.....	11
2.1.1 Inpatient palliative care .....	13
2.1.2 Specialist palliative home care .....	13
2.2 Healthcare reporting and geographical approaches.....	14
2.2.1 Variations in accessibility to health care services.....	15
2.2.2 Accessibility to specialist palliative care services .....	17
2.3 Complexity in specialist palliative care .....	18
2.3.1 Symptom clusters in specialist palliative care.....	19
2.3.2 Patients in specialist palliative home care .....	19
2.3.3 Description of the nationwide study COMPANION.....	20
2.4 Objectives and contents of this thesis .....	20
2.5 References .....	22
<b>3. Zusammenfassung .....</b>	<b>28</b>
<b>4. Abstract (English).....</b>	<b>31</b>
<b>5. Paper I.....</b>	<b>34</b>
<b>6. Paper II.....</b>	<b>35</b>
<b>Danksagung .....</b>	<b>36</b>

## List of abbreviations

EAPC	European Association of Palliative Care
GIS	Geographical Information System
SD	Standard Deviation
SPHC	Specialist Palliative Home Care

## List of publications

### Paper I:

**Gesell D**, Hodiamont F, Bausewein C, Koller D. Accessibility to specialist palliative care services in Germany: a geographical network analysis. *BMC Health Services Research*. 2023;23(1):786. DOI:10.1186/s12913-023-09751-7.

### Paper II:

**Gesell D**, Hodiamont F, Wikert J, Lehmann-Emele E, Bausewein C, Nauck F, Jansky M, for the COMPANION study group. Symptom and problem clusters in German specialist palliative home care - a factor analysis of non-oncological and oncological patients' symptom burden. *BMC Palliative Care*. 2023;22(1):183. DOI:10.1186/s12904-023-01296-0.

## Other Publications

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- **Gesell D**, Bethmann A, Alt C. Potentiale geographischer Daten für die Sozialberichterstattung im Rahmen der Familienforschung. *Diskurs Kindheits- und Jugendforschung*. 2017;12(2), 241-246. DOI: 10.3224/diskurs.v12i2.10.

**Abstracts/Posters:**

- **Gesell D**, Hodiamont F, Wikert J, Lehmann-Emele E, Bausewein C, Nauck F, Jansky M for the COMPANION study group. Symptom clusters of oncological patients in specialist palliative home care – What are their needs? (36. Deutscher Krebskongress 2024, Berlin)
- **Gesell D**, Hodiamont F, Bausewein C, Koller D. Potential geographical accessibility to specialist palliative care services: An accessibility and network analysis (18<sup>th</sup> World Congress of the European Association for Palliative Care 2023, Rotterdam).
- **Gesell D**, Hodiamont F, Wikert J, Lehmann-Emele E, Bausewein C, Nauck F, Jansky M, for the COMPANION study group. Symptom burden of patients in specialist palliative home care in Germany (18<sup>th</sup> World Congress of the European Association for Palliative Care 2023, Rotterdam).
- Lehmann-Emele E, Hriskova K, Hodiamont F, Wikert J, **Gesell D**, Jansky M, Nauck F, Bausewein C, for the COMPANION study group. Palliative Care Phases in specialist palliative care - cross-sectional analysis of patient episodes in three settings (palliative care unit, hospital advisory team, specialist palliative home care) (18<sup>th</sup> World Congress of the European Association for Palliative Care 2023, Rotterdam).
- Hodiamont F, Walden F, Rémi C, Lehmann-Emele E, **Gesell D**, Jansky M, Wikert J, Nauck F, Bausewein C, for the COMPANION study group. Confusion and Agitation in Palliative Care Patients: A red flag to identify delirium? (Oceanic Palliative Care Conference 2023, Sydney)
- **Gesell D**, Koller D, Bausewein C, Hodiamont F. Regionale Disparitäten in der spezialisierten Palliativversorgung in Deutschland. (14. Kongress der Deutschen Gesellschaft für Palliativmedizin, Zeitschrift für Palliativmedizin, 2022. 23(05), P190.)
- Lehmann-Emele E, Wikert J, **Gesell D**, Jansky M, Nauck F, Bausewein C, Hodiamont F, für die COMPANION-Studiengruppe. Welche Patient:innen werden von Palliativdiensten in deutschen Kliniken mitbetreut? - Eine deskriptive Datenanalyse (21. Deutscher Kongress für Versorgungsforschung 2022, Potsdam).
- Hodiamont F, **Gesell D**, Schatz C, Nauck F, Boulesteix A-L, Jansky M, Leidl R, Kranz S, Wikert J, Melching H, Bausewein C. Das COMPANION Projekt – Komplexität greifbar machen. (Zeitschrift für Palliativmedizin, 2020. 21(05), P36.)
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**Oral presentation:**

- **Gesell D**, Hodiament F, Wikert J, Lehmann-Emele E, Bausewein C, Nauck F, Jansky M, für die COMPANION Studiengruppe. Symptom- und Problemcluster von erwachsenen Patient:innen in der spezialisierten ambulanten Palliativversorgung in Deutschland – Eine diagnosebezogene Faktorenanalyse. (DEGAM Kongress 2023, Berlin).

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

## **1.1 Contribution to Paper I**

DG conceived the idea for this study and additional advice for conceptualization was provided by DK, FH and CB. She was responsible for data management and adjustment and conducted statistical accessibility and network analyses. DK provided statistical advice and FH and CB advised the analyses. DG drafted the manuscript, which was critically revised by all co-authors. All authors approved the final version and gave their agreement for publication. DG is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Moreover, DG was responsible for the publication process as corresponding author and edited the manuscripts while peer review processes.

## **1.2 Contribution to Paper II**

The conceptual work of this study was designed by FH and CB. DG was involved in the implementation of the study, namely in the development and preparation of data collection (March 2021 - September 2022). She regularly conducted plausibility and quality checks during and after the final data collection to ensure high data quality, as well as few missing values and reduced data bias. She regularly contacted and visited participating study sites. With support of MJ and other team members, DG defined specific research questions and analysis plans with critical revision of all co-authors. DG conducted the exploratory factor analysis, and designed and conducted the structural equation model in form of confirmatory factor analysis. DG drafted the manuscript and JW, ELE, FH, CB, FN and MJ revised it critically for important intellectual content. All authors had full access to all data and approved the final version and gave their agreement for publication. DG is accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Moreover, DG was responsible for the publication process as corresponding author and edited the manuscripts while peer review processes.

## 2. Introduction

Palliative care has developed from a philosophy of providing care in the final days of life to a professional medical field that offers holistic, multi-professional care to patients diagnosed with life-limiting illnesses.<sup>1</sup> The World Health Organization defines palliative care as *'a crucial part of integrated, people-centred health services. Relieving serious health-related suffering, be it physical, psychological, social, or spiritual, is a global ethical responsibility. Thus, whether the cause of suffering is cardiovascular disease, cancer, major organ failure, drug-resistant tuberculosis, severe burns, end-stage chronic illness, acute trauma, extreme birth prematurity or extreme frailty of old age, palliative care may be needed and has to be available at all levels of care.'*<sup>2</sup>

The history of the modern hospice development began in 1967 when Cicely Saunders founded St. Christopher's Hospice in London. She developed the concept of total pain by integrating psychosocial and spiritual dimensions equally to physical aspects of burden.<sup>3</sup> Although there have been some challenges, including scarce resources, limited availability of medications, and a lack of awareness of hospice work among both the public and health professions, the concept of palliative care has spread throughout Europe.<sup>4</sup> In 1975, Balfour Mount tried to introduce palliative care as common term to emphasize the holistic approach. He opened one of the first palliative care units in Montreal, which consisted of the unit itself, a home care service, and a consultative service for other hospital wards.<sup>5, 6</sup> In the following years, numerous palliative care teams were established in both inpatient and outpatient clinical settings, which opened up the way for early integration into palliative care for patients with advanced, life-threatening diseases.<sup>7-9</sup> In previous years, substantial progress was made in the development of palliative care services, particularly in Western Europe. However, Central and Eastern countries are still lacking in sufficient improvements.<sup>10</sup>

### 2.1 Palliative care in Germany

Over the years, palliative care has become an integral part of the German healthcare system, with developments in legislation and education of medical students, nursing and other professionals working in palliative care settings.<sup>11</sup> The Law for the Improvement of Hospice and Palliative Care in Germany (Hospice and Palliative Act) contains a wide range of measures to improve the medical, nursing, psychological, and pastoral care of people in the last phase of life and promotes a nationwide expansion of palliative and hospice care.<sup>12</sup> The law has explicitly integrated palliative care into the standard care offered by statutory health insurance. A recent study showed a significant increase of

the utilization of palliative care services in the last years in all settings of palliative care including generalist and specialist palliative care.<sup>13</sup>

A distinction is made between generalist palliative care and specialist palliative care in both, inpatient and home care settings (see Figure 1). Whereas generalist palliative care is part of general medical care and is often provided by general practitioners, specialist palliative care requires higher qualifications and is provided by a team of professionals from different disciplines.<sup>6, 14</sup> Patients with complex situations are cared for by specialist palliative care teams, regardless of their diagnosis, a particular stage of the disease or life expectancy. The care is primarily focused on meeting the needs of patients and their relatives. Providing comprehensive symptom relief and support through specialist teams with expertise in pain management and symptom control, as well as ethical considerations, aims to preserve patients' autonomy and enhance the quality of life of patients towards the end of their life.<sup>15-17</sup> Specialist palliative care is provided in three settings within the German health system, which differ in team structures, care practises and place of care: Palliative care units, palliative care advisory teams and specialist palliative home care (SPHC) teams.

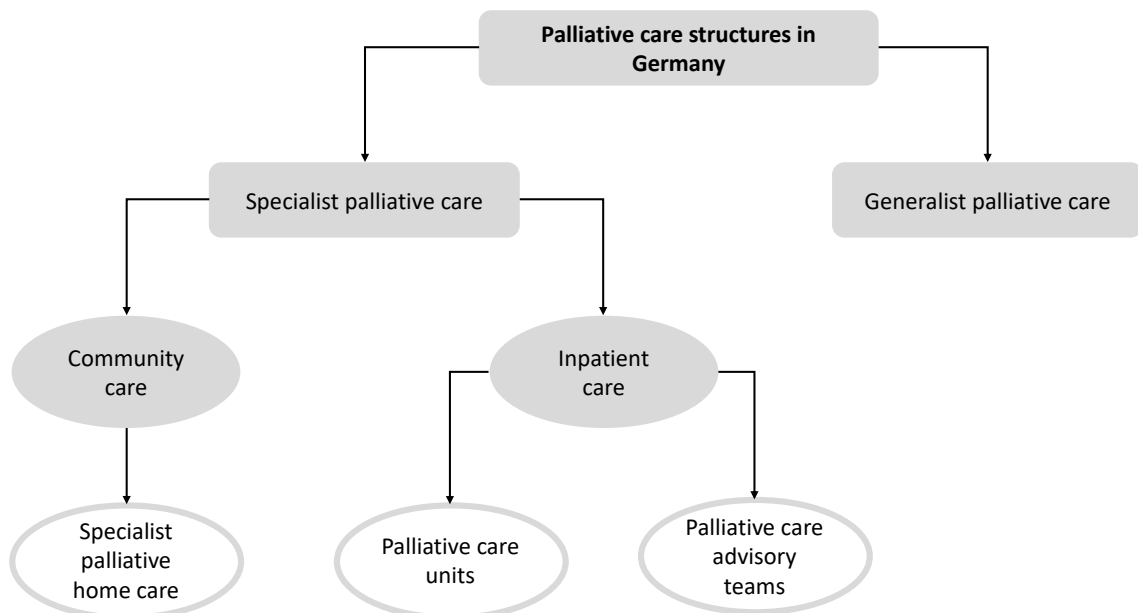


Figure 1. Palliative care structures in Germany adapted from Radbruch et al.<sup>18</sup>

### **2.1.1 Inpatient palliative care**

Specialist inpatient palliative care is divided into two areas, namely palliative care units and palliative care advisory teams in hospitals. Palliative care advisory teams provide support to healthcare professionals in hospital units not specialized in palliative care. A primary goal of these teams is to alleviate the wide range of symptoms experienced by patients in the various hospital wards by providing guidance to the attending staff and provide support to patients and their families.<sup>18</sup> Several studies have shown significant improvements in quality of life, reductions in symptom burden and anxiety, and in family distress when comparing multi-professional palliative care advisory teams with routine care.<sup>1, 19-21</sup> In addition to the positive impact of these teams on patients' outcomes, studies have shown significant positive cost saving effects on hospital costs.<sup>22, 23</sup> Patients who require more intensive care than what an advisory team can provide are often admitted to a palliative care unit, which offers specialist inpatient care, usually as wards in hospitals. The goal of a palliative care unit is to alleviate complex symptoms related to illness and therapy and, if possible, to stabilize the patient's functional status. They provide psychological and social support to patients and their relatives and enable them to be discharged or transferred to another setting.<sup>18</sup>

### **2.1.2 Specialist palliative home care**

Community based palliative care can ensure continuity of care and ongoing support after discharge from inpatient settings. Since 2007, with the 'Act to Strengthen Competition in Statutory Health Insurance', the legal entitlement to community palliative care has been anchored in the Social Insurance Act (Sozialgesetzbuch),<sup>11</sup> as a form of care for people with life-limiting conditions and increasingly complex care needs.<sup>24</sup> The number of SPHC teams, that have signed a contract has increased threefold up to over 360 teams between 2010 and 2019.<sup>25</sup> SPHC teams provide specialist palliative care to patients at home and support their relatives and care givers. Moreover, they give specialist advice to general practitioners and nursing services of the patients at home.<sup>18</sup> SPHC is a specific service for palliative care patients with complex symptom burden and psychosocial problems. Preserving patients' autonomy and quality of life at the end of their lives, as well as providing comprehensive support for pain management and symptom control, are crucial duties of SPHC teams, to avoid unnecessary hospital admission.<sup>24</sup> SPHC can be provided in the patient's home, in the home of their family or in residential care facilities. Individuals have a legal entitlement to SPHC if they have an incurable, progressive disease that is advanced to a point where it limits their life expectancy. Additionally, they require particularly complex care, which can also be provided on an ambulatory basis following the principles of palliative medicine and palliative care. Support by an SPHC

team can be prescribed by general practitioners or clinicians if general outpatient palliative care no longer meets the need due to the complexity of the patient's situation and the associated particularly complex care.<sup>26</sup> While most of the patients prefer home-based care, ideally until their passing,<sup>18</sup> there is evidence, that an early integration of SPHC can reduce the chance of hospital death.<sup>27, 28</sup> In recent years, the utilization of SPHC teams has increased continuously.<sup>13</sup>

## 2.2 Healthcare reporting and geographical approaches

The increased utilization and development in the distribution of specialist palliative care services in recent years is, among a variety of other topics, a part of healthcare reporting. The following chapter will provide an overview about the development of healthcare reporting and geographical approaches in medicine and embed theoretical frameworks of accessibility in palliative care.

The origins of medical geography in Germany derives primarily from the work of Leonhard Ludwig Finke and August Hirsch in the 18th century, who contributed significantly to advancing the field of disease ecology. Disease ecology deals with the representation of the regional distribution of a disease based on regional units and environmental health influences.<sup>29</sup> The research primarily focused on bacteriological aspects, which explain the occurrence of infectious diseases through the distribution of pathogens. In 1948, Jacques May, a physician and Director of Medical Studies in the American Geographical Society, published an article on the actual methods and objectives of medical geography.<sup>30, 31</sup>

After the founding of the Commission on Medical Geography, under May's chairmanship, medical geography became a separate field of research in geography, which can be divided into two predominantly quantitative main tracks: The research field of disease ecology and the geography of health care delivery, which deals with the spatial distribution and utilization of health care services.<sup>30, 32</sup> Since the 1990s, research on disease occurrence has expanded to include not only the analysis of spatial distribution and the relationships between disease occurrence locations but also psychological, social, and cultural aspects of health.<sup>33</sup> These are increasingly considered and included in analyses.<sup>33</sup> Population growth, globalization, and demographic change have led to spatial developments with growing importance for health in recent years.

In Germany, regional and local healthcare reporting has become an important component for planning in the healthcare system, enabling the identification and spatial analysis of regional disparities. In 2000, Jacob and Michels have already pointed out the relevance of such analyses for healthcare reporting.<sup>34</sup> These analyses are crucial for public

health, epidemiology, and health services research.<sup>29</sup> Healthcare reporting provides information on the health status, health conditions determinants of the population, healthcare provision and prevention, and thus can identify health-related problems.<sup>35</sup> Meanwhile there is a wide range of data, some of which are freely available<sup>36</sup> to display regional disparities.<sup>29, 37</sup> The availability of healthcare data at the regional level has increased and user-friendly software solutions offer a convenient way to perform spatial analyses and present results in form of maps.<sup>29</sup>

Analyses with spatial reference can be performed using software like geographic information systems (GIS). GIS are spatial-relational databases that can create and combine a variety of information layers.<sup>30</sup> Data is placed in a GIS on thematic layers that can be related to each other. Thus, the use of regional data allows a spatial evaluation of the supply close to one's home as well as the density of supply.<sup>37</sup> In recent years, small-scale spatial statistical analyses of health care have become increasingly common, as this is the best way to depict existing regional disparities.<sup>29, 38</sup> In addition to the simple presentation of disease ecology information in form of maps, broader temporal relationships between space and health, as well as accessibility of facilities, can be explored.<sup>29</sup>

### 2.2.1 Variations in accessibility to health care services

Access to health services is often related to the use of services according to the individual needs of patients<sup>39, 40</sup> and presents a concept that summarizes dimensions which explain the fit between the patient and the health care system – the better the fit, the better the access.<sup>41, 42</sup> In 1981, Penchansky and Thomas first tried to describe the specific dimensions as '*availability, accessibility, accommodation, affordability and acceptability*'.<sup>41</sup>

Peters et al. further developed a conceptual framework, based on the established definitions, which '*is build on longlasting descriptions of access to health services that includes actual use*'.<sup>40</sup> (see Figure 2) It includes four key dimensions of access, taking both supply and demand into account. The centre of the framework is 'quality' which builds an important aspect of each single dimension. The main elements are:

1. '*Geographic accessibility*' - the physical distance or travel time from the place of the delivery service to the user.<sup>40</sup>
2. '*Availability*' - ensuring that individuals in need have access to the right kind of care, involves meeting the demands of potential care recipients by offering suitable hours of operation and waiting times, as well as ensuring the presence of adequate service providers and materials.<sup>40</sup>

3. '*Financial accessibility*' - the connection between service pricing (partially influenced by cost factors) and the willingness and capacity of users to afford these services, while also safeguarding them from the economic impact of healthcare expenses.<sup>40</sup>
4. '*Acceptability*' - The alignment of healthcare service providers' responsiveness with the social and cultural expectations of individual users and communities.<sup>40</sup>

The framework displays the quality of care as the central aspect of the four dimensions mentioned above, with determinants of more remote factors influencing access to health services on the left side of the circle. These factors are presented at the policy or macro-environmental level influencing the access to health services, as well as at the individual levels, with poverty as determinant for illness and for disparities across various aspects of healthcare access.<sup>40</sup>

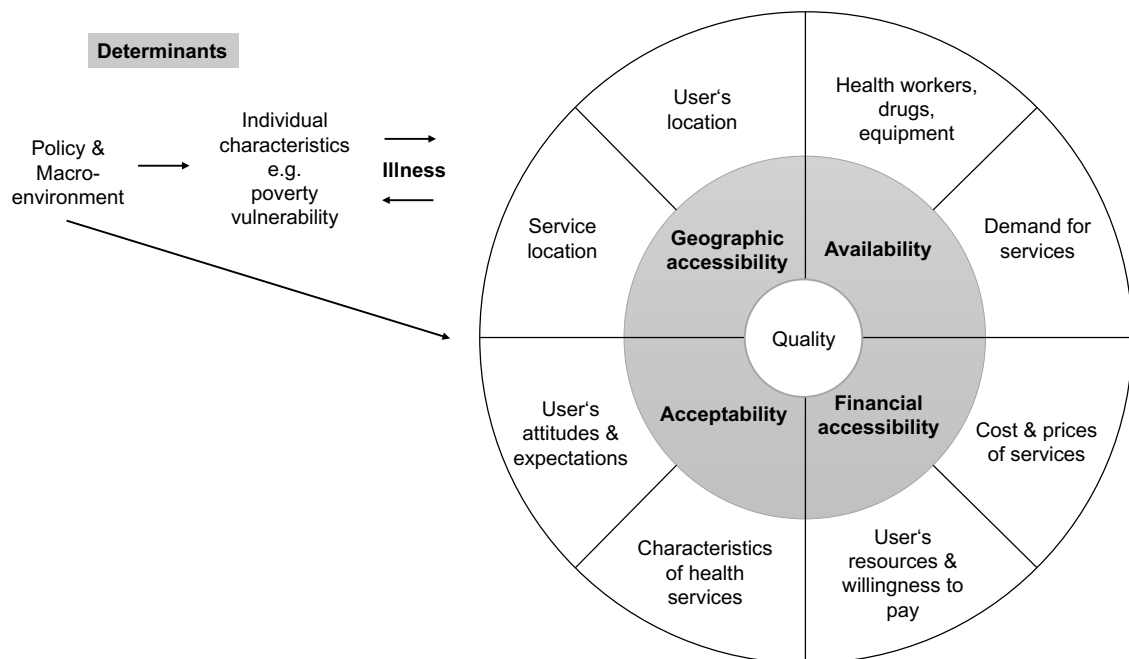


Figure 2. Conceptual framework for access to health services according to Peters et al.<sup>40</sup>

Saurman further developed the framework of Penchansky and Thomas and modified it with one additional category – '*awareness*'.<sup>42</sup> The author states that the services maintain awareness by using effective communication and information strategies when engaging with relevant stakeholders, such as healthcare professionals, patients, and the wider community. This includes taking into account the current context and the health literacy of all parties involved. Awareness can enable the fit between the patient and the service.<sup>42</sup>



### 2.2.2 Accessibility to specialist palliative care services

While the definition of palliative care indicates that all patients, irrespective of their diagnosis, should have access to palliative care,<sup>2</sup> in 2011 a study group analysed about 4,100 patients with and without cancer diagnosis and found, that non-cancer patients are the minority in inpatient specialist palliative care in Germany. The palliative care needs of these patients will pose a challenge for the German health care system due to the increasing workload for existing specialist palliative care services in meeting them.<sup>43</sup> Beyond that, a current literature review demonstrates that inequalities in the provision of hospice care remain for patients without cancer, older patients, ethnic minorities and people living in rural and disadvantaged areas.<sup>44</sup> Mills et al. suggest two important steps towards equity in access, the first is to explore and value the existing strengths of the community. The second step would be to identify what kind of support members of the different communities want, to complement the existing strengths. According to the authors, it is important to enhance community-based interventions and supportive environments. In addition, the relevance of public health partnerships and community involvement needs to be recognized by existing palliative care services.<sup>45</sup>

Due to the demographic change and growing numbers of elderly, comorbid individuals,<sup>46</sup> the German health care system will encounter an economic challenge, requiring a distribution of care services based on individual needs. Given that the European Association of Palliative Care (EAPC) recommends two specialist palliative care services every 100.000 inhabitants,<sup>46</sup> the geographic accessibility is an important aspect to consider. As one of the first, Wiese et al. analysed the regional distribution of specialist palliative care services in Germany in 2010. They compared regional emergency medicine structures with palliative care structures, however there was no nationwide distribution of services. The analysis did not reveal any structures that would suggest a nationwide implementation of palliative care services.<sup>47</sup> Radbruch et al. addressed in 2015 the issue, that there are not yet sufficient generalist and specialist palliative care services throughout the country.<sup>48</sup> Especially in rural areas, there is often a lack of specialist services, and the accessibility of existing services is usually limited, or distances are long. They concluded that, in principle, Germany has the structures in place to enable end-of-life care to be provided in accordance with patients' individual wishes, although there are regional differences.<sup>48</sup> Currently, there are about 320 palliative care units, over 400 SPHC teams and 84 hospitals with palliative care advisory teams in Germany.<sup>49, 50</sup>

A cross-sectional analysis by van Baal et al. examined regional differences for SPHC in Lower Saxony.<sup>51</sup> Statutory health insurance data from Lower Saxony of deceased patients were consulted and analysed based on selected quality indicators. The analysis

showed the different regional distribution of SPHC. Population density, gender distribution, age of the deceased, and number of SPHC teams were identified as explanatory factors for the identified regional differences.<sup>51</sup>

As this challenge is not unique to Germany, there are already several international studies that deal with the regional distribution and accessibility of palliative care services. In England, for example, zip codes of deceased patients have been geocoded to determine travel times to palliative care services.<sup>52</sup> The study analysed the variation in access to facilities according to the type of settlement of the deceased, and the relationship between regional access to facilities and the location of the patients' deaths, controlled for sociodemographic and clinical characteristics.<sup>52</sup> Patients' travel times were used as a proxy to estimate access to palliative care services. The results demonstrated that patients living more than ten minutes away from the next specialist palliative care service were less likely to die there compared to those living closer to the next service. The effects were larger in rural than in urban areas. The analysis provides evidence that access to palliative care services is related to the location where patients die.<sup>52</sup> Considering, that most of the older patients prefer to be cared for at home, if possible until they die, this suggests the need to consider settlement structures in future analyses of distributing palliative care services.<sup>18, 52, 53</sup>

In Canada, the access to palliative care services is a growing challenge, particularly in rural communities where health care is limited and access to local palliative care is lacking. The development of an index enabled the spatial identification of the population's potential need for palliative care services at population level. Census data was used as the data base and four selected indicators were used to develop the index: socioeconomic status, age, gender, and housing situation. This resulted in spatial variation in the potential need for palliative care services in the population.<sup>54</sup> Based on this, a model was developed that identifies the needs of underserved rural areas and analyzes existing regional capacity that can be used to support rural development of palliative care.<sup>55</sup>

### **2.3 Complexity in specialist palliative care**

Admission to specialist palliative care is linked to the degree of complexity of the patient's situation. The concept of complexity is used to differentiate and classify varying care requirements, resulting in the distinction between generalist and specialist palliative care.<sup>56</sup> To provide a consensus-based recommendation for patients with an incurable illness, it is necessary, according to the German S3 Guideline for Palliative Care in patients with incurable cancer, to assess the patients' needs and determine their complexity.<sup>14</sup> The complexity of a situation is determined both by the intensity of individual

symptoms or psychosocial, spiritual or ethical problems, and by their simultaneous occurrence (including the simultaneous presence of comorbidities). It can be derived from the recorded needs, problems and burden of patients and their relatives.<sup>14</sup> In addition, the complexity is described by the functional status and the palliative care phase.<sup>14, 57, 58</sup> Hodiament et al. developed a conceptual framework and provided a comprehensive understanding of complexity in palliative care. They describe palliative care situations in a complex adaptive system consisting of three subsystems (patient, social system, and team), and analysed the characteristics, roles and relationships of the involved stakeholders (called agents) in the holistic approach of palliative care.<sup>59</sup>

### **2.3.1 Symptom clusters in specialist palliative care**

As the complexity of a patient's situation is influenced by the intensity and simultaneous occurrence of physical symptoms and psychosocial problems,<sup>14</sup> patients with life limiting diseases commonly experience multiple concurrent symptoms, such as pain, fatigue, and depression.<sup>60, 61</sup> Patients with higher levels of symptom complexity and co-occurring symptoms tend to have lower functional status and quality of life.<sup>60, 62, 63</sup> The simultaneous occurrence of symptoms in groups is called symptom clusters. They are defined as two or more symptoms in stable groups, distinct from other symptom groups.<sup>61</sup> Evidence indicates that clusters showing consistent patterns are defined by the presence of similar core symptoms over time.<sup>64</sup> Furthermore, the identification of a sentinel symptom within a cluster can serve as a predictor for the presence of other relevant symptoms,<sup>64</sup> and therefore help to develop appropriate strategies for intervention to improve quality of life of the patients and to maintain their autonomy.

### **2.3.2 Patients in specialist palliative home care**

Preserving patient's autonomy and quality of life are assignments of SPHC teams.<sup>24</sup> They provide the holistic approach of palliative care and allow most patients to die in their own homes, fulfilling their presumed desires regarding end-of-life care.<sup>53, 65</sup> There is evidence, that a high amount of patients receiving SPHC suffer from oncological diagnoses.<sup>66</sup> Besides oncological patients, there is an increasing demand for palliative care from non-oncological patients, with special symptom-related needs. These patients are often older, with lower performance status, and shorter duration of care.<sup>66</sup> Just et al. showed that performance status is a relevant predictor of short survival times in SPHC, with no relevant influence of the diagnosis. Moreover, according to the authors, high age and various symptoms like loss of appetite and confusion are also influencing factors for a decreased survival time.<sup>67</sup> They indicated higher overall symptom burden of patients with non-oncological disease, while pain was equally distributed.<sup>67</sup> A German study in

North Rhine-Westphalia showed, that disorientation is more prevalent with higher burden in patients without cancer in SPHC, as well as the risk of care issues like pressure ulcers.<sup>65</sup> Due to the particular complexity of the physical and psychosocial symptoms and problems that arise when caring for patients at home, it is crucial that SPHC teams are composed of professionals with diverse perspectives and expertise to ensure high-quality care.<sup>68</sup>

### **2.3.3 Description of the nationwide study COMPANION**

The data base of the second publication included in this thesis (see Chapter 6) based on data of the cross-sectional study COMPANION, which was conducted from 09/19 to 08/23. To get an overview of COMPANION, a brief outline of the contents follows in this section. The study's background was the lack of a valid and evidence-based classification in Germany to differentiate the complexity of patients and their needs. In Australia, a casemix classification for palliative care was developed in the 1990s to classify patients according to their complexity and resource requirements.<sup>58</sup> Based on this, the nationwide research project '*COMPANION: development of a patient-centred complexity and case-mix classification for adult palliative care patients based on needs and resource use*' aimed to develop such a classification in Germany.<sup>69</sup> Three subprojects were carried out: a prospective, multi-centre cross-sectional study, a qualitative study to develop a typology for specialist palliative care services and a multi-centre costing study.<sup>69</sup> Among other aims of the study, one main purpose was to describe and assess the patients' and relatives' needs that reflect the complexity of the patients' situation, and the resources spend to meet these needs. The problems and burden, palliative care phases as well as the functional status were operationalized and measured using chosen assessment tools in three specialist palliative care settings (palliative care units, palliative care advisory teams in hospitals and SPHC teams).<sup>69</sup>

## **2.4 Objectives and contents of this thesis**

The overall aim of this thesis is to provide a comprehensive description and examination of the regional healthcare provision for patients requiring specialist palliative care and their individual symptom burden in form of symptom and problem clusters in Germany.

Objectives were I) to describe the spatial distribution of specialist palliative care services in Germany, to calculate the potential accessibility of facilities and to assess potential spatial under-provision in serving areas of specialist palliative care services and II) to describe the prevalence of physical symptom burden and psychosocial problems of adult patients in SPHC, and to evaluate diagnosis-related symptom clusters.

To meet these aim and objectives two specific papers were published, the first (Chapter 5) focuses on the regional distribution of specialist palliative care services in Germany and the potential accessibility of the existing services, to highlight regional differences in the distribution and to identify potential regional gaps in care.<sup>70</sup> The second paper (Chapter 6) examines symptom burden among patients in SPHC, considering diagnosis-related differences, depicted by symptom and problem clusters.<sup>71</sup> The results of both publications are decisive to support the expansion of specialist palliative care services in Germany and to further develop patient-orientated care.

**Chapter 5** refers to a retrospective cross-sectional study with regional statistical analysis of specialist palliative care services in Germany to examine their distribution. The regional analysis included the geocoding of address data of services registered online in three palliative care settings: Palliative care units, palliative care advisory teams in hospitals and SPHC teams. Data was analysed on district and postal code level. Accessibility and network analyses were conducted to determine the proportion of the population living up to 60 minutes driving time to the next potential service. The results showed that the distribution of services is heterogeneous with every fourth district lacking a specialist palliative care service, but a widespread expansion of palliative care units and SPHC teams and a deficient expansion of palliative care advisory teams in hospitals. Regional analyses in the field of specialist palliative care generate relevant results for the planning and further development of end-of-life care and represent an enrichment for the (palliative) medical context.

**Chapter 6** refers to a quantitative secondary analysis of data, collected within the multi-centre cross-sectional national study COMPANION, to describe the prevalence of physical symptom burden and psychosocial concerns of adult patients in SPHC and to evaluate the occurrence of diagnosis-related symptom and problem clusters. The data included symptom burden of adult patients at the beginning of their care episodes. Besides descriptive statistics to examine the prevalence of symptoms and problems, exploratory and confirmatory factor analyses were conducted to identify symptom and problem clusters and the differences of patients with and without cancer diagnoses. The results showed that patients in SPHC differed in their patient characteristics, like performance status and age as well as in their symptom prevalence and occurrence of symptom and problem clusters. The findings indicate the high relevance of care planning in SPHC to enhance patient-orientated symptom control and problem assistance.

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### 3. Zusammenfassung

Die Palliativversorgung hat sich in den vergangenen Jahrzehnten zu einem festen Bestandteil der Gesundheitsversorgung in Deutschland entwickelt. Während in den Anfängen der Palliativ- und Hospizbewegung maßgeblich onkologische Patient:innen in den palliativmedizinischen Einrichtungen versorgt wurden, steigt aufgrund des demographischen Wandels und der Zunahme an chronischen, nicht-onkologischen Erkrankungen in der Gesellschaft der Bedarf an palliativmedizinischer Versorgung fortwährend an. Damit geht die wachsende Herausforderung einher, den räumlichen Ausbau palliativer Einrichtungen zu fördern. Neben der rein räumlichen Erweiterung des Angebots erfordert der zunehmende Anteil an Patient:innen eine kontinuierliche Weiterentwicklung und Anpassung der Patient:innenbetreuung in den versorgenden Teams, um den unterschiedlichen Bedürfnissen und Anforderungen der verschiedenen Patient:innengruppen gerecht zu werden.

Das Ziel dieser Arbeit ist eine umfassende Beschreibung und Untersuchung der regionalen Versorgungssituation von Patient:innen in Deutschland, die eine spezialisierte Palliativversorgung benötigen, sowie ihrer individuellen Symptombelastung in Form von Symptom- und Problemclustern. Der erste Artikel befasst sich mit der regionalen Verteilung der spezialisierten Palliativversorgung in Deutschland und der potenziellen Erreichbarkeit der bestehenden Angebote, um regionale Unterschiede in der Verteilung aufzuzeigen und mögliche regionale Versorgungslücken zu identifizieren. Der zweite Artikel untersucht die Symptombelastung von Patient:innen in der spezialisierten ambulanten Palliativversorgung unter Berücksichtigung diagnosebezogener Unterschiede, die durch Symptom- und Problemcluster abgebildet werden. Die Ergebnisse beider Publikationen sind entscheidend, um den Ausbau der spezialisierten Palliativversorgung in Deutschland zu unterstützen und eine patient:innenorientierte Versorgung weiterzuentwickeln.

Der erste Artikel ist eine retrospektive Querschnittsstudie mit einer regionalstatistischen Analyse von spezialisierten Palliativeinrichtungen in Deutschland. Die Adressen von online registrierten Einrichtungen wurden geokodiert und Erreichbarkeits- und Netzwerkanalysen durchgeführt. Als empirischer Wert wurde eine Fahrtzeit von 60 Minuten als maximaler Schwellenwert für die Erreichbarkeit der nächstgelegenen Einrichtung definiert. Darauf basierend wurde der Bevölkerungsanteil, der eine längere Fahrtzeit als 60 Minuten hat, berechnet. Für den zweiten Artikel wurden im Rahmen einer prospektiven, multizentrischen Querschnittsstudie zur Komplexität von Palliativpatient:innen in Deutschland Daten in Form einer Sekundäranalyse ausgewertet. Neben deskriptiven Analysen von Versorgungsepisoden zur körperlichen Symptombelastung und zu psychosozialen Problemen der Patient:innen in der spezialisierten ambulanten Versorgung wurden

explorative und konfirmatorische Faktorenanalysen zur Identifizierung von Symptom- und Problemclustern durchgeführt.

Die Ergebnisse des ersten Artikels zeigen eine heterogene Verteilung von spezialisierten palliativen Einrichtungen in Deutschland. Insgesamt wurden 673 Einrichtungen in die Analyse eingeschlossen. In jedem vierten der 401 Kreise gibt es keine spezialisierte palliative Einrichtung (110/401; 27,4%). In der Hälfte der Fläche Deutschlands sind die vorhandenen Palliativstationen und spezialisierten ambulanten Teams innerhalb von 30 Minuten zu erreichen, wobei fast 90% der Bevölkerung dort leben. Krankenhäuser mit Palliativdiensten sind in 17% der Gesamtfläche innerhalb von 30 Minuten erreichbar und versorgen 43% der Bevölkerung. Fast eine halbe Million Menschen haben keinen wohnortnahen Zugang zu Palliativstationen und mehr als 10 Millionen Menschen haben keinen wohnortnahen Zugang zu Palliativdiensten in Krankenhäusern, da sie mehr als eine Stunde Fahrzeit von der nächsten Einrichtung entfernt leben. Fast eine Viertelmillion Menschen leben in Regionen, die von einem spezialisierten ambulanten palliativen Team nicht innerhalb von 60 Minuten erreicht werden können. Die Anzahl der Einrichtungen pro Kreis variiert je nach Setting und Größe des Kreises und reicht von Kreisen ohne Einrichtung bis zu elf Einrichtungen. Obwohl die regionale Verteilung ungleichmäßig ist, lebt der Großteil der Bevölkerung in einem Umkreis von bis zu 30 Minuten Fahrtzeit zu einer spezialisierten Palliativeinrichtung.

Die Ergebnisse des zweiten Artikels zeigen Unterschiede in der Symptom- und Problembelastung von onkologischen und nicht-onkologischen Patient:innen. Es wurden 778 Versorgungsepisoden von Patient:innen aus neun ambulanten Palliativteams in die Analysen einbezogen. Das durchschnittliche Alter aller Patient:innen betrug 75,3 Jahre (SD  $\pm$  12,2 Jahre), mit einer durchschnittlichen Episodendauer von 18,6 Tagen (SD  $\pm$  19,4 Tage). Ein Drittel der Patient:innen hatten eine nicht-onkologische Diagnose (212/778; 27,2%). Die nicht-onkologischen Patient:innen waren am häufigsten durch eingeschränkte Mobilität belastet (194/211; 91,9%) und die onkologischen Patient:innen durch Schwäche (522/565; 92,4%). In fast allen Versorgungsepisoden von Patient:innen mit nicht-onkologischen (210/212; 99,1%) und mit onkologischen (563/566; 99,5%) Diagnosen war mindestens ein Symptom oder Problem prävalent und in 181/212 (85,4%) und in 495/566 (87,5%) Episoden 5 oder mehr Symptome oder Probleme. Darüber hinaus konnten Symptom- und Problemcluster in beiden Gruppen identifiziert werden - Zwei Cluster (psychosozial und körperlich) für die nicht-onkologische und drei Cluster (psychosozial, körperlich und kommunikativ/praktisch) für die onkologische Gruppe. In der nicht-onkologischen Gruppe wiesen prozentual mehr Patient:innen mindestens ein Symptomcluster auf (83/212; 39,2% vs. 172/566; 30,4%). Der Hauptunterschied war das

Vorhandensein des Clusters, welches kommunikative/praktische Probleme beinhaltet, in der onkologischen Gruppe.

Die Ergebnisse dieser Arbeit zeigen, dass die Strukturen der palliativen Versorgung in vielen Regionen Deutschlands bereits flächendeckend ausgebaut sind, mit einer hohen Präsenz ambulanter Palliativteams. Während die Mehrheit dieser Teams vor allem onkologische Patient:innen versorgen, zeigen die Ergebnisse, dass die identifizierten Cluster die verschiedenen Dimensionen der körperlichen Symptombelastung und der psychosozialen Belange von Patient:innen in der palliativmedizinischen Versorgung abbilden und auf unterschiedliche Bedürfnisse von sowohl onkologischen als auch nicht-onkologischen Patient:innen in der ambulanten Palliativversorgung hindeuten.

Zusammenfassend kann festgestellt werden, dass die Palliativversorgung ein wichtiger Bestandteil der medizinischen Praxis ist, der eine ganzheitliche und interdisziplinäre Betreuung von Patient:innen mit schweren Erkrankungen gewährleistet. Der regionale Ausbau palliativer Versorgungsstrukturen in Deutschland ist bereits weit fortgeschritten. In diesem Zusammenhang spielt die steigende Anzahl an onkologischen sowie nicht-onkologischen Patient:innen mit unterschiedlichen Bedürfnissen und Ansprüchen an die Teams und dem Bestreben, alle Patient:innen frühzeitig in eine palliative Betreuung zu integrieren, eine wichtige Rolle. Obwohl das Angebot an palliativen Einrichtungen flächendeckend ausgebaut erscheint, ist ein weiterer Ausbau nicht nur entscheidend um die steigende Nachfrage zu erfüllen, sondern auch um sicherzustellen, dass die unterschiedlichen Bedürfnisse, Anforderungen und Präferenzen sowohl von onkologischen als auch nicht-onkologischen Patient:innen im Rahmen der ambulanten Palliativversorgung angemessen berücksichtigt und erfüllt werden können.

## 4. Abstract (English)

In recent decades, palliative care has become an integral part of healthcare in Germany. The early days of the palliative and hospice movement involved mainly caring for oncological patients in palliative care facilities. However, the need for palliative care is constantly rising, due to demographic changes and the prevalence of chronic, non-oncological diseases in society. This has brought about the growing challenge of fostering the spatial expansion of palliative care services. In addition to expanding services spatially, the increasing number of patients requires ongoing development and adaptation of patient care within the care teams to meet the diverse needs and requirements of the different patient groups.

The overall aim of this thesis is to provide a comprehensive description and examination of the regional healthcare provision for patients requiring specialist palliative care and their individual symptom burden in form of symptom and problem clusters in Germany. The first paper focuses on the regional distribution of specialist palliative care services in Germany and the potential accessibility of the existing services, to highlight regional differences in the distribution and to identify potential regional gaps in care. The second paper examines symptom burden among patients in specialist palliative home care, considering diagnosis-related differences, depicted by symptom and problem clusters. The results of both publications are decisive to support the expansion of specialist palliative care services in Germany and to further develop patient-oriented care.

The first paper presents a retrospective cross-sectional study that performs a regional statistical analysis of specialist palliative care services in Germany. Firstly, addresses of services registered online were geocoded, then accessibility and network analyses were conducted. As an empirical value, a travel time of 60 minutes was set as the maximum threshold value for the nearest service's accessibility. Based on this, the proportion of the population with a travel time exceeding 60 minutes was calculated. For the second paper, as part of a prospective, multi-centre, cross-sectional study on the complexity of palliative care patients in Germany, a secondary analysis of the data was conducted. In addition to descriptive analyses of care episodes on the physical symptom burden and psychosocial problems of patients in specialist palliative home care, both exploratory and confirmatory factor analyses were performed to identify clusters of symptoms and problems.

The results of the first paper demonstrate a rather heterogeneous distribution of specialist palliative care services throughout Germany. The analysis examined 673 services in total. In one in four of the 401 districts, there is no specialist palliative care service at all (110/401; 27.4%). Approximately 50% of all German citizens can access palliative care

units and palliative home care teams within 30 minutes, with nearly 90% of the country's population living in these areas. Hospitals with palliative care advisory teams can be reached within 30 minutes in 17% of the total area and covering 43% of the population. Almost 500,000 people do not have immediate access to palliative care units and over 10 million people do not have immediate access to a hospital with a palliative care advisory team because they live more than an hour's drive from the nearest service. Additionally, approximately 250,000 people reside in areas that are not reachable by a specialist palliative home care team within 60 minutes. The number of services per district varies based on the setting and district size, ranging from districts having no services and others offering up to eleven. Despite uneven regional distribution, the majority of the population lives within a 30-minute drive to a specialist palliative care service.

The results of the second paper demonstrate a difference in symptom and problem burden between oncological and non-oncological patients. 778 care episodes of patients across nine home care teams were included in the analyses. The average age of all patients was 75.3 years (SD  $\pm$  12.2 years), with an average episode duration of 18.6 days (SD  $\pm$  19.4 days). One third of the patients had a non-oncological diagnosis (212/778). Patients without cancer diagnosis were most frequently burdened by poor mobility (194/211; 91.9%) whereas patients with cancer were primarily burdened by weakness (522/565; 92.4%). In almost all care episodes of patients with non-oncological (210/212; 99.1%) and oncological (563/566; 99.5%) diagnoses, at least one symptom or problem was prevalent and in 181/212 (85.4%) and in 495/566 (87.5%) episodes 5 or more symptoms or problems. In addition, symptom and problem clusters were identified in both groups - two clusters (psychosocial and physical) in the non-oncological group and three clusters (psychosocial, physical and communicational/practical) in the oncological group. A greater proportion of patients in the non-oncological group had at least one symptom cluster (83/212; 39.2% vs. 172/566; 30.4%). The main difference was the presence of the cluster involving communicational/practical problems in the oncological group.

The results of this thesis demonstrate that palliative care structures are already extensively developed in many regions of Germany, with a notable number of specialist palliative home care teams. While most of these teams mainly care for oncological patients, the findings show that the observed clusters reflect the various aspects of physical symptom burden and psychosocial concerns of patients receiving specialist palliative home care and indicate different needs of both oncological and non-oncological patients.

In conclusion, palliative care is a crucial part of medical practice offering interdisciplinary and holistic care to patients with serious illnesses. In Germany, there has been considerable progress in the expansion of regional palliative care structures. In this context, the



rise in both oncological and non-oncological patients, along with the diverse needs and demands on the teams and the aim of early integration into palliative care for all patients are of great importance in this context. Although the supply of palliative care services appears to be well established across the country, further expansion is crucial not only to meet the increasing demand, but also to ensure that the different needs, requirements, and preferences of both oncological and non-oncological patients can be adequately considered and met in the context of specialist palliative home care.

## 5. Paper I

### **Accessibility to specialist palliative care services in Germany: a geographical network analysis**

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Gesell D, Hodiament F, Bausewein C, Koller D

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## 6. Paper II

### **Symptom and problem clusters in German specialist palliative home care - a factor analysis of non-oncological and oncological patients' symptom burden**

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Gesell D, Hodiament F, Wikert J, Lehmann-Emele E, Bausewein C, Nauck F, Jansky M, for the COMPANION study group. Symptom and problem clusters in German specialist palliative home care - a factor analysis of non-oncological and oncological patients' symptom burden. BMC Palliative Care. 2023;22(1):183. DOI:10.1186/s12904-023-01296-0.

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