Für meine Liebsten.

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Further development of palliative care planning concepts

Weiterentwicklung von Konzepten der palliativen Versorgungsplanung

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Contents

Affidavit 4

Contents 5

List of Abbreviations 6

List of Publications 7

1. Individual Contribution of the Author 11
1.1 Contribution to Paper I 11
1.2 Contribution to Paper II 11
1.3 Contribution to Paper III (Appendix) 11

2. Introduction 12
2.1 Outcome Measurement and Quality of Life in Palliative Care 13
2.1.1 Outcome Measurement Tools 14
2.1.2 Challenges for Application and Implementation of Outcome Measurement in Clinical Practice 16
2.1.3 The Palliative Care Outcome Collaboration in Australia - an Example of successful national Outcome Measurement 17
2.2 Outcome Measurement in Palliative Care in Germany 19
2.2.1 The COMPANION Study 20
2.3 Objectives and Contents of this Thesis 20
2.4 References 23

3. Zusammenfassung 27

4. Abstract (English) 30

5. Paper I 32

6. Paper II 33

Appendix: Paper III 34

Acknowledgements 35

List of Abbreviations

WHO	World Health Organization
PROM	patient-reported outcome measurement
PROMs	patient-reported outcome measures
PCOM	patient-centred outcome measurement
PCOMs	patient-centred outcome measures
PCOC	Palliative Care Outcome Collaboration
QIFs	Quality Improvement Facilitators
SPC	specialist palliative care
SPHC	specialist palliative home care
NPT	Normalization Process Theory
SAPV	Spezialisierte ambulante Palliativversorgung

List of Publications

Paper I

Lehmann E, Hodiamont F, Landmesser M, Knobloch CS, Nauck F, Ostgathe C, et al. Adaptation of the Australian Palliative Care Phase concept to the German palliative care context: a mixed-methods approach using cognitive interviews and cross-sectional data. BMC Palliative Care. 2021;20(1):128.

Paper II

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Appendix: Paper III

Lehmann-Emele E, Gesell D, Bausewein C, Hodiamont F. Das australische Konzept der Palliativphasen in der deutschen Versorgungspraxis. Zeitschrift für Palliativmedizin. 2022;23(06):285-289.

Other Publications

Original Research

Manuscript: **Lehmann-Emele E***, Gesell D*, Hodiamont F, Wikert J, Jansky M, Nauck F and Bausewein C for the COMPANION study group (2023). Symptom and problem burden, performance status and palliative care phases in specialist palliative care - cross-sectional analysis of care episodes. Planned Journal: Palliative Medicine.

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Die Palliativen Vitalparameter in der klinischen Praxis: Darstellung von Patient:innen in der SAPV, Palliativdienst und Palliativstation (Accepted for: 15. DGP Kongress 2024 - Deutsche Gesellschaft für Palliativmedizin, Aachen).

Die Palliativphasen als neues Assessmentinstrument in der Palliativversorgung - ein Konzept auch für die Onkologie? (35. Deutscher Krebskongress 2022, Berlin).

Förderliche und hinderliche Faktoren für die Anwendung von Komplexitätsassessments in der Praxis am Beispiel der SAPV (14. DGP Kongress 2022 - Deutsche Gesellschaft für Palliativmedizin, Bremen).

Poster

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1. Individual Contribution of the Author

1.1 Contribution to Paper I

CB and FH obtained the funding and developed the concept of the study. Development of the design, interview guides and assessment sheet: ELE, BG, and CB. Conduction of interviews: ELE (14/15) and BG (1/15). First mapping of data, identification of codes and development of the coding guide: ELE and BG. Coding: ELE. BG second coded. ELE, CB, ML, CK, FN, CO managed data collection on specialist palliative care units. Statistical analysis: BG. ELE and BG drafted the manuscript. CB and FH critically reviewed the manuscript for important intellectual content and contributed with expertise to the discussion of results. ML, CK, FN and CO commented the draft. All authors provided critical comments on drafts of the manuscript and approved the final manuscript. ELE was responsible for the publication process as corresponding author and was the main contributor to editing and reviewing the manuscripts.

1.2 Contribution to Paper II

Development of the design, interview guides and analysis: ELE, FH, and MJ. Conduction of interviews: ELE (14/17) and FH (3/17). First mapping of data, identification of codes and development of the coding guide: ELE and FH. Coding: ELE. ELE drafted the manuscript. SC, CB, and FH critically reviewed the manuscript for important intellectual content and contributed with expertise to the discussion of results. MJ and SDL commented the draft. All authors provided critical comments on drafts of the manuscript and approved the final manuscript. ELE was responsible for the publication process as corresponding author and was the main contributor to editing and reviewing the manuscripts.

1.3 Contribution to Paper III (Appendix)

Development of the idea, design, and analysis: ELE, FH, and CB. Statistical analysis: ELE and DG. ELE drafted the manuscript. CB and FH critically reviewed the manuscript for important intellectual content and contributed with expertise to the discussion of results. DG commented the draft. All authors provided critical comments on drafts of the manuscript and approved the final manuscript. ELE was responsible for the publication process as corresponding author and was the main contributor to editing and reviewing the manuscripts.

2. Introduction

The Global Atlas of Palliative Care states that *„the need for palliative care has never been greater and is increasing at a rapid pace due to ageing of the world's population, increases in cancer and other non-communicable diseases, and the recent emergence of COVID-19. By 2060, the need for palliative care at the end of life is expected to double."*[1, 2] Palliative care, as defined by the World Health Organization (WHO) in 2002, is a comprehensive approach to improve the quality of life for patients and their families confronted with life-threatening disease. Palliative care seeks to alleviate suffering through the early identification, assessment, and treatment of pain, as well as other physical, psychosocial, and spiritual concerns. It therefore includes the integration of psychological and spiritual dimensions of care, as well as providing a support system for patients' families/caregivers, offering emotional, practical, and bereavement support.[3] In summary, high quality palliative care, within a multidisciplinary approach involving healthcare professionals from various specialties, aims to enhance patients' overall quality of life, which includes respecting their autonomy, facilitating effective communication, and providing compassionate care, regardless whether he or she receives inpatient or outpatient/community care.[4]

Considering that outside North America, Europe and Australia, high quality palliative care is still underdeveloped and difficult to access, despite 76% of the need being in low-and-middle-income countries; the importance of further developing palliative care becomes even clearer. While in these countries, the primary focus lies on enabling access to palliative care, which involves overcoming numerous barriers like medication availability, cultural particularities, policy or education;[1] the challenges in developed countries, like Germany, are to provide palliative care that meets the needs and wishes of patients and their families/caregivers and to avoid futile treatments, as resources in the healthcare system are limited.[5, 6] To assess the needs of patients and their families/caregivers, and the complexity of palliative care situations, the use of standardised outcome measures plays a decisive and increasing role in clinical practice.[7-9] Furthermore, recording needs and wishes is essential for effective care planning and resource utilisation, as knowledge of the diagnosis alone is not sufficient to predict likely care needs or the time to death or discharge.[10, 11] In addition, standardised outcome measurement helps to improve quality, efficiency and to demonstrate the effectiveness of palliative care.[11]

The following first sections introduce outcome measurement in general, how it has evolved in palliative care, the benefits for patients, families and healthcare professionals, as well as the challenges it may present. Furthermore, a successful example for nationwide implementation of outcome measurement is presented and how benchmarking is possible in clinical practice. The second part refers to current developments and the status quo of outcome measurement in German specialist palliative care and how this thesis contributes to it.

2.1 Outcome Measurement and Quality of Life in Palliative Care

In the early days of palliative care, outcome measurement in research of anticancer treatments and therapy mainly focused on survival and disease-specific outcomes as well as physical domains;[12] or in palliative care specific research to describe study populations.[11] Nonetheless, it was recognised that to achieve the main goal of palliative care – optimising the quality of life for patients with life-limiting disease, including symptom control and family/caregiver support – care outcomes should be evaluated to assess the degree to which these goals have been achieved.[12-14] The assessment of change has shifted from solely focusing on the disease and clinical tests, which traditionally emphasized measures such as vital signs, blood tests, and other (physical) examinations in modern medicine, to now also considering the individual's personal and social concerns.[15] However, quality of life is a highly individual, subjective and dynamic construct, which does not have a consensus definition, making it therefore difficult to assess and account for all life chracteristics.[15-17] Calman postulated in 1984 the gap between expectations and the subjective experiences of the individual which affects the perceptions of his or her health related quality of life. This means that quality of life cannot be assumed to be static, as it can vary within a person over time and between different people.[14, 15, 18] Accordingly, a person's quality of life is high when their desires are met and fulfilled through their experiences.[18] This indicates and there is evidence, that even patients with serious physical illness and symptom burden can have a high quality of life[17] as they might have reduced but more realistic expectations or are satisfied with what they have. Moreover, the high individuality of the quality of life is emphasised, which is why the patients' state of health should ideally be self-reported.[14, 18, 19]

Health-related quality of life in the context of palliative and end-of-life care is based on certain dimensions including for example physical and psychological comfort, role functioning, maintaining independence, hope and pleasure, social support and spiritual well-being.[12, 14, 20] These domains are operationalised in the development of suitable outcome measurement tools which is described further in chapter 2.1.1.

Usually, the palliative care situation of patients and their relatives/caregivers is assessed at the beginning of care, as a baseline and repeated on certain occasions during the trajectory of care.[11, 21] An international expert consensus workshop in 2019 recommended to use ‘Phase of Illness’/’Palliative care phase’[22] as a time period measure.[23]

However, it is at least necessary that the assessment framework is repeated once at the end of care, meaning at the time of death or discharge/transfer, ensuring that there are minimum two measurement points to compare.[24] Using validated outcome measures routinely in clinical practice has benefits for patients and their families/caregivers: They help to identify, monitor and prioritise problems, take clinical action, facilitate communication, screen for unrecognised problems, facilitate the process of shared decision making and help to evaluate change or the responsiveness of treatment. In summary, they lead to an improvement through person-centred care.[15, 21, 25-27] It does not mean that the use of outcome measures replaces the therapeutic relationship between patients and healthcare professionals, but rather complements it.[28]

Recent developments show that outcomes are increasingly recorded digitally and that this represents an opportunity to intensify and deepen communication between patients and healthcare providers, and also helps to identify potential complications more quickly (e.g. in the home care setting). [19, 29] Another recent development is the use of outcome measures to screen for patients with palliative care needs in primary care.[30]

Specific outcomes are not only important to evaluate and improve the patients' quality of life[31], but by capturing patient-centred outcomes, it is also possible to measure the quality of care comprehensively; as according to Donabedian's widely adopted framework, outcome quality is the third dimension alongside structure and process quality.[21, 32] Whereas structure and process characteristics focus on more objective aspects such as staff qualification or the way care is delivered, outcomes are based individually on change in a person's health status and, consequently, quality of life. Furthermore, outcomes also reflect the performance at a system/population level using administrative data like duration of care or deaths in hospital.[21, 32] Therefore, measuring outcomes is also important on a higher level to check whether services are meeting their objectives,[33] to determine the effectiveness and even cost-effectiveness of care[34]; and to assess novel palliative care service provider models or new interventions.[35]

2.1.1 Outcome Measurement Tools

Patient and family/caregiver outcomes are commonly measured with the help of questionnaires[21] and the demands on these tools are complex: For clinical practice, they should be easy to understand and use (non-burdensome), short, valid and suitable for quickly identifying symptoms and concerns in all dimensions of palliative care; furthermore guide care planning and evaluate treatment.[36, 37] They have to be appropriate for the patient group cared for, as they must not be changed in their wording, because even small adjustments can affect the measurement properties of a questionnaire.[38]

Measurement or psychometric properties of health status questionnaires refer to the following main quality criteria according to the EAPC White Paper on outcome measurement in palliative care: ‘Validity, Reliability, Appropriateness and Acceptability, Responsiveness to change (and) Interpretability’.[11] To obtain valid information from the assessment, it is important that high quality tools are used, who had been developed and tested based on these requirements. This is especially important when the data collected is further used for research and comparisons or meta-analysis.[39, 40] Terwee et al. aimed to develop quality criteria for design, methods, and outcomes of studies on the development and evaluation of health status questionnaires, which are shown and further described in Table 1.[41]

Table 1. Quality criteria for measurement properties of health status questionnaires[41]

Property	Definition
1. Content validity	The extent to which the domain of interest is comprehensively sampled by the items in the questionnaire.
2. Internal consistency	The extent to which items in a (sub)scale are intercorrelated, thus measuring the same construct.
3. Criterion validity	The extent to which scores on a particular questionnaire relate to a gold standard.
4. Construct validity	The extent to which scores on a particular questionnaire relate to other measures in a manner that is consistent with theoretically derived hypotheses concerning the concepts that are being measured.
5. Reproducibility	
5.1. Agreement	The extent to which the scores on repeated measures are close to each other (absolute measurement error).
5.2. Reliability	The extent to which patients can be distinguished from each other, despite measurement errors (relative measurement error).
6. Responsiveness	The ability of a questionnaire to detect clinically important changes over time.
7. Floor and ceiling effects	The number of respondents who achieved the lowest or highest possible score.
8. Interpretability	The degree to which one can assign qualitative meaning to quantitative scores.

As mentioned earlier, using patient-reported outcome measures (PROMs) is the gold standard of assessment. However, in palliative care, PROMs are not always easy to record because patients are getting sicker and are often too ill, burdened, cognitively impaired or unconscious to self-report their symptoms, needs, and wishes.[42-44] To not exclude these vulnerable patient groups from outcome measurement, it was recognised that not only patient self-reporting, but also the possibility of proxy-reporting and thus patient-centred outcome measurement (PCOM) is needed and further developed.[25] The proxy assessment is provided either by people close to the patient, such as family/friends/(lay) caregivers, or by the treating healthcare professionals.[44] Although proxy-assessment presents certain difficulties, a review by Sneeuw et al. showed that while proxies tend to rate quality of life limitations worse than patients themselves, agreement between patients and proxies in the included studies was generally moderate to high, and major mismatches appeared only in a few of the cases.[45] A recent review from last year revealed few new findings and confirms the results of earlier studies.[46] However, it draws attention to the fact that a first crucial step in gaining an understanding of patient wishes is to establish timely and open communication with patients and relatives.[46]

Another crucial point is, that questionnaires/measurement tools are used that are translated, adapted in a culturally sensitive way and validated in relation to the specifics of the respective country.[37] Otherwise, it cannot be ensured that they meet the psychometric requirements mentioned above. Methods that are suitable for this are forward-backward translations, cognitive interviewing, and cross-cultural evaluations.[11, 47-49]

A Europe-wide survey in 2011 showed that there are about 100 different tools used in palliative care clinical practice and research.[39] Not all of them meet the (psychometric) demands and, to enable national and international comparisons and collaboration, at least suitable core tools must be determined that are accepted and used by all countries and services. However, the development of new tools is not necessary, as there are already appropriate ones that meet all of the requirements.[39] Subsequently, the already mentioned EAPC White Paper on Outcome Measurement in Palliative Care was published to define and provide recommendations on which requests outcome measurement must meet and what has to be taken into account when striving for Europe-wide comparisons and collaboration. In addition, specific recommendations were provided on which tools are suitable for this purpose.[11] Furthermore, patient-related domains where it is most important to measure outcomes on a routine basis were agreed upon in an expert consensus workshop. The domains are ‘overall wellbeing/quality of life’, ‘pain’, and ‘information needs/preferences’. Each area should be assessed over the ‘Phase of Illness’/’Palliative care phase’ to enable national and international comparison and benchmarking.[23]

2.1.2 Challenges for Application and Implementation of Outcome Measurement in Clinical Practice

Not only is it a challenge to establish a core outcome measurement framework in Europe and preferably on international level, the bigger challenge is to implement and routinely use PROMs/PCOMs in clinical practice as this is not common practice yet. An example of (main) challenges are summarised in the following:

A much noted systematic review by Antunes et al. has examined facilitating and inhibiting factors, as well as needs and lessons learned for PROM implementation in clinical practice. The primary facilitators for successful implementation of PROMs were firm yet sensitive leadership to motivate individuals and reinforce the benefits of PROMs towards improving patient outcomes. Providing feedback to clinicians can influence their beliefs and attitudes towards the use of PROMs, and adequate training and education are crucial for successful implementation in clinical practice.[28] For example, not enough staff were perceived as a barrier, and with it a lack of time and fear of too many tasks. In addition, too little guidance on how to use the tools, fear of burdening patients and relatives, and concerns about change.[28]

In 2018, Pinto et al. investigated qualitatively the perspectives of patients, family caregivers and health professionals on the use of outcome measures in palliative care and they emphasise the importance of the data collected through PCOM being fed back and used directly to improve care. This can be supported by integrating PCOMs directly into clinical information and making them part of the decision-making process. They also found that the use of PCOMs was not perceived as burdensome by patients and relatives; on the contrary, they felt more safe and reassured.[50]

A more recent qualitative study by Bradshaw et al. in 2021 investigated the use of PCOMs in clinical practice of different palliative care settings and showed that understanding and using certain instruments can be challenging in practice and therefore inhibit the use; and to address this training, education and peer support is necessary. Furthermore, that it needs a participatory approach to implementation from the button-up, constant communication and prompts about the use, and as well as mentioned by Antunes et al., a strong leadership and champions who are experienced and support the use in everyday life. Another current issue is the electronic availability of the collected data, as this is extremely helpful for clinicians and promotes the acceptance of using PROMs; provided there are people who know how to use it.[51]

In summary, outcome measurement, while valuable, is not self-explanatory, but continuous time and effort must be invested to implement and use it beneficially and routinely in clinical practice.

2.1.3 The Palliative Care Outcome Collaboration in Australia - an Example of successful national Outcome Measurement

Founded in 2006, the Palliative Care Outcome Collaboration (PCOC) has become a well-established, national Australian initiative focussing on improving the quality and outcomes of palliative care through standardised data collection using nationally agreed clinical measurement tools, analysis/interpretation, and collaboration among healthcare providers. By employing evidence-based practices and benchmarking, PCOC enhances the delivery of palliative care services and optimises patient outcomes.[24, 26, 33]

Participation in PCOC is voluntary and in 2021, 177 palliative care services from inpatient as well as community settings collected data on patient outcomes. The PCOC model is integrated into the services' routine clinical practice and besides patient demographics and setting information the following clinical assessment tools are used:[52]

- Palliative Care Phase[22]
- Palliative Care Problem Severity Score (PCPSS)[53]
- PCOC Symptom Assessment Scale (PCOC SAS)[54]
- Australia-modified Karnofsky Performance Status (AKPS)[55]
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)[56]

The standardised assessment framework is undertaken daily and at phase change in inpatient setting and at each contact and at phase change in the community setting, by either the patients themselves or through family/unpaid caregivers or the treating palliative care professionals. Socio-demographics and the diagnosis are recorded once at the beginning of care.[57]

The national performance at service level is assessed on the basis of these patient outcomes and involves a systematic comparison of different services or relevant subgroups. Each service is measured against national benchmark standards set by PCOC. In addition, aggregated data are analysed and then shared with participating services, allowing them to compare their performance with other participating services across the country. This comparative data is provided every six months and all services remain de-identified in the reporting process. There is also an active effort to implement quality improvement initiatives. While each service has its own quality improvement programmes, there are nationally employed staff who help to identify priorities for clinical and system change. They also support the process of implementing these changes across all participating services through communities of practice led by Quality Improvement Facilitators (QIFs).[26]

The defined benchmarks refer, for example, to the time in the unstable phase or to the share of patients cared for, for whom a reduction in moderate/severe pain was achieved by the end of the phase, or to the maintenance of absent/mild pain at the beginning of the phase until the end. PCOC data from 2021 shows, that:

- *"Almost 9 in 10 (88%) unstable phases (urgent needs) were resolved within 3 days or less.*

- *9 in 10 palliative care phases that started with absent/mild patient pain remained absent/mild at the end of the palliative care phase (89% for pain severity and 88% for distress from pain).*
- *3 in 5 palliative care phases that began with moderate/severe patient pain reduced to absent/mild by the end of the palliative care phase (62% for pain severity and 59% for distress from pain)".*[52]

The PCOC initiative demonstrates that national outcome measurement and benchmarking is possible and helps to improve outcomes of palliative care patients and their families/caregivers.

2.2 Outcome Measurement in Palliative Care in Germany

In Germany, palliative care structures are established both in the community setting and in inpatient/day-care settings and are further subdivided into general palliative care and specialist palliative care (SPC). General palliative care is usually provided in the community setting by general practitioners as well as by nursing and/or hospice services, and in the inpatient setting by health professionals on general hospital wards or in nursing homes that have basic palliative care knowledge. For the vast majority of dying patients, this kind of palliative care is adequate and sufficient and does not cause additional costs for health insurances.[7, 58, 59] However, if general palliative care is no longer sufficient because the patient's needs require more elaborate and thus more complex care, a multi-professional team of trained SPC providers should be involved. They have specific palliative care qualifications and experience and are predominantly working in this type of care. SPC is usually provided on inpatient palliative care units, by palliative care advisory teams in hospitals, or in the home care setting through specialist palliative home care (SPHC) teams, and is only needed by a smaller proportion of terminally ill patients.[7]

Inpatient SPC in Germany is currently reimbursed either through the Diagnosis-Related-Group (DRG) system or the palliative care unit as a special facility, which leads to a focus on costs, revenues and operationalisable structural and minimum characteristics rather than on the actual outcome for the patient.[60] Nonetheless, the German consensus-based guideline for patients with incurable cancer (Erweiterte S3-Leitlinie Palliativmedizin für Patienten mit einer nicht-heilbaren Krebserkrankung) recommends that all patients diagnosed with incurable cancer and their relatives undergo an assessment of needs as well as symptom/problem burden and information needs using validated multidimensional outcome measures. Furthermore, they recommended to assess the functional status, situation of family/relatives, and phase of illness.[7] This includes reassessments when the clinical situation changes and the guideline also suggests to align palliative care to the complexity of the patient's situation.[7] A high complexity is characterised by the high intensity of individual symptoms and/or psychosocial, spiritual or ethical problems and their simultaneous occurrence.[8] However, complexity of patients has not yet been operationalised in German SPC and outcome characteristics are not yet routinely measured. Furthermore, there is no evidence-based system, to distinguish between the need for general, or specialist palliative care. To fill this gap, the COMPANION project was conducted, which is explained in more detail in the following point.

2.2.1 The COMPANION Study

COMPANION was a nationwide German research project, funded by the Innovations Fund of the Federal Joint Committee (grant number 01VSF18018), which among other purposes, aimed to describe patients cared for in SPC in Germany and patients' needs that reflect the complexity of the respective patient situation, as well as the resources used to meet/address these needs.[61] To assess the complexity, socio-demographics, diagnosis and several PCOMs related to symptom/problem burden and severity, functional status and palliative care phase were documented electronically by palliative care health professionals in three SPC settings (palliative care unit, hospital advisory, and SPHC), over a three month time period. In addition, they documented their time spent on meeting patient needs in five-minute intervals, divided into direct patient care, care of relatives, inter-professional exchange about the patients' situation and administrative activities related to the patient.[61]

First results show that the overall goal of the project, to develop a case-mix classification for SPC, is more challenging than expected. Nevertheless, many new insights were gained through the study, such as the fact that the symptom burden of patients does not differ greatly in the three SPC settings.[62] However, these and other findings will be reported elsewhere. The study also demonstrated that the application of an assessment framework in the clinical practice of SPC is feasible.

2.3 Objectives and Contents of this Thesis

The overarching aim of the thesis was to facilitate the further development of palliative care planning concepts and patient-centred outcome measurement in German SPC to improve the quality of care for patients and relatives; as this is not yet established in a standardised way. For this purpose, the palliative care phase concept, an internationally established tool was first translated and culturally adapted to German SPC practice and its reliable use demonstrated. This process is described and illustrated in the first publication (chapter 5) of the thesis.

In the second publication (chapter 6) of the thesis, facilitators and barriers for the successful use of PCOMs in daily practice in SPHC were identified from the perspective of healthcare professionals participating in the COMPANION-study data collection. The results are crucial to develop suitable implementation strategies for using PCOMs routinely in clinical practice.

Lastly, the third publication, included in the appendix, shows how PCOMs interact in clinical practice, based on routinely collected clinical data of a palliative care unit and how they can be used to describe care situations and help the SPC team to manage care planning.

Chapter 5 refers to a mixed-methods study which included the translation and cultural adaptation as well as testing the reliability and applicability of the Australian palliative care phase concept.[63] The qualitative part included cognitive interviews with health professionals from three SPC settings: Palliative care inpatient unit, hospital advisory and SPHC. Interviews were conducted iteratively in three rounds using verbal probing and think-aloud techniques. After each round, transcripts were analysed using a systematizing qualitative analysis approach, accordingly phase descriptions were adjusted, and the changes tested in the next round. This was followed by a consecutive multicentre cross-sectional study in which two clinicians (doctors, nurses, and allied health professionals) independently assigned the adapted phase definitions to patients on three palliative care units. The results show that the concept can be applied in German SPC practice with moderate inter-rater reliability. However, it became apparent from the interviews and comments that the concept is not intuitively applicable and not self-explanatory. For implementation and use, it is necessary that training and an ongoing support is provided in clinical practice.

Chapter 6 refers to a qualitative study that explored the experiences of healthcare professionals working in SPHC about the use of PCOMs in their clinical practice during and after the COMPANION-project data collection.[64] Semi-structured interviews were conducted with staff at management and non-management level from five different SPHC teams. Framework analysis, contextualised within the Normalization Process Theory (NPT), was used to identify barriers and enablers for the successful use of PCOMs in the home care setting. Results show that is especially important that clinicians develop coherence about the benefits of using PCOMs in a standardized way and that the management level plays a major role in this. In addition, the working environment (context) in which teams operate are different and this must be taken into account when planning implementation strategies.

The paper in the **appendix** contains a detailed description of the translated and culturally adapted German palliative care phase concept and demonstrates the benefits of its application in clinical practice.[65] For this purpose, the application was exemplified by means of a case vignette and data routinely collected on a palliative care unit was analysed descriptively.

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3. Zusammenfassung

Das standardisierte Erfassen von Bedürfnissen und Bedarfen von Patient:innen mit lebenslimitierenden Erkrankungen und deren Angehörigen gewinnt zunehmend an Bedeutung in der Palliativversorgung. Es trägt nicht nur dazu bei, dass Patient:innen und Angehörige in Entscheidungsprozesse einbezogen werden, die Versorgung personenzentriert gestaltet werden kann und sich dadurch die Zufriedenheit erhöhen kann, sondern ist aus professioneller Sicht ebenso relevant für die palliative Versorgungsplanung. Auch im Hinblick auf Qualitätssicherung ist es elementar, nicht nur Strukturen und Prozesse zu evaluieren, sondern auch das Ergebnis der Betreuung und damit das Outcome für die Patient:innen; also in wie weit die erhobenen Bedürfnisse und Bedarfe erfüllt werden konnten. Trotz Herausforderungen bei der Umsetzung in der klinische Praxis zeigen Initiativen wie die Palliative Care Outcome Collaboration in Australien, dass standardisierte Outcome-Messung national möglich ist und durch Benchmarking und die Zusammenarbeit von Palliativeinrichtungen die Versorgung der Patient:innen nachhaltig verbessert werden kann. In Deutschland ist die standardisierte Outcome Messung in der spezialisierten Palliativversorgung noch nicht verbreitet und nicht ausreichend etabliert um patient:innenzentrierte Outcomes tatsächlich zu messen und national zu vergleichen. Dies liegt unter anderem daran, dass dafür geeignete Outcome-Messinstrumente nicht in deutscher Sprache verfügbar sind und dementsprechend nicht in der klinischen Praxis verwendet werden können.

Ziel dieser Arbeit ist es daher, die Nutzung patient:innenzentrierter Outcomes in der deutschen spezialisierten Palliativversorgung zu ermöglichen, um die Versorgungsqualität für Patient:innen und Angehörige zu verbessern. Dafür wurde zunächst mit dem Konzept der Palliativphasen ein geeignetes (internationales) Messinstrument ins Deutsche übersetzt, an die spezialisierte Versorgungspraxis adaptiert und im Anschluss die Reliabilität der Palliativphasen in der Praxis getestet (Artikel I). Im Rahmen des zweiten Artikels wurden Strukturen und Prozesse ermittelt, die sich förderlich oder hemmend auf die Anwendung von Outcome-Messinstrumenten auswirken können und bei der Planung von Implementierungsstrategien berücksichtigt werden müssen. Der dritte Artikel beinhaltet erste Daten, die anhand von Outcome-Messinstrumenten routinemäßig auf einer Palliativstation erhoben wurden. Es wird aufgezeigt, wie verschiedene Messinstrumente miteinander interagieren, palliative Versorgungssituationen bzw. Outcomes beschrieben werden können und welchen Nutzen dies hat.

Im Rahmen des ersten Artikels wurden kognitive Interviews in drei Zyklen geführt mit Vertreter:innen der verschiedenen Berufsgruppen (Ärzt:innen, Pflegende, Sozialarbeitende und Therapeut:innen) und Settings der spezialisierten Palliativversorgung (Palliativstation, Palliativdienst und spezialisierte ambulante Palliativversorgung (SAPV)). Es wurden „Think aloud“ und gezielte Nachfragetechniken eingesetzt und die Auswertung erfolgte anhand einer systematisierenden qualitativen Analyse. Die Interrater-Reliabilität wurde auf drei Palliativstationen anhand der Berechnung von Cohens‘ Kappa getestet. Für die Erhebung im zweiten Artikel wurden semistrukturierte Leitfadeninterviews mit allen an der Datenerhebung des COMPANION-Projekts beteiligten Berufsgruppen auf Leitungs- und Nicht-Leitungsebene in der SAPV geführt. Die Auswertung erfolgte anhand der Framework Methode im theoretischen Rahmen der Normalization Process Theory. Datengrundlage des dritten Artikels (Appendix) stellte die routinemäßige Dokumentation der Palliativstation der Klinik und Poliklinik für Palliativmedizin am LMU Klinikum München dar. Die quantitativen Daten wurden entsprechend aufbereitet und deskriptiv ausgewertet.

Die Ergebnisse des ersten Artikels bestätigen, wie wichtig eine passende Übersetzung und kulturelle Adaption internationaler Messinstrumente ist und dass es Modifikationen braucht, um diese in der deutschen Versorgungspraxis reliabel verwenden zu können. Weiterhin wurde deutlich, dass das Konzept der Palliativphasen nicht intuitiv angewendet werden kann und es für die Implementierung in die Praxis fortlaufende Begleitung und Schulung braucht. Die Ergebnisse des zweiten Artikels haben gezeigt, dass nicht nur die Einstellung/Haltung der Professionellen sowie der Leitungsebene gegenüber der Verwendung von Outcome-Messinstrumenten Einfluss auf die Akzeptanz hat, sondern auch der Kontext und damit das Arbeitsumfeld, in dem die Teams in der SAPV agieren. Dennoch spielt auch der persönliche Prozess jedes Einzelnen eine Rolle und als sehr hilfreich benannt wurden Vorbilder in und aus der Praxis. Der Sinn von Outcome-Messung wurde in den Teams teilweise erkannt und die Messinstrumente als hilfreich im klinischen Alltag empfunden. Artikel drei zeigt exemplarisch, dass es möglich ist, routinemäßig Outcome-Messinstrumente bei Patient:innen einer Palliativstation einzusetzen und gewinnbringend auszuwerten. Weiterhin wurde deutlich, dass für die umfassende Darstellung von Patient:innensituationen mehrere, sich ergänzende Outcome-Messinstrumente eingesetzt werden sollten.

Zusammenfassend zeigen die im Rahmen der Thesis gewonnenen und herausgearbeiteten Erkenntnisse, dass Outcome-Messung auch in der deutschen Versorgungspraxis kein Selbstläufer ist und gezielt implementiert und fortlaufend gefördert werden muss. Weiteres (Verbesserungs-) Potential besteht sicherlich hinsichtlich der digitalen Umsetzung. Dies betrifft zum einen die Integration der Outcome-Messinstrumente in das elektronische Dokumentationssystem der jeweiligen Einrichtungen als eine zwingende Voraussetzung für die erfolgreiche Umsetzung. Zum anderen gestaltet sich die statistische

Auswertung der erhobenen Daten bisher eher aufwändig und klinisch arbeitende Teams verfügen in der Regel weder über die wissenschaftliche Qualifikation, noch über zeitliche Ressourcen, um dies zu leisten.

4. Abstract (English)

Standardised assessment of the needs and concerns of patients with life-limiting illness and their relatives is increasingly important in palliative care. Not only does it contribute to the inclusion of patients and relatives in decision-making processes, to the person-centred design of care and thus to increased satisfaction, but it is also relevant for palliative care planning from a professional perspective. Also, with regard to quality assurance, it is crucial not only to evaluate structures and processes but also the result of the care provided and thus the outcome for the patients, i.e. to what extent the needs and requirements identified could be met. Despite challenges in implementation in clinical practice, initiatives such as the Palliative Care Outcome Collaboration in Australia show that standardised outcome measurement is possible nationally and that benchmarking and collaboration between palliative care facilities can sustainably improve patient care. In Germany, standardised outcome measurement in specialist palliative care is not yet sufficiently established to actually measure patient-centred outcomes and compare them nationally. This is partly due to the fact that suitable measurement tools are not available in German and therefore cannot be used in clinical practice.

The aim of this thesis is therefore to enable the use of patient-centred outcome measurement in German specialist palliative care, to improve the quality of care for patients and relatives. For this purpose, the concept of palliative care phases, a suitable (international) outcome measurement tool, was translated in German, adapted to specialist palliative care practice and then tested to see whether the phases can be reliably applied in practice (paper I). In the second article, structures and processes were identified that are facilitating or inhibiting for the application of outcome measurement tools and must be taken into account when planning implementation strategies. The third article includes first data collected routinely in a palliative care unit using outcome measurement tools. It shows how different measurement tools interact with each other, how palliative care situations and outcomes can be described and what the benefits are.

In the first paper, cognitive interviews were conducted in three rounds with representatives of different professional groups (doctors, nurses, social workers, and therapists) and settings of specialist palliative care (palliative care unit, palliative care advisory and specialist palliative home care (SPHC)). "Think aloud" and probing techniques were used and the analysis was based on a systematising qualitative analysis. Inter-rater reliability was tested on three palliative care units using Cohen's Kappa calculation. For the investigation in the second article, semi-structured interviews were conducted with all professional groups involved in the data collection of the COMPANION study at management and non-management level in SPHC. The analysis was carried out using the framework method contextualised within the Normalisation Process Theory. The data basis of the third article (appendix) was the routine documentation of the palliative care unit of the Department of Palliative Medicine at LMU University Hospital Munich. The quantitative data were processed accordingly and analysed descriptively.

The results of the first paper confirm the importance of a suitable translation and cultural adaptation of international outcome measures and that modifications are needed to use them in a reliable way in German specialist palliative care practice. Furthermore, it became clear that the palliative care phase concept cannot be applied intuitively and that it needs ongoing support and training for implementation in practice. The results of the second paper have shown that not only the attitude of the professionals and the management level towards the use of outcome measures have an influence on acceptance, but also the context and thus the working environment in which the teams in SPHC operate. Nevertheless, the personal process of each individual professional also plays a role and champions in and out of the field were named as very helpful. The purpose of outcome measurement was partly recognised in the teams and the tools were found to be helpful in everyday clinical practice. Paper three shows exemplarily that it is possible to use outcome measurement instruments routinely with the patients of a palliative care unit and to evaluate them beneficially. It also shows that several complementary outcome measures should be used for the comprehensive depiction of patient situations.

In summary, the findings obtained and elaborated within the scope of the thesis show that outcome measurement is not a self-runner in German specialist palliative care practice, and needs to be implemented in a targeted manner and promoted on an ongoing basis. There is certainly further (improvement) potential with regard to digital realisation. This applies to the integration of the outcome measures into the existing documentation system of the respective institutions as a mandatory prerequisite for successful implementation. Furthermore, the statistical analysis of the collected data has so far been rather time-consuming and clinical teams usually have neither the scientific qualifications nor the time resources to do this properly.

5. Paper I

Adaptation of the Australian Palliative Care Phase concept to the German palliative care context: a mixed-methods approach using cognitive interviews and cross-sectional data.

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Eva Lehmann, Farina Hodiamont, Mirjam Landmesser, Carina S. Knobloch, Friedemann Nauck, Christoph Ostgathe, Bettina Grüne, Claudia Bausewein

Lehmann E, Hodiamont F, Landmesser M, Knobloch CS, Nauck F, Ostgathe C, et al. Adaptation of the Australian Palliative Care Phase concept to the German palliative care context: a mixed-methods approach using cognitive interviews and cross-sectional data. BMC Palliative Care. 2021;20(1):128.

6. Paper II

Using normalization process theory to evaluate the use of patient-centred outcome measures in specialist palliative home care - a qualitative interview study

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Eva Lehmann-Emele, Maximiliane Jansky, Sabina Clapham, Susanne de Wolf-Linder, Claudia Bausewein, Farina Hodiamont

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Appendix: Paper III

Das australische Konzept der Palliativphasen in der deutschen Versorgungspraxis.

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